S. HRG. 105–872

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1999

HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

UNITED STATES SENATE

ONE HUNDRED FIFTH CONGRESS

SECOND SESSION

ON

H.R. 4274/S. 2440

AN ACT MAKING APPROPRIATIONS FOR THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES, FOR THE FISCAL YEAR ENDING SEPTEMBER 30, 1999, AND FOR OTHER PURPOSES

Department of Education
Department of Health and Human Services
Department of Labor
Nondepartmental witnesses

Printed for the use of the Committee on Appropriations

Available via the World Wide Web: http://www.access.gpo.gov/congress/senate

U.S. GOVERNMENT PRINTING OFFICE

46–105 cc WASHINGTON : 1999

For sale by the U.S. Government Printing Office
Superintendent of Documents, Congressional Sales Office, Washington, DC 20402
ISBN 0–16–058158–3

COMMITTEE ON APPROPRIATIONS

TED STEVENS, Alaska, *Chairman*

THAD COCHRAN, Mississippi
ARLEN SPECTER, Pennsylvania
PETE V. DOMENICI, New Mexico
CHRISTOPHER S. BOND, Missouri
SLADE GORTON, Washington
MITCH McCONNELL, Kentucky
CONRAD BURNS, Montana
RICHARD C. SHELBY, Alabama
JUDD GREGG, New Hampshire
ROBERT F. BENNETT, Utah
BEN NIGHTHORSE CAMPBELL, Colorado
LARRY CRAIG, Idaho
LAUCH FAIRCLOTH, North Carolina
KAY BAILEY HUTCHISON, Texas

ROBERT C. BYRD, West Virginia
DANIEL K. INOUYE, Hawaii
ERNEST F. HOLLINGS, South Carolina
PATRICK J. LEAHY, Vermont
DALE BUMPERS, Arkansas
FRANK R. LAUTENBERG, New Jersey
TOM HARKIN, Iowa
BARBARA A. MIKULSKI, Maryland
HARRY REID, Nevada
HERB KOHL, Wisconsin
PATTY MURRAY, Washington
BYRON DORGAN, North Dakota
BARBARA BOXER, California

STEVEN J. CORTESE, *Staff Director*
LISA SUTHERLAND, *Deputy Staff Director*
JAMES H. ENGLISH, *Minority Staff Director*

SUBCOMMITTEE ON DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES

ARLEN SPECTER, Pennsylvania, *Chairman*

THAD COCHRAN, Mississippi
SLADE GORTON, Washington
CHRISTOPHER S. BOND, Missouri
JUDD GREGG, New Hampshire
LAUCH FAIRCLOTH, North Carolina
LARRY E. CRAIG, Idaho
KAY BAILEY HUTCHISON, Texas
TED STEVENS, Alaska
(Ex officio)

TOM HARKIN, Iowa
ERNEST F. HOLLINGS, South Carolina
DANIEL K. INOUYE, Hawaii
DALE BUMPERS, Arkansas
HARRY REID, Nevada
HERB KOHL, Wisconsin
PATTY MURRAY, Washington
ROBERT C. BYRD, West Virginia
(Ex officio)

Majority Professional Staff
BETTILOU TAYLOR
MARY DIETRICH

Minority Professional Staff
MARSHA SIMON

Administrative Support
JIM SOURWINE and JENNIFER STIEFEL

CONTENTS

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1999

THURSDAY, MARCH 5, 1998

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 2 p.m., in room SD–192, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.

Present: Senators Specter, Cochran, Gorton, Faircloth, Harkin, Hollings, Bumpers, and Kohl.

Also present: Senators Stevens and Byrd.

DEPARTMENT OF EDUCATION

OFFICE OF THE SECRETARY OF EDUCATION

STATEMENT OF HON. RICHARD W. RILEY, SECRETARY OF EDUCATION
ACCOMPANIED BY THOMAS P. SKELLY, DIRECTOR, BUDGET SERVICE

OPENING REMARKS OF SENATOR ARLEN SPECTER

Senator SPECTER. Good afternoon, ladies and gentlemen. The hour of 2 o'clock has arrived which is the starting time for our proceedings.

Would the distinguished Senator from South Carolina like to make a comment about our distinguished witness?

OPENING REMARKS OF SENATOR ERNEST F. HOLLINGS

Senator HOLLINGS. And that witness is distinguished. I think the whole country is very proud of Secretary Riley's leadership and his contribution to education. I just wanted to amen the sentiments here. At this particular time, Mr. Chairman, our full committee, unfortunately, has got a regular hearing now, but I wanted to welcome him to the committee.

I think the President's initiatives are well-founded, and the question is where do we get the money. That is what we have got to do. I am going this afternoon to the Budget Committee.

For the information of everyone, we will be marking up on next Thursday, just 1 week from today, in the Commerce Committee to back a settlement bill, hopefully. I hope it is a comprehensive package approach because otherwise if they just break down into different parts and leave out this or put in some other thing objection-

able, then we are not going to get anywhere. But the idea with Chairman McCain is that we get together and report out a package bill of some kind so that the Congress will then be prepared to work because we at the Budget Committee know the moneys for, let us say, Social Security, Medicare, and otherwise——

Senator SPECTER. Are you still introducing the witness, Senator Hollings? [Laughter.]

Senator HOLLINGS. Let me yield to the chairman. Thank you very much.

Senator SPECTER. We have a crowded agenda today. We have not only the Secretary, but we also are having a hearing on campus crime. The Governmental Affairs Committee has scheduled a meeting at 4 o'clock this afternoon, which was scheduled after this hearing was scheduled. We expect the meeting to be not as bipartisan as this subcommittee hearing will be. So, it is our hope to conclude our proceedings by 4 o'clock.

We are pleased to welcome Secretary Riley here this afternoon.

PREPARED STATEMENT

The Department of Education's budget request for discretionary spending for fiscal year 1999 totals $31.2 billion, an increase of $1.7 billion, or almost a 6-percent increase over fiscal year 1998. We congratulate the Secretary and we congratulate the President for emphasizing education in addition to the increase which occurred last year.

Without objection, my full statement will be made a part of the record.

[The statement follows:]

PREPARED STATEMENT OF SENATOR ARLEN SPECTER

This afternoon, the Subcommittee on Labor, Health and Human Services and Education will begin its series of hearings on the President's fiscal year 1999 appropriations requests.

We are pleased to once again welcome Secretary Richard Riley to the subcommittee to discuss the budget for the Department of Education for the upcoming fiscal year.

The Department of Education's budget request for discretionary spending for fiscal year 1999 totals $31.2 billion, an increase of $1.7 billion or 5.9 percent over the fiscal year 1998 amount.

You can see from the chart to my right the difficulty facing this subcommittee by the President's assumption that savings will be realized through enactment of user fees or new taxes.

In fiscal year 1997, discretionary spending for this subcommittee totaled $74.7 billion.

In fiscal year 1998, discretionary spending increased to a total of $80.4 billion.

For fiscal year 1999, the President has requested $84.5 billion, but $1.9 billion of this amount would be financed by new user fees and assumed receipts from tobacco legislation.

Mr. Secretary, the administration's budget request has put us in a real spot, basically $1.9 billion in the hole, and I fully expect that you will work closely with this committee as we try to resolve this dilemma.

Mr. Secretary, of all of the funds contained within this subcommittee's jurisdiction, by far the most, direct, rewarding, and important investment we can make is in the education of this Nation's youth.

Today we are also pleased to have a second panel of distinguished witnesses who will testify following Secretary Riley. These witnesses will discuss the issues surrounding security on our college campuses.

Mr. Secretary, we will be pleased to hear your testimony at this time.

INTRODUCTION OF SENATOR ROBERT C. BYRD

Senator SPECTER. We are graced today by having the distinguished Senator from West Virginia, former President pro tempore, chairman of the Appropriations Committee, and just about every other title you can find. I would make one comment. Senator Dodd was at the funeral eulogizing Senator Ribicoff and said that Senator Ribicoff had to speak very briefly because his introduction was so long because he had held so many positions. Well, that is like Senator Byrd.

The floor is yours, Mr. Chairman.

OPENING REMARKS OF SENATOR ROBERT C. BYRD

Senator BYRD. Thank you, Mr. Chairman. I am very flattered by your making this opportunity available to me. I am not on the subcommittee, but I am very interested in the work of this subcommittee. I will be very brief because I am somewhat of an intruder here, but I am extremely interested in the education of our people.

Mr. Chairman, members of the subcommittee, I thank you for holding this hearing on the Department of Education budget for fiscal year 1999. I extend my appreciation to you, Mr. Chairman, and to Mr. Harkin, for all of your hard work and commitment in the area of education.

Mr. Secretary, I welcome you today. I realize that my time is limited, so I am going to have to be direct and succinct in my remarks.

I am very concerned with the declining state of the American education system and our Nation's lack of progress in the area of education. As I said last year in this subcommittee, the Federal Government continues to pour massive amounts of money into education, and I have voted for every appropriation for education since the Senate and House embarked on Federal aid to education. I have never voted against one of those bills. I just am sorry to see zero improvement.

THIRD INTERNATIONAL MATHEMATICS AND SCIENCE STUDY

Why is it that from 1993 to 1998, education spending has increased by 25 percent and at the same time results from the third international mathematics and science study [TIMSS] ranked the U.S. high school seniors among the worst participants in the areas of math and science? Why is it that in all three content areas of advanced mathematics, U.S. advanced mathematics students' performance was among the lowest of the 21 participating nations? These are supposed to be our Nation's stellar students.

ROBERT C. BYRD HONORS SCHOLARSHIPS

I am 100 percent for education, Mr. Secretary. I do not want to vote against increased spending for education. It gives me great pleasure to see well-deserving students—and there are many of them who are committed to their studies, and I am glad to see them attend college. That is precisely the reason that I began the Robert C. Byrd honors scholarship so many years ago, to provide the opportunity for an advanced education for those individuals who realize the meaning and the importance of a good education, not just for the time being, but forever.

PARENTAL INVOLVEMENT

If we ever hope to improve the quality of students being produced in this country, it is essential that we recultivate an interest in education for education's sake, not only in our Nation's children, but also in their parents. Our Nation's ailing education system is, in part, influenced by the parents of those children and young adults attending high school and college. Parents are role models, or should be, and children are likely to emulate them in a multitude of ways. Those parents who partake in intellectually stimulating activities and encourage their children to do likewise are slowly becoming extinct.

What is much more usual is the example of the couch potato type of existence involving half-awake adults sipping a Budweiser and staring at mind-numbing—mind-numbing—violent or offensive TV programs. This lifestyle has been glorified and replicated in the deplorable, mindless TV sitcoms which crowd network TV and which are watched all too much by our young people. It is like a vicious circle, an example of life imitating popular entertainment, if such junk can be called entertainment, and vice versa.

I just do not believe that merely proliferating education programs will solve the problems of improving our Nation's quality of students. On a fundamental level, there is something askew with the way we are approaching education in this Nation. I started out in a two-room schoolhouse where we did not have high technology. We did not have computers. We did not know anything about them. We did not have much money for supplies, but what we did have were dedicated teachers who really cared about the future of education and, therefore, exerted discipline to keep the focus of the schoolroom strictly on learning.

My old coal miner dad told me that if I got a whipping at school, I could expect to get another one at home. He meant it and I knew he meant it. We had on that grade card a little item called deportment, and I was always very careful to get a good grade in deportment.

We also had parents, as I say, who would back up the teachers. They did not say, "I will go up and whip the teachers." They said, "I will whip you." Today, this has all but disappeared, I am afraid. We have undisciplined students intimidating teachers and impeding the learning of their classmates. We did not have that in my day in school back in West Virginia. We have teachers who are more concerned with lawsuits today—and can you blame them—should they try even feebly to exert authority than in trying their best to impart useful knowledge.

TIMSS RESULTS

Mr. Secretary, no longer can we afford to fabricate excuses for why our students are not doing well. While it is true that the third international mathematics and science study is a rigorous test, posing difficult questions to students, other countries appear to be mastering these very same skills and concepts. Rather, we must look for solutions.

According to the study, our high school students devote a significantly smaller portion of time to their studies and are less likely

to take 4 years of math and science instruction. Now, why is that? Why are they permitted to opt out of these two critical disciplines? Obviously, getting back to the basics is where we need to focus.

I am not here today to prescribe the solution for our Nation's lack of progress in the area of education. I wish it were that simple, and I could with the snap of my fingers change the results of the third international mathematics and science study and rank U.S. seniors as No. 1 in the world.

PARENTAL INVOLVEMENT

But I think we concentrate too much on what is the best team in the league, though no ball game ever changed the course of history. I like to watch games. I get all tensed up sitting on the edge of my chair, too, but when it is all over and I have watched that football game, I can say truthfully that when you have seen one game, you have seen them all. They are all alike. They never change, and no ball game is ever going to change the course of history. Ball games did not put man on the Moon. It takes the brain of the person who has a mind and heart, the dedication to study, and who is willing to work, and to exercise that drive and ambition, to get somewhere. And good teachers can go a long way in encouraging that and so can good parents.

I think that all of my colleagues here would agree that "U.S. Seniors Rank Among the Best and the Brightest" would be a thrilling headline to have emblazoned on the front page of the New York Times or the Washington Post or the Washington Times or my hometown newspaper. But the question is: Why are we not the best?

I suspect that part of the reason is because we have taken the focus off teaching the basics and using discipline to make sure order is maintained in the classroom and instead stressed pleasing everyone—parents, lobby groups, and students—with curriculums, dumb-downed textbooks, and teaching methods. We are subjugating time-honored techniques for grounding students with basic educational skills in history and geography, for example, to other laudable concepts and interests such as social sciences, which are good, but when students do not know when the Civil War occurred or in what century it occurred, and can only remember Abraham Lincoln because he got shot, something is wrong.

I view such a juxtaposition as a grand mistake and I think test results continually prove me correct, unfortunately.

I thank the chairman for giving me this opportunity to speak before the subcommittee.

I have some questions, Mr. Chairman, that I would like to submit for the record. I will not impose on the time of the subcommittee, whose members have been so generous already with me. I would like to include them in the record, but I would like if I might ask if Secretary Riley would like to respond to my statement.

Senator SPECTER. Well, Mr. Secretary, let me first call on Senator Cochran for an opening comment, and then we will call on you. Your response to Senator Byrd's statement may well constitute your testimony. [Laughter.]

I would make just one comment on my father's agreement with Senator Byrd about football. My father watched a brief part of a

football game once and a fumble occurred, one of those plays where 16 different people touched the ball and finally someone fell on it. And my father looked at it and said, why do they not give all those men another football? [Laughter.]

Senator BUMPERS. Mr. Chairman, may I just make one remark on Senator Byrd's statement about getting a whipping, if he got a whipping at school, he got one at home that night. There is a story up in the Ozarks about a kid who got a whipping every day. He got in trouble, and every night when he got home, he got another one. He got tired of that, and one day he made a commitment that he was going to do absolutely nothing to get a whipping at school for. And he had made it just fine, and about 10 minutes before the bell rang, the teacher was walking up and down the aisle. And he stopped by this kid's desk, and he said, Johnny, who wrote the Declaration of Independence? And he was intent on not getting in trouble. He says, I don't know. I know I didn't do it. [Laughter.]

When he got home that night, his father said, well, did you get a whipping in school today and he said, yes, I did, but he said, it wasn't my fault this time, Dad. He says, that's what you always say. What happened?

So, he told him. He said the teacher asked me if I wrote the Declaration of Independence, and I told him, no, I didn't do it. He asked, if I knew who did it, and I said, no, I don't know. I know I didn't do it. His old man said, well, if you didn't do it, you probably had it done, and proceeded to give him another one. [Laughter.]

Senator SPECTER. There will not be time for your testimony. [Laughter.]

We thank Senator Bumpers for his opening statement. [Laughter.]

Senator Cochran.

OPENING REMARKS OF SENATOR THAD COCHRAN

Senator COCHRAN. Thank you, Mr. Chairman.

NIH RESEARCH ON READING

Mr. Chairman, I wanted to bring to the attention of the Secretary the fact that we are making progress on an initiative that we discussed at last year's hearing, and that was the convening of a reading panel to try to analyze research that had been done at NIH in NICHD, the National Institute of Child Health and Development, affecting the ability of children to learn to read or not learn to read at early ages. I am glad to see that the progress we have made has now resulted in the selection of some of these panel members and the work of the panel will begin soon.

AMERICA READS CHALLENGE

I bring it up in this context: the budget proposal by the administration suggests that the President's reading program and a House-passed bill may form the basis of the Department's initiative on this subject, and substantial funds—I think about $200 million—are requested or predicted to be spent in support of this.

HOUSE DIRECTIVE ON CONVENING READING RESEARCH PANEL

I wonder whether or not you can react for the record during your comments or for the record in writing later, if you like, whether there will be an opportunity for the President's initiative to proceed with the benefit of the findings of this panel, which was supposed to be analyzing research data, coming up with techniques for screening, for teaching, suggestions about new ways to deal with problems of learning disabilities or reading disabilities, whether physical or emotional. The findings it seems to me can go a long way toward heading us in the correct direction and the right direction in trying to deal with this problem that is nationwide.

I am not suggesting we need to federalize the reading instruction in our Nation's schools. What I am suggesting is for parents to have a better knowledge base in what to look for in terms of detection of early problems in children, and school districts to have the benefit of knowledge that has been developed by scientific-based research that is respected in this area so that we can develop at the local level or the State level, whatever the appropriate level is, the right kind of curriculum and initiatives to deal with reading problems at early ages.

I am hopeful that you will look at the conference report again that was adopted by conferees on this subject wherein we talk about the importance of this reading panel that is going to be developing its findings and its recommendations. And I am going to read again into the record.

"The conferees endorse the language outlined in the Senate report"—this is the appropriations bill for this current fiscal year—"regarding research programs on reading development and disability, and also concur in the directive to the Secretary of Education to consult with the Director of the National Institute of Child Health and Human Development to convene a panel to assess the current status of research and effective approaches to teaching children to read."

We hope that the Department of Education will closely monitor the progress and try to see that the benefits of this research are disseminated for all who have responsibilities and interests in this area.

TITLE I ALLOCATION FORMULA

One other subject that I would like for you to look at and that is the title I program. It is designed to deal with the reality of poverty and the effects of poverty on children who grow up in that environment and the difficulties that they are confronting in trying to learn and succeed in school. We all know that the program was designed to provide school districts who have large numbers of these children with additional funds to help meet those needs.

What worries me is that with the redesign of the title I allocation formula, a lot of States like mine are projected to get less money in the future than they have in the past for this program when we still have huge numbers of children who fall into the category of the population designed to be served by title I.

What I am suspecting is that the reality of the political weight of the votes in the House of Representatives from population areas

that are more influential because of their sheer numbers, we are seeing smaller States like my State of Mississippi and others like that getting less money now because of the pure, simple weight of the votes in the Congress and the influence that brings to bear on the policies that are made by this administration and by the Congress. I know the Congress helps write the allocation formula, but I suspect that there needs to be a new degree of attention being paid to this problem and I hope you can help ensure that this is done. Your comments along that line are what I am requesting.

TEACHER TRAINING MODEL

Also your submission about the fact that our policies with respect to teachers, that we need to develop some kind of national model. I think the national writing project, which the administration has agreed needs to be funded this year, which I am glad to see, could serve as a nationwide model for teacher training. Rather than spending only $5 million on a program like this, make it the national model and spend the money that you had intended to spend in another area that would just be kind of spread out for everybody to experiment on their own. Here is a program that has proven to be effective. It has a huge constituency among those who have had the experience of the program. It works. Adopt it as the national model and fund it as the administration's model for teacher training.

I have some other observations and questions which I will submit for the record, but I appreciate your attention to those issues.

Senator SPECTER. Thank you very much, Senator Cochran. Before yielding to our distinguished chairman of the full committee, let me call on the ranking member of this subcommittee, Senator Harkin.

OPENING REMARKS OF SENATOR TOM HARKIN

Senator HARKIN. Thank you, Mr. Chairman. I apologize for being a little late. I just wanted to be here to again welcome Secretary Riley back to the subcommittee to discuss the administration's budget for the Department of Education.

I want to state unequivocally that for the past 5 years, Mr. Secretary, you have been the voice and the advocate, the leading voice and the leading advocate, for improving public access, access to our schools, public education, and college education for countless Americans. There is no question, Mr. Secretary, about your dedication to making education a top priority in this country and your outstanding leadership. Indeed, President Clinton made a very wise choice in picking you to be Secretary of Education during this crucial period leading to the 21st century.

I just want to commend you and compliment you in public for all that you have done. I have been involved in education a long time. I travel around the country, and everything I hear all over this country is thank God for Secretary Riley because we are moving ahead and we are making differences and we are making changes in this country.

FEDERAL EDUCATION FUNDING

Last year we had the single largest increase in education funding in more than 30 years. We enacted tax credits to help millions of Americans attend college. Again, this was done because of Secretary Riley's leadership, but it was also done on a bipartisan basis.

I compliment our chairman, Senator Specter, for his leadership in guiding and directing this bill through, the largest single increase in education funding in 30 years out of this subcommittee. Senator Specter, you are to be commended for leading that charge.

FEDERAL EDUCATION INITIATIVES

Now, the administration's budget for next year builds on that success. It proposes bold actions. Too many students are taught in classes that are too large; 14 million students attending buildings that are unsafe; 5 million kids left unsupervised after school hours.

So, these are all areas I know, Mr. Secretary, that you want us to look at and to approach in our appropriations process this year.

So, I just want to say I applaud your leadership in attacking these serious concerns head on. These new investments that have been proposed by the President in these critical areas are ones that I strongly endorse, as well as many of the other recommendations in the 1999 budget request.

Again, Mr. Secretary, welcome back and thank you for your great leadership.

Secretary RILEY. Thank you, sir.

Senator SPECTER. Thank you very much, Senator Harkin.

Our distinguished chairman of the full committee, Senator Stevens.

Senator STEVENS. Mr. Chairman, I am pleased to be here. I am familiar with your questions that you are going to ask about the gap in the amount of money that is sought and where it is coming from. So, I will just defer and wait for your questions.

Nice to see you, Mr. Secretary.

Secretary RILEY. Thank you, sir.

Senator SPECTER. Senator Bumpers.

OPENING REMARKS OF SENATOR DALE BUMPERS

Senator BUMPERS. Mr. Chairman, let me just say that I want to echo virtually everything that Senator Harkin said about my admiration and respect for the Secretary. He is an educational icon to educators in this country. He has been a good personal friend of mine for many years, and I have never known anybody whose reputation is any higher for probity or dedication and determination, especially the latter two, in the field of education.

My reason for being here is not to squawk at the budget. Everything about the budget pleases me. I am glad to see the increases. I have the utmost confidence in this Secretary to spend the money very wisely.

When the time comes for me to ask questions, I can alert the Secretary to a very simple $1.8 million grant application that we included in the bill last year and have just been told by the Department that they would not fund. Is the Secretary familiar with that?

Senator SPECTER. Well, Senator——

Senator BUMPERS. I just want to make sure he is prepared for the question.

Senator SPECTER. Let us proceed with his testimony and we will come back to questions, if we may.

Secretary Riley, that is a long introduction. [Laughter.]

But a good part of it was filled with compliments which you may not have objected to too much. You have quite a lot of questions pending already from Senator Byrd and Senator Cochran and Senator Bumpers.

SUMMARY STATEMENT OF HON. RICHARD RILEY

Secretary RILEY. If I might give a brief statement, Mr. Chairman, or would you like me to just go ahead and answer questions? I would like to cover a couple of points.

Senator SPECTER. Your full statement will be made a part of the record, and to the extent you can summarize it and perhaps address the questions, I think that the questions which Senator Byrd and Senator Cochran have articulated are probably ones which you have on your mind in any event. So, the floor is yours as you see fit.

Secretary RILEY. If I might move through very quickly a very brief statement and submit the longer statement.

Senator SPECTER. Fine.

Secretary RILEY. I am pleased to have Tom Skelly with me, my Budget Director, who has been with our Department, by the way, 24 years and worked side by side with Sally Christiansen for many years. So, Tom, it is good to have you with us.

FISCAL YEAR 1999 EDUCATION BUDGET REQUEST

I am going to move quickly through the discretionary side of the budget. I would say that this budget continues our strong emphasis on helping children master the basics, turning around failing schools, protecting children from drugs, and speeding up the process of getting technology in the classroom.

READING PROGRAMS INCREASES

Our 1999 request includes a $392 million increase for title I and a total of $260 million for America Reads. Our goal for both of these programs and others is to make sure that every child can read well and independently by the end of the third grade, if not earlier.

THIRD INTERNATIONAL MATHEMATICS AND SCIENCE STUDY

And we must do a better job at teaching our children math and science, Senator Byrd, as you pointed out. America's 12th graders really hit the bottom in the latest third international mathematics and science study, and the results are unacceptable to me and I am sure to each of you.

Our schools, according to the TIMSS study, actually do a very good job of teaching the basics of science and math in the first four grades. Senator, this is dealing primarily with the question you asked. We fall behind, however, in the middle years. As you recall,

in grade four, we were second only to Korea in science—with all the diverse schools in this country and all the fourth graders, second only to Korea and all of the countries in the study. In math we were way above average, in the top levels, up above above average. In middle school, we dropped. We were about average. We were just barely above average in science, barely below average in math, and then in high school, as you point out, we dropped.

I can respond to some questions and some analysis about that in a moment.

But among the problems is that only about 20 percent of our eighth graders take algebra; 100 percent of the eighth graders in Japan take algebra. Many high school students check out and do not take the tough math and science courses. They just kind of drift through school, oftentimes not taking those difficult courses.

The reality is that many science and math teachers are teaching out of field. I was talking to a foreign education secretary recently and I said something about how that was a problem. They said, I don't know what you are talking about. They could not imagine having a math teacher who did not finish in math—whose field of study was not math. That is a real problem in this country.

RAISING EXPECTATIONS, STANDARDS, AND TEACHER PREPARATION

All of this is compounded by the fact that we set very low expectations for our students, and I think that is probably at the heart and it touches much of what you said.

The results from the TIMSS study provide ample evidence for why we need national standards of excellence. I think that is a very important move that you have made and all of us have made together, and why the Senate should continue to support the President's call for voluntary national tests in reading and math. Parents not only want to know how their country is doing from the sample test like TIMSS and NAEP, but they also want to know how their children are doing as well. The only way we can find that is to have a comparable test for an individual child, and that is what the proposal is.

Our budget includes $32 million to begin implementing an action strategy developed jointly by the Department and the National Science Foundation to improve math and science instruction. We are also proposing to create a $67 million teacher recruitment and preparation program in the reauthorized Higher Education Act, which will go a long way I think toward preparing many more teachers to teach math and science.

PROGRAMS TO REFORM FAILING SCHOOLS

Now, to turn around failing schools, we seek your support for a new $200 million education opportunity zones program, a $30 million increase in the comprehensive school reform program to help some 3,500 schools—that was a part of the proposal of last year, to increase that—and an increase of 25 percent in charter schools, enough funding to start up 1,400 new or redesigned schools. Urban school districts from Philadelphia, Mr. Chairman, to Chicago to Seattle are putting promising practices into place and are getting some results. I was in Seattle recently and was very pleased with what I saw there.

But to turn around failing schools, you have to begin with safety, and that is why we propose a $200 million major expansion of the 21st century community learning centers program, the after-school program, supporting 4,000 after-school centers, which serve as safe havens and learning places. We are requesting $50 million to put well-trained drug and violence prevention coordinators in one-half of all of America's middle schools.

TEACHER TRAINING AND TECHNOLOGY INITIATIVE

Education technology remains high on our agenda. We are placing a special emphasis on a new $75 million teacher training and technology initiative to make sure that all new teachers can use technology effectively in the classroom.

STUDENT FINANCIAL ASSISTANCE PROPOSALS

Our request for higher education builds on last year's many accomplishments. We are seeking to increase the maximum Pell award from $3,000 to $3,100.

We are proposing a $53 million increase for TRIO, a strong expansion of the very effective work-study program.

PARTNERSHIP PROGRAMS DESIGNED TO RAISE STANDARDS

Over 930 colleges and universities now have committed their work-study students to America Reads, 48 of those being in Pennsylvania. Penn State, for example, has over 400 students involved, and the University of Pennsylvania has over 90 students involved who are working with middle school-aged students, tutoring them for help.

Finally, I make special reference to the high hopes for college proposal. Our $140 million request would create new partnerships between 2,500 middle schools and our Nation's colleges and universities over the next 5 years. These types of partnerships are, to my way of thinking, one of the most effective and low cost ways to get high standards into our Nation's classrooms.

The Tell Them We Are Rising Program at Temple, and the Berkeley Pledge Program at UC-Berkeley are two examples of these. I had the opportunity to be at Berkeley recently and to go out to a school in Richmond with Bob Berdahl, the chancellor, to see the wonderful work that Berkeley is doing with this little, relatively poor—many of the kids are poor—school. They are working one on one with them.

In conclusion, I am prepared to work with the committee to craft a budget that reflects the high priority that the American people are placing on education. I think that is apparent. I believe we can succeed in the effort, if we continue as we have in the past, to leave politics at the schoolhouse door and work for the common good of all children.

PREPARED STATEMENT

Now I would be happy to respond to questions, Mr. Chairman. Do you want me to address Senator Byrd's? Senator Cochran has left, and I will be glad to respond to his questions or give them to him in writing. How would you like me to proceed?

[The statement follows:]

PREPARED STATEMENT OF RICHARD W. RILEY

Mr. Chairman and Members of the Subcommittee: I am pleased to have this opportunity to talk with you about President Clinton's 1999 budget request for the Department of Education. This Subcommittee has produced strong budgets for education over the past few years, but I think you will find that the President's 1999 budget represents the most comprehensive effort yet to raise standards and give schools, teachers, and students the tools to reach those standards.

The American people have made education their number one priority, and the President's budget for education reflects their concerns. In particular, the 1999 request includes the largest increase in 30 years for Federal elementary and secondary education programs. Our purpose is straightforward: we want our elementary and secondary schools to match the world-class quality of our colleges and universities.

The President's 1999 budget proposal would reduce class size in grades 1–3, help school districts build new schools and modernize existing ones, improve teacher quality, target new assistance to poor urban and rural schools, help bring technology into the classroom, and give all Americans the financial support and information they need to go to college.

We are requesting a total of $31.2 billion in discretionary budget authority for fiscal year 1999, an increase of $1.7 billion or almost 6 percent over the 1998 level. The request also includes two major education initiatives that fall outside of the discretionary budget, and I want to briefly mention these before moving on to a summary of our discretionary request.

CLASS SIZE AND SCHOOL CONSTRUCTION

First, President Clinton is proposing to spend $12 billion in mandatory funds over the next 7 years to recruit and train 100,000 new teachers. These teachers would help reduce class sizes in grades 1–3 to a nationwide average of 18 students. We believe that small classes are critical to giving our youngest students the foundation they need for high achievement in the later grades. In particular, small classes would help ensure that all children are able to read well and independently by the end of the third grade.

In addition, small classes would make it possible for teachers to provide extra support and attention to children with special needs, including children with disabilities and children with limited English proficiency. The 1999 budget includes $1.1 billion in mandatory funding to launch the Class-Size initiative.

Second, the President is proposing Federal tax credits to pay the interest on almost $22 billion in bonds to build and renovate public schools. Schools across the country are suffering from overcrowding, created in part by the "baby boom echo" that will increase school enrollments every year for the next 10 years. These growing enrollments create a tremendous need for new schools in many districts.

In addition, the General Accounting Office has reported that existing schools require over $100 billion in repairs to ensure that teachers can teach and students can learn in safe and orderly conditions. I would also note that beyond the issue of safety is the need to modernize schools to take advantage of educational technologies like computers and the Internet.

The President's proposal would help to build or modernize an estimated 5,000 public schools, with half of the support allocated to the 100 school districts enrolling the largest numbers of poor students. I want to emphasize, however, that the Class-Size and School Construction initiatives would improve educational opportunity and achievement for all students.

HELPING CHILDREN MASTER THE BASICS

Turning now to the President's discretionary request for the Department of Education, we are continuing our emphasis on helping children master the basics. We know that early competence in reading and math is critical for all children, but it is particularly important for disadvantaged and limited English proficient students, who often fall behind early and find it difficult to catch up in the later grades.

The primary Federal program for raising the achievement of such children remains the Title I Grants to Local Educational Agencies program. The 1999 request includes a $392 million increase for Title I, all of which would be distributed to high-poverty urban and rural schools through the Concentration Grants and Targeted Grants formulas.

We also are proposing to increase the number of teachers qualified to teach the basics to Hispanic and other limited English proficient students by doubling funding for Bilingual Education Professional Development to $50 million.

The budget provides $260 million for America Reads, which would support local programs that provide tutoring and help improve reading instruction in our schools, so that every child can read well by the end of the 3rd grade.

In mathematics, we have new and disturbing evidence that our students are far short of where they need to be to compete in the knowledge-based economy of the 21st century. Last week, the Department released the latest results of Third International Math and Science Study (TIMSS), on which U.S. 12th graders outperformed only two of the 21 participating countries in math and science.

This level of performance is just unacceptable, and to my mind confirms the need to raise standards dramatically in American schools. When the 8th grade math curriculum in American schools looks like the 7th grade curriculum in other countries, and when 28 percent of our high school mathematics teachers did not major or minor in mathematics in college, it is clear that we have not set our expectations high enough. The TIMSS results provide yet more evidence that we need national standards of excellence in core subjects like mathematics and science. The President's call for voluntary national tests in reading and math is intended to address this need, and I hope the Senate will continue to support the development of these tests.

The 1999 budget also would help improve teaching and learning in math and science by providing $32 million to implement an Action Strategy developed jointly by the Department and the National Science Foundation. The strategy is designed to improve the math teaching of elementary and middle school teachers, assist communities in the selection and implementation of rigorous instructional materials, maximize the effective use of existing Federal resources, and promote public understanding of the importance of challenging middle school math.

RAISING ACHIEVEMENT IN POOR URBAN AND RURAL SCHOOLS

A second priority in the Department's discretionary request is to support fundamental change in America's urban schools, where promising efforts to turn around low-performing schools are starting to take hold. While much of our proposed investment in helping children master the basics will help urban schools, the budget includes several initiatives targeted on the special challenges faced by poor urban and rural schools.

For example, the new $200 million Education Opportunity Zones program would make approximately 50 grants to poor urban and rural districts to improve accountability, raise teacher quality, and expand public school choice. A $30 million increase in the Title I Comprehensive School Reform program would help some 3,500 schools accelerate educational improvements and turn around failing schools. A 25-percent increase in Charter Schools would support the expansion of public school choice through the start-up of up to 1,400 new or redesigned schools. And to help recruit and train new teachers for urban and rural areas, we are proposing to create a $67 million Teacher Recruitment and Preparation program in the reauthorized Higher Education Act.

School safety is a special concern in high-poverty areas, and extended learning time can help disadvantaged students catch up in their academic skills. That is why this budget includes a $200 million major expansion of the 21st Century Community Learning Centers program, which would support keeping approximately 4,000 schools open after-school as extended learning safe havens. In addition, we are requesting $50 million to hire Safe and Drug-Free Schools Coordinators, who would help almost half of all middle schools develop and implement effective strategies for keeping our kids away from drugs.

EDUCATIONAL TECHNOLOGY

A third priority—one that I know is shared by several members of this Subcommittee—is educational technology. A $50 million increase for the Technology Literacy Challenge Fund would help more schools buy hardware, train teachers to use technology, and develop and buy software. The $106 million request for Technology Innovation Challenge Grants would support 24 new awards to develop or adapt cutting-edge technology for America's classrooms. And a new $75 million Teacher Training in Technology initiative would help make sure that all new teachers can use technology effectively in the classroom.

HELPING STUDENTS PREPARE AND PAY FOR COLLEGE

Finally, our 1999 request builds on last year's historic achievement in helping students and families pay for college, which included a $300 increase in the maximum Pell Grant award and the creation of the HOPE Scholarship and Lifetime Learning tax credits.

The President's budget proposes $7.6 billion for the Pell Grant program, an increase of $249 million that would further raise the maximum Pell award from $3,000 to $3,100. A $70 million increase for Work-Study would reach the President's goal of giving one million recipients the opportunity to work their way through college, while also supporting additional Work-Study tutors for America Reads.

We are asking for $583 million for the TRIO programs, a $53 million increase aimed at expanding the number of Upward Bound projects—especially in underserved areas including Hispanic students. TRIO's efforts to encourage low-income students to prepare for and enter postsecondary education would be reinforced by the HIGH HOPES initiative.

HIGH HOPES for College for America's Youth would promote partnerships between colleges and middle or junior high schools in low-income communities. Beginning in the sixth or seventh grade, the program would give students information about college and what it takes to go to college, along with support services like mentoring and after-school activities that help children stay on track to complete high school and enroll in college. The $140 million request for HIGH HOPES would be the first step toward serving more than 1 million students in 2,500 middle schools over the next five years.

CONCLUSION

The 1999 request for the Department of Education reflects an ambitious and comprehensive effort to help States and communities address critical issues in education and prepare our children for the challenges of the next century. I believe we can succeed in this effort if we continue—as we have in recent years—to leave politics at the schoolhouse door and work for the common good of all our children.

I will be happy to take any questions you may have.

MATH AND SCIENCE ACHIEVEMENT

Senator SPECTER. Well, Senator Byrd cannot be with us long, as I understand his schedule, so if you would respond at this point to his question, we will then proceed with a round of questions for the members.

Secretary RILEY. Fine.

Senator, I certainly agree with the tenor of the strong concern you have for excellence in education, and I tried to address in my statement some of the TIMSS issues.

Let me say some more on that. It is very clear to me that, for example, our 8th grade students, generally, in math and science are taking what 7th grade students are taking in most of the countries that did a lot better than us in the middle schools and in the 12th grade.

However, we have improved performance in math and science almost a grade level over the last 12 to 14 years. That has been a result of targeting on math and science—coming out of putting a person on the Moon and all those other efforts to target math and science education. Obviously, we have not improved enough. Others have gone up probably a grade level plus.

So, we have made improvement. We are making improvement.

The fact that we do so well in the fourth grade certainly makes it right clear that the basics that we have up through the fourth grade we are excelling in, leading the world in science and almost in math. Then we begin to drop. I think a good part of it is low expectations. We do not demand enough, I think, for some of our students, as you pointed out, and of teachers in the system. In high

school, 25 percent of our students, for example, take physics. In countries we are competing with, about 75, 80, to 85 percent take physics. So, our students compare on a physics exam very poorly.

Those kinds of things I think we can do something about. I do think we ought to start urging 4 years of math and science. I remember when I was Governor of South Carolina and raised it to 3 years of math and science, people thought that was rather dramatic. Now it is clear to me that we need 4 years of math and science, and, of course, I hope States would use the TIMSS information to move that forward.

As you know, I support the tenor also of the Byrd scholarship which is merit driven, and that also makes a very good statement I think and I am very pleased that it is in our budget.

PARENTAL INVOLVEMENT

So, I think high expectations and parental involvement are needed. Parents are involved more in elementary school obviously than middle school and high school. I think it is a good thing for us to urge parents to get more involved with their children in middle school and high school and talk with them about the kinds of courses they ought to be taking to go to college, to be successful in life, and talk with them about drugs and about smoking and about alcohol or whatever. So, I think parents are a very critical part of the mix also.

Mr. Chairman, do you want me to address Senator Cochran's issues or wait——

Senator SPECTER. I think Senator Cochran may be rejoining us. He said he would try to return. So, let us await his return.

Now we will start 5 minute rounds for members.

Senator BYRD. Mr. Chairman, before you begin, may I thank you again and may I thank all the members of the subcommittee for being so patient with me. I am not a member, and the subcommittee has been very gracious.

And I thank you, Mr. Secretary.

Secretary RILEY. Thank you, sir.

Senator SPECTER. Senator Byrd, I know I speak for all the members. We are glad to have you here. Thank you.

I said at the outset, and a number of members have joined since, that following your testimony, Mr. Secretary, we have a hearing on campus safety, and after we had scheduled these hearings, Governmental Affairs scheduled at 4 o'clock a proceeding on the report which is going to be very complicated and contentious. So, it is my hope we will conclude by 4 o'clock.

BUDGET OFFSETS—TOBACCO SETTLEMENT AND USER FEES

We are going to proceed now with 5 minute rounds. So, the first question I have for you, Mr. Secretary, is in making your budget projection, $1.9 million is based upon proceeds from a tobacco settlement and from unauthorized user fees. If we do not get those sources of revenue, which are right now highly speculative, how will we pay for that $1.9 billion?

Secretary RILEY. Well, I understand from what was said earlier by Senator Harkin or one of the Senators that there is some positive information developing, hopefully, on that issue.

Senator SPECTER. Positive information developing, hopefully.

Secretary RILEY. Hopefully. [Laughter.]

Senator SPECTER. That is a long way from being a bird in hand.

Secretary RILEY. If that is resolved and, of course, those funds are there——

Senator SPECTER. If not?

Secretary RILEY [continuing]. Then we think the best use of the funds would be as we indicate. If not, which is your question, then we still think the idea of sending funds to the States for them to use to reduce classroom size for those early grades one, two, and three, and especially for hiring teachers specially trained in reading, that this would be very, very helpful for this country. All we can say is that we think those are very worthwhile purposes. If this offset is not there, then we would welcome other offsets or suggestions and would be happy to discuss those kinds of things with you.

Senator SPECTER. We too would be interested in welcoming other suggestions, but this budget is very problemsome, Mr. Secretary, because of that $1.9 billion gap.

CLASS SIZE REDUCTION—USE OF PAROCHIAL CLASSROOMS

But let me go on to another question and that is on the President's initiative on class size reduction. The subcommittee asked for a study by your Department, which is not yet complete except for some information. This is an idea advanced by Cardinal Bevalaqua of Philadelphia where the schools are overcrowded, yet the Catholic schools have a lot of space. It costs $7,000 a year to educate a student in the Catholic schools. Cardinal Bevalaqua would like to open his doors for $1,000.

It obviously implicates church-State separation. Can you give me your view on that sort of a proposal?

Secretary RILEY. Of course, we were asked to give a report back on that subject, and we will have that to the Congress by, probably, April. We are just about completed with it.

Some of the initial findings of the report are that among the 34 large urban school districts, 22 reported some overcrowding in anywhere from 13 to 91 percent of their schools. The associations representing private schools indicated that private and parochial schools have some space available, but approximately one-half of those associations believe that the space is quite limited. That was a mixed view. As I say, this is not final information.

The associations also indicated some problems and concerns that would develop in such a transfer. Schools could maintain their current curriculum, their current admissions, assessment, and other policies without change. These concerns are what came back to us. Religious schools would not be required to permit exemptions from religious instruction to transfer students. Private schools would not be required to serve a large number of students with special needs. There would be no increase in Government control of private schools and so forth.

So, you have a lot of concerns expressed by private schools that if they get into this, they do not want to shift the nature of their private school basis. We have not completed that study, but those are some questions that have been raised to us by some of the private school people.

CAMPUS SECURITY ACT PANEL

Senator SPECTER. Well, my yellow light is about to turn to red, and I want to maintain the timing. So, I will conclude my round simply by pointing out another panel we are going to have on compliance with the Campus Security Act, and I would hope that you could stay for a few minutes, Mr. Secretary, although your assistant, Mr. David Longanecker, will be the principal witness.

Senator Harkin.

Senator HARKIN. Thank you, Mr. Chairman.

YOUTH VIOLENCE AND AFTER-SCHOOL PROGRAMS

Mr. Secretary, I have here an article from the Des Moines Register last fall, and the headline reads "Killing Time Literally After School." It talked about a study that was done at Northeastern University, the College of Criminal Justice in Boston by Mr. James Allen Fox about the fact that juvenile crime is worse in the afternoon—and not late at night—between 2 p.m., and 8 p.m. Almost 50 percent of violent juvenile crimes occur between 2 p.m., and 8 p.m. Only one-seventh occurs between 11 p.m., and 7 a.m., when curfews typically are in effect.

I know that you want to address this issue, and you can tell us more about your efforts, what you want to do in getting after-school programs?

I will just say that James Allen Fox said in the afternoons we used to have sports, drama, and music. We had violins and now it is violence.

So, what exactly are you proposing, Mr. Secretary?

21ST CENTURY COMMUNITY LEARNING CENTERS

Secretary RILEY. Well, last year, this current budget year, you approved our request for the 21st century community learning centers and appropriated $40 million for that program. That was in my judgment a very wise move.

AFTER-SCHOOL PROGRAMS

We have proposed in this budget to raise the $40 million to $200 million and to have it funded for 5 years, $1 billion over 5 years going to after-school programs. It is all involving partnerships, quality programs that would address the issue that you raise. Parents want children, if they are in after-school programs, to have access to computers, art programs, academic programs, sport programs, those exciting, interesting, engaging things to do, not just to bide time, but for there to really be learning time that is also interesting.

MOTT FOUNDATION FUNDS FOR AFTER-SCHOOL PROGRAMS

The Mott Foundation, by the way, a private foundation, was so interested in that purpose, the after-school purpose, that they have committed $55 million over a 5-year period to place emphasis on quality in those programs. They had people come in and meet and talk about how best to implement after-school proposals, how to set up the after-school programs. Mott had bidders conferences around the country and 5,000 people attended.

In this $40 million program that you all approved last year, we had room for funding perhaps 400 of these programs; 16,000 requests were made about the program.

I do not think there is any question that this is the right direction to go. If we are going to solve many of the problems that TIMSS and other studies have shown, we have got to make good use of that after-school time for all children. That is it, and as you point out, youth crime and victimization both happen primarily during the time, as they say, the school bell rings and before the factory whistle goes off. So, I am very hopeful that you all would fund that additional amount for that existing program.

Senator HARKIN. Thank you, Mr. Secretary.

I also think that that is one of the most important things that we can be about. I think it is one of the great helps that we can give our elementary and secondary students around the country.

I see my time is running out.

MATH AND SCIENCE ACHIEVEMENT—TIMSS

I just want to ask you about the TIMSS study. How come? Just one more time. Why in the 12th grade we are so low, 4th grade we are so high? What is happening between the 4th and the 12th grades?

Secretary RILEY. Well, I will not repeat all of the things, but the TIMSS study observed in eighth grade that the American curriculum was an inch deep and a mile wide. The curriculum, for example, in Japan in eighth grade would have like seven topics. America would have like 32 to 33. There is not anything wrong with that at all, but it is just kind of the way we go about teaching math and science, a little bit of everything.

Their suggestion, of course, is to get deeper into fewer topics early to build a foundation for high school. A key way to do that is algebra. To have algebra in the eighth grade we think is absolutely critical. There is no reason in the world why our students cannot have algebra and some geometry by the eighth grade. That is what happens in practically every other country we are competing with and having difficulty with.

I think the programs that we have proposed are having a quicker effect in elementary school also. The high standards I think are working, and the technology things that we are doing. Title I largely funds those early school years, and the changes in title I, doing away with the watered-down curriculum, and so forth are producing results. I think all of that is making a big difference.

Then when you get on up into high school—this test was given in 1995. Maybe there are some changes that are taking place now, but not near enough, not near quickly enough.

Senator HARKIN. Thank you very much, Mr. Secretary.

Senator SPECTER. Thank you, Senator Harkin.

We are going to proceed with order of arrival, which is the subcommittee rule. We next go to Senator Bumpers, then Senator Faircloth, Senator Gorton, and Senator Kohl. Senator Bumpers.

Senator BUMPERS. Thank you, Mr. Chairman.

MISSISSIPPI DELTA EARLY CHILDHOOD SERVICES PROJECT

Mr. Secretary, last year this committee and the conference committee put a $1.8 million grant in its report for the Easter Seals of Arkansas to do a demonstration project in the delta region of Arkansas, Louisiana, and Mississippi. The idea being that early childhood specialists would serve children with disabilities in the delta region—right now these children have to be taken to Little Rock. Transportation is a big problem, so a lot of them do not even bother to go.

They are wanting to prove something which really I suppose we all already know, but at the end of the three demonstration projects, they intended to put rehabilitation experts there to live in the delta and serve the poor disabled children there.

MISSISSIPPI DELTA PROJECT—EASTER SEALS FOUNDATION

We thought it was all saucered and blowed, as we say in Arkansas. Senator Specter was very kind to put it in his mark. The members of the delegation in the House from those three States, as well as the Senators from those three States, wrote letters. We did not put it on our wish list until we talked to the Office of Special Education and Rehabilitative Services of the Department of Education who assured us that they would honor this report language.

The worst part of it is, the Easter Seals of Arkansas began hiring medical and planning staff and then suddenly we get a letter about 1 or 2 weeks ago saying the Department will not provide the $1.8 million.

And this has created a real problem. Not only do we need the demonstration project for one of the poorest areas of the United States, but the Easter Seals of Arkansas have agreed to take on the continuation of this at the end of 3 years by, as I say, providing special education and rehabilitative services down there to those children. It seems like a really wonderful deal for the Department of Education, but right now it is a traumatic thing for everybody because we suddenly get this letter out of the blue sky from a Judith Heumann. Is that the way you pronounce it?

Secretary RILEY. Yes.

Senator BUMPERS. Saying they were not going to honor it. As I say, we would not have even put it in our wish list had we not known it was going to be honored.

Secretary RILEY. Well, Senator, let us continue to work with you on it. These were competitive grants, that is the way these are handled. Another competition I think, Tom, is coming out very soon?

Mr. SKELLY. The Easter Seals Foundation may be eligible for more than one competition. The competition that you addressed in the report is one where the average grant is about $150,000 per year.

Senator BUMPERS. That does us no good. We got the letter. That was the suggestion, that this competition was available to us. If we won it, it would be $150,000. It does not even scratch the surface on what we are trying to do.

Mr. SKELLY. It would be $150,000 per year.

We are considering yet another competition for which Easter Seals might also be eligible. We have not announced that competition yet. So, it is possible that the second competition would be for a larger amount of money. We have not worked out all the details.

Senator BUMPERS. Mr. Skelly, with the utmost respect, why did you not make all of these excuses back when we talked to you in the first place before you committed to us that you would honor this? I mean, I am aware of all of that. Easter Seals is aware of all of that. The letter said that we had substantial unexpended funds. The truth of the matter is we do not have substantial unexpended funds, and $150,000 does not get the water hot. I have a list of five things that were set out in Ms. Heumann's letter and none of them really help us at all.

Mr. SKELLY. We will be looking into that situation again more, Senator. There are funds provided under State grants to the area, and our staff have talked to the State representatives and others down there about possibly getting more of that money that is already provided from the Federal Government to the States for these same services. But I understand there is a problem in getting enough trained staff to work there, and that is why we are interested in looking at Easter Seals as a source of the kinds of services that could be provided to students down there.

Senator BUMPERS. Mr. Secretary, this is really a dismaying situation for me personally and especially for the Easter Seals of Arkansas who looked forward to doing this project and, as I say, who have already hired some people in anticipation of it. Then all of a sudden out of the clear blue sky, 4 months after the President signs the bill, we get a letter saying the Department would not honor it.

Secretary RILEY. Well, Senator, I certainly will take a look at that and be back with you on it. I understand the technicalities that we are talking about, but I would strongly support the sentiment of what you are trying to do. Let me take a look at it and see if there is any earthly way that we could visit it.

Senator BUMPERS. Thank you, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Bumpers.

Senator Cochran had been here earlier, had propounded a series of questions, and the Secretary had wanted to know whether he should answer them earlier and I said you expected to be back. So, if it is your pleasure, he will proceed now to answer them.

Senator COCHRAN. Thank you very much, Mr. Chairman. I appreciate that very much.

Secretary RILEY. Senator, I have gone through so much since you left.

AMERICA READS CHALLENGE

Senator COCHRAN. I will refresh my memory and yours too. I discussed the reading research initiative at NIH.

Secretary RILEY. I think we are together on that. I do not have any problem with that, and I think we are together on that as far as the America Reads Challenge. It is a locally driven program, as you know, America Reads. We do not tell them what to do. OERI does work hard, though, to give out research findings like these, and I will assure you that that will be done. It will be disseminated

and they will have it. Of course, as you point out, we do not control that and do not try to, but they will have that information.

TITLE I ALLOCATION FORMULA REVISION

Senator COCHRAN. The other subject was title I and the allocation formula. It looks to me like the money is now going where the votes are rather than where the needs are.

Secretary RILEY. Well, what we want the money to do is to go where the kids are, and if it is for disadvantaged kids, that is what we are trying to help develop, a formula to target the money to go where they are. That is our philosophy on it. I realize you differ with some of the census procedures as far as determining the allocation. But what I am trying to do—and of course, the National Academy of Sciences is advising us on that—is to try to have the money go where the poor children are.

NATIONAL WRITING PROJECT

Senator COCHRAN. The third topic that I broached was the writing project and the efficacy of that program as a national model for teacher training. You are spending money for teacher training, only a small amount, although I am glad you are suggesting that we spend some on the writing project. I am suggesting enlarging that as a national model and using it nationwide.

Secretary RILEY. Well, let me take a look at that. We agree with you on the writing project. I think that is a grand project and we recommended funding of it, as you point out, and I will look at further use of it. I think that is a good suggestion, but certainly we agree with you on the project.

"READLINE" AND "MATHLINE"

Senator COCHRAN. Some of the submitted questions include things like "Readline." That is a televised program. WETA has pioneered an effort to help develop reading competence, and I hope you will look at that as a program that ought to be funded with Federal dollars by the Department of Education.

Secretary RILEY. All right, sir.

Senator COCHRAN. And "Mathline" is a similar project. "Readline" and "Mathline." Well, they are similar things but they are using the technique and the technology of television. We do know that children watch a lot of television, and we are trying to, in the process, help to educate by the use of that technology too, and these are new techniques for doing that.

Senator SPECTER. Thank you very much, Senator Cochran.

Senator Faircloth.

Senator FAIRCLOTH. Thank you, Mr. Chairman.

EDUCATION FUNDS GOING DIRECTLY TO STUDENTS AND TEACHERS

Secretary Riley, when will the Department submit to the Congress the report on how much money reaches the students and teachers that I requested in last year's appropriation?

Secretary RILEY. It is my understanding that April 1—is that right, Tom?

Mr. SKELLY. That is right. We plan on having our report, Senator, by April 1.

Senator FAIRCLOTH. You are going to have it by April 1.

Secretary RILEY. April 1.

I am very interested in the subject, and I am glad you are. I really think it is worthy for us to be doing some work on. This idea of what gets down to the classroom I think is very important.

Senator FAIRCLOTH. We will get it in April.

Secretary RILEY. My estimate here is by April 1, yes, sir. I will try to get it to you by then.

INTEREST RATE ON STUDENT LOANS

Senator FAIRCLOTH. Mr. Secretary, as you know, after July 1 of this year, there will be a decrease in the interest rates that banks and other institutions can charge for federally backed student loans. Banks have indicated that this will make student loans completely unprofitable for them, and they will significantly reduce their participation in the program unless there is an adjustment made, I assume leaving many students stranded for lack of loans.

As a member of the subcommittee and as a member of the Banking Committee, I have been somewhat concerned about the matter and wanted to know if you would please comment as to where this is going and address the problem.

Secretary RILEY. Yes, sir, Senator. The Treasury Department has done substantial work on that. I think it is a very serious problem that needs to be dealt with. They have come up with a proposal and it was announced recently by the Vice President. It was a proposal that would use the 91-day Treasury bill, which is what they very much wanted. They wanted it to be consistent with the 91-day movement and not into the 10- to 20-year securities. That part I think would be a tremendous help, stabilizing help, for the lending institutions.

The main part of the change that was made originally, of course, was to help students, to help them get a reduction in rate. The proposal that the Treasury Department comes up with protects the students with a low rate but changes the method around to where we think it would be a lot more appealing to the lenders.

So, that is now into the process of discussion, but we have put a very substantive, which I think is a very good and fair proposal, on the table. I know some other committees are looking at that here. That discussion is now underway. Of course, we would like to get it resolved by the July 1 deadline and think that is very important. We do have what I think is a very responsible proposal on the table.

Senator FAIRCLOTH. Are you going to get it solved by July 1?

Secretary RILEY. I think so. I think clearly we will. I think everybody is now coming together to try to get it resolved, and everybody wants to get it resolved. So, I think it will be resolved, yes, sir.

SCHOOL UNIFORMS

Senator FAIRCLOTH. Secretary, one time way back when—early on with President Clinton early in office, the Department put out a notice with a lot of material, pamphlets, on how schools could switch to school uniforms like Winthrop and what a great thing it

would be. There was a lot of effort that went into it. I am interested in how many schools went to the uniform system.

Secretary RILEY. I do not know exactly. That is a very good question, and I will check that out and let you know. I will tell you this: a lot of them. I go around to a lot of schools and I am seeing more and more, especially elementary schools and a lot of middle schools, with children in uniform.

What our information, which was an analysis of where school uniforms are used around the country successfully, like Long Beach—and I was just out there the other day, and it is very successful out there—said, is that the discipline is better. Crime is down. Violence is down, and so forth. It does not solve all problems, but in most places it is a help—and our data showed us if you go to the parents first and you get the parents to support uniforms, then you have kind of a collegial feeling about that and not a top-down attitude, saying to people, this is how it is going to be, you have to do it. If you get them involved in the decision, it seems to work better than if you do not. But those places that have done that, it seems like they have had very good success with it, and we are very positive about it.

Senator FAIRCLOTH. I think it is an excellent idea and I hope you will push it. Thank you.

Secretary RILEY. Thank you.

Senator SPECTER. Thank you, Senator Faircloth.

Senator Gorton.

Senator GORTON. Mr. Secretary, because of this 5-minute rule, I am going to go through three subjects and see if I can get through all of them, and then ask you to answer.

CLOSED CAPTIONING

The first one is simply a bit of advice. In the last couple of days, you have come into this controversy with respect to your grant programming for closed captioning of television by reason of a letter to you from Senators Lieberman and Coats. One of your assistants has said that it is perfectly appropriate to fund closed captioning for the "Jerry Springer Show," described by the letter as the closest thing to pornography on broadcast television and by another as a show that puts on more fights than Don King because it is a part of the culture, according to your subordinate.

Your other spokeswoman yesterday said that, well, these grants are given to people who then give the grants, so you are not responsible for what goes on after that, and you are not in the business of censoring.

Now, I should remind you, Secretary Riley, this was exactly the way NEA got into problems with Maplethorpe by saying, well, we did not really do it, one of our grantees did it. I spent a lot of my time barely saving the existence of the National Endowment for the Arts, and I would strongly advise you that you do something about this one, rather than get into the kind of controversy NEA found itself in. That is pure advice. You can respond to it or not.

Secretary RILEY. Let me——

Senator GORTON. I have got to go through all of this.

Secretary RILEY. Well, if you could have a little extra time, I would appreciate it because I would like to just give a response.

Senator GORTON. Fine, but my light is going to go off. So, I am going to give you two other subjects now and then I will listen to your answer to all three of them.

LOCAL CONTROL

You were in Seattle last month and you called for people to choose solutions instead of choosing sides, a statement that was quite consistent with your state of the education speech last year when you said that we should not—and I quote—"cloud our children's future with silly arguments about Federal Government intrusion."

It seems to me—and you can comment on this if you think this is an erroneous interpretation—that agreeing with your philosophies is choosing solutions, and espousing a philosophy that states that educators, parents, teachers, administrators, and school board members in our local communities should have far more authority and you far less in choosing sides and making silly arguments about Federal Government intrusion.

I would like your comment on that. Is this just rhetoric, or do you really believe that those who feel that these decisions should be centralized are making silly arguments and are choosing sides?

And finally, with respect to the specifics of your budget, I find it interesting to note that those areas, the two major areas that provide the greatest degree of flexibility to local school districts to make their own choices, are the ones that are least favored in this appropriation.

You simply wiped out the title VI block grant program, stating in your budget some States and districts funded the same activities year after year with little thought as to the most appropriate use of title VI funds. That seems to me consistent with the proposition that the locals do not know what they are doing but you do, so we wipe that out and put it into prescriptive forms of funding. That was cut out completely.

The other area in which you have substantial reductions is impact aid where again school districts are able to make their own choices and are funded for the impact that the Federal Government has on them.

Finally, IDEA. I have had several education seminars in the last few weeks, and the overwhelming reaction from the people who run our schools is utter frustration with IDEA. We passed the reauthorization of that law last year that we intended to be at least slightly less prescriptive on locals. Your proposed regulations make it more prescriptive, and at the same time that you make it more prescriptive, you effectively cut the budget, at least the student budget, for IDEA.

Why is it, Mr. Secretary, that in a program like that with detailed regulations from the Federal Government, you propose to fund about 9 percent of the cost to school districts but to take all kinds of money, literally millions of dollars, and fund new programs with rules and regulations from the Federal Government? Should we not first fund the activities we have already mandated on school districts before we start a bunch of new programs?

Senator SPECTER. I compliment my distinguished colleague, Senator Gorton—you are a very experienced questioner—for being within the 5-minute rule. [Laughter.]

Now we will see how long the answers take.

Secretary RILEY. I will proceed to respond, but there are five or six very serious questions, Mr. Chairman, if I can respond to them.

Senator SPECTER. You may respond.

CLOSED CAPTIONING

Secretary RILEY. First of all, on the closed caption issue, I think I would agree with you on the particular show. The "Jerry Springer Show" I have never seen. I do not care to see it. I have never heard anything about it that I liked.

There is a process that we use for these captioning programs. We give the grants out. The grantees then bring in panels of deaf, hard-of-hearing people to say what they would like to have included.

I will say that the closed captioning program, Senator, has done a lot of good. We funded 100 percent of captioning in the beginning and now private industry is picking some up. As you watch on television, a certain company will pay for it. Now we fund about 40 percent, and I hope to get that down to zero. We are moving that down very quickly, and I think it is. Captioning has gotten tremendously improved. So, it is a good thing.

Picking the programs, we try not to do that. We let the grantees, through panels of deaf people, pick the programs to be captioned. This program happens to be the most popular talk show in daytime television. The FCC approves it for daytime television. That is what other people want to watch, and the fact that deaf people and hard-of-hearing people want to watch it, I think, is understandable. It becomes a censoring kind of problem.

I will follow your advice and take another look at any way that we think we ought to get involved. I want to be honest with you. I want to be very, very careful about telling hard-of-hearing and deaf people what they ought and ought not want to see.

One person told me today, when I was asking about that, that if there was a deaf parent who had speaking children who could hear, that parent would like to know what that program is about so they could say whether or not they wanted their child to watch it. I do not know how many other situations are like that.

But it is quite different I think from the art situation. This is a group of people that have a right to see things on television and hear them just like we do.

Senator SPECTER. Mr. Secretary, you have two more complex questions pending. If you could give an encapsulated answer to each and perhaps supplement it in writing, I would appreciate it.

BLOCK GRANTS AND LOCAL CONTROL

Secretary RILEY. All right, sir. The question of block grants generally, let me speak to that, because I think that is a very important issue and it touches two of the things that you mentioned.

I do not think that we should be prescriptive, but I do think that we should in the Federal Government, as far as the Federal role is concerned—that it makes very good sense for us to set focused,

targeted priorities that are broad and measurable. This idea of being measurable I think is very important. Is there accountability? How can you judge whether a program is getting better or worse, whether it is performing a function or not? Or are the programs' funds just being moved into the general budget of the State or of the local school district?

So, that is my general feeling, that the Federal role is not control but it should provide funds that are focused and targeted but measurable. I think taxpayers deserve to know how their dollars are being spent, and the dollars that are taxed at this level, I think they should have a directed purpose, but the control of that should be as flexible as it could possibly be.

As you know, we have pushed for that. We have eliminated two-thirds of the regulations in elementary and secondary education since we have been here, over 5 years, two-thirds of them. We have recommended Ed Flex which is now in 12 States, and the President, as you know, recommended to the Governors the other day that it be extended to 50 States. With Ed Flex, the State then could handle a waiver of a program, but it would not change the overall focus of the program and the accountability of the program.

So, that is my general feeling. We do not think the general revenue proposals of time past were successful, and we think that special areas of concern, whether it is poor children or disabled children or whatever, do deserve attention.

Let me say this about the States also. Over one-half the States now are in legal controversy stemming from constitutional issues over the equity funding formulas within the States. The idea of sending large numbers of block grant funds into a situation that is really up in the air in a lot of States—as to whether their entire financing process is based on equity—must be carefully considered. I think that is an important point.

GAO STUDY ON BLOCK GRANTS

Then finally, the GAO study that just came out the last couple of days certainly indicates that if money goes down to the States and the States spend the money as they have in the past, it would cause the poor to be the losers. The people that we often target funds to on this level would be the losers.

Those are some of my general answers on that.

IMPACT AID

As you know, we favor funding part A programs and we have favored not funding part B programs, and that has been kind of an ongoing difference of opinion.

SPECIAL EDUCATION BUDGET INCREASES

IDEA gets into another whole matter of issues that I think are very, very important. As you know, in the last 2 years, we have had a 64-percent increase in IDEA, and that is very significant. I congratulate all of you for that and am pleased with it.

If you look at a 64-percent increase in the last 2 years, this year we did not recommend an increase but level funding, but we do have $10 million in there for another 15 States to move forward

with a State education reform strategy in terms of disabled children, and a $20 million increase for grants for the infants and families program.

Then the main thing is that 80 percent of the special education children in America—80 percent of them—spend over 40 percent of their time in regular classrooms. What we tried to do this year was to have a special emphasis on the regular classroom.

The size of the classroom—if you reduce the pupil/teacher ratio in grades one, two, and three, and give those teachers special help in reading, it is amazing how that would help children who are borderline special education children. If they can have some special attention, individual attention from those teachers, many of them would not have to go into special education we think.

So, we think title I, some of those other programs, the Eisenhower program, the reading program, the testing program—all of those things that we recommend for the general regular classroom—we think will be tremendously helpful to disabled children.

Senator SPECTER. Senator Kohl.

Senator KOHL. Thank you very much.

AFTER-SCHOOL PROGRAMS

Mr. Riley, one part of the President's program that I am very interested in is the demonstration project run by these three Departments, the Education Department, HHS, and Justice, that will coordinate Federal after-school programs. I understand that the purpose of this initiative is to designate three to five pilots for these and to prove that you can do a better job by coordinating these programs, the after-school programs.

How are you going do to this? How are you going to select the pilot cities? What are you looking for?

Secretary RILEY. Well, Senator, we strongly support, by the way, the work that they are going to be doing. I think it makes a whole lot of sense for us to coordinate those programs.

I think there will be what? Three target areas?

Mr. SKELLY. Three to five cities will be selected as pilot projects.

Secretary RILEY. One, I think, in there will be Washington, DC, so that leaves several. Whether Milwaukee will be chosen would be dependent on what information we have and the criteria we establish. But Education, HHS, Labor, and Justice are among a number of different agencies that have pieces of after-school programs, and we very strongly support the program.

You would like to see Milwaukee as one of the test cities. I will see that they have that for their consideration. I do not know if you have already written us to that effect. If not, please submit that. I know your superintendent, Allen Brown. If you would ask him to submit why he thinks that would be——

Senator KOHL. I will do it.

Secretary RILEY. We certainly will see that that goes to the people.

Senator KOHL. Thank you. One more question.

BILINGUAL AND IMMIGRANT EDUCATION

In the school district of Wausau, WI, we have 22 percent Hmong and Laotian students. We have 45,000 Hmong and Laotian in Wis-

consin. It is the second largest in the country, and they desperately need programs, such as bilingual and immigration education.

Now, I know that you have an account for bilingual and immigration education, and the President's budget increases that account. Could I ask you to take a special look at the situation in Wausau, particularly the 25 percent of Hmong and Laotian students in Wisconsin, and in Wisconsin, where there are 45,000, the second largest concentration in the country? Can we see whether we could not provide some special assistance to that population?

Secretary RILEY. I certainly will do that. I have been there with you at one time and heard those concerns, and they are real. The Hmong children are refugee children, are they not?

Senator KOHL. Yes.

Secretary RILEY. Are the Laotian refugee children too?

Senator KOHL. Yes.

Secretary RILEY. And they are in a different situation than other immigrants certainly. They are in a preferred situation.

We are meeting with HHS on that today in fact. We are having some meetings on it.

Another very important program for them, of course, is title I. With the title I increases in here, and better targeting, title I really makes a big difference.

But we are meeting with HHS to take a look at that situation, and I will try to get you some information on that.

Senator KOHL. I do appreciate it, Secretary Riley.

Secretary RILEY. Thank you.

Senator KOHL. Thank you, Mr. Chairman.

ADDITIONAL COMMITTEE QUESTIONS

Senator SPECTER. Thank you very much. Secretary Riley, there will be some additional questions which will be submitted for your response in the record.

[The following questions were not asked at the hearing, but were submitted to the Department for response subsequent to the hearing:]

ADDITIONAL COMMITTEE QUESTIONS

NATIONAL TEST INITIATIVE—COST PROJECTIONS, PARTICIPATION, AUTHORITY AND OVERSIGHT

Question. How much of the fiscal year 1998 appropriations for the Fund for the Improvement of Education do you intend to use for development of national tests of 4th grade reading and 8th grade mathematics achievement?

Answer. We are unsure at this time of the exact amount that will be needed in 1998 funds for the development of these national tests. We are awaiting a request from the National Assessment Governing Board, which now has exclusive control over the contract for development of the tests. Based on informal discussions with NAGB staff, we are expecting NAGB to request approximately $8 million in 1998 funding.

Question. How much of the amount requested for fiscal year 1999 for the Fund for the Improvement of Education do you intend to use for future test development, field testing, etc., of the national tests, if you obtain authorization to continue this activity after the end of fiscal year 1998.

Answer. Our current estimate, again based on informal discussions with NAGB staff, is that we will allot $13.5 million to NAGB in 1999 for the test development contract.

Question. What is your current position on authorization for national test development and implementation after the end of fiscal year 1998—do you believe that you

have authority to proceed with this activity unless new restrictions are enacted, or do you believe that you need specific and explicit authority to continue with this activity beyond the actions and time period referred to in the fiscal year 1998 appropriations act?

Answer. We believe that we have authority, under the current authority for the Fund for the Improvement of Education, to proceed in 1999 with the development and pilot testing of these voluntary national tests. Our proposed appropriations language would ensure that the National Assessment Governing Board continues to have exclusive authority and oversight with regard to the voluntary national tests. The NAGB schedule for the development of these tests calls for pilot testing in March of 1999 and field testing in March of 2000. Absent the enactment of new restrictions, funds provided to NAGB in 1999 would support item development and pilot testing. Funds provided in 1998 cannot be used for pilot testing or field testing of the national tests.

Question. How many States have committed themselves to participate in the national tests, should they ever be implemented?

Answer. We no longer have a good count of the number of States committed to using these tests, given that the first administration of the tests is now scheduled for March of 2001.

Question. Does the number of States agreeing to participate justify the planned level of expenditure for this activity?

Answer. We believe that the costs of developing these tests is well justified. The annual cost of test development we estimate will be approximately $13 million. States and districts will bear the costs of administering the tests, which they will use on a voluntary basis. We expect that a large number of States, as well as many districts located in States that do not decide to use the tests on a statewide basis, will choose to use these tests when they become available in 2001.

Question. Is there any reason why we should authorize any post-fiscal year 1998 activity on the national tests before receiving the recommendations of the National Academy of Sciences on this initiative and such possible alternatives as linking scores pupils receive on current State and national tests?

Answer. We believe that the national test development activities should continue pending receipt of these recommendations from the National Academy. We should not risk discontinuing these activities when the Academy could conclude that linking is not a viable alternative.

Question. What changes in the national test development contracts and schedule have been made since oversight responsibility was shifted to the National Assessment Governing Board under the fiscal year 1998 appropriations act?

Answer. The National Assessment Governing Board is in the best position to respond with regard to changes in the contract. We do know that they have adopted a new schedule, which calls for pilot testing of potential test items in March of 1999 and field testing of alternative test booklets in March of 2000, with the tests first available for use in March of 2001. The Administration's original proposal was for the tests to be available for use in March of 1999.

CHILDREN'S LITERACY INITIATIVE—AMERICA READS CHALLENGE

Question. As you are aware, the $210 million provided in the 1998 appropriation for the Children's Literacy Initiative is contingent on the enactment of authorizing legislation by July 1, 1998; without that enactment, the funds transfer to the Special Education account. Given the lack of Senate action thus far on new reading legislation, should we ignore your request for $50 million in additional funding for Children's Literacy, or assume those funds should be appropriated for Special Education as well?

Answer. The Chairman of the Senate Labor and Human Resources Committee has indicated that he will push forward with a children's literacy initiative after the Congressional Easter recess. In fact, hearings on the literacy bill have been tentatively scheduled for April 28, 1998. Therefore, we fully anticipate the passage of a children's literacy initiative by July 1, 1998, and stand by our request of $50 million in additional funding.

ADMINISTRATION'S POSITION ON THE READING EXCELLENCE ACT—H.R. 2614

Question. Do you support the provisions of H.R. 2614, the Reading Excellence Act, as passed by the House last fall? Do you have any concerns about provisions of H.R. 2614?

Answer. On November 7, 1997, the President's Office of Management and Budget issued a Statement of Administration Policy (SAP) on the Reading Excellence Act. Following is a verbatim repetition of the SAP.

The Administration supports House passage of H.R. 2614 if the anticipated amendments are included in the bill. The bill is consistent with the objectives of the President's America Reads Challenge insofar as it: (1) provides tutoring assistance to children who need it; (2) promotes family literacy programs to help parents be their child's first teacher; and (3) improves teachers' ability to teach reading effectively.

The Administration does have concerns that need to be addressed in the Senate. First, while some progress has been made on the issue of tutorial assistance grants, the separate authority for these grants in the House bill should be deleted or substantially modified. In their current form, these grants are inadequately connected to, and supportive of, in-school reading programs and the local reading grants that the bill would also authorize.

Second, the Administration objects to the bill's new mandate on colleges participating in the work-study program. The current approach of providing incentives to colleges to use voluntarily more of their work-study funds for reading tutors is working well, and a new Federal mandate is not needed.

Third, the Administration objects to the bill's failure to include schools funded or operated by the Bureau of Indian Affairs (BIA) in the local reading improvement subgrant provisions of the bill. The BIA educates a considerable number of preschoolers and elementary school children, many of whom live in the poorest counties in the Nation and are in need of reading instruction assistance.

Additionally, the bill's provisions relating to the peer-review panel to be created under the bill should be revised to place the convening authority in the hands of the Secretary of Education, who administers this new program, in order to ensure accountability in the award of Federal funds.

Finally, the Administration is concerned that many of the provisions in the bill remain overly prescriptive and may limit the flexibility of local educational agencies in designing their programs.

TITLE I AND THE AGOSTINI DECISION—IMPACT ON PRIVATESCHOOL PUPIL PARTICIPATION

Question. Since the Supreme Court ruled, in the 1997 Agostini decision, that Title I services may be provided to eligible private school pupils in their own schools, has there been a significant increase in the number of private school pupils served under this program?

Answer. We need to give the decision some time to take effect before we can gauge the effects on private-school student participation in Title I.

The Court reversed its 1985 decision in June 1997, which means that LEA's and schools began planning and implementing new instructional arrangements beginning with the current school year (1997–98). We plan to collect data on private-school students' participation in Title I about mid-way into the 1998–99 school year, as part of the National Assessment of Title I. Since the Court has now removed a significant obstacle in serving private school children, we expect that participation will increase significantly.

TITLE I CAPITAL EXPENSES AND THE AGOSTINI DECISION

Question. Should we continue to provide funds for Capital Expenses related to serving private school pupils under Title I?

Answer. We believe that the 1999 Capital Expenses funds should be substantially less than the 1998 appropriation of $41 million, but that it may be prudent to retain a small amount of funding in the program for districts that have legitimate needs for these resources. Our $10 million request for 1999 would provide a third and final year of phase-out funding to districts that entered into long-term leases and other arrangements to comply with the Supreme Court's initial decision. In addition, school districts have use of the 1997 and 1998 Capital Expenses appropriations, totaling $82 million, to buy out leases, dispose of equipment, and make other less costly instructional arrangements to serve religious school students effectively.

Since the new decision removes the legal necessity for school districts to maintain costly arrangements to serve religious school students at neutral sites, the need for Capital Expenses funds is already dropping, and the demand for funds can be expected to decline sharply by 1999. Data show that, in the fall of 1997 (only 3 months after the Felton reversal), 21 States turned back all or some of their funds to the Department, compared to 18 States the year before. Also, 5 States requested additional funds, but 7 did the year before. The requests from New York and Pennsylvania, two of the States serving the largest numbers of private school children, both dropped by 40 percent from the previous year.

Question. What has been the total amount spent for Capital Expenses related to serving private school pupils under Title I, under either Capital Expenses or general Part A funds, between the 1985 Aguilar decision and the reversal of Aguilar by Agostini in 1997?

Answer. Before the Court's reversal of its 1985 decision on June 23, 1997, the Congress provided $323 million in annual appropriations for the Capital Expenses program, which school districts used to create and maintain arrangements for providing Title I services to private-school students off the premises of religious schools. We have no information on the amount of Title I, Part A funds, that were also used for this purpose. Under Title I, the extra administrative costs of providing equitable Title I services for private school children must be taken "off the top" of a district's Title I allocation.

Question. How can we avoid such an expensive flip-flop of national policy toward serving private school pupils in the future?

Answer. We do not expect the Supreme Court to change its position on this issue. The Court reached the common sense result of permitting Title I supplemental services to be moved out of vans into school classrooms, with appropriate safeguards to ensure there is no improper appearance of State endorsement of religion.

The Administration argued for and strongly supports the Court's decision because it eliminates the legal necessity for costly and often less educationally effective alternative arrangements for providing Title I services to private school students. For more than 10 years, the Department, and State, local, and private school officials, struggled with the problems created by the 1985 decision. That decision made it much more difficult to provide Title I services to educationally disadvantaged religious school students, since those students had to leave their buildings in order to be served, and time was lost getting those children to and from Title I programs. It was hard to provide equitable access when instruction for public school children takes place in their school building, while private school students had to leave their schools in order to be served.

UPDATED CENSUS DATA AND TITLE I ALLOCATIONS TO COUNTIES

Question. Have you made a formal decision regarding use of census population update estimates for counties in the allocation of fiscal year 1998 appropriations for Title I?

Answer. Yes. We were able to make a decision early this year, thanks to the splendid work by the Census Bureau and the Committee on National Statistics' Panel on Estimates of Poverty for Small Geographic Areas, convened under the auspices of the National Academy of Sciences.

To give you some background, in making Title I allocations, the Department (by statute) is required to use the Census Bureau's updated poverty data at the county and school-district levels, unless the Secretaries of Education and Commerce determine that these data would be inappropriate or unreliable for this purpose. In making this determination, the Secretaries must consider the recommendations of the National Academy of Sciences.

Between June and October 1997, the Census Bureau carried out extensive evaluations of its model for updating the number of school-age children from low-income families in counties. On the basis of those evaluations, the Bureau revised its model and prepared a revised set of 1993 county estimates. After conducting a full assessment of the Census Bureau's work and its evaluation results, the Academy, in January 1998, published its findings and recommendations on the Bureau's model for producing updated county-level estimates of poor school-aged children. This report, entitled "Interim Report 2, Evaluation of Revised 1993 County Estimates for Title I Allocations," concluded that the updated estimates are superior to those from the outdated 1990 census, and that the revised estimates should not be averaged with estimates from the 1990 census, as was done for last year's allocations.

Secretary Daley and I have accepted the Academy's recommendations. The Department will allocate the 1998 Title I appropriation on the basis of the Census Bureau's updated county-level estimates.

UPDATED CENSUS DATA ESTIMATES FOR LOCAL SCHOOL DISTRICTS

Question. Are you, the Census Bureau, and the National Academy of Sciences on schedule to produce and evaluate population updates for local school districts, as required under the Title I statute to be used in allocating fiscal year 1999 appropriations?

Answer. While we have a workable schedule for producing and evaluating the Bureau's current approach for updating poverty estimates, both the Commerce and Education Departments continue to have major uncertainty about the feasibility of

producing reliable estimates at the school-district level. As the National Academy of Sciences notes in its January 1998 report, creating poverty estimates at the local educational agency (LEA) level is far more complex than making estimates for counties, because of limitations in the data available for producing these estimates and because of the physical characteristics of school districts. For example, most districts are very small, most have boundaries that do not conform to any other boundary or administrative unit, and some districts overlap counties. Using the Census Bureau's model for updating county-level poverty estimates is not an option, since that model relied on data on food stamp recipients, income taxes, and population that do not exist at the school district level. In addition, Department staff believe that other problems, such as changes in school district boundaries and the unavailability of the required noncensus counts of children at the LEA level, may also hamper fiscal year 1999 implementation of LEA allocations.

The current schedule calls for the Bureau to transmit its LEA-level estimates to the National Academy of Sciences for review and evaluation by October 1998. The Academy is required to issue a report 90 days later outlining its recommendations with regard to the use of the LEA data for fiscal year 1999 Title I allocations. Based on the Academy's recommendations, the Secretaries of Commerce and Education expect to be able to make a decision by January 1999 about whether to use the data for fiscal year 1999 Title I allocations.

Question. What is your view of the reliability of the population update process at Census thus far?

Answer. We agree with the National Academy of Sciences that the Census Bureau's process produced updated county poverty estimates that are demonstrably superior to estimates from the outdated 1990 census and that they are appropriate and reliable for making fiscal year 1998 Title I allocations.

IMPACT OF CENSUS UPDATES ON TITLE I FORMULA ALLOCATIONS

Question. Why have the updates produced thus far appeared to be biased against certain high poverty parts of the Nation, such as several Southern states, and in favor of certain low poverty areas, such as many fast-growing suburban counties?

Answer. The updates reflect large demographic shifts in poverty and population that took place between 1989 and 1993.

Through the operation of the Title I formula, States and counties with above-average increases in their number of poor children gain funds, while States and counties with reductions in poor children (or increases lower than the national average increase of 28.2 percent) lose funds. Indeed, most States and counties that lose Title I funds do so because of below-average increases in poverty rather than actual decreases. High-poverty areas that receive reductions, using the updated estimates, in their Title I funds do so because they have a smaller proportion of the Nation's poor children compared to where they were four years earlier.

High-poverty school districts will continue to receive larger allocations per poor child due to the Concentration Grant formula. In fact, the fairest and most effective way to increase targeting is by directing more funds through the Concentration and Targeted Grants formulas, not by using out-of-date poverty data. The President's budget request for fiscal year 1999 would direct almost all the increase ($391 million) through these two formulas.

High-poverty counties and school districts also receive protection through the statutory "hold-harmless" provision, which ensures that those with poverty rates of 30 percent or more receive at least 95 percent of their prior year allocation.

INNOVATIVE EDUCATION PROGRAM STRATEGIES—GOALS 2000: EDUCATE AMERICA ACT AND TITLE VI OF ESEA

Question. For the fifth year in a row, the Administration is proposing termination of funding for the education block grant, the State grant program for Innovative Education Program Strategies authorized under Title VI of the Elementary and Secondary Education Act. How do you justify the elimination of one of the most flexible and popular forms of Federal assistance for elementary and secondary education?

Answer. The Administration believes that the Title VI program is not well designed to support the types of State and local efforts that can result in real improvements in teaching and learning. Findings from the most recent evaluation of the former Chapter 2 program, Title VI's predecessor, suggest that programs that provide greater accountability, but offer the flexibility of Title VI, have a better chance of effecting real change in the classroom. For example, the evaluation found that program funds were used by fewer than half of the States to support reform efforts such as revising and developing standards for student performance, developing alternative measures of student achievement, or encouraging public-private partner-

ships. Districts were even less likely than States to use Chapter 2 funds to support education reform efforts. Although more than half of all districts reported some systemic reform efforts, fewer than one-fourth of them used Chapter 2 funds to support these activities.

The Department believes that a more effective way to utilize scarce resources lies in targeting funds on comprehensive systemic reform and areas of high need. For example, programs under the Goals 2000: Educate America Act provide almost the same flexibility as Title VI, but make the critical link between expenditures and educational reform that Title VI does not. States are using Goals 2000 funds to establish challenging academic standards and to coordinate their curriculum frameworks, student assessment programs, and other aspects of their educational systems to help children achieve to the State standards.

States distribute at least 90 percent of their Goals 2000 funds directly to local educational agencies (LEA's) for local reform, the improvement of preservice teacher education programs, and professional development. At least half of the money for local reform goes to LEA's that have a greater percentage or number of disadvantaged children than the statewide average. LEA's must ensure that at least 75 percent of their first-year money and at least 85 percent of subsequent years' funds go to individual schools so that schools can tailor their own improvement plans to help students meet the State or local standards.

EVALUATION OF TITLE VI, ESEA PROGRAM

Question. The education block grant program appears to achieve its popularity through being one of the few sources of funds that can be used for educational improvement purposes as determined by local educational agencies. For what school year did you last conduct an evaluation of the accomplishments of this program at the local level?

Answer. The 1994 evaluation of Chapter 2, "How Chapter 2 Operates at the Federal, State, and Local Levels," which collected data in the 1991–1992 school year, is the most recent evaluation of the program. Several findings from the evaluation have prompted the Administration to question the effectiveness of the Title VI program. For example, the evaluation found that LEA's tended to concentrate their Chapter 2 expenditures on instructional materials rather than educational reform activities. In addition, States and LEA's sometimes used Chapter 2 funds for activities and programs that were not directly related to classroom instruction; for example, LEA's often purchased equipment for administrative use, and SEA's also used Chapter 2 funds for various administrative activities. The evaluation also found that the majority of activities supported by Chapter 2 funds would have continued without Chapter 2, because these funds typically constituted a small percentage of any program's funding.

The 1994 evaluation determined that, because States had a wide latitude in how they conducted their self-evaluations for effectiveness and in how they used accountability mechanisms for LEA's to access compliance with Federal and State regulations and fiscal matters, there was a problem across Chapter 2 programs regarding the lack of good evaluations. Almost one-fourth of LEA's conducted no evaluations of their Chapter 2 activities, and those that did tended to collect informal feedback or anecdotal evidence about program outcomes.

The Department has not followed up the 1994 study with another stand-alone evaluation of Title VI. This course of action has seemed wise, given limited evaluation resources, because the 1994 reauthorization did not make significant changes to the statute, and there is little reason to believe that State and local program practices have changed since the early 1990's. However, the Department will collect data on the uses of funds under Title VI (as well as Titles I, II, III, IV, and Goals 2000) through the forthcoming "Targeting and Resource Allocation Study." This study should be completed in early 1999.

PROGRAM EVALUATIONS AND INNOVATION PRIORITIES

Question. Do your program evaluations show the extent to which local schools have any other source of funds to meet locally determined improvement and innovation priorities?

Answer. Goals 2000 provides assistance for States to develop their own strategies for comprehensive reform of elementary and secondary education. With the help of Goals 2000, States are establishing academic standards and coordinating their curriculum frameworks, student assessment programs, teacher preparation and licensure requirements, parental and community involvement activities, and other aspects of their education system to help children achieve the State standards. As mentioned above, States must distribute at least 90 percent of their Goals 2000

funds directly to LEA's, and at least 75 percent of the LEA's' first-year money and at least 85 percent of subsequent years' funds go to individual schools so the schools can tailor their own improvement plans to help students meet the State or local standards.

In addition, beginning in 1995, more schools became eligible to operate schoolwide programs, which allow high-poverty schools to use Title I funds, in combination with other Federal, State, and local funds, to improve the overall instructional program for all children in a school. About 25,000 schools receiving Title I funds are now eligible to implement the schoolwide approach, compared to about 10,400 under the previous law.

Finally, Congress appropriated $120 million to support comprehensive reform in schools eligible for Title I funds in fiscal year 1998. An additional $25 million is available to all public schools, including those eligible for Title I. The Comprehensive School Reform Demonstration program (CSRD) is focused on assisting schoolwide changes in schools where there is the greatest need to substantially improve student achievement. CSRD funds are intended to help schools improve their entire educational operation through curriculum changes, sustained professional development, enhanced involvement of parents, and other reforms, based on a careful identification of local needs.

BLOCK GRANTS AND OTHER FEDERAL REGULATORY AND PAPERWORK REDUCTION EFFORTS

Question. The education block grant program has reduced Federal regulatory and paperwork burdens to a minimum. Have you considered modifying other Federal education programs to be more like it, rather than proposing block grant termination?

Answer. In addition to the programs mentioned above, which provide considerable flexibility to States and LEA's, the Department offers other means to keep paperwork and regulatory burdens to a minimum, including the Education Flexibility Partnership Demonstration Program (Ed-Flex) and the waiver authorities under the Elementary and Secondary Education Act, the Carl D. Perkins Vocational and Applied Technology Act, and Goals 2000.

Question. As you can see last year from the Senate passage of the Gorton amendment to the 1998 appropriations that would have created a $13.4 billion elementary and secondary education block grant, the Congress continues to give considerable support for reducing the number of education programs, and reducing the administrative and paperwork burdens associated with such programs. What steps are you taking that might increase State and local flexibility while streamlining the administrative procedures connected with the current array of Federal education programs?

Answer. In addition to the programs and activities that provide State and local flexibility mentioned above, Goals 2000 allows the Secretary the authority to: (1) waive certain Federal regulatory and statutory provisions that may impede State or local reform efforts; (2) delegate up to 12 States the authority to waive these provisions without having to secure additional Federal approval through Ed-Flex; and (3) distribute Goals 2000 funds directly, on a competitive basis, to LEA's in States that choose not to participate in Goals 2000.

The Department has worked hard to ensure that States and LEA's can benefit fully from these authorities. For example, the Department has granted Ed-Flex status to 12 States and will seek congressional approval to expand the authority so that all States are eligible. In addition to Goals 2000, the Department can grant waivers under the Carl D. Perkins Vocational and Applied Technology Act and the Elementary and Secondary Education Act, including most of the requirements of major Federal education programs such as Title I, Even Start, Eisenhower Professional Development, and Safe and Drug-Free Schools. To date, the Department's Waiver Board has granted over 200 waivers to States and LEA's to provide increased flexibility in exchange for increased accountability for raising student achievement. This flexibility allows States and LEA's to address local needs with locally designed solutions. Finally, only two States, Oklahoma and Montana, have chosen not to participate in Goals 2000, and the Department will award grants to LEA's in those States in early summer, following a competition.

In its program reauthorization proposals, the Department has proposed statutory revisions to increase State and local flexibility and reduce administrative overhead. For example, our vocational education proposal would eliminate numerous set-asides and provide States with flexibility by eliminating many requirements and providing for Federal waivers. For the reauthorization of the Adult Education Act, the Department has proposed to streamline numerous existing authorizations and

provide States with flexibility provisions similar to those in our vocational education proposal. The Department will look for similar opportunities in the Elementary and Secondary Education Act, which comes up for reauthorization next year.

FUNDS USED FOR CLASSROOM AND ADMINISTRATIVE COSTS

Question. One of the issues frequently heard in support of education block grants is that too great a portion of each Federal program dollar never reaches the actual classroom. Do you have any data showing the allocation between classroom and non-classroom uses of funds under the major elementary and secondary education programs administered by the Department?

Answer. The Department recently prepared a report, The Use of Federal Education Funds for Administrative Costs, that provides the most up-to-date information about the amount of Federal elementary and secondary funds that are used by States and LEA's for classroom instruction, instructional materials, and other programs and services that benefit teachers and students directly, and the extent to which those funds are used for administrative purposes. The report summarizes data obtained from several sources, including: (1) the GEPA 424 report, a Department of Education data collection report with information on the distribution of Federal funds for a wide range of Federal programs supporting elementary and secondary education for fiscal year 1995; (2) data from a Coopers & Lybrand Financial Analysis Model provided by Milwaukee, by South Carolina for 33 of its school districts, and by Rhode Island for seven of its districts, as well as published data for 13 other school districts for earlier school years; and (3) GAO reports.

Major findings include the following:

—For programs under the Elementary and Secondary Education Act, the percent retained at the State level is about 2 percent; for Title I, the percent is 1 percent.

—In general, States retain substantially less money at the State level than is permitted by law. For example, in fiscal year 1995, States were permitted to retain up to 20 percent of Title VI (Chapter 2) money, but only retained 9 percent in actual practice.

—At the local level, about four-fifths of Title I funds are used for instruction, with additional funds used for supporting activities, such as professional development, curriculum development, counseling, and other activities that have a direct impact on teachers and students. Local administrative expenses appear to range from 4 to 13 percent of local expenses, depending on the location and the data base considered.

—Across all Federal elementary and secondary programs, instruction and instructional support account for 88 percent of local expenditures.

Question. To what extent do the non-classroom uses of Federal education dollars meet important national education objectives?

Answer. States and LEA's use Federal funds to support a range of non-classroom activities that directly support instruction, including the development and implementation of standards and assessments, professional development, curriculum development, parent and community involvement programs, and technical assistance.

CLASS SIZE REDUCTION AND TEACHER FINANCING INITIATIVE

Question. Why would the proposed Class Size Reduction initiative be funded through mandatory budget authority?

Answer. The initiative is proposed for mandatory funding because it is intended to be funded through tobacco settlement revenue. In addition, the Administration believes that the annual discretionary appropriations process would not provide districts with the necessary certainty that funds will be available, and that the program requires the firm commitment provided through a mandatory appropriation.

Question. For school districts who hire new teachers with funding from the proposed Class Size Reduction initiative, there are potentially significant long-term financial costs as these teachers gain experience and further training, and move up their respective pay scales. Does the Administration intend that the Class Size Reduction initiative continue beyond the 7-year time period cited in the budget request in order to assure participating districts that the burden of those long-term costs does not fall solely upon them?

Answer. Yes, the Department does intend for the Class Size Reduction initiative to continue beyond the 7-year time period. The initiative is to be financed through revenues from a tobacco settlement, and any settlement is likely to provide revenues for at least 25 years.

Question. Why are States' average class sizes in grades 1 through 3 not used at all in determining State shares of funds under the Class Size Reduction initiative?

Answer. The Title I formula allows funds to be targeted to the States with the highest levels of poverty and the greatest financial need. For within-State allocations, States would be required to distribute funds based on each local educational agencies class sizes and their relative ability and effort to finance class-size reductions with their own resources.

ACHIEVEMENT GAINS FROM CLASS SIZE REDUCTIONS

Question. The proposed Class Size Reduction is intended to reduce the average class nationwide in grades 1 through 3 from 22 students to 18 students. How do you respond to critics who state that a reduction of this size is not sufficient to generate student achievement gains commensurate with the cost of the initiative?

Answer. Two recent research studies have found that smaller classes can mean higher levels of student achievement, at least through the elementary school grades, particularly for minority, poor, and inner-city children.

One study examined the results on the 1992 National Assessment of Educational Progress (NAEP) mathematics assessment for 10,000 fourth- and eighth-graders. The study found that students in small classes, those classes with fewer than 20 students, performed better than students in large classes for both grade levels, even taking into account student demographics, overall resource levels, and the cost of living.

Studies of the Tennessee Student-Teacher Achievement Ratio (STAR) project have also found that students in small classes performed better than students in large classes in each grade from kindergarten through third, and that the achievement benefits persisted through at least the eighth grade. The same benefits from small classes were found for boys and girls alike. While all types of school districts—inner-city, urban, suburban, and rural—realized significant gains from small classes, the gains were greatest for minority and inner-city students in each grade. Further analyses of the results have found that students in small classes are less disruptive and less likely to be retained than their peers in larger classes.

One of the biggest advantages to reduced class sizes is that it provides teachers with an opportunity to better gauge their students' strengths and weaknesses and get to know them as individuals. Research verifies this by demonstrating that classroom structures that allow teachers to know students and their families well are associated with increased achievement, more positive feelings toward school, and more positive behavior.

In addition, reduced class size allows teachers to work more closely with their students and, as a result, they are better able to identify students with learning disabilities. Potentially, early identification of, and remediation for, children with learning disabilities can reduce the need for special education services in the later grades and eliminate, or substantially reduce, the costs associated with such services.

SIZE REDUCTION AND OTHER STRATEGIES TO IMPROVE ACHIEVEMENT

Question. Are there other kinds of improvement strategies that promise as much or more achievement gain, but at a lower cost?

Answer. The Department believes that reducing average class sizes in grades 1 through 3 is an essential component of any strategy to raise the educational achievement of all students. Rigorous research has shown the benefits of small classes for all children, but particularly for minority and inner-city students. If the benefits of small classes are to be fully realized, this strategy must be a part of comprehensive educational reforms.

In order for the benefits of small classes to be fully realized children cannot simply be placed in smaller classes, but must also be: expected to achieve to challenging content and performance standards, and have their progress measured by tests aligned to those standards; attend schools that are able to recruit and retain a qualified teaching staff; and taught in environments conducive to high achievement.

21ST CENTURY COMMUNITY LEARNING CENTERS

Question. The Administration's fiscal year 1999 budget request of $200 million for 21st Century Community Learning Centers represents a 400 percent increase above the fiscal year 1998 appropriation. At the proposed level, the program would support extended-day activities in approximately 4,000 schools serving up to half a million school children. What evaluations and program outcomes justify such an increase?

Answer. The importance of these programs has been demonstrated through various studies, including FBI statistics that show the greatest rates of crime and violence to be between the hours of 2 to 8 p.m. Additionally, research clearly shows that positive and sustained interactions with adults contribute to the overall devel-

opment of young people and their achievement in school. Research also indicates that in high-quality programs—where student to staff ratios are low, staff are well-trained, and a wide variety of activities are offered—students have more positive interactions with staff, better peer relations, and better grades and conduct in school than their peers in other care arrangements. These outcomes are particularly beneficial for disadvantaged or low-achieving students, who typically lack resources such as technology and outside tutoring.

The six current 21st Century Community Learning Centers projects, now in their final year, have successfully established community centers offering important services to students, families, and low-income adults, provided through the development of partnerships between schools and local agencies, organizations, businesses, and colleges. Because the projects are completing their final year of funding, the Department will not have specific outcome data until the final reports are received. However, we do have information on what each project has accomplished thus far.

For example, the Clinton County 21st Century Community Learning Center created a GED program for high-school drop-outs. Its initial goal was to enroll 20 students; ultimately it enrolled 72 students. During its second year, the project expanded to include distance learning and technology classes for 150 participants. The Center also served over 100 individuals in professional development and continuing education courses. This project involved such community groups as the Western Kentucky University, the Bank of Clinton County, Berea College, and the Department of Social Services.

Another project administered by the Chicago Public Schools involved 37 school principals, in conjunction with parents, community organizations, municipal service providers and local agencies. Together, these groups established literacy, GED, and tutoring programs, as well as workshops on computer skills, nutrition, and parenting. A series of Saturday sessions promoted family involvement by providing instruction to both parents and children together.

AFTER-SCHOOL CENTERS A FEDERAL CONCERN

Question. Why should a program of after-school services become a Federal rather than State or local concern?

Answer. It has become a Federal concern because of the demonstrated need for these centers in communities across the Nation and the potential of these centers to improve achievement and safety in schools. Recent studies estimate that 5 million children are left unsupervised after school. The requested funds would provide services for only a percentage of these children. The majority of schools do not currently have such programs. The most recent survey from the National Center for Education Statistics (NCES) revealed that in 1993–94, 30 percent of all public elementary schools had centers. In urban areas, more than 40 percent of schools had centers, and in rural areas, only 18 percent. Availability in high-poverty schools was similar to that of low-poverty schools, but high-poverty schools showed greater participation rates.

This year, over 5,000 people attended the information sessions on the 1998 competition that were sponsored by the C.S. Mott Foundation. The Department received nearly 2,000 applications, and many more requests for applications and information.

ADMINISTRATION OF 21ST CENTURY LEARNING CENTERS

Question. Why should the Department of Education administer this program rather than the Department of Health and Human Services (HHS)?

Answer. This question was carefully considered by the Administration before submitting its request. The Department of Education is administering this program because this enables us to emphasize educational services and the use of schools as community centers.

HHS currently administers the Child Care and Development Block Grant (CCDBG) which provides, through the States, direct support to low-income parents to help them pay for child care; it also provides funding to providers of after-school programs to subsidize the participation of children from poor families. As a complement to the CCDBG focus on meeting demand by helping poor parents pay for child care, the 21st Century Community Learning Centers addresses the supply issue by providing seed money to establish or expand programs that utilize public school buildings cost-effectively to serve school-age children.

School-based programs also providealong with recreational and nutritional programsunique opportunities to link out-of-school learning activities with the core curriculum, providing advancement, enrichment or extra help that can make a difference in each student's academic success. Schools are convenient and accessible to students and parents and have much of the resources needed for such programs.

Also, school-based centers can result in increased community and parent involvement in the school. Yet, despite high demand from parents and overwhelming support from educators for school-based programs, the majority of the Nation's elementary and middle schools still do not offer after-school programs.

EDUCATION OPPORTUNITY ZONES PROPOSAL

Question. Why do you propose another new program targeted at high-poverty areas when we already have not only the Title I, Elementary and Secondary Education Act program but also the new Comprehensive School Reform program initiated in the fiscal year 1998 appropriations act?

Answer. The Education Opportunities Zones program would differ in emphasis from both Title I and the Comprehensive School Reform Demonstrations. While Title I and the Comprehensive School Reform Demonstrations focus on improving achievement at individual schools, the Education Opportunity Zones program would emphasize implementation of policies that improve student achievement districtwide. These programs would be complementary, and all three would focus on assisting students to achieve to high standards.

The Education Opportunity Zones program would distribute comparatively large grants to a limited number of competitively selected, high-poverty urban and rural school districts. To be eligible for a grant, the district would have to demonstrate that it had already begun to implement educational reforms and raise student achievement, at least in some schools. The purpose of the program would be to demonstrate that districts that expect all students to achieve to high standards and hold students, teachers, and schools accountable for achieving to those standards, can help raise achievement across an entire district.

The Comprehensive School Reform Demonstration program provides funds by formula to States which then distribute the funds competitively to districts on behalf of individual schools. The program focuses exclusively on comprehensive school-level reform programs that have a strong research basis and have been successfully replicated. The program can help bring together Title I schoolwide funds, and other Federal, State, local, and private resources to support an integrated strategy to enable all children in a school to reach challenging academic standards. Comprehensive School Reform funds can help schools in Education Opportunity Zones implement proven models of reform, and can provide additional resources for Education Opportunity Zones to use for turning around failing schools.

UNIQUE FEATURES OF EDUCATION OPPORTUNITY ZONES

Question. What would be the unique contribution of the Education Opportunity Zones initiative?

Answer. The Education Opportunity Zones initiative would have a focus on district-wide reforms, rather than the focus on school-level reform efforts contained in Title I and the Comprehensive School Reform Demonstrations. The Zones initiative would differ from other programs in that it would provide support only to high-poverty urban and rural school districts that have already begun to implement accountability-based, comprehensive educational reform policies, and have begun to show significant improvement, in at least some of their schools, in the educational achievement of all students. The grants would enable selected districts to expand the scope and accelerate the pace of their reforms, so that they can achieve, in more schools, the kinds of successes realized in some schools in these districts. Districts could use their funds for such activities as: (1) implementing a school-performance-information system to measure the performance of schools in educating their students to high standards; (2) increasing public school choice through such strategies as open enrollment policies or charter schools; or (3) improving teaching through the development of a system for identifying ineffective teachers, providing them with assistance to improve their performance, and removing those teachers whose performance does not improve.

Question. Why should we not focus on expanding and improving the existing programs aimed at the same problems?

Answer. The Administration has requested funds to expand current programs like Title I, Goals 2000, and the Comprehensive School Reform Demonstrations. However, for the reasons outlined above, we believe the Education Opportunity Zones program will address a unique and difficult mission, and strongly support its enactment and funding as well.

Question. When do you anticipate that legislative language for this proposal might be transmitted to the Congress?

Answer. The Secretary transmitted the Education Opportunity Zones proposal to Congress on March 3, 1998.

CALIFORNIA BALLOT INITIATIVE "ENGLISH FOR THE CHILDREN"

Question. A State ballot initiative entitled "English for the Children" will go before California voters in June 1998. The initiative would significantly alter instructional services for limited English proficient (LEP) children in California elementary and secondary schools. Among other things, the initiative calls for programs of sheltered English immersion as the primary means to teach English to LEP students. Would there be any conflict between the initiative, if enacted, and Federal civil rights laws enforced by the Department of Education?

Answer. The Departments of Education and Justice are currently reviewing the language of the "English for the Children" initiative to determine if it would conflict with civil rights law. We are not yet ready to make a judgement on this issue, but expect to be able to do so in the near future.

Question. Could sheltered English immersion programs as specified in the initiative qualify for assistance under the Bilingual Education Act?

Answer. A significant number of the projects funded under the Bilingual Education Act employ instructional methods that use only English. At first glance, it seems likely that such projects would not conflict with the "English for the Children" ballot initiative, although the one-year timeframe specified in the initiative could be a problem.

ENSURING ENGLISH LANGUAGE ACQUISITION THROUGH BILINGUAL EDUCATION

Question. Public Law 105–78, the Departments of Labor, Health and Human Services, and Education and Related Agencies Appropriations Act, 1998, includes a requirement that the Department of Education only support Bilingual Education Act instructional services grants that "ensure that students completely master English in a timely fashion (a period of 3 to 5 years) while meeting rigorous achievement standards in the academic content areas." (111 Stat. 1500) How is the Department of Education implementing this requirement in the grant-making process?

Answer. This language, which was first included in the fiscal year 1996 appropriations act, reinforces language in the authorizing statute. The authorization makes it clear that helping limited English proficient students learn English and meet challenging State academic standards is the primary goal of all bilingual education projects funded under the statute. While the authorizing statute does not include a specific time frame for these goals, the appropriations language is fully consistent with the language in the statute.

Applications for new awards are rated by outside peer reviewers who are given training in how to rank applications in accord with statutory and Departmental requirements. Departmental officials brief the reviewers on the statutory requirements for these projects, and on each of the published selection criteria. One of the criteria is "quality of the project design" and another is "proficiency in English and another language."

Once the peer reviewers complete their ratings, staff from the Office of Bilingual Education and Minority Languages Affairs review the applications to make sure that they comply with statutory requirements, including that they are designed to ensure that students completely master English in a timely fashion (a period of 3 to 5 years) while meeting rigorous achievement standards in the academic content areas.

The statute requires grantees to submit evaluations every two years. These evaluations must include information on the progress of students served by the program in attaining English proficiency.

YEAR 2000 COMPUTER CONCERNS

Question. There has been lots of public speculation that many computer systems, including mainframes and desktops and many of the software programs as well, will become unworkable on January 1, 2000. What are the major uses of computers within the Department, both for management activities and program operations?

Answer. The Department uses mainframes and desktops for many of its management activities and program operations. Computers are used to operate the Department's delivery systems dealing with student financial aid and Impact Aid programs, to foster communications internally and externally through the Internet and e-mail, and to operate the Department's accounting system. Many of these systems have been identified as mission- critical for Year 2000 purposes.

Mission-critical department computer systems

Following is a list of the 14 mission-critical systems along with a description of each system's purpose:

—Campus-Based Program System—receives summary data from participating schools, determines institutional awards, allocates funds and reconciles institutional accounts.
—Central Processing System—confirms applicants' eligibility for Federal student financial assistance.
—Direct Loan Central Database—functions as the central repository for summary-level data on Federal Direct Loan Program (FDLP) loans, including aggregated financial data reported from the FDLP servicer(s).
—Direct Loan Origination System—supports FDLP loan origination to book loans, reconciles with schools, and receives disbursement information from schools as each loan is disbursed to a recipient.
—Direct Loan Servicing System—services FDLP loans while the borrower is in school, in deferment status, or in repayment.
—Federal Family Education Loan System—pays interest and special allowances to lenders.
—Multiple Data Entry System—receives paper applications for Federal student financial assistance.
—National Student Loan Data System—functions as a national database of loan/grant-level data on the Title IV programs. Among its many purposes, it is used to prescreen Title IV applicants for eligibility.
—Pell Grant Recipient Financial Management System—supports delivery of aid under the Federal Pell Grant program.
—Postsecondary Education Participants System—maintains data on school participation. These data include eligibility, certification, and program participation information.
—Title IV Wide Area Network (TIVWAN)—a value-added network that functions as a participant management system through which users indicate which services they want to use from the systems TIVWAN supports.
—Education Central Administrative Processing System—(EDCAPS) the redesign of the Department's core financial functions, work processes and procedures. (This system is Year 2000 compliant.)
—Education Central Network—the Department's hardware/software infrastructure.
—Impact Aid System—receives summary data from participating school districts, determines awards, allocates funds and reconciles school district accounts.

GAO PLAN FOR MINIMIZING OR ELIMINATING THE YEAR 2000 COMPUTER PROBLEM

Question. What steps has the Department taken to eliminate or minimize the "Year 2000" computer problem from these activities and operations, and, how much additional work, if any, remains to be done?

Answer. The Department follows the five-phase approach recommended by the General Accounting Office and the Office of Management and Budget. The five phases are: awareness, assessment, renovation, validation and implementation.

The awareness phase is an ongoing activity to help the Department's customers inside and outside the Federal government and the education community understand the scope of the Year 2000 problem. During this phase, customers are advised of the steps needed to be taken to ensure that their systems are Year 2000 compliant.

The assessment phase, completed in February 1998, resulted in an inventory of the information technology systems used at the Department, the classification of each system by criticality, and the determination of the appropriate compliance strategy or disposition for each system. Criticality, expressed as "mission-critical" (most critical), "mission-important" and "mission-supportive" (least critical) indicates which of the Department's systems are most essential to its functions.

The dispositions determined from the assessment phase—compliance, repair, replacement or retirement—form the basis of the renovation phase. A system determined to be compliant can skip to the validation phase. If a system needs repair, modifications are scheduled to bring it into compliance. If a system needs to be replaced, a new compliant system will be developed to serve its function. Finally, a system will be retired if its functions can be eliminated or assumed by another system that is compliant.

During the validation phase, compliant systems and those with completed renovations are tested to prove compliance. An independent third party will verify and validate each of the mission-critical and high risk mission-important systems.

The implementation phase will assure that all data exchange agreements are in place and that non-compliant systems are replaced with the renovated compliant

systems. This phase requires a relatively short period of time compared to the others.

Currently, the assessment phase is complete, renovations are in process for noncompliant systems, and validations are in process for compliant and renovated systems. Several systems have been validated and implemented. Overall there are 14 mission-critical, 30 mission-important, and 144 mission-supportive systems at the Department, most of which will require additional renovation, validation and implementation efforts.

CONTRACTED DEPARTMENTAL COMPUTER ACTIVITIES

Question. What major computerized activities does the Department have under contract?

Answer. All of the Department's mission-critical computer systems are under contract. They include the following: Campus-Based Program System; Central Processing System; Direct Loan Central Database; Direct Loan Origination System; Direct Loan Servicing System; Federal Family Education Loan System; Multiple Data Entry System; National Student Loan Data System; Pell Grant Recipient Financial Management System; Postsecondary Education Participants System; Title IV Wide Area Network; Education Central Administrative Processing System; Education Central Network; and Impact Aid System.

In addition, a number of mission-important systems are under contract. An example of a mission-important system is the Department's payroll processing system, maintained by the Department of the Interior.

ENSURING YEAR 2000 COMPLIANT SYSTEMS FOR DEPARTMENTAL PROGRAMS DEPENDENT ON COMPUTER SYSTEMS

Question. Which major programs, such as the National Assessment of Educational Progress, are heavily dependent on computers?

Answer. The programs most dependent on computers in the Department include those that are directly supported by one or more of its mission-critical systems. These programs are the Federal Family Education Loan Program, the William D. Ford Direct Loan Program, the Pell Grant Program, Campus Based programs and the Impact Aid Program. In addition, all programs within the National Center for Educational Statistics (NCES), including the National Assessment of Educational Progress depend on computer processing due to the large amount of data that needs to be analyzed. Please note, however, that in addition to validation procedures, none of the computer programs used to support NCES perform date calculations.

Question. What steps have you taken to ensure that these various contracted systems will survive the "Year 2000" problem?

Answer. To ensure that the Department's systems operated by contractors will be Year 2000 compliant, each step of the renovation and validation phases of the project is closely monitored and tracked by the Department's Year 2000 staff and experts from the firm of Booz-Allen and Hamilton. Status reports on each system are provided to the Year 2000 Steering Committee on a weekly basis. The Steering Committee is chaired by the Deputy Secretary, and includes the Chief Financial and Chief Information Officer and senior executives from program and staff offices responsible for major systems and Year 2000 renovations.

As each mission-critical system is renovated, a qualified third party will conduct an independent verification and validation (IV&V) on the system to confirm that it is Year 2000 compliant. Results of each IV and V analysis will be reported to the Steering Committee.

In addition, the Department is developing contingency plans for each mission-critical system. These plans will provide for continued delivery of services in the event of a system failure.

YEAR 2000 DEPARTMENTAL OUTREACH EFFORTS TO THE STATES

Question. What steps have you taken to find out what education activities at the State level are dependent on computerized activities?

Answer. The Department is conducting an inventory of all of its data exchanges with the States. Once the inventory is completed, the Department will provide States with points of contact and any new data formats to ensure that all future data exchanges are Year 2000 compliant.

Numerous written communications have been made with the Department's data exchange partners and customers regarding Year 2000. For example, in January 1998, the Deputy Secretary and the Executive Director of the Council of Chief State School Officers sent a Dear Colleague Letter to the Chief and Deputy Chief State School Officers in the 50 States, the District of Columbia, and the territories. In the

same month, the Deputy Assistant Secretary for Student Financial Assistance sent a Dear Colleague Letter to the 7,000 postsecondary education institutions participating in the Department's student aid programs.

The Year 2000 Project Management Team has made telephone contact with several State Year 2000 coordinators and various constituent groups, including the Council of Great City Schools and the District of Columbia School System.

Year 2000 outreach efforts

Examples of other Year 2000 outreach efforts that have been conducted include:

—In July 1997, the Department briefed the National Association of Student Financial Aid Administrators on the need to address the Year 2000 issue;

—In October 1997, the Deputy Assistant Secretary for Student Financial Assistance programs sent a Dear Colleague Letter to all State and private college and university presidents and financial aid administrators that included a clear message about Year 2000 compliance;

—In December 1997, the Department briefed the National Council of Higher Education Loan Programs on Year 2000 issues. The Council includes representatives from the lending and guaranty agency community, secondary markets, and third party servicers;

—In December 1997, the Assistant Secretary for Special Education and Rehabilitative Services sent a Dear Colleague Letter on Year 2000 issues to all National Institute on Disability and Rehabilitation Research grantees, Special Education Program Resource Centers, and Rehabilitation Services Administration Independent Living Centers;

—In January 1998, the Department met with the National Association of College and University Business Officers to discuss Year 2000 issues;

—In February 1998, a Dear Colleague letter was sent to all State higher education executive officers from the Assistant Secretary for Postsecondary Education and the Executive Director of the State Higher Education Executive Officers;

—In March 1998, a Dear Colleague Letter was sent to each of the 36 State and private non-profit guaranty agencies participating in the Federal Family Education Loan Program; and

—In March 1998, a Dear Colleague Letter from the Deputy Assistant Secretary for Postsecondary Education was sent to the approximately 7,000 lenders in the Federal Family Education Loan Program.

Over the weeks ahead, Department officials will continue to participate in education association meetings and conferences, issue Dear Colleague Letters, and use the electronic media to contact and consult with the education community on Year 2000.

The Department also works with over 30 boards, commissions, councils, and independent agencies that serve the education community. To ensure that all of these organizations develop a Year 2000 compliance strategy, principal office coordinators are consulting closely with their constituent entities. In addition, the Department's Office of Intergovernmental and Interagency Affairs is working with Project management Team to facilitate communication with these organizations.

PROVISION OF TECHNICAL ASSISTANCE TO STATES ON YEAR 2000 COMPUTER PROBLEMS

Question. To what extent is the Department providing technical assistance to the States for Year 2000 computer problems?

Answer. The Department has taken several steps to provide technical assistance to the States regarding Year 2000 computer problems. One initiative is a series of "Dear Colleague" letters sent to officials in the education community. The letters provide information and guidance on how to ensure that computer systems are Year 2000 compliant. Other steps include consultations with State information technology officials and the distribution of outreach materials that provide information on best practices and tools that are useful in addressing the Year 2000 challenge.

In addition, the Department has widely distributed an informational brochure on year 2000 to the education community, set up a Year 2000 web site (www.ed.gov/y2k/), and opened two Year 2000 electronic mailboxes (y2k@ed.gov and ope—y2k@ed.gov) to answer questions.

QUESTIONS SUBMITTED BY SENATOR TED STEVENS

EDUCATION TECHNOLOGY

Question. The Administration is proposing a new $75 million program for Teacher Training in Technology intended to increase new teachers' ability to apply technology in their classrooms. To what extent are funds authorized to be spent, and already being spent, on preservice training in technology under the following programs: Regional Technology in Education Consortia, Technology Literacy Challenge Fund, and Eisenhower Professional Development State grants?

Answer. The Department cannot provide the amounts that the two State-formula grant programs, the Technology Literacy Challenge Fund and the Eisenhower Professional Development State Grants, are spending on preservice training in technology. The Regional Technology in Education Consortia currently spend approximately 5 percent of their funding, or $500,000, on preservice activities. However, the Department does not feel that any of the programs listed is well-suited to increase dramatically the percentage of new teachers prepared to use technology effectively in their classrooms.

The Regional Technology in Education Consortia (RTEC's) do assist institutions of higher education to establish programs that prepare teachers to use educational technology in their classrooms. That is just one aspect of the RTEC's broad mandate to provide technical advice and training to States, schools, districts, adult literacy centers, and other educational institutions about the use of advanced technologies to improve teaching and student achievement.

The Technology Literacy Challenge Fund provides formula grants to States for competitive grants to local educational agencies, to fund a wide range of technology needs. The strength of this program is that it allows States to determine their own needs and provides comprehensive funding for educational services. Funding for preservice education is not specifically authorized. For this reason, it would not be the best funding source for training new teachers.

The Eisenhower Professional Development State Grants may be used to fund preservice training; however, the vast majority of Eisenhower funds flow to local school districts and are used primarily to fund inservice professional development activities. Sixteen percent of program funds are allocated to State agencies for higher education to award competitive grants to institutions of higher education or nonprofit organizations. The majority of these funds are also used for inservice professional development. In addition, the first $250 million of any funds appropriated for the program are to be used for professional development activities in mathematics and science.

SPENDING ON EDUCATIONAL TECHNOLOGY

Question. How much is the Department spending on technology for education?

Answer. The Department has several programs dedicated specifically to supporting educational technology. These programs are:

The Technology Literacy Challenge Fund is helping States and local school districts integrate technology into school curricula. The fiscal year 1998 appropriation is $425 million.

The Technology Innovation Challenge Grants support public-private partnerships that generate new learning content and instructional practices that may be adopted by schools and communities across the country. The fiscal year 1998 appropriation is $106 million.

The Regional Technology in Education Consortia provide technical assistance to State and local educational agencies on the use of advanced technologies to improve teaching and student achievement. The fiscal year 1998 appropriation is $10 million.

Star Schools supports innovative projects in distance learning education for elementary and secondary education, providing courses and professional development through telecommunications technology. The fiscal year 1998 appropriation is $34 million.

Ready to Learn Television supports the development of educational programming centered on school readiness, as well as grants for local educational and community outreach activities related to school readiness. The fiscal year 1998 appropriation is $7 million.

The Telecommunications Demonstration Project for Mathematics provides support for PBS "Mathline," a year-long course of professional development in mathematics based on the standards developed by the National Council for Teachers of Mathematics. The fiscal year 1998 appropriation is $2.035 million.

The total for appropriation for programs that specifically support educational technology is $584.035 million. In addition to the programs listed above, funds from Title I, Goals 2000, Special Education State Grants, and other programs, can also be used for educational technology.

TECHNOLOGY PLAN

Question. Have you completed and submitted the overall education technology plan that the Congress requested in the fiscal year 1998 appropriations?

Answer. No, the Department has not yet completed this plan that Congress requested in the fiscal year 1998 appropriation. We intend to submit such a plan to the Committee later this spring.

IDEA AMENDMENTS OF 1997—REGULATIONS BENEFITS AND COSTS

Question. On June 4, 1997, President Clinton signed into law the Individuals with Disabilities Education Act (IDEA) Amendments of 1997, Public Law 105–17. On October 22, 1997, the Department of Education issued a Notice of Proposed Rulemaking (NPRM) to implement the Amendments. The NPRM, as required, discussed the potential costs and benefits of the proposed regulations (62 FR 55054). Through the public comment period, has the Department of Education gained any additional information concerning the costs and benefits of the regulatory package?

Answer. The Department received over 4,500 comments on the proposed regulations. Many comments addressed the benefits to families and children of various changes and the potential impact of the proposals on teachers and schools. However, virtually none of the comments provided specific cost information that could be used in refining the Department's analysis of the costs and benefits of the regulations.

SPECIAL EDUCATION EXPENDITURES

Question. Special education expenditures in the United States are estimated at approximately $36 billion. What portion of special education expenditures are devoted to costs not directly related to special education and related services such as attorneys' fees/litigation and administrative expenses?

Answer. We do not currently collect information from the States on special education expenditures. However, a study conducted by Decision Resources in 1988 indicated that about 7 percent of the funds used for special education services are used for administrative costs. We do not know how much money is used for costs associated with litigation or attorney's fees, but we believe that it is very small. A study by the General Accounting Office found that there were 73 civil actions in 1988. Attorneys are also frequently present at due process hearings, which are held for about one out every 1,000 children each year.

STATE ADMINISTRATION AND LOCAL PROGRAM FUNDING UNDER IDEA

Question. What percentage of the Federal appropriation reaches the classroom?

Answer. We do not know what percentage of the Grants to States appropriation reaches the classroom. From funds appropriated in fiscal year 1997, States may use up to 25 percent of the funds they receive for State level activities and at least 75 percent of the funds must be passed through to local educational agencies. Data reported by the Department in response to a directive in the fiscal year 1998 appropriations conference report indicate that States actually retain only about 8 percent of their funding for State level activities. Because of changes made in the authorizing legislation by the Individuals with Disabilities Education Act Amendments of 1997, from fiscal year 1998 appropriations, States will be allowed to retain an average of only up to 21 percent of the funds they receive for State level activities and at least 79 percent must be passed through to local educational agencies. The percentage of funds that can be retained for State level activities will continue to decline to the extent that State allocations increase by amounts greater than inflation.

Local educational agencies may use the funds they receive for a wide range of purposes including salaries for special education teachers, specialized instructional materials, and training personnel. We do not have information on the extent to which local educational agencies use Federal funds for in-class purposes. South Carolina, which has compiled a detailed break-down of expenditures for a variety of programs, has data that indicate that instruction and instructional support account for 83 percent of the Federal special education funds used by local school districts.

PROPOSED EXPANSION OF THE EDUCATION FLEXIBILITY DEMONSTRATION PROGRAM

Question. In a speech to the National Governors' Association on February 23, 1998, you proposed eliminating the 12 State cap under the Education Flexibility

Demonstration Program (Ed-Flex) authority. When will legislative language be introduced for this proposal?

Answer. The Department is currently preparing legislative language to make all States eligible to receive the authority to waive certain Federal statutory and regulatory requirements. The Department anticipates that legislative language will be ready for introduction in late spring.

REQUIREMENTS FOR PARTICIPATION IN THE ED-FLEX PROGRAM

Question. Do you propose adding any new requirements for States to participate in Ed-Flex?

Answer. The Department intends to propose that, before a State may receive the authority to waive certain Federal statutory and regulatory requirements, it have in place the content and performance standards and aligned assessments required by Title I of the Elementary and Secondary Education Act of 1965, and also have in place procedures for holding local school districts and schools accountable for meeting academic performance goals. Though the 12 States currently participating in the Education Flexibility Demonstration Program were not required to have their content and performance standards or aligned assessments and accountability procedures in place before receiving the waiver authority, an analysis of how these States have used their waiver authority indicates that well-developed State assessment and accountability systems allow for a more effective implementation of the waiver authority. For example, Texas, a State that has developed a statewide assessment and accountability system that provides disaggregated student achievement data, has made more extensive and effective use of the waiver authority than other States with the waiver authority.

When the Ed-Flex authority was created under Goals 2000, the Title I performance requirements did not yet exist. Our proposals would thus align Ed-Flex with the current Elementary and Secondary Education Act requirements.

Question. Would you continue to require that States participate in the Goals 2000 program in order to be eligible for Ed-Flex?

Answer. No, States would not have to participate in the Goals 2000 program to be eligible. To receive the waiver authority, States would have to have in place the content and performance standards and aligned assessments required by Title I, and provide their State educational agency with the authority to waive State statutory or regulatory requirements while continuing to hold the local educational agencies that receive waivers accountable for the performance of students affected by the waivers.

PROPOSED EXPANSION OF PROGRAMS ELIGIBLE FOR ED-FLEX WAIVERS

Question. Currently, the number of programs under which requirements can be waived is substantially fewer under Ed-Flex than under most other Federal education waiver authorities, such as the authority covering all of the Elementary and Secondary Act. Do you propose that the number of programs covered by Ed-Flex be expanded?

Answer. Yes, the Department is proposing to expand the number of programs for which States could waive certain Federal statutory and regulatory requirements so that it is more closely aligned with the waiver authority provided under the Elementary and Secondary Education Act of 1965. The authority would extend to all of the Department's major State formula programs for elementary and secondary education, except those under the Individuals with Disabilities Act.

EXPERIENCE WITH ED-FLEX AND OTHER WAIVER AUTHORITIES

Question. What has been your experience thus far with Ed-Flex, and with other waiver authorities relevant to Federal elementary and secondary education programs?

Answer. The Department's experience with waivers has been that relatively few waivers have been requested from the Department and the Ed-Flex States, and that the range of provisions requested to be waived is similarly small. This would seem to indicate that Federal laws and regulations are not acting as significant barriers to State and local improvement initiatives, and that most States, local school districts, and schools already possess the flexibility needed to accomplish their objectives without waivers of Federal requirements.

The States that are making the most extensive and effective use of the waivers are those with well-developed assessment and accountability systems. The data provided by such systems allows the State to determine whether the waiver is promoting increased achievement among all students affected by the waiver. The absence

of strong assessment and accountability systems makes it nearly impossible for a State to ensure that there is adequate accountability for the flexibility provided.

Question. Are the authorities being extensively exercised?

Answer. No, the authorities are not being extensively used. From school year 1994–95 until the beginning of the 1997–98 school year, the Department received 435 waiver requests from State educational agencies and local school districts in 48 States. State educational agencies had submitted 60 waiver requests. The remaining 375 requests were from school districts, representing less than 3 percent of school districts nationally.

The majority of Ed-Flex States are also not using the waiver authority extensively. Ten of the 12 approved States have received fewer than 35 waiver requests. Oregon, which was the first State granted the authority in February of 1995, has received only 20 requests for waivers since then. The waiver authority is being used most extensively by Texas, which has received 4,248 waiver requests since obtaining the authority in January of 1996. The great majority of Texas waivers, 89 percent, have been for statewide waivers of administrative requirements.

RANGE OF PROVISIONS BEING WAIVED

Question. What sorts of requirements are being waived?

Answer. The experience of both the Department and the Ed-Flex States indicates that the range of provisions being waived is relatively small, and waivers of similar provisions are being requested of the Department and the Ed-Flex States.

The waivers requested of the Department fall into 5 general categories: (1) waivers granted to State educational agencies that help to strengthen State school reform efforts and increase the flexibility available to school districts within the State; (2) waivers of the minimum poverty threshold for implementing schoolwide programs under Title I of the Elementary and Secondary Education Act of 1965; (3) waivers of provisions for targeting Title I funds within a school district; (4) transition waivers to accommodate temporary situations during periods of change; and (5) waivers of the mathematics and science priority under Eisenhower Professional Development program.

Similarly, in the Ed-Flex States, the great majority of programmatic waivers have been to waive some of the requirements of Title I, such as the minimum poverty threshold for implementing a schoolwide program or provisions for targeting Title I funds within a school district. As does the Department, Ed-Flex States receive requests for waivers of the Title II mathematics and science requirement.

Question. Are there types of requirements that many States or local school districts would like to waive but they may not do so under existing waiver authorities?

Answer. The requirements that some States and local school districts would like to waive, but which currently may not be waived, are certain provisions of the Individuals with Disabilities Education Act (IDEA), particularly the reporting requirements. However, the Department does not feel that this authority is the appropriate place to address these issues.

RATIONALE FOR ED-FLEX EXPANSION

Question. Is Ed-Flex expansion being proposed now primarily to counter the increasing interest—on the part of many Members of Congress, Governors, and others—in consolidating many Federal education programs into block grants?

Answer. No, we are not proposing the Ed-Flex expansion in order to counter the consolidation proposals. The Department is committed to providing States, local school districts, and schools with flexibility in implementing the educational reforms necessary to ensure that all children are able to achieve to high standards. The Elementary and Secondary Education Act already provides States and local educational agencies with a great deal of flexibility. Examples of the increased flexibility provided under the 1994 reauthorization include the authority to use a consolidated State plan to apply for Federal program funds, the ability to consolidate administrative funds from several different programs, and the authorization for greater numbers of schools to implement Title I schoolwide programs.

The Department's experience with waivers indicates that the current legislation provides much of the flexibility needed by State and local educators to implement their school reform efforts. Often, the barriers to local reform are created by State statutory or regulatory restrictions. The Department feels that, in exchange for gaining the ability to waive many Federal statutory and regulatory requirements, States will be willing to provide their State educational agencies with the authority to waive many State requirements. The Department also believes that providing greater numbers of local school districts and schools with waivers of certain Federal and State statutory and regulatory requirements will provide them with an environ-

ment that promotes creative and innovative school improvement plans that lead to increased achievement for all students.

Question. Beyond the 12 States already participating in Ed-Flex, how many other States are you aware of that might be prepared to offer waivers of their own requirements and meet the other conditions of Ed-Flex participation?

Answer. The Department believes that all States will eventually meet the conditions necessary to receive the authority to waive certain Federal statutory and regulatory requirements. The requirements to have in place content and performance standards along with an aligned assessment system and procedures to hold local school districts and schools accountable for student academic performance are already contained in the Elementary and Secondary Education Act of 1965. In addition, as it is often the case that State requirements serve as a the major barrier to the successful implementation of local reform efforts, the Department expects that States will be willing to provide the authority to waive State requirements that impede reform in return for the ability to waive some Federal requirements.

EFFECT OF IMPACT AID POLICIES

Question. While you are requesting about 5 percent less for Impact Aid basic support payments (a $36 million reduction), payments to LEA's in some States decrease by substantially higher percentages. For example, overall payments to LEA's in Alaska would decrease by over 50 percent according to estimates in your table on page C–47 of the Justification. To what extent does each of your three proposed changes in the Impact Aid formula account for these shifts in funding?

Answer. The table below indicates the amount of funds that would shift due to each of the proposed changes in the Basic Support Payments formula. The table displays these results separately for Alaska and for all States combined. These numbers were determined by simulating the formula in current law for 1999 at the requested appropriation level of $626 million. Then the formula was simulated three additional times at $626 million using current law and one of the three proposed changes in the formula: (1) the weighted child count; (2) the Learning Opportunity Threshold (LOT); and (3) the calculation of maximum payments. The figures in the table represent the gross dollars that shift due to each change in the formula. Because the Basic Support Payments formula is "non-linear," the changes in the components of the formula do not necessarily add to the net change for a State when all three proposed changes to the formula are included together.

EFFECT OF PROPOSED CHANGES IN THE BASIC SUPPORT PAYMENTS FORMULA

[Estimates of the number of dollars by which impact aid basic support payments change, by formula component, for fiscal year 1999 at an appropriation of $626 million]

	Dollars lost or gained by Alaska	Dollars transferring among States [1]
Weighted child count	$15,543,663	$94,205,848
Learning opportunity threshold [LOT]	(18,921,824)	143,744,371
Maximum payments	(34,535,155)	98,499,296

[1] These dollars reflect the amount of funds that shift among States due to changes in formula components. For instance, the change in the weighted child count would cause all States that gain funds under the formula change to gain a total of $94,205,848 and all of the States that lose funds to lose a total of $94,205,848.

IMPACT AID—PROPOSED LEARNING OPPORTUNITY THRESHOLD FORMULA CHANGE

Question. You have justified changes in the calculation of the learning opportunity threshold (LOT) in part because current law encourages LEA's to decrease their tax efforts. What evidence do you have that current law has had this effect?

Answer. We have proposed the change in calculating LOT in part because it would eliminate a pernicious effect of current law—the potential reward for LEA's that reduce local tax effort. We are not aware of any LEA that has actually reduced local tax effort for this reason.

The current LOT potentially benefits LEA's that reduce their tax effort because the LOT percentage is the sum of: (1) the percentage of federally connected students and (2) the percentage of the maximum payment under the Basic Support Payments formula as a percentage of total current expenditures. The sum of these two percentages may not exceed 100 percent.

An LEA could reduce its tax effort and its total current expenditures, which would increase the latter of the two components of the LOT percentage. The LOT percentage is an important component of the Basic Support Payments formula. The LOT

percentage is multiplied by the maximum payment to determine the LOT payment when funds are insufficient to fully fund maximum payments. LOT payments have been the basis for calculating actual payments because the formula has not been fully funded since its inception.

NUMBER OF IMPACT AID LEA'S DECREASING THEIR TAX EFFORTS

Question. How many LEA's receiving Impact Aid payments have substantially decreased their efforts since 1992?

Answer. We do not know how many LEA's have substantially decreased their tax effort since 1992. However, as noted above, we know that a potential reward exists for LEA's that decrease their tax effort. As part of an effort to minimize paperwork burden on LEA's, we do not require LEA's to submit data on tax effort when they apply for Basic Support Payments.

IMPACT AID REDUCTIONS RESULTING FROM PROPOSED FORMULA CHANGES

Question. How many LEA's would receive payments that are less than 85 percent of their prior year Impact Aid payment (the current-law hold harmless requirement) as a result of your proposed formula changes?

Answer. Among those LEA's that would receive funds in 1999, we estimate that (under the Administration's proposed budget and formula) 228 would receive payments that are less than 85 percent of their prior-year Impact Aid payment.

Question. How will these LEA's make up for the sudden reduction in Federal aid?

Answer. We do not know specifically how these LEA's will make up for the decrease in Federal aid, but they should be the best positioned to absorb the loss of funds. We have proposed the formula changes because we are concerned that Basic Support Payments are not being directed to those LEA's with the greatest need for these funds: (1) LEA's with students living on Indian lands and children of members of the uniformed services who live on Federal property; (2) LEA's that are responsible for funding a large proportion of the cost of educating their students; and (3) LEA's with large percentages of federally affected students. LEA's that lose funds under our proposed formula do not meet these criteria and should be able to more easily absorb the cost of educating their federally connected students than other LEA's.

Question. Can you assure the Subcommittee that there will be no negative impacts on the quality of education in those LEA's?

Answer. We cannot assure the Subcommittee that there would be no negative impacts on the quality of education in LEA's with smaller Basic Support Payments in 1999 than 1998. As indicated under the preceding question, however, we believe that these LEA's can more easily absorb the cost of educating federally affected students than can other districts.

THE COST OF COLLEGE

Question. The Federal investment in higher education through the student aid programs administered by the U.S. Department of Education has grown markedly over the past century, as has the price of college. Has this increased Federal support of student financial assistance prompted increases in the prices charged students and their families?

Answer. We also are concerned about the rise in college tuition costs in recent years. We do not believe, however, that the increase in college prices can be attributed in any significant way to the increased availability and amount of Federal student aid. A number of recent studies have examined this issue, including those performed by the National Commission on the Cost of Higher Education, Professors McPherson and Shapiro, and the National Association of Independent Colleges and Universities and have failed to find a correlation between the growth of Federal student aid programs and the increase in college tuitions. In fact, the NAICU study showed the opposite effect. NAICU found that Federal grant aid actually helps to slow the rate of tuition growth at independent colleges and universities.

Question. What impact will the new Hope Scholarships and Lifetime Learning credits have on college prices?

Answer. We do not anticipate that the new Hope Scholarships and Lifetime Learning tax credits will provide have any effect on college prices. There is no evidence of a relationship between the presence of Federal student aid and tuition increases. Institutions cannot easily raise tuitions when only a portion of their students, many of them part-time, receive education tax benefits or Federal grants. State institutions have a particularly difficult time raising tuitions since their services are viewed as a public benefit to their citizens and they must typically go through the State legislature for approval of tuition increases.

PERCENT OF COST COVERED BY FEDERAL GRANTS

Question. What is the percentage of the average cost of education that can currently be covered by the maximum and average Pell Grant or Supplemental Educational Opportunity Grant?

Answer. Below is a chart comparing the average tuition, fees, and room and board to the maximum and average Pell Grant and Supplemental Educational Opportunity Grant (SEOG) programs for the 1996–97 award year. In general, the maximum Pell Grant of $2,470 in 1996–97 was sufficient to cover approximately 27 percent of the average cost of education at all schools. However, the average Pell Grant was approximately $900 lower than the maximum, so that the average Pell Grant was sufficient to cover about 17 percent of the average cost of attendance. These percentages, as expected, are higher for public institutions, and generally lower at more expensive private institutions.

The maximum SEOG of $4,000 would cover approximately 44 percent of the average college cost. However, the average SEOG in 1996–97 was significantly lower than the maximum ($701 versus $4,000), so the amount of college cost covered by the average SEOG was less than 8 percent.

PELL GRANT AND SEOG AWARDS AND COST OF EDUCATION—1996–97

	Average cost [1]	Maximum Pell	Percent of cost	Average Pell	Percent of cost	Maximum SEOG	Percent of cost	Average SEOG	Percent of cost
Total	$9,199	$2,470	26.9	$1,574	17.1	$4,000	43.5	$701	7.6
Public 4-year	7,331	2,470	33.7	1,668	22.8	4,000	54.6	743	10.1
Public 2-year	4,412	2,470	56.0	1,493	33.8	4,000	90.7	404	9.2
Private 4-year	18,476	2,470	13.4	1,673	9.1	4,000	21.6	1,131	6.1

[1] Cost includes tuition, fees, room and board.

Sources: ''Digest of Education Statistics'', 1997, NCES; Pell Grant: Pell grant cost estimation model, OPE; SEOG: ''Federal Campus-Based Programs Distribution of Awards 1996–97'', OPE.

IMPACT OF BUDGET PROPOSAL ON

Question. What impact on these statistics will your budget request or your proposal for reauthorization of the Higher Education Act have?

Answer. In our fiscal year 1999 Budget, we are proposing an increase of $100 in the maximum Pell Grant from $3,000 to $3,100. This maximum award increase builds on the two years of unprecedented growth in the maximum Pell Grant for 1997–98 and again for 1998–99, when the maximum grants increased 9.3 percent and 11.1 percent, respectively. The large increases in the maximum Pell Grant between 1997–98 and 1998–99, coupled with the increase we propose in 1999–2000, will increase the percent of college cost covered by the maximum Pell Grant by over 2 percent, to slightly over 29 percent, and the percent of cost covered by the average Pell Grant from 17 percent to 18 percent.

PELL GRANTS AND COST OF EDUCATION—1996–97 TO 1999–2000

Award year	Estimate average cost	Maximum Pell	Percent of cost	Estimate average Pell	Percent of cost
1996–97	$9,199	$2,470	26.9	$1,574	17.1
1997–98	9,659	2,700	28.0	1,699	17.6
1998–99	10,142	3,000	29.6	1,894	18.7
1999–2000	10,649	3,100	29.1	1,936	18.2

Source: Pell grant cost estimation model, OPE.

ACCESS TO STUDENT LOANS

Question. The Administration's proposal for addressing issues arising from the reduction in the Federal Family Education Loan's interest rate, scheduled to occur on July 1, 1998, would lead to a significant reduction in lender returns. To what extent will this reduction cause some lenders to stop making loans under the FFEL program?

Answer. Based on a Department of Treasury analysis, the Administration proposed an interest rate formula that would ensure an adequate rate of return to lenders at little or no net cost to students. Therefore, the Administration believes that lenders would not stop making loans under its proposal which the Treasury study showed provided sufficient profits to maintain FFEL lender participation.

ENSURING CONTINUED ACCESS TO FFEL LOANS

Question. How will the Department deal with any access problems that result?

Answer. We are taking steps to implement the broad authority granted by Congress to ensure continued access to FFEL loans. We are committed to assuring that no student is denied the financial help he or she needs to go to college.

As part of the effort to ensure uninterrupted access to college student loans, we have held discussions with the Student Loan Marketing Association (Sallie Mae) and have contacted all 36 guaranty agencies about their capacity to fulfill their statutory obligation to issue loans if necessary. Of the 36 guaranty agencies contacted, nearly all indicated they could serve in some capacity as lender of last resort.

One of these guaranty agencies, the Pennsylvania Higher Education Assistance Agency, has already informed the department that it could be available right away to make at least one million student loans to assist students across the nation. This is triple the number it currently makes and about one-fifth of all FFEL loans made nationwide. Nearly all of the guaranty agencies have indicated that they are ready to make loans if necessary to ensure loan access.

STUDENT FINANCIAL AID INFORMATION SYSTEMS

Question. What steps has the Department taken to address the recent criticisms by the GAO of the accuracy and efficiency of its information systems used in determining student eligibility for financial aid, processing aid applications, and informing students and institutions about the status of grants and loans?

Answer. In 1995, the Department recognized the need to use cutting-edge technology and business processes to transform the administration of student financial aid and improve customer access to information and funding for education beyond high school, and began to work with our partners in the postsecondary education community to design, integrate and develop a comprehensive student financial aid delivery system using state-of-the-art information technology.

The effort has become known as Project EASI (Easy Access for Students and Institutions). The following is an update on this important project:

Delivery of Systems Architecture Report—Completed

The Department developed the Technical Vision and Target Architecture Report in September 1997. This presents a conceptual framework for EASI's technical environment but is only one component of an overall architecture.

Development of Standard Data Formats and Definitions—In process

A data model is being developed for Project EASI. This will contain standard data definitions and formats. ED has met with the Postsecondary Education Standards Council (PESC) to solicit their support in reviewing these standards. Our goal is to obtain buy-in from the higher education community on EASI's data model.

As additional steps toward data standardization, we are also working on two projects to pilot EDI technology. These include allowing lenders to submits requests for interest and special allowance on FFEL loans in an EDI format and allowing schools to submit Pell Grant origination records in an EDI format.

Student Enrollment Verification—In process

ED continues to work closely with schools, guarantee agencies and enrollment servicers to ensure that enrollment data is timely and accurate. In cases of schools not responding to our requests for data, ED has initiated fines as an enforcement mechanism. If this is not successful, ED will consider limitation, suspension and termination actions against the school.

Development of a Multi-View Enterprise Architecture—In process

SFA must develop an enterprise architecture that addresses more than just the technical environment. An enterprise architecture would describe four additional architectural views: (1) which organizations perform which pieces of work (this is called the work view); (2) what information these organizations need to do their work (the information view); (3) what software applications will be needed to perform the work (application view); and (4) the technical standards which will provide a framework for implementing EASI (technical infrastructure). We have hired an expert in this field who is working to provide the completed enterprise architecture by December 1998.

Movement toward an Integrated Data System—In process

In December 1997 Project EASI entered the definition phase of the system development life cycle. Specifically this stage involves: (1) defining what the Title IV delivery process will look like in the future; (2) establishing the standards for tech-

nology and data and (3) establishing a detailed implementation schedule. When current tasks for the definition phase are completed in September 1998, development work on the new system is expected to begin.

Project EASI's vision of integrating the data processing systems that the Department uses has prompted ED to reconsider the student financial assistance programs' current contracting structure. Early in 1997, ED identified an alternative way to structure the Title IV information technology and support services contracts. This contracting strategy introduces a functionally driven approach to procuring the services ED requires for the Title IV programs. Part of this approach is to consolidate all of the Title IV systems into a single data center. Through this approach we will gain economies of scale and reduce costs. This will also set the stage for a common operating environment that will facilitate system integration. During February of 1998 we moved the National Student Loan Data System to the new data center and we plan to move the remaining systems during 1998 and 1999.

PERFORMANCE BASED ORGANIZATION FOR STUDENT AID PROGRAMS

Question. Please share with the committee what steps the Department has taken to create a "performance-based organization" to administer student aid information, processing and delivery systems?

Answer. The Department has taken several steps toward creating a performance based organization (PBO). I believe that the Student Financial Assistance (SFA) Programs meet many of the criteria identified by the National Partnership to Reinvent Government (NPRG) and is a good candidate to become a PBO because of its clear mission, measurable services to external customers and its opportunities for significant improvement.

Acting Deputy Secretary Mike Smith is leading the overall effort. Our main vehicle for PBO planning is the SFA Action Plan. This tool was developed under Acting Deputy Assistant Secretary for Student Financial Assistance Diane Rogers' to guide the work of SFA, the PBO outreach, design, and transformation process. The Department is working with the SFA Modernization Board, the White House, the OMB, the Treasury and Congress.

The PBO will be managed by a Chief Operating Officer (COO) with a demonstrated record of effective management. The COO will report to the Secretary and have a fixed contract and term. The COO's compensation will be tied to performance under an agreement with the Secretary. The COO will have authority to hire senior managers whose compensation will also be tied to the achievement of PBO performance goals. The Department's target is to identify a COO by the end of summer 1998.

Question. Does the Department's action to date reflect the legislative proposal under consideration by the Congress?

Answer. Yes, the Department's actions are generally consistent with the intent of the legislative proposals (S. 1182) and (H.R. 6) under consideration.

Question. Do you believe that the Department needs any new statutory authority to establish such an organization?

Answer. Generally, a PBO can be established without legislation. Legislation may be required in some instances to provide flexibility under existing statutes or to establish special reporting or consultation requirements. The Department is starting discussions now regarding how current authorities might be used to establish the PBO without legislation. The Department's goal is to use this new organizational tool in ways that are beneficial to students and families, taxpayers, schools, financial institutions, and employees.

PARTICIPATION OF HISPANIC-SERVING INSTITUTIONS IN TITLE III

Question. What is the universe of institutions potentially eligible to receive funding under the Hispanic-serving institutions program authorized by the Part A program of Title III of the Higher Education Act?

Answer. The Department of Education estimates that about 135 institutions of higher education are eligible Hispanic-serving institutions (HSI's).

Question. To what extent are potentially eligible HSI's participating in the Hispanic-serving institutions program authorized by the Part A program of Title III of the Higher Education Act?

Answer. In 1995, the first and only competition for the HSI program, 90 institutions applied for funding. Of those that applied, 37 institutions received awards. Therefore, just over 25 percent of potentially eligible HSI's in 1995 participated in the HSI program.

DIFFERENCES BETWEEN HISPANIC-SERVING INSTITUTIONS AND HISTORICALLY BLACK COLLEGES AND INSTITUTIONS

Question. What are the differences in what constitutes an Hispanic-serving institution (HSI) under Part A of Title III and an historically black college or university (HBCU) under Part B of Title III?

Answer. There are many differences in what constitutes an HSI and an HBCU under Title III. For the HSI program, eligible institutions must first have a high enrollment of needy students and low educational and general expenditures. Should they meet this criteria, then the institution must also have at least 25 percent Hispanic undergraduate full-time equivalent enrollment. Fifty percent of these Hispanic students must be low-income and first-generation college students and an additional 25 percent of these Hispanic students must be low-income or first-generation. Further, the program gives absolute priority in funding to institutions that have a collaborative arrangement with a local education agency to reduce the high Hispanic drop out rate, improve Hispanic rates of academic achievement, or increase the rates at which Hispanic students enroll in higher education.

Eligibility for the HBCU program requires only that the institution be accredited and established prior to 1964 with a mission to educate black Americans. There are no student or financial criteria. In 1996, there were 96 HBCU's eligible under Title III statute, all of which receive annual funding.

Question. Have these differences in what constitutes a Hispanic-serving institution under Title III Part A and a historically black college and university under Title III Part B lead to any significant or obvious inequities in the administration of the program?

Answer. These differences do not create any obvious inequities in the administration of the programs. However, the statutory differences in eligibility between the HSI's and HBCU's programs do require that they be administered differently.

The HBCU program awards grants to all eligible institutions and the amount of each award is based on a formula allocation. In contrast, the HSI program is a competitive program—only the best applications are funded, not all eligible institutions.

While both programs grant five year institutional aid awards, the minimum annual award for HBCU's is $500,000 while the maximum annual award for HSI's is $350,000. In fiscal year 1997, the average award for each HBCU was $1.1 million while for HSI's the average award was $292,000.

HBCU'S WITHOUT MAJORITY BLACK ENROLLMENT

Question. How many historically black colleges and universities no longer serve substantial black student populations, yet still receive assistance under the Title III program?

Answer. Of the institutions that receive assistance under the Title III, Part B program, there are six HBCU's that have less than a 50 percent black student population. Of these institutions, four HBCU's have less than 25 percent black student population.

GOVERNMENT PERFORMANCE AND RESULTS ACT MEASUREMENT

Question. The Government Performance and Results Act of 1993 (GPRA), Public Law 103–62, requires all Federal agencies to phase in a process that uses performance measures to set management and budgeting objectives. What is the current situation at the Department regarding full implementation?

Answer. The Department has identified performance indicators for all the goals and objectives put forth in our cross-cutting Strategic Plan. Data systems are in place to collect required information for many of the indicators; and we are modifying existing data systems or developing new data systems for the others.

In addition, each program in the Department now has a performance plan with objectives and performance indicators. The performance data for some programs are readily available and of high quality, but for others baseline data are under development or improvement is needed to ensure quality. Currently we are working to (1) align existing data collections including evaluations, statistical surveys, and grantee performance data systems; (2) establish new data collections as needed; and (3) verify and validate data by developing standards and quality assurance systems.

GPRA IMPLEMENTATION CHALLENGES

Question. What problems have you encountered in the application of the GPRA procedures to date?

Answer. Most of the challenges we face in the application of GPRA relate to collecting good performance data. These challenges include:

—Gaining employee acceptance for taking responsibility to collect and use information on performance indicators when they have little or no control over the results;
—Obtaining uniform performance measures across grantees;
—Ensuring high-quality, timely performance data;
—Improving self-reported information from grantees;
—Developing intermediate performance indicators that provide early warning of problems; and
—Obtaining valid measures for complex indicators.

The other area with many challenges is how to make the Strategic Plan's goals and strategies meaningful to all ED employees. We are working on communication strategies, changes to employee evaluations, and internal reporting.

Question. What changes if any, do you anticipate making in the coming year to your strategic goals and performance plans?

Answer. Over the coming year the Department may make minor changes in Strategic Plan indicators, but we do not foresee making any changes to our Strategic Plan goals and objectives.

The Annual Performance Plan for the Department's objectives and programs will be updated during the fiscal year 2000 budget development process, which begins this summer. We have a number of improvements already planned for the program plans in particular, including adding baseline data and setting performance goals for all the program plans.

GPRA MEASURES IN THE FISCAL YEAR 1999 BUDGET

Question. To what extent has the Department used GPRA measures in developing the fiscal year 1999 budget request?

Answer. GPRA has provided a framework for performance planning in the Department, for developing both long-term and annual goals and objectives, and budget proposals to support them. The Department built GPRA into its internal budget process. In preparing their proposals, senior managers were instructed to relate their request to meeting the Strategic Plan priorities and objectives, to use performance information to support their request, to gear their proposals to implementing strategies to achieve their performance goals and objectives, and to identify resources to carry out the strategies in the performance plans including resources needed to collect and verify performance data.

We have done extensive work on developing performance measures for all of the Department's programs and have incorporated performance measures and indicators into the Congressional Justifications as well as into individual program plans. In developing the fiscal year 1999 budget request, GPRA helped us to focus in a more comprehensive way on the expected outcomes of our programs and benefits of future investments and to consider much more concretely the impact of our programs on our customers, particularly students.

While the Department has included performance data in its budget requests in the past, with GPRA we will have data for all programs, the quality of data will be improved, and the information we receive will focus on results, not just processes. While we will not have outcome data for every program in every year, we will continue to collect data as it becomes available. It should be noted that fiscal year 1999 funding would primarily support activities during the 1999–2000 school year. We will assess the impact of this funding in the next 2 years.

IMPACT OF GPRA ON DEVELOPMENT OF FISCAL YEAR 1999 BUDGET DECISIONS

Question. For which programs have you requested major funding changes, either increases or decreases, because of the application of the GPRA procedures?

Answer. The Department has long been committed to using performance data to inform decisions. In developing the fiscal year 1999 budget request, GPRA measures played a key role in our focusing on certain strategic goals and the resources needed to accomplish those goals. The following are some examples of fiscal year 1999 program budget requests that reflect funding changes that would help enable us to meet Strategic Plan and Annual Plan performance indicator goals.

—The America Reads program ($260 million) supports Strategic Plan Objective 2.2: Third Grade Reading and is part of the Department's comprehensive strategy to increase the percentage of students performing at or above the basic level in reading on the National Assessment of Education Progress (NAEP).

As reported in the Department's fiscal year 1999 annual plan, our goal is to increase the percentage of 4th graders reading at basic, proficient, or advanced levels in reading on NAEP from 60 percent in 1994 to 65 percent in 1998, and to 68 percent in 2000. In the most recent (1994) National Assessment of Edu-

cational Progress (NAEP), 60 percent of fourth graders scored at or above the "basic" level in reading. The NAEP is not administered to third graders, but the fourth-grade NAEP data capture reasonably well how students are reading at the end of the third grade.

—Our proposed new Teacher Training in Technology program ($75 million) supports Annual Plan Objectives 3.1: Training tied to certification and 3.3: Staff training. A recent report by the National Council of Accreditation for Teacher Education criticizes the majority of teacher education programs for teaching computer literacy rather than the application of technology in the classroom. While the current programs focus on training existing teachers, they are not well-suited to increasing dramatically the percentage of new teachers prepared to use technology effectively in their classrooms. This new program will help ensure that all new teachers can teach effectively with technology.

—The Pell Grant program supports Strategic Plan Objective 3.2: Postsecondary students—financial aid and support. Under GPRA, the Department identified the Pell Grant program's primary objective as providing continuing access to postsecondary education for low-income students. Performance indicator data show that Pell Grants are successful in helping low-income students overcome financial barriers to postsecondary education and that low-income students who receive them have much higher participation and graduation rates than low-income students who do not. A key indicator of how well the program is doing in achieving this goal can be measured by the income distribution of students who benefit from the program. Our request of $7.594 billion (+$249 million) for Pell Grants will benefit students with greatest financial need by targeting more of them and by increasing the maximum award.

—The Work Study program also supports Strategic Plan Objective 3.2. Studies show that first-year students who work during the academic year are more likely to complete the academic year, and that work has an increased impact on students' academic performance when a job is more closely related to the course of study. Our request of $900 million for Work-Study (+$70 million) will achieve the goal of expanding the program to one million students and improve the level of participation in community service by continuing to waive the 25 percent matching requirement for participating colleges.

—The TRIO programs request (+$53 million) and two new program proposals, High Hopes for College (College-School Partnerships) ($140 million) and College Early Awareness Information ($15 million), also support Strategic Plan Objective 3.2: Postsecondary students—financial aid and support, as well as 3.1: Secondary students—information and support. Indicator data for postsecondary education enrollment rates continue to show that there is still a gap in college attendance rates between high and low-income students. Research demonstrates that early intervention programs that are sustained for a number of years are very successful, and that academic services, mentoring, counseling, and tutoring for students are critical. Both High Hopes and TRIO are designed to provide needed support services to a large population of disadvantaged students in order to motivate and prepare these young people for postsecondary education. High Hopes would operate quite differently from TRIO and would be coordinated with, complement and enhance services received by participating schools and students under the TRIO programs and other related Federal and non-Federal programs.

—Research also shows that students, especially low-income students, often do not aspire to higher education, do not discuss college with their parents, think about college at an early enough age, or take the proper courses to ensure college entrance. Many who do manage to attend college are not fully prepared and require remedial courses. This lack of information and awareness would be addressed by the College Early Awareness Information program.

CONSULTATION ON DEVELOPMENT OF 1998–2002 STRATEGIC PLAN

Question. The development of GPRA measures requires extensive consultation with stakeholders and the Congress regarding the development of strategic goals and performance plans. How extensive an undertaking have these activities been to date, and to what degree will these activities be continued during the current year?

Answer. The Department consulted extensively with outside interested parties on the 1998–2002 Strategic Plan, and made changes as a result of those consultations.

The Department met with and received feedback on the Strategic Plan goals, objectives and indicators from: Staff from Congressional authorizing, appropriations, budget, and government operations committees; General Accounting Office (GAO);

Office of Management and Budget (OMB); and The Council for Excellence in Government.

The Department consulted with relevant Federal agencies on our respective strategic plans, including the Departments of Health and Human Services, Labor; and Treasury; National Science Foundation; Social Security Administration; and the Office of National Drug Control Policy.

Consultation on development of program level performance plans

The Results Act only mandates consultation on the Strategic Plan. While the program indicator plans are part of our Annual Plan (in Volume 2) and therefore consultation isn't required, in many cases, assistant secretaries and heads of program offices have discussed the program level performance plans with grantee and stakeholder groups. For example:

—The assistant secretary for vocational and adult education shared the vocational and adult education plans with State directors to get feedback and suggestions for improvement.

—The director for bilingual education and minority languages affairs presented the draft bilingual education program performance plans to the annual conference of the National Association for Bilingual Education.

—The assistant secretary for postsecondary education has shared and discussed the set of student financial aid program performance plans at regular meetings with key stakeholders and had these program plans posted on the Office of Postsecondary Education web page to make them available to stakeholders and the general public.

—The director of Indian education programs shared the program's plan and indicators at the National Indian Education Association conference in November 1997. This is after discussing them with State directors of Indian education in July 1997.

—Other elementary and secondary education program directors have regularly presented program indicator plans at meetings with their State and local program directors, including State migrant education directors, Eisenhower professional development program directors, and the Title VI State grant program directors.

We have found the consultation process to be very helpful in identifying areas of stakeholder interest, areas for coordination, and ways to improve the quality of our strategic plan and performance measurement. The Department will continue to present information on and engage in discussions around the Department's goals and objectives at conferences for stakeholders like the National Association of Federal Education Program Administrators. Many of our program managers are now routinely presenting their plans to key stakeholders and constituent groups as well. Finally, the fiscal year 1999 Annual Plan (Volume 1 on Strategic Plan objectives and Volume 2, program performance plans) is being placed on ED's website—the Strategic Plan is already there. We will continue to seek and respond to inquiries and suggestions.

COST TO COMPLY WITH GPRA

Question. What have been the administrative costs for the Department necessary to comply with the GPRA requirements?

Answer. The Department views GPRA requirements as key elements of good management practice and not separate from other administrative costs. We are striving to have all levels of the agency fully performance-driven. Managers at all levels have participated in activities that support GPRA/good management practices, including developing strategic and annual plans; revising or developing data collection systems; and assuring data quality. Specifically:

Developing strategic and annual plans.—Senior leadership in the Department was involved in developing the four goals and twenty-two objectives set forth in our strategic plan. Program managers were heavily involved in developing performance plans for the Department's programs. Some of these program performance plans were updated versions of existing performance plans, but for other program managers this was the first time they had developed program performance plans.

Revising or developing data collection systems.—Effectively reporting the Department's performance in achieving its Strategic Plan goals and objectives requires developing some new data systems and fixing old ones. Existing data systems need to be strengthened to ensure the Department receives high quality and timely data on its programs and their effects. Our efforts include:

—Reviewing existing data collections, administrative record sharing, questionnaires, etc. to align with performance indicators; and

—Develop new collections. The new systems will seek to redirect data collections toward gathering performance information of the accomplishment of Department-wide and program goals.

An example of a new collection is the planned survey to determine the percentage of teachers and principals across the Nation who are rated as very effective. This survey would establish the baseline and be the sole source of data for this indicator (indicator 25, objective 1.4).

Assuring data quality.—To ensure the quality of performance indicator data, the Department is following a four-part improvement strategy.

—Develop Department-wide standards for performance indicator measurements.

—Develop employee training in the application of the data standards for performance measurement.

—Monitor data quality.

—Have managers attest to the reliability and validity of their performance measures or submit plans for data improvement.

Over the next year the Department will be strengthening its two major data performance indicator systems, one for the elementary and secondary education and a second for student aid. In addition, the Department plans on extending its independent evaluations to include management evaluations.

FULL-TIME EQUIVALENT STAFF NEEDED TO CONDUCT GPRA ACTIVITIES

Question. Do you have an estimate of the full-time equivalent staff needed to conduct GPRA activities?

Answer. The Department views GPRA requirements as key elements of good management practice and does not have an estimate of the full-time equivalent (FTE) associated with GPRA activities. The core offices responsible for coordinating implementation are the Office of the Under Secretary (OUS) and the Office of Management (OM). However, managers and senior staff throughout the agency participate in at least some GPRA activities. As we move toward being a performance-driven agency, we fully expect all employees to be focused on performance and using performance information. Developing strategic plans, whether at the agency or office/program level, should be a standard management function for managers, not an add-on done only to comply with legislation.

Question. What administrative activities, if any, have been curtailed or eliminated to undertake GPRA?

Answer. GPRA and the Department's Strategic Plan have provided the Department with a framework and a focus for its activities. It has required additional effort on the part of staff, but we are not aware of any activities that have been curtailed or eliminated during our implementation of GPRA.

SUBCOMMITTEE RECESS

Senator SPECTER. The subcommittee will stand in recess to reconvene at 2 p.m., Tuesday, March 10 in room SD–192. At that time we will hear testimony from the Secretary of Health and Human Services, Hon. Donna Shalala, and from Hon. Nancy Ann DeParle, Administrator, Health Care Financing Administration.

We are going to proceed now to panel 2, but I would like you to stay for just a moment, Mr. Secretary.

[Whereupon, at 3:25 p.m., Thursday, March 5, the subcommittee was recessed, to reconvene at 2 p.m., Tuesday, March 10.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1999

TUESDAY, MARCH 10, 1998

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 2 p.m., in room SD–192, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.

Present: Senators Specter, Cochran, Gorton, Gregg, Faircloth, Bumpers, and Kohl.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

OFFICE OF THE SECRETARY

STATEMENT OF HON. DONNA SHALALA, SECRETARY

HEALTH CARE FINANCING ADMINISTRATION

STATEMENT OF NANCY-ANN MIN DePARLE, ADMINISTRATOR

OPENING REMARKS OF SENATOR SPECTER

Senator SPECTER. Good afternoon, ladies and gentlemen. The hour of 2 o'clock has arrived.

Senator Gorton and I were talking on the subway on the way over, after we left our caucus a little early, that we wanted to be on time. We have the distinguished Secretary of Health and Human Services.

Today the Subcommittee on Labor, Health and Human Services, and Education continues our hearings. The Department of Health and Human Services has become even more important than its former lofty position of importance as health care has emerged as an issue which is second to none in controversy and importance in America. Health spending constitutes about $1 trillion, or one-seventh of our gross national product. Enormous changes have occurred in the health care field, since the President's plan came forward in 1993, and while not accepted, it stimulated enormous debate and there have been enormous changes in health care delivery. This Department is at the center of all of these changes.

One of the concerns which our subcommittee and the entire Congress has is where we find the funding for the President's programs. And there is a gap of $1.9 billion, as the chart to my right

shows, which comes from user fees which are not yet authorized and from projected settlements which are highly, highly speculative at this time.

PREPARED STATEMENT

The Senators are still in their caucuses. Most of my colleagues are still in their caucuses. And I expect we will have very substantial representation before the hearing is over. And there are quite a number of topics which we will need to cover in the dialog, the Q&A. So I am going to put my full statement in the record and ask you at this time to proceed Secretary Shalala.

[The statement follows:]

PREPARED STATEMENT OF SENATOR ARLEN SPECTER

Today we will continue the fiscal year 1999 hearings of the Subcommittee on Labor, Health and Human Services and Education. This afternoon, we are delighted to have before the subcommittee the distinguished Secretary of Health and Human Services, the Honorable Donna Shalala, and welcome her once again to our hearing.

Madam Secretary, your department is charged with a formidable task: overseeing over $380 billion in entitlement and discretionary programs that Congress appropriates to your department for meeting the health and human service needs of the nation.

You can see from the chart to my right the difficulty facing this subcommittee by the President's assumption that savings will be realized through enactment of user fees or new taxes.

In fiscal year 1997, discretionary spending for this subcommittee totaled $74.7 billion.

In fiscal year 1998, discretionary spending increased to a total of $80.4 billion.

For fiscal year 1999, the President has requested $84.5 billion, but $1.9 billion of this amount would be financed by new user fees and assumed receipts from tobacco legislation.

Madam Secretary, the administration's budget request has put us in a real spot, basically $1.9 billion in the hole, and I fully expect that you will work closely with this committee as we try to resolve this dilemma.

We will be taking a careful look at your budget recommendations, with their implications for the future health and well-being of our citizens.

One of the top priorities will be expanding biomedical research. A fair target is to double NIH's budget over five years. Last year we made good progress toward that goal and I, along with Senator Harkin, will again work this year to improve that record.

Following Secretary Shalala's panel, we will have a second panel with the Administrator of HCFA that will discuss important issues regarding physician reimbursement policies under medicare.

We face difficult tradeoffs in the coming months, Madam Secretary. I look forward to working with you to craft an appropriations bill that maintains the commitment to fiscal restraint while preserving funding for high priority programs like NIH.

I will now turn to Senator Harkin for any comments or opening statements that he may wish to make.

SUMMARY STATEMENT OF HON. DONNA SHALALA

Secretary SHALALA. Thank you, Mr. Chairman. I am pleased to be here.

I have a few words at the beginning of my testimony, in tribute to Senator Bumpers, but I think I will wait for his appearance here before I make my statement.

Senator SPECTER. Well, I think anything good about Senator Bumpers ought to be said behind his back. [Laughter.]

Of course.

Secretary SHALALA. Mr. Chairman, I am pleased to appear before you today to discuss the President's fiscal year 1999 budget for the

Department of Health and Human Services. Last year we spoke at great length about the need to balance the budget. The President's 1999 budget achieves that goal, thanks to extensive cooperation between the Congress and the administration last year. We proved that by working together, working out innovative solutions, and working every dollar harder, we can guarantee a better fiscal future.

And the President's new budget for the Department of Health and Human Services provides that, with fiscal discipline, we can address the needs of America's families in the context of a balanced budget. Let me just touch on the highlights, beginning with our three new initiatives.

Last month, the President announced the 21st century research fund, to launch a new era of path-breaking scientific inquiry. HHS will play the largest role, with new resources for our constellation of stellar research agencies: the Centers for Disease Control and Prevention, the Agency for Health Care Policy and Research, and the National Institutes of Health. Indeed, the NIH will receive its single largest budget increase in its history, $1.1 billion, next year, a down payment on an historic 5-year, 50 percent expansion.

The new resources will allow NIH, CDC, and AHCPR to attack our most defiant diseases in a coordinated, integrated way, and to speed research results from labs into clinics and hospitals. We also propose giving every Medicare patient the chance to participate in a cancer clinical trial, so each can benefit and perhaps benefit others.

The second new initiative in this budget is the President's child care initiative. In millions of families, both parents must work to support their children. In millions of other families, single parents work doubly hard to support their children. The President's child care initiative will help families find and afford the quality child care they need. It includes $24 billion over 5 years in block grants to States, tax credits for families, tax incentives to businesses, and resources to help States enforce child care quality standards.

This budget also advances the President's commitment to bring 1 million children into Head Start by the year 2000, and more infants and toddlers into early Head Start.

The third new initiative in this budget is the Medicare buy-in plan. It answers the question troubling millions of aging Americans: What if I lose my health coverage before I am 65? The buy-in plan would allow those age 55 and over to breathe a little easier.

In addition to these new initiatives, this budget advances the fight against our most pressing public health challenges, requesting $165 million new dollars for Ryan White treatment activities for HIV and AIDS, $200 million new dollars for the substance abuse performance partnership block grant to help States and communications strengthen their control and treatment efforts, and $200 million new dollars to fight tobacco's impact on public health and to keep it out of children's hands.

Mr. Chairman, this budget also focuses new attention and resources on the challenge of ensuring the safety of our food. Each year, millions of Americans get sick from food-borne diseases. Some die. I have heard a great deal about the food safety challenge yesterday, when I attended the CDC's International Conference on In-

fectious Diseases in Atlanta. The problems are new and varied. There are new food-borne microbes. Americans are eating more food prepared outside the home. And, ironically, healthier diets often mean Americans are eating more imported fruits and vegetables that need careful washing or preparation.

This budget will help protect Americans from food-borne illnesses, with a $55 million increase in food safety efforts by both the FDA and the CDC. This increase will expand our new national early-warning surveillance system for monitoring, detecting, and stopping outbreaks of food-borne illnesses. It will also further improve seafood inspections and boost the President's initiative to ensure the safety of imported produce.

Mr. Chairman, let me also take this opportunity to voice the President's strong desire to work with the Congress to protect our children from tobacco. To do that, we must have comprehensive, not piecemeal, tobacco control legislation that includes the President's five principles, including a very large price increase.

As we advance our public health promises, the President's budget for the first time addresses the serious inequities in health services and health status for minorities. This budget includes $80 million to address several areas of disparity: diabetes, infant mortality, breast and cervical cancer, heart disease and stroke, HIV/AIDS, and child and adult immunization. We must correct these disparities so that all Americans have equal opportunities for healthy futures.

Finally, Mr. Chairman, I am proud of how this budget makes every dollar work harder. First, there is no better investment than busting fraud. Last year, our inspector general's crackdown on Medicare fraud returned almost $1 billion to the Medicare trust fund. Our new budget includes another $138 million to fight fraud. Moreover, we are offering new fraud-busting legislation that would return another $2.4 billion to Medicare.

In addition to fraud busting, we are proposing $264.5 million in new user fees. Not only are these user fees smart Government, they are also crucial for HCFA to meet its obligations under the balanced budget agreement, and the Health Insurance Portability and Accountability Act. Speaking of smart Government, we sent you our first GPRA annual performance plans, which we developed in collaboration with Congress, States, local and tribal governments, as well as private partners. To us, GPRA is more than an acronym. It is a way to ensure that the line items in our budget truly bring America's promise to all Americans.

PREPARED STATEMENT

Mr. Chairman, Senator Kohl, I believe this is a historic budget for HHS which launches a new era for health and social policy at the Department. It proves that with innovation and discipline, we can take strong steps for family and fiscal health and well-being. We have accomplished a lot together. I would be happy to address any questions you may have.

[The statement follows:]

PREPARED STATEMENT OF HON. DONNA E. SHALALA

Good afternoon, Chairman Specter, Senator Harkin, and members of the Subcommittee. I am pleased to appear before you today to discuss the President's fiscal year 1999 budget for the Department of Health and Human Services.

BALANCING THE BUDGET

Last year we spoke at great length about the need to balance the budget. I am pleased to inform you that the President's 1999 budget achieves that goal. But we were able to meet this challenge only because of the extensive cooperation between the Congress and the Administration last year. We proved that by working together, seeking innovative solutions, and squeezing every dollar from our budget, we can put our fiscal house in order. Emerson once said that "success is leaving the world a bit better than you found it." We have left the budget much better than we found it and in doing so we have provided our children with a path to a better fiscal future. This budget proves that we can take on new initiatives in the context of a balanced budget—if we are innovative and disciplined. I am very proud of our collective accomplishment, and I'm sure each of you shares my pride.

Because of our success in achieving a balanced budget, we can now turn renewed attention to the pressing problems of tomorrow: strengthening the public health and human services, continuing strong fiscal management and preparing for the 21st Century.

PREPARING FOR THE 21ST CENTURY

This is the last budget we will prepare for this millennium, and it sets forth the priorities for the next century, ranging from major increases in health research to promising child care for a million additional children to ending the scourge of youth tobacco use.

The 21st century research fund

The President announced the 21st Century Research Fund to launch a new era of path-breaking scientific inquiry. HHS will play the largest role, with new resources for our constellation of stellar research agencies—including the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Agency for Health Care Policy and Research.

First, the 21st Century Research Fund provides the resources necessary to combat cancer, heart disease, diabetes, AIDS, Alzheimer's, cancer, Parkinson's, Hepatitis C and other diseases. The President's budget includes an additional $1.2 billion increase to put us on a path to double our investment in medical knowledge, bridge the gap between scientific knowledge and health care delivery and prevent the spread of disease. By increasing by nearly 50 percent over five years our nation's commitment to NIH at the same time that we increase our commitment to CDC and AHCPR, this fund provides the resources necessary to achieve a better integrated system of health research.

We believe that a coordinated system of health research is the best way to achieve significant results in battling complicated diseases. We must continue to coordinate the efforts of NIH, CDC and AHCPR to attack these serious health threats.

To make our investment worthwhile, we must move our research from the laboratories into the clinics and hospitals. To illustrate this point, consider diabetes. Untreated diabetes is the sixth leading cause of death from disease and the leading cause of adult blindness, kidney failure and non-traumatic amputations. It also is a risk factor for stroke and heart attack. It is estimated that thirty-three percent of people with diabetes—over 8 million people—have gone undiagnosed. The incidence of diabetes is growing in the American population. Medical research alone will not cure this problem. In order to attack diabetes, we need the coordinated efforts of NIH, CDC, and AHCPR.

NIH focuses basic research on the causes of diabetes, including the genetic ones, and researches possible new avenues for treatment. Yet, NIH cannot alleviate diabetes alone. We need CDC's efforts in identifying those with diabetes and persuading them to seek treatment and to educate physicians on how to better detect this disease. We also need AHCPR's research which focuses on finding the most economic and least intrusive methods to screen individuals for diabetes. Without the essential research of NIH and the prevention services of CDC and AHCPR we will not likely reduce the serious threat that diabetes poses to our society.

The 21st Century Research Fund solidifies the foundation for a coordinated biomedical research system, providing $25 million for CDC's prevention research programs, increasing AHCPR's funding by $25 million in fiscal year 1999 alone, and setting the course to increase NIH funding by nearly half by 2003.

Cancer research and clinical trials

Cancer has been one of the cruelest killers of this generation. The President's budget moves dramatically on this front. The NIH budget, for example, pays special attention to cancer research, increasing funding across NIH by 10 percent in 1999 and 65 percent by 2003. The President also seeks $750 million for a three year demonstration to enable Medicare patients to participate in cancer clinical trials. Medicare patients represent 50 percent of all cancer patients and are ten times more likely to get cancer. It is therefore appropriate to undertake this demonstration for those eligible for Medicare. This demonstration is fully financed by revenues which would result from passage of tobacco legislation.

Vice President Gore has lead the Administration's effort to step up our fight against cancer, and I am personally grateful for his tireless efforts to achieve these historic increases for cancer research.

Child care

We live in changing times. Families are not the same as they were 30 years ago, the last time we balanced the budget. In millions of American families, both parents must work to support their children, and in millions of other families, single parents work doubly hard to support their children. Building on the Earned Income Tax Credit, the Child Tax Credit, the Family and Medical Leave Act, minimum wage increases and the new child health insurance program, the President's Child Care Initiative is another critical step in this Administration's commitment to our nation's families.

Our fiscal year 1999 budget proposes new child care investments that will support parents' choices, so that they will be able to find and afford quality child care for their children while they work. It will answer their most troubling questions about child care: Can I get it? Can I afford it? And can I trust it for my children's safety and development?

At the center of the President's Child Care Initiative is our proposal to expand the Child Care and Development Block Grant by $7.5 billion over five years (an increase of $1.2 billion in fiscal year 1999). This will provide funds to the states to serve over 2 million children by 2003.

The budget also grants tax credits to 3 million working families for child care and tax incentives for businesses that provide child care for their workers. Moreover, this budget includes $3 billion over five years to improve the quality of child care by providing challenge grants distributed by states to communities to improve early childhood education and the quality and safety of child care for children under five years old. In addition, the budget includes $250 million for investing in the education of child care workers and $500 million to help states enforce child care standards, and $150 million for research and consumer education.

Head Start

One of the President's top priorities has been and continues to be investing in Head Start. The President's budget contains $3.8 billion over five years. Because early investment in children gives them the best chance of continued success, by the year 2002 we will serve one million children in Head Start, including doubling to 80,000 the number of children 0–3 served by the Early Head Start Program.

Medicare buy-in

Our Medicare buy-in program provides solutions to one of the most troubling problems our aging population faces: what happens if I lose my health coverage before I'm 65? The President's budget allows individuals aged 55 and over without access to health insurance to breathe a little easier. The budget proposes a three-pronged solution. First, it enables Americans ages 62 to 65 to buy into Medicare, through a premium designed so that the policy is self-financing. It also provides displaced workers who are ages 55 to 61 with an option to purchase Medicare. Finally, the President's proposal gives individuals who retired early and whose companies have reneged on their health benefits the option to buy into their former employers' health care.

PUBLIC HEALTH CHALLENGES OF THE 21ST CENTURY

Public Health services affect every single American every day of their life. From AIDS prevention and treatment to tobacco control for our youth, our fiscal year 1999 budget builds on and expands our commitment to programs that will make all Americans more health conscious and protect them from traditional and emerging threats to our public health.

Ryan White

We have seen significant progress in the fight against HIV and AIDS. In the first half of 1997, AIDS deaths decreased by 44 percent. Nonetheless, more progress must be achieved. In 1997, the Department of Health and Human Services and the Henry K. Kaiser Family Foundation issued new guidelines for standardizing and improving the quality of care for HIV-infected persons. The quest to ensure access to new methods of treatment must continue. The President's budget addresses this issue and provides $1.3 billion, an increase of $165 million, for Ryan White treatment activities. The AIDS Drug Assistance Program (ADAP) will receive $100 million of this increase for helping individuals gain access to combination drug therapies consistent with the new guidelines.

Food Safety and Emerging Infectious Diseases

The President's budget includes an additional $25 million for a combined effort by CDC to develop and expand national early warning systems for unsafe food and emerging infectious diseases. We must make certain that food-borne diseases don't affect our families. Similarly, we need to closely monitor infectious diseases. Our budget develops an effective national surveillance network and expands the geographic coverage of this early warning network to 30 states. The food safety initiative improves the quality and scope of food-borne disease surveillance in eight FoodNet sites, links the federal and state health laboratories with computer technology that will enhance data sharing, and provides training to detect food-borne diseases in exports from foreign countries, including Mexico and some Latin American countries. In addition, FDA is seeking $50 million to complement efforts in food safety.

Racial disparities

We have already talked of the serious threat diabetes poses to Americans. Yet, there is another disturbing statistic associated with diabetes. Between 1980 and 1994, the number of African-Americans with diabetes rose 33 percent, 3 times the rate of increase for all other Americans. Native Americans also suffer from diabetes at extremely high rates. If we are to ensure a better future, we must find the answers to this disparity and correct this problem and the many other racial health disparities that exist. The President's budget includes $400 million over five years as part of a broader initiative to find new targeted means of reducing the health disparities that persist among minorities. This money is intended to target health outcomes in six areas where minorities experience serious inequalities in health services and health status. These include: infant mortality, breast and cervical cancer, heart disease and stroke, diabetes, HIV/AIDS, and child and adult immunization. This effort will be Department-wide and will be coordinated by the Centers for Disease Control and Prevention and will be supplemented by a host of non-budget activities that involve the community and experts in this area to help solve this urgent problem.

Substance abuse

We must continue our efforts at all levels of government and in the private sector to eliminate substance abuse. Consequently, the President's fiscal year 1999 budget provides an additional $200 million in funds for the Substance Abuse Performance Partnership Block Grant. A total of $1.5 billion will enable states and local communities to enhance their treatment capacity and continue efforts to control and treat substance abuse. We also are concentrating our research efforts in the biological basis of addiction, enhancing prevention techniques, and assessing prevention intervention approaches. With a coordinated effort, we can end this destructive plague.

Tobacco

Our budget request reflects the strong commitment of this Administration and all Americans to ending the tragic and destructive use of tobacco products by children and teenagers. We also are committed to finding the most effective methods for adults who want to quit the addiction that tobacco use creates. For example, CDC and FDA tobacco education and control programs will receive $200 million from the President's budget proposal. CDC will direct a total of $51 million to fund state-based prevention and control activities, including: training and programmatic support for school-based smoking cessation programs; national surveillance activities; state prevention and control plans to protect nonsmokers from exposure to environmental smoke; and state programs to address oral cancer.

The President has made clear his strong desire to work with the Congress to protect our children from the disease and death caused by tobacco use. To do that, we must have comprehensive legislation. Five key elements must be included in such legislation: (1) a significant price increase to reduce teen smoking, including tough

penalties if targets are not met; (2) full authority for FDA to regulate tobacco products; (3) changes in the way the tobacco industry does business; (4) progress toward other public health goals; and (5) protection for tobacco farmers and their communities. The President has called for tobacco legislation that will raise the price of cigarettes by up to $1.50 per pack over ten years and curtail tobacco use among youth. We estimate that the President's budget proposal, coupled with sales and advertising restrictions, would reduce underage tobacco use by 39 percent to 46 percent in 2003 and spare almost one million of today's young people from the premature deaths related to tobacco use.

INNOVATIVE PROGRAM AND FISCAL MANAGEMENT

In describing our budget, we must not forget that this committee played a major role in achieving balanced budget savings. It is important to note that our Department played a significant role, as well, in balancing the budget and will contribute $150 billion over the next five years in Medicare and Medicaid savings. After all, at HHS, we believe in responsible, innovative management. In this budget, we have developed innovative solutions to squeeze every ounce of productivity from our taxpayer dollars. We also intend to add additional non-federal resources to meet our program obligations in the years ahead. We need your support for new legislation on many of these proposals. We will work closely with the Congress and this subcommittee to enact this necessary legislation.

Fraud-busting

While I have just mentioned future management efforts, I would like to mention briefly one of our most recent success stories. It's no secret—it's called fraud-busting. In 1997 alone, thanks to the outstanding efforts of the Office of the Inspector General, we returned almost $1 billion to the Medicare Trust Fund in our aggressive pursuit of those organizations and individuals who steal from the Medicare system. When you steal from the Medicare system, you steal from our most vulnerable citizens and we will not tolerate it. New HCFA legislation that we are offering will return an additional $2.4 billion in savings to the Medicare system. We also are proposing a new audit user fee within the Medicare Integrity Program (MIP) that will allow us to double our audit and medical review spending.

The Administration on Aging (AoA), with its vast network of state and area agencies on aging and community-based services, is another partner in the long-term federal effort to fight and prevent fraud and abuse in the Medicare and Medicaid programs. AoA uses the funds allocated under the Health Insurance Portability and Accountability Act (HIPAA) to train and educate both paid and volunteer staff in the aging network. The results are in—fraud-busting is a smart investment.

User fees

With the passage of Balanced Budget Act (BBA) and HIPAA, the Health Care Financing Administration (HCFA) has acquired substantial new responsibilities. Without adequate resources these responsibilities simply cannot be accomplished. Given the tight limitations of the BBA, we have sought out alternative fiscal resources. We have proposed $264.5 million in new user fees for services that we furnish our nation's health care providers. I ask the Congress to enact these essential user fees. Our proposed user fees provide for more efficient administration of the Medicare program while allowing greater control against fraud, waste and abuse. Without such fees, HCFA's ability to implement the BBA and HIPAA requirements would be hindered. Our total program level, including user fees, would allow us to implement the new legislative requirements and help ensure millennium compliance of internal and external computer systems.

Government Performance and Results Act (GPRA)

The budget we have presented highlights the incremental changes that HHS is proposing through its programs. Along with the fiscal year 1999 budget, we also sent to you our first GPRA annual performance plans. These plans focus on the Department's stewardship of all of the resources entrusted to HHS. Our performance plans have been developed in partnership with the states, local and tribal governments, and non-governmental partners who use these resources efficiently.

For example, to help improve health outcomes for individuals in need, particularly children, we have set a performance goal for community health centers to serve an additional 150,000 uninsured and under-served persons in fiscal year 1999.

Similarly, we plan in fiscal year 1999 to increase to 59 percent the proportion of Medicare beneficiaries age 65 and older who will have received a screening mammogram in a 2-year period. As you know, a mammogram is a safe, effective means of detecting breast cancer at an early and treatable stage. This common-sense goal will

lead to improved health outcomes for Medicare beneficiaries and avoid the financing of unnecessary, high-cost medical services.

These are brief illustrations of the results that HHS and its partners want to achieve through all of our programs, but they are representative of the goals presented throughout our performance plans for fiscal year 1999. In the coming years, we believe that the focus on results that is fostered by GPRA will enable us to improve our ability to match the most effective forms of service delivery with populations that have the greatest need. GPRA will be an ongoing process. It is neither a quick management fix nor a vague management plan. It can and will work to improve our programs as long as there is a clear and continuing cooperation between the executive and legislative branches on the means to improve programs once the GPRA results are in.

We have proposed our blueprint for the next millennium and I believe it is an excellent drawing.

CONCLUSION

Mr. Chairman, we share many common goals in this budget. Most importantly, our concern for a balanced budget continues. We share the common goal of the best health research program ever. We want to end the tragedy of underage tobacco use. We want to expand safe, affordable, high quality child care to another million children. We want to sustain our commitment to Head Start. We want to improve food safety and curb emerging infectious diseases. And, we most assuredly want to maintain a vigorous attack on health care fraud.

Chairman Specter, Senator Harkin and members of the subcommittee: I want to join you in meeting the health and human resource challenges before us in this budget. We have much to accomplish together. I would be happy to address any questions you may have.

TRIBUTE TO SENATOR BUMPERS

Secretary SHALALA. Mr. Chairman, with your permission, rather than speaking behind his back, I would like to make a few comments about a departing Senator.

Senator SPECTER. We would be delighted to hear your comments as to our distinguished colleague, Senator Bumpers.

Senator BUMPERS. You have the rest of the afternoon, Madam Secretary. [Laughter.]

Senator SPECTER. Madam Secretary, he is right to cite the timing. I think you have about 40 seconds left. [Laughter.]

Secretary SHALALA. Mr. Chairman, before I begin to answer questions, I would like to pay tribute to a beloved and highly respected member of this subcommittee, a man who the National Journal has called a "Senator to whom other Senators pay attention," Senator Dale Bumpers of Arkansas.

I am fortunate to count Senator Bumpers as my friend and a true supporter of Government's role to help those who need help: our children, our seniors, and the disabled. Senator Bumpers and his wife, Betty, have vividly demonstrated over so many years devotion, to child immunization. He recently stood up for David Satcher in his nomination to be Surgeon General. When I look across the span of Senator Bumpers' quarter century of public service, I am reminded of the words of the poet Maya Angelou, who grew up in Arkansas: "If you are for the right things," she said, "then you could do it without thinking."

Senator Bumpers has always been among the most thoughtful Members of the Senate. Doing the right thing clearly has been second nature to him. Last fall, in paying tribute to the Little Rock Nine, Senator Bumpers said: "Sometimes we worry that there are no heroes in our country today, no one for our children to look up to, no one to inspire us to be our best selves." Well, when we see

Senator Bumpers, we know there are heroes in our country today, leaders to inspire our children, all of us, and our better selves. Thank you, Senator Bumpers, from all of us.

Senator BUMPERS. Donna, thank you very much.

Thank you, Mr. Chairman.

TWO HCFA CONCERNS

Senator SPECTER. Madam Secretary, there are a great many subjects that I want to take up with you today—the gap in funding which we have to find an answer to—but perhaps the most important issue which faces this subcommittee, perhaps the country, on the question of health care is the destruction of the doctor-patient relationship. And that is something which has been emphasized by the President. I know it has been something you have articulated. It is something that is obviously extraordinarily fundamental in our society. And it is rock bed on health care.

But we see disintegration of that relationship, as there are so many intervenors, people between the doctor and the patient. That has come up with the gag rule, where we had hearings on November 13, 1996, and finally got some HCFA changes. It came up as we legislated on drive-by deliveries, where the Congress got into the business of micromanaging medical decisions. Legislation is pending on drive-by mastectomies. There is a capitation issue, where doctors are motivated to not refer to specialists. And one item of great importance that I had written to you about on two occasions.

On November 25, I wrote to you about the issue of EPO. I got back what I consider to be a pretty perfunctory letter from Administrator Nancy-Ann Min DeParle. She will be before us later today. And then I wrote to you with some great specification about that issue earlier this month. I had called you last week about it. And I know you returned the call a little before 1 o'clock today; we were in our conference.

But in Administrator DeParle's letter, she said that in September, based on concerns about evidence that such physician justifications were being routinely submitted, resulting in overutilization of EPO, we decided to eliminate this exception from our coverage policy. Today I received a letter dated March 9, yesterday, from Chairman Archer, of Ways and Means; and chairman of the subcommittee, Thomas; and the ranking member, Peter Stark, raising the same issue about the drug EPO with the Health Care Financing Administration.

And I have two points that I would like your responses on the specifics here, that there is an urgent necessity to have a broader use of this drug and, second, the disregard of physician justifications.

Secretary SHALALA. Let me answer both parts of your question. We share Congress' concern about interference in physicians' judgment in evidence-based health care, which is where we want the health care system to go. In the President's support of the consumer bill of rights proposed by the Commission that I chair are a set of rules for which we hope there will be bipartisan support. They make orderly access to physicians, access to information people need in their health care system, help people understand what

their appeal rights are, and ensure that people have access to emergency rooms when they are needed.

On the specific question of the provision of Epogen [EPO] to dialysis patients, we are going to revise the EPO policy as of April 1. I am sorry that we did not connect earlier on the phone, but let me announce it here to you. Under the revised policy, with which I think that those who have raised an issue about this policy will be pleased, we will replace the current full denial for exceeding the thresholds with a partial denial. I can go into that in some detail or provide it for the record.

REDUCTION IN EPO DOSAGE

We agree that the revised policy needs to create incentives for a gradual reduction in EPO dosage if the patient is above the target range, consistent with the appropriate medical practice and FDA recommendations. And I think that this revision, as of April 1, will satisfy the concerns that you, other Members of Congress, and members of the medical community have raised to me.

Senator SPECTER. Well, I think this is important enough to take it up in some detail. The level for reimbursement was changed from a single monthly fixed limit to a rolling average over a 3-month period of 36.5 percent. And that percentage was viewed by the physicians as being too low because of the hematocrit variability of each patient. The nephrologists have made generalized complaints from all over the country that the 36.5-percent level needs to be raised for the natural fluctuation of the patient's hematocrit.

The technical information that has been provided to me requires that there be a number of changes. First, to reinstate the medical justification, to allow for physician discretion for selected patients, as needed, raising the hematocrit to at least 37.5, and replacing HCFA's current practice of total reimbursement denial with a partial denial. And my question to you specifically is, are all three of those items addressed on the change of policy as of April 1?

Secretary SHALALA. I believe they are. Nancy-Ann Min DeParle can answer that in more detail when she testifies after me. But if you would like me to march through what we are going to do, I would be happy to do that.

Senator SPECTER. What I would like you to do is to respond to these three elements which have been raised to me.

Secretary SHALALA. OK.

Senator SPECTER. Is Ms. DeParle here? Let her come join us now. And let us resolve this issue.

Secretary SHALALA. She comes at 3 o'clock. But we could do it at the end of this session, and we can call her and ask her to come up right now, if you would like that.

Senator SPECTER. OK. Let us do that.

Secretary SHALALA. And if we could have the three questions, then we will answer them on the record for you before the hearing is completed.

Senator SPECTER. OK, we will await her arrival.

But before she comes, why April 1? Why not March 10 or March 1?

Secretary SHALALA. Well, it is going to take us a few months to modify our computer systems. And we are making the policy effective for services provided on or after April 1. I think this is probably a notification question, and we will check with Ms. DeParle, again, on that question.

Senator SPECTER. Will you have somebody check that out? You say probably a notification question, maybe yes, maybe no?

Secretary SHALALA. It may be a notification question, but let me ask the question so I can give you an accurate answer.

Senator SPECTER. Let us find out about that. And let us find out about the computerization. Because a lot of people are suffering every day, from the avalanche of complaints which I have heard.

Secretary SHALALA. Well, we will make payment adjustments retrospective to April 1. So while it takes a few months to modify the computer systems to reflect the new policy, the policy will be effective for services provided on or after April 1. We will make payment adjustments retrospective to that date.

Senator SPECTER. That is 21 days away.

Secretary SHALALA. That is right.

Senator SPECTER. I would like to have it today.

Secretary SHALALA. Let me have the Administrator answer that question.

Senator SPECTER. Well, let us see if we can find a way to do it effective today.

Senator Kohl.

FEDERAL AFTER-SCHOOL PROGRAM

Senator KOHL. Thank you very much, Senator Specter.

And, Madam Secretary, it is good to see you. And we appreciate your coming down to talk to us.

Secretary Shalala, one part of the President's budget that I am interested in is a demonstration project run by the Education, Health and Human Services, and Justice Departments that would coordinate Federal after-school programs. I understand that this initiative is to designate three to five pilot cities, and show how they can coordinate all the various government programs that serve children after school.

I have three inquiries. No. 1, how do you intend to ensure that these programs are educational and not just custodial? No. 2, how are these pilot cities to be chosen? And, No. 3, can I request that my home city of Milwaukee be seriously considered?

Secretary SHALALA. You certainly can request that any city in Wisconsin be seriously considered.

The answer to your questions about our selection process and the coordination, I will have to provide for the record.

[The information follows:]

CHILD CARE INITIATIVE

The initiative you are referring to was part of the Child Care Initiative announced by the President on January 7, 1998. The President announced at that time a collaborative effort involving numerous federal agencies to eliminate duplication and better coordinate existing federal funding for after-school programs in three to five pilot cities, including the District of Columbia. A working group within the Administration has been formed to put this collaborative effort in motion. It comprises representatives from HHS, Department of Education, the Justice Department, as well

as other interested federal agencies. This working group will be looking at previous collaborative efforts to gain some lessons learned as criteria is developed for considering other cities that may be included as part of this effort. The key goal of this initiative is healthy development and learning, and not custodial. I will communicate to the working group your interest to have Milwaukee be considered as one of the possible sites and your concern that this effort not be focused on custodial issues.

AFTER-SCHOOL PROGRAMS

Secretary SHALALA. But let me make a substantive point about what is expected. We obviously want an educational component in after-school programs. But there really is a difference between dealing with after-school programs for young children and for older children. One of the ways to keep adolescents in after-school programs is to give them some choices—certainly getting their homework done—which have an educational component, perhaps combined with something else.

What has been cut out of schools in this country are extracurricular activities, for example, sports after school. We would suggest some choices for young people which include an educational component, but also make an investment in their health and exercise and all the other things that will keep them emotionally and physically healthy in an integrated manner to certainly make a difference.

The point, I think, of the demonstration is to make sure that communications have a strategy, so that no child is left out from these kind of choices, particularly for adolescents, and make sure communications use schools and boys and girls clubs and other kinds of organizations as part of this strategy, so that no child is left without a program, so that no parent is left without a program. Parents should identify what is convenient for them, and what that can occupy usefully and have an educational component for their child after school.

Senator KOHL. All right. Thank you.

ELDER ABUSE

Madam Secretary, last year the Milwaukee Journal Sentinel ran a series of articles, focusing on the prevalence of elder abuse by health care workers, many of whom had prior criminal backgrounds. Similar stories have appeared nationwide, and abuse is not isolated just to nursing homes.

To respond, I have introduced and continue to work on legislation that would create a national registry of abusive long-term care workers, and require criminal background checks for prospective employees of long-term care facilities. This, hopefully, will make sure that abusers cannot travel from State to State and continue to prey on vulnerable patients.

Would you, Madam Secretary, support such a proposal and work with me to push for it this year? And would you help me move this along this year by also looking for a way to perhaps do this administratively?

Secretary SHALALA. Well, we certainly will work with you on anything that will strengthen our ability to reduce elder abuse in this country, and anything that will hold in particular the States' feet to the fire on doing the survey and certifications and make

sure that they are regularly providing oversight for nursing homes and home care settings. We have already published regulations in this area. Obviously, there is still abuse going on in this country. So we would be pleased to have a conversation with you about what you are proposing.

Senator KOHL. Well, unless you have something like a national registry, there is no way for facilities from one State to another to know what occurred in another State with respect to employees and abusive behavior. That is what a national registry would provide for long-term care facility operators. And our bill would provide for that national registry. And it is your opinion on that, the advisability and the desirability of that, that I am interested in.

Secretary SHALALA. What I would want to do is to look at the actual proposal itself and the administrative costs that are tied into it. But, in principle, we want to support anything that can strengthen the oversight of nursing homes in this country.

Senator KOHL. All right. I thank you.

PRESIDENT'S CHILD CARE INITIATIVE

Last question: The President's $20 billion child care proposal contains over $5 billion in spending that goes through this subcommittee, spending for programs like teacher scholarships, child care facility inspections, and after-school programs. Now, currently, that money is considered outside of our spending caps, and the President has suggested paying for it with part of the revenues from a new cigarette tax bill. Will the administration still stand by its child care proposal if we are unable to reach agreement on a new tobacco tax?

Secretary SHALALA. First, we believe that there is bipartisan support for a price increase and a comprehensive strategy to reduce children smoking in this country. So we believe that what the President has identified as a source of funds for the child care initiative will, in fact, be available. But, yes, the President, in all of his top priorities, will work with the committee, or appropriate committees, to find a source of funds if for some reason the source of funds we have identified does not come through. We have been willing to do that in the past and we certainly would be willing here.

PREPARED STATEMENT

Let me add that your assumption that any of the President's proposals breaks the cap is not consistent with the way we have presented the budget. The President believes he has presented a budget that is paid for. He has identified sources of revenues. And we believe that is within the context of the balanced budget commitment which we all made last year.

Senator KOHL. Thank you, Madam Secretary.

Senator SPECTER. Thank you, Senator Kohl.

[The statement follows:]

PREPARED STATEMENT OF SENATOR HERB KOHL

Thank you, Mr. Chairman. Secretary Shalala, it's good to see you again, and I look forward to your testimony today.

This is a unique time in our nation where we have tight budget constraints and tremendous opportunities at the same time. Last year, we passed the Balanced Budget Act, which wisely requires Congress to comply with spending caps in order to get rid of the deficits of the past three decades. But we also have a strong economy, the deficits of the past are all but gone, and both OMB and CBO are projecting surpluses for the next several years. Many people in our country are doing well—it is now time to focus on those who are not, and give them the tools to live productive, safe and successful lives.

I am pleased that the President's budget has taken advantage of these prosperous times by placing a high priority on child care programs. Both the public and private sectors must get involved in seeing that we have enough child care for working parents. The President's budget includes a proposal, which I have worked on for several years, to provide a tax credit to businesses who help their employees find quality child care. This benefits not only families, but businesses as well, as it will help reduce absenteeism and increase productivity. I look forward to working with the Administration to make this and other child care proposals a top priority.

On the other end of the age spectrum, we must take a close look at the issue of how well we protect our elderly once they require long-term care arrangements. With 43 percent of Americans over the age of 65 likely to spend time in a nursing home, and the increasing utilization of home care arrangements, we have to make sure that facilities are safe and provide the best care possible. I have introduced legislation that would require background checks of long-term care workers, and I look forward to working with the Administration on other efforts to protect our nation's elderly and frail patients.

Again, I thank you, Secretary Shalala, for coming here today to address the question of how we can strengthen our investment in programs for our most vulnerable populations while still complying with the budget constraints required to keep the budget in balance.

PATIENTS' BILL OF RIGHTS

Senator SPECTER. We will proceed in order of arrival. Senator Bumpers is next.

Senator BUMPERS. Thank you, Mr. Chairman.

Madam Secretary, let me thank you again most profoundly and sincerely for your very kind, laudatory remarks, all of which are true, and more. [Laughter.]

I am reminded of the widow, at her husband's funeral. The preacher just kept going on and on about what a great citizen he was. Finally she leaned over to one of her children and said, honey, you go up and look in that casket and make sure that is your daddy they are talking about. [Laughter.]

I listened to the President's speech to the AMA on NPR last night on the way home. And every time he mentioned the patients' bill of rights he got the loudest applause. That coming from the AMA. And the applause is even louder, of course, when he is speaking to lay groups.

But while there is a House bill dealing with the so-called patients' bill of rights, as far as I know, there is nothing pending in the Senate. Is the administration preparing a bill to be introduced in the Senate on this subject?

Secretary SHALALA. We have not sent a bill to the Senate. But we have sent a lot of detail to the Senate, including technical assistance on legislative language. It is not very complicated to provide technical assistance on legislative language. But we have sent up the specifics as a result of the commission which I chair with the Secretary of Labor. So we have articulated areas in which the President would like legislation as well as have provided technical assistance on the legislative language.

Senator BUMPERS. Well, people obviously have a very strong feeling that they are not only being neglected, but that their health is often jeopardized by the lack of options, and some gatekeeper who says, no, you are not eligible for this. And the President, yesterday—I am sure you heard it, too—gave the illustration of the youngster whose leg ultimately had to be amputated because he could not get permission for the treatment that might have saved his leg. People hear too much of that.

Of course, some of that is embellished. In the coffee shop you hear stories like that. And I must say, in the few times I have been hospitalized in the last few years—sometimes I guess it is just lack of care—you wonder if they treat Senators like that, what does the poor guy who just walks in off the street get? But that is often a matter of care in particular institutions as opposed to managed care and lack of choices.

But I would like to see the Finance Committee, if the administration is not going to submit such a proposal, I would like to see the Finance Committee take the suggestions and some of the information that you are going to forward over here, and get on this. I would like to see this—as you pointed out, this is my last year—I would like very much to see something happen on that this year.

And let me just conclude, Madam Secretary, by saying you have now been on this job for a little over 5—almost 5 years. And I would like to reciprocate by saying I think you have done an outstanding job.

Secretary SHALALA. Thank you, sir.

Senator BUMPERS. Most of my dealings with you have been in the immunization area. And that is small potatoes, moneywise, compared to the budget you administer. But your tenacity and your determination on causes that really make people's life better has been most admirable. And certainly I am one of your biggest fans also. And I will miss being associated with you after I leave here.

Secretary SHALALA. Thank you, Senator.

Senator BUMPERS. Thank you, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Bumpers.

Senator Faircloth.

NURSE ANESTHETISTS

Senator FAIRCLOTH. Thank you, Mr. Chairman.

And thank you, Secretary Shalala, for being with us today. And I thank you for your enthusiastic support of transferring some IRS agents to the drug control.

Secretary SHALALA. I apologize again, Senator.

Senator FAIRCLOTH. But I think it needs to be done. I think one is a bigger problem than the other. And I think that drugs are it.

Madam Secretary, in December of last year, your group issued a proposed rule that would delete the current requirement that nurse anesthetists administer anesthesia only under the supervision of operating surgeons and anesthesiologists. Now, I have heard from a lot of individual groups of people who are raising a lot of concern about the effect of this and the quality of the service.

Now, no one has greater respect for nurses and what they have done and what they mean to the medical profession than I do. Nurse midwives, nurse practitioners all come to mind. But I have

a lot of concern about this change of rules. How can you document that this does not represent a compromise?

Secretary SHALALA. Senator, we actually are reinforcing State medical practice whatever the standard is in the State. Twenty-nine States actually allow that to take place. So in this case, the Department's rule reflects standard State medical practice since 29 States allow it. They are often States that have large rural populations, where they think this is an appropriate medical practice. So it is not as new or as dramatic a change, since so many States allow it.

Senator FAIRCLOTH. Well, the States besides, do you think it is an adequate way to do business?

Secretary SHALALA. Well, it is a proposed rule now. When we drafted the rule——

Senator FAIRCLOTH. Wait a minute now. What is the proposed rule?

Secretary SHALALA [continuing]. The proposed rule is to allow this to occur. And it has not in final——

Senator FAIRCLOTH. Well, we have not allowed it to occur before, is that right?

Secretary SHALALA [continuing]. Except in States where it is standard practice, which I indicated it was in 29 States.

Senator FAIRCLOTH. But as I understand it, you are going to allow it in all States.

Secretary SHALALA. That is correct.

Senator FAIRCLOTH. And that is what the problem is.

Secretary SHALALA. We are collecting comments now from individuals, organizations, and different States so we have not gone to the final rule. I do appreciate your comments on that.

Senator FAIRCLOTH. Well, I would be glad to give you comment. I think it is a terrible practice. And I do not think it should be allowed. And I do not think you should be into it.

I think the standard question in opposition to it is very simple. If you had to have major surgery this afternoon in Walter Reed Hospital, do you think they would bring in a nurse to give you the anesthesia?

Secretary SHALALA. Well, Senator, I have made it a practice not to answer a hypothetical question, since I do not know what the standard practice is at Walter Reed. But let me say that 29 States in which——

Senator FAIRCLOTH. All right, I will change my question. If you had all morning to decide if you were going to have an operation, would you request a nurse anesthetist or an anesthesiologist? That is not hypothetical.

Secretary SHALALA. Senator, I would defer to my physician as to what he or she thought was appropriate in my case, and would not second guess my physician if I were going into an operation.

Senator FAIRCLOTH. I will give you a pretty good idea of what he would say.

DISEASE PREVENTION

Now, we spend less than 1 percent of our budget on programs related to health prevention. We know that heart disease is a leading cause of death in this country. Yet CDC can only afford to fund

prevention programs for cardiovascular diseases in 3 of the 50 States. If money talks, it is clear the message still focuses on treatment and not prevention.

Would you give me your thoughts as to what we can do and how we might reverse this trend?

Secretary SHALALA. Well, as part of this budget, we have asked for two increases that are directly related. First, because cardiovascular disease disproportionately affects minorities, we have asked for resources for the CDC to help close gaps in terms of prevention as well as access to services, and also in helping people manage their own health situation. Second, we have asked for a new CDC prevention fund as part of this budget to help us expand our investment in prevention of diseases like cardiovascular disease. We would agree with you that we need additional investment. We believe this budget reflects that.

Senator FAIRCLOTH. Thank you. My time is up.

Secretary SHALALA. You are welcome, Senator.

Senator SPECTER. Thank you very much, Senator Faircloth.

Senator Cochran.

Senator COCHRAN. Thank you, Mr. Chairman.

Madam Secretary, welcome to our committee.

Secretary SHALALA. Thank you.

FRAUD AND ABUSE

Senator COCHRAN. We appreciate very much your cooperation with our effort to understand the budget request and to deal with problems that may be presented at the Department of Health and Human Services.

We have had an opportunity to look at some of the requests for additional funds and user fee imposition that is contemplated by the President's budget request to make up for some of the shortfalls in funding. And one thing struck me as interesting in talking to some of my constituents in my State is this new effort to deal with fraud and abuse of the program, which we applaud generally as a very important undertaking, is creating some obvious instances of abuse by the Government, it seems to me.

And let me cite one example that was brought to my attention the other day. In early February, one of the small-town hospitals in our State received a letter from a U.S. attorney in the State of Pennsylvania. The letter, which I am going to put in the record, dated February 9, recites that this is coordinating office for Federal False Claim Act cases arising under the medicare program. And that as a result of an audit by the Office of Inspector General, this hospital had been found to have filed two claims for nonphysician outpatient services of $204.34, in 1990, between November 1, 1990, and December 31, 1991, and another for $220.92, between the dates December 1, 1987 and October 31, 1990. And after reciting the fact that they found that these were duplicate claims and should not have been filed, it pointed out all the penalties under the False Claim Act that can be visited upon this small-town hospital, and then says:

The total financial exposure of your hospital arising from these reviews is $61,054.86.

And then they go on to talk about the fact that if you would like to settle this case before litigation, please contact the undersigned in writing at the address indicated within 20 days of the date of this letter. And on and on. And just reading this letter that was handed to me is frightening, just in and of itself. But you can imagine a small-town hospital, with claims that they say they have gone back 10 years, or thereabout, and they have had $400 in alleged false claims filed, and your exposure is $61,000.

I know you are not the U.S. attorney in the Middle District of Pennsylvania.

Secretary SHALALA. I am not.

Senator COCHRAN. But that is who signed the letter. And Yalobusha County Hospital, in north Mississippi, gets this letter. And, of course, the reaction has to be one of terror. Is this a terrorist state? What is going on here?

My question is, what oversight is the Department, or HCFA, engaged in to monitor situations where alleged abuses are being handled in this fashion? Is there a Government policy, is there an administration policy to do this kind of thing to a small-town hospital?

Secretary SHALALA. As you indicated, Senator Cochran, I have no authority over U.S. attorneys or their decisions as to which part of the law applies to a fraud case. I would appreciate it if you would refer that letter, and ask that question, to my colleague, the Attorney General. And, in addition, I would like to have it myself. In general, we do audits. The inspector general has a conversation with the hospital. They work out a settlement. A lot of this is a routine relationship. Recently, some U.S. attorneys have been using the False Claims Act. These cases have been brought to my attention. But the way in which our responsibilities are divided, our responsibilities include the inspector general being the leader or being part of teams that are investigating fraud. And we certainly do a large number of audits in this area.

Senator COCHRAN. We will send that to you and to HCFA as well. I wanted to bring it to your attention, to let you know what seems to be a case of clear abuse of power by the Federal Government against this small-town hospital in my State. And you are the head of the Department, and I am bringing it to your attention.

Secretary SHALALA. And I appreciate that.

HOME HEALTH SURETY BOND

Senator COCHRAN. And I appreciate your consideration of it. And you are using up my time. I have got a little question I am going to ask you about, and that is the surety bond requirement on home health agencies. We have got a lot of small-town operations that are not connected with big hospitals or multistate corporations, that can afford 15 percent surety bonds. This is a requirement, as I understand it, you have to file to get Medicare eligibility for accepting authorized reimbursement. A surety bond that is the greater of $50,000 or 15 percent of the annual amount paid to the HHA by the Medicare program.

This is operating as a very difficult financial burden for a lot of small-town home health care operations. And I am just reporting that as something that has been brought to my attention. I hope

that there is some way to review that and make exceptions if they are justified or, in some other way, keep from putting out of business the small-town operators, and preferring instead the massive, big corporations to run the home health service programs.

Secretary SHALALA. We have given these agencies more time to comply with the law, and we still are not clear what the final rule will look like. So, I delayed the deadline for agencies to have bonds so that we could respond to some of the comments that we received in this area, particularly from small companies from the home health care business.

Let me also say that this was clearly an effort by the Congress and by the administration to try to reduce the amount of fraud in the system. In particular, it was an effort to keep fly-by-night providers out of these programs. But there was no interest in keeping appropriate small businesses out, nor to put them out of business. So, certainly we have looked at this. And the industry itself, the surety bond industry, has made comments in this area, because they are also concerned.

Senator COCHRAN. Thank you.

Senator SPECTER. Thank you very much, Senator Cochran.

Senator Gregg.

Senator GREGG. Thank you.

Madam Secretary, it is a pleasure to see you today.

Secretary SHALALA. Thank you.

CHILD IMMUNIZATION

Senator GREGG. The immunization program in New Hampshire is projected to receive a 46-percent cut this year and a bigger cut next year. New Hampshire has the highest percentage of immunized children in the country. It has the best program in the country, I believe. And yet if it is subjected to these types of cuts, the program will be thrown into chaos, especially the relationship it now has with Maine.

I would not presume you would be familiar with a unique New Hampshire situation, but I would ask that you go back to CDC and find out what is going on.

Secretary SHALALA. I will go back and look at that. We did indeed cut back, because States, in many places, were not drawing down the money that was available, and we reallocated some of that money.

Senator GREGG. That ran out. What happened was there was an $80 million carryover. And we ran through that over the last 2 years. And I think that that has affected the budgeting process, so that we are working off a baseline that is not compatible with what the reality is.

Secretary SHALALA. That may be what occurred. What I have said, Senator, is that we do not intend to underfund the vaccine program if we need to adjust that decision. We also do not want to leave money sitting around that is not being used.

Senator GREGG. I understand that.

Secretary SHALALA. So we are attempting to find a balance.

Senator GREGG. I think this was that. I think the pendulum went one way, and now it has swung back the other way.

Secretary SHALALA. We will be happy to look at that. As we continue in the appropriations process, we will want to make sure that our number is correct.

Senator GREGG. Well, I am concerned about other States, but I am specifically concerned about the New Hampshire situation. Because it is a program that has worked extremely well.

TOBACCO LEGISLATION

On the tobacco settlement, why should we give these companies, these tobacco companies, any immunity at all from lawsuits? I mean, their action has been pretty reprehensible here, especially as we see this documentation coming out, that reflects the fact that they have produced a product that they knew was addictive, and targeted it on children. I cannot see, from my standpoint, why we should have any settlement around here that deals with giving immunity at all. And I am interested in why the administration has signed on to the Conrad bill, which, while it does not specifically state immunity, but obviously it presumes immunity, because it presumes the tobacco companies will sign off on it.

Secretary SHALALA. Senator, I did not assume that the Conrad bill had a large section on immunity.

Senator GREGG. No; it does not. But it is going to have immunity in the end, because it has an unconstitutional advertising language in it. So that the only way you are going to get that is by a contract agreement with the tobacco companies, which requires immunity.

Secretary SHALALA. The reason the President endorsed that bill was that it covered the principles which he laid out that he would have to have in any comprehensive tobacco legislation. And that bill clearly does, from the price increase to——

Senator GREGG. Well, OK, but let us go back to just the immunity issue. What is the position on that?

Secretary SHALALA. What the President has said on the issue of immunity is that not until all of the issues—principles—that he has outlined are covered in a piece of legislation does he believe that any other issue ought to be considered. And that would obviously include immunity or any other issue that anyone wanted to bring up at that time.

But, first, we want to see a comprehensive piece of legislation with a significant price increase. Plus, we want provisions that care for tobacco farmers and their communications, and stop tobacco companies from doing business as usual, and which keeps the FDA a nimble, clear organization with oversight over tobacco. We have outlined our principles. And we have not spoken to any other issues other than those covered in what the President considers to be critical parts of comprehensive tobacco legislation.

Senator GREGG. So the administration has no position on immunity?

Secretary SHALALA. The administration has said repeatedly that we want a comprehensive piece of legislation, with a significant price increase, which covers the major issues the President has recommended. If all of those are covered, and Congress, working in a bipartisan manner, then wants to bring up other issues, we would be happy to consider them at that time.

At this moment, we will endorse only comprehensive packages which cover all of the issues the President has outlined.

Senator GREGG. So if we pass a bill that addresses those issues which you have just addressed, and include in it that there will be no immunity, you would accept that?

Secretary SHALALA. The President has outlined the critical issues. He would be happy to support a comprehensive piece of legislation that covers all of those issues. But we also have reiterated over and over again that it must have a price increase as part of it. We think that is critical.

Senator GREGG. But what I am saying is if we passed a bill that had all the elements that you wanted—a price increase, FDA unilateral authority—I have forgotten the other ones—and then included in that bill that there be no immunity, that would be acceptable, because you have gotten everything you wanted, and a no immunity, no immunity language would then, therefore, be acceptable?

Secretary SHALALA. He will endorse a comprehensive bill, which covers his issues, that has bipartisan support. He just did that in the case of the Senator Conrad's bill. He indicated that he would support that bill and would be prepared to sign it.

Senator GREGG. All right. Thank you.

Secretary SHALALA. You are welcome.

Senator SPECTER. Thank you very much, Senator Gregg.

Ms. DeParle is in the room. Would you please join the Secretary at the witness table.

REVISIONS TO EPOGEN POLICY

Secretary SHALALA. We want to talk about the revisions to the EPO policy.

Senator SPECTER. Let me revisit the chronology, review the bidding here for just a minute. In the legislation passed last year, the bill expressed concern that HCFA's new Medicare payment policy for EPO may negatively impact on the quality of care received by patients with end stage renal disease, and may increase overall health costs. And I then wrote to you, especially about it, Secretary Shalala.

And I got back a response, dated February 13, from Ms. DeParle. And the first question I have is, why does it take us so long—almost 3 months—to get a response to a letter like that?

Ms. DEPARLE. Mr. Chairman, thank you for the opportunity to testify today. The question of how long things take is a big struggle for me, in Government, and I am sure for the Secretary, in the Department. I am particularly aware of this issue because, as you may know, I was confirmed in November. And in December, I became aware of this problem, primarily from letters I was getting from Members on both sides of the aisle. They seemed to be concerned about this policy.

Senator SPECTER. You got a lot of letters?

Ms. DEPARLE. Yes, sir; I did.

Senator SPECTER. How many, roughly?

Ms. DEPARLE. I do not know how many, but I will tell you the thing that struck me was that, over the holidays, the Christmas holidays, I read all the congressional correspondence—I started

doing that—and I remember one night I took home a letter from Senator Connie Mack and a letter from Congressman Pete Stark that both said the same thing, that they were concerned about the new policy, thought we ought to look at it again, and particularly they were concerned about the lack of an exceptions policy, physician justification, which had been the case before.

And I was not familiar with this issue at all. And so what I undertook to do—and this was around the holidays, so late December—was to ask my staff to provide me with background on it. What had the policy been? What was the problem? Why had we changed it? And they probably held up a response to you during the time that we were looking at it.

My staff told me, Senator, that there had been problems with, they felt, overutilization of the drug Epogen. I do not know how to pronounce it. Epoiten, I suppose, is the hormone.

Senator SPECTER. Well, in your letter, dated February 13, 1998, says that in September, based on concerns about evidence that such physician justifications were being routinely submitted, resulting in overutilization of EPO, we decided to eliminate this exception.

What I would like you to do is to respond in writing to the subcommittee as to what took so long, from November 25 to February 13. According to your letter, it is based upon information you had prior to that time, before September. So without going through the specifics, I would like you to give us a response in writing as to what happened.

Now, you have talked about letters from Congressman Stark and Senator Mack. How about my letter of November 25?

Ms. DEPARLE. Sir, I did not particularly remember your letter, but I did say that I had seen a lot of letters on this. And what I was trying to say was that we had a problem, the staff informed me, with overutilization. And also, apparently, there was some problems with there were some studies that indicate that, with some patients, the use that—keeping them at a hematocrit that is about 36 can be a problem. And that was why they had chosen to go with a new policy.

Senator SPECTER. Well, that is a matter for the doctors. That is a matter I was raising with Secretary Shalala before you walked in, as to what is being eroded here is the doctor-patient relationship.

Ms. DEPARLE. I agree with you. And that is why I personally looked at this. There was a lot of disagreement within our agency about this, frankly.

It appeared to me, two things, Senator. One was my instinct was that it was not correct to have a policy that did not allow for a physician exception, which had been the policy we had before. Second, it was my impression, Senator, that the decision to change the policy had been made rather hastily. And I wanted to be sure that I had a chance to look at the data. So I asked the staff to give me the data on the impact of the new policy.

The good news is, I think, that it does not appear, from the data, that it has had a negative effect on people. But I still think the policy was not well founded. And that is why, today, I wanted to advise you that I want to change the policy. And, in fact, I did look

at your most recent letter, which I saw over the weekend. And, in general, I think you and I agree.

There is only one area where I think there is a bit of a difference between what you are recommending and where I came out. But I think, actually, because I am saying we need to look at the hematocrit levels, that we are closer than you may think or that it may appear.

Senator SPECTER. Well, I am going to come to that in just a minute. But what I am trying to ascertain is why it takes so much congressional oversight. You are going to get for me the sequence of events as to why it took from November 25 to February 13 to respond to the letter. Then the next question I have for you is, you are now saying that you are concerned about the doctor's evaluation. But in the letter of September 13, you talk about evidence that such physicians' justifications were being routinely submitted.

Is that to suggest that the physicians' justifications are wrong?

Ms. DEPARLE. Not necessarily. And I do not have evidence to say that, sir.

OVERUTILIZATION OF EPO

Senator SPECTER. Well, that is why I wonder why you say resulting in overutilization of EPO. I am trying to find out what the basis is for your conclusion that there is overutilization, as you put it, because physician justifications were being routinely submitted.

I would like you to tell me what that means. I would like you to tell me what evidence you had to say that. Because you are denigrating the physicians' recommendations by saying that they are routinely submitted, which is to suggest that they are not thoughtfully submitted.

Ms. DEPARLE. No, sir; I would not want to do that.

Senator SPECTER. Well, I would like to know why you say routinely submitted. This is a recurrent problem that we have with HCFA, where there is a fury out there in the medical community as to what you are doing. So I want to find out what you did in this case, because we have taken a lot of time and a lot of effort on this particular matter. So I would like you to tell me in writing what led you to say that there was overutilization and that the physicians' justifications were being routinely submitted.

I do not want to take any more time with it now.

Ms. DEPARLE. I will be happy to do that.

Senator SPECTER. We have a lot of ground to cover. And I do not think you can really do it without referring to your files.

[The information follows:]

LETTER FROM NANCY-ANN MIN DEPARLE

DEPARTMENT OF HEALTH AND HUMAN SERVICES,
HEALTH CARE FINANCING ADMINISTRATION,
Washington, DC, March 13, 1998.

Hon. ARLEN SPECTER,
U.S. Senate,
Washington, DC.

DEAR SENATOR SPECTER: I appreciated the opportunity to appear before your subcommittee on Tuesday to discuss a number of issues relating to HCFA's work in developing a proposed rule on physician practice expense. At the hearing you raised several questions in regard to HCFA's policy concerning EPO and our coverage of

the Salitron System for treating disorders associated with Sjogren's syndrome. You also inquired whether it is possible to waive the salary equivalency guidelines in certain circumstances, or for certain providers. This letter responds to those questions.

First, in your letter to the Secretary about EPO, you asked for a justification of our original policy and urged us to revise that policy. At the hearing, you also asked for the reason for the delay in the revision of the policy.

HCFA altered Medicare's national coverage policy for EPO in the ESRD population effective September 1, 1997 in an effort to promote national consistency in application of EPO coverage policy and to protect beneficiaries from the potential adverse consequences of over-administration of EPO. Under that policy, Medicare moved from an absolute limit of a hematocrit reading of 36 percent to a rolling 90-day average hematocrit of 36.5 percent. In addition, the exception providing physicians with discretion to exceed the 36 percent level was eliminated based on a lack of evidence in the medical literature of any benefit for exceeding the target range (31–36 percent). In fact, there was evidence of the potential for harm to patients with cardiac conditions if hematocrits were maintained above that range. In implementing this new policy, HCFA committed to closely monitor the hematocrit data reported through the claims processing system to assure that the new policy did not result in adverse consequences.

Our staff did not consult with the renal community before announcing the new policy. In hindsight, I believe this was a serious mistake. However, during the period of time between announcement of the policy and implementation staff met several times with representatives from Amgen, the National Renal Administrators Association, the Renal Physician Association, and the Renal Coalition. Since that time, HCFA staff have had three meetings with researchers from Amgen or associated with Amgen. At one of these meetings, other representatives from the renal community were also present. In addition, this issue was also raised informally by members of the renal community at nearly every discussion where other items were the main agenda topic.

Upon receiving your earlier letter, and numerous others, and based on concerns raised by the renal community, in December, I asked our staff to review the impact of the new policy. Given normal time lags in submitting and processing claims, we did not have even preliminary data on the impact of the new policy until December. That preliminary data did not indicate any negative impact. Additional data that became available in February, while still not indicating any negative impact, did appear to show that the steady improvement in the percentage of patients within the target hematocrit range (30–36 percent) had stopped. Fostering improvement in this area was a major focus of joint quality improvement efforts by the renal community and HCFA. The fact that there appeared to be no further improvement since the revised coverage policy was implemented caused us to reexamine this policy and develop alternatives.

As you are aware, on March 10, I announced a revised policy with two components. First, we have reinstated a medical justification policy to allow physicians discretion to exceed the 36 percent level for selected patients as needed. Second, in the absence of medical justification, if the hematocrit level for a given month exceeds 36 percent and the 90-day rolling average exceeds 36.5 percent, payment for that month will be reduced rather than denied (i.e., a "partial" denial rather than a complete denial for the whole month). Payment will be made at the lower of the actual dosage administered or 80 percent of the allowable dosage for the previous month. As you requested, we made the new policy effective on March 10, and payment adjustments will be made retrospectively to that date. (I have attached a copy of the Program Instruction effecting this change. This instruction was faxed to your office on Thursday). In the months ahead, HCFA will work with the renal community to develop guidelines regarding when it is medically appropriate for patients to exceed the 36 percent standard in order to assure that the medical justification policy is not subject to abuse.

Our revised policy creates incentives for a gradual reduction in EPO dosage, if the patient is above the target range, consistent with the appropriate medical practice for titration of drugs and FDA recommendations. The revised policy also allows the 36 percent level to be exceeded according to physician discretion. By promoting the maintenance of patients at as high a level within the target range as possible, the revised policy is consistent with the National Kidney Foundation's Dialysis Outcomes Quality Initiative. Recommendations of the Anemia Work Group included in the Dialysis Outcomes Quality Initiative indicate that hematocrit be maintained between 33 percent and 36 percent. I recently met with a representative from the American Association of Kidney Patients, and they fully supported this policy change.

Second, in regard to HCFA's coverage of the Salitron System, in 1994, HCFA published a notice in the Federal Register indicating an intent not to cover Salitron based upon a 1990 technology assessment that HCFA had commissioned. As your February 12 letter points out, no final rule was ever published.

We received very few comments on that notice. In the meantime, the Durable Medical Equipment Regional Carriers (DMERC's) have had discretion regarding coverage.

On Monday, March 9, based on your continued interest in this device, I directed staff to request the Agency for Health Care Policy and Research (AHCPR) to conduct a new technology assessment. We will ask the manufacturer to submit any significant data to AHCPR. We will publish a Federal Register notice outlining this course of action (and withdrawing the 1994 notice).

Finally, you asked me to address my review of the incoming letters from you on these issues. In regard to your letter of February 12, about the Salitron System, I did not see that letter, even though I have instructed staff to provide me with copies of all correspondence from Members of Congress. Unfortunately, a mistake was made within our correspondence control system. Please consider this letter a response to your February 12 letter.

In regard to your letter of November 25, I responded with a letter in February which said that staff were monitoring the data but did not convey the fact that I was actively revisiting the EPO policy and in fact, was on the verge of announcing a new policy. We should have moved more quickly on revising this policy and provided you with a more responsive answer. Such an answer would have obviated the need for your second letter to the Secretary dated March 5.

In the hearing on Tuesday, you also inquired whether it is possible to waive the salary equivalency guidelines in certain circumstances, or for certain providers. The salary equivalency guidelines regulation was published with an effective date of April 10, and we believe that we do not have the authority to change or waive that date for one provider or a group of providers. Existing regulations do provide for exceptions to the guidelines for unique circumstances or special labor market conditions although any exceptions may reduce the savings from these guidelines. These exceptions are available to providers of services as I'll explain below.

The guidelines apply to payments that the Medicare program makes to skilled nursing facilities, home health agencies, and other providers, for therapy services provided under arrangement, HCFA pays the entity (the provider) that claims the therapy costs in its cost report. This means a provider can apply for an exception if (1) that provider files the cost report with HCFA and (2) it contracts with another entity to provide therapy services, because the guidelines do not apply to therapists directly employed by the provider.

I thank you for the opportunity to appear before the committee and I trust that I have answered your questions. I look forward to continuing to work with you on these and other issues in the future.

Sincerely,

NANCY-ANN MIN DEPARLE,
Administrator.

HCFA ACTION

Senator SPECTER. The point I want to come to now is the minimum HCFA action, which has been presented to me—and I am prepared to get into the details of it, to find out what is involved—but there are three items which have been articulated in my letter to you, to reinstate the medical justification, to allow physician discretion for selected patients as needed. My question to you is: Is that part of your new policy?

Ms. DEPARLE. Yes, sir; it is. This is your letter of March 5, last week?

Senator SPECTER. That is right.

Ms. DEPARLE. Yes, sir; it is.

Senator SPECTER. OK. The second point is raising the hematocrit to 37.5 at least. Is that part of your new policy?

Ms. DEPARLE. No, sir; it is not.

Senator SPECTER. And why not?

Ms. DEPARLE. Because, sir, our policy in the past, as you know, was to keep it at 36 percent. And the package insert that goes with this drug, that was approved by the FDA, indicates that patients should be kept in a range of 30 to 36 percent.

Our policy now, as revised, as I understand it, is that we look at a rolling 3-month average. And if the patient is around 36.5 percent, that is judged to be appropriate. And I did not have a basis, based on the evidence and data that we have, to change that number, although I am happy to work with the nephrologists and with the renal community to see if they can provide data for a different number. But I did not have a basis for the number you suggested, sir, which was 37.5.

Senator SPECTER. Well, have not the physicians in this field asked you to raise that level to 37.5?

Ms. DEPARLE. Sir, I am not aware that they have.

Senator SPECTER. Well, I believe they have. I believe that is the point. I believe the point is that in the rolling averages, as you take them, they go low. And there are very, very serious consequences when you have the percentage of blood taken up by the red blood cells is lowered—weakness, fatigue, poor oxygenation of tissues. It generally leaves the patient in a condition where they just cannot function.

Ms. DEPARLE. Sir, as I understand it, this policy was, in fact, an improvement on our earlier policy, which held things to 36. And especially now, when you reinstate the medical justification policy, I think there should be room here to maintain the hematocrit at the levels that are recommended in the package insert that was approved by the FDA. That was the basis for this decision. I will be happy to meet with anyone you want me to meet with in the nephrology community who thinks otherwise. But what I was aware of was that evidence.

Senator SPECTER. Well, we are meeting right now. This is the meeting.

Are you aware that the National Kidney Foundation's dialysis outcome quality initiative guidelines recommended that there be a 37.5 level to ensure that a majority of patients are targeted in the 33 to 36 percent range?

Ms. DEPARLE. No, sir; I am not.

Senator SPECTER. Well, what have you considered, in terms of medical evidence, in reaching the decision not to use the 37.5 level?

Ms. DEPARLE. Sir, the staff in our Office of Clinical Standards and Quality, which worked on this, it is my understanding, met with a number of representatives of the nephrology community, including a number of medical specialists, as well as the carrier medical directors, who administer this policy for us. And in that office there are a number of physicians. And I personally have talked to other Members of Congress and their staffs, as well as, as I said, reviewed your letters and the memoranda and other documents from our staff. That is what I have looked at.

I just did not have a basis, based on what I was presented with, to make a decision to go higher than what the package insert recommended.

Senator SPECTER. Ms. DeParle, what is your level of expertise in this field? What is your background and training?

Ms. DEPARLE. I am a lawyer, sir.

Senator SPECTER. So there is no special level of expertise that you have to make this kind of an evaluation?

Ms. DEPARLE. Sir, I do not have a special level of expertise to make a medical evaluation, but my staff does—the staff at the Health Care Financing Administration, including a number of medical professionals, as well as—as I said, this decision, as I understand it, which was—the initial decision was made before I was there—but, as I said, it was made in consult with many doctors who work in HCFA, as well as those who work for our carriers.

Senator SPECTER. Well, I think you and I have gone about as far as we can go on this issue. And the experts who were complaining to me will have to sit down with the experts who are advising you and try to figure it out. And if necessary, you and I will join them. But I have heard a lot of complaints about the levels that you have attached here.

The third requirement that we have here is to replace HCFA's current practice of total reimbursement denial with a partial denial. Do your new regulations include that?

Ms. DEPARLE. Yes, they do. I agree with you on that.

Senator SPECTER. And what else do your new regulations include, if anything?

Ms. DEPARLE. Well, there really is not a new regulation, sir. What happened was I just made this decision over the weekend, and instructed staff to get working on implementing it. And I wanted to advise you of it today at our hearing. So the next step will be to do a program instruction, it is my understanding, so that those who administer our policies in the field will know that, in the future, this is the policy.

Senator SPECTER. So could we put that policy into effect today?

Ms. DEPARLE. Yes, sir; I can try. I bet they cannot get it written until tomorrow, but I can say that it is effective today.

Senator SPECTER. Well, there is a fair amount of time left today. Let us try to get it done today.

Ms. DEPARLE. I will try.

Senator SPECTER. OK, we have quite a few more questions in the second panel, Ms. DeParle, so we will proceed now with Secretary Shalala.

Senator Faircloth, I would yield to you. I finished that one subject. I regret taking a little extra time on it.

Senator FAIRCLOTH. That is all right. I could tell you were interested in the subject. [Laughter.]

Senator SPECTER. I have that bad habit.

Senator FAIRCLOTH. No; that is fine. Thank you, Mr. Chairman.

I have two questions I wanted to bring up, Madam Secretary. And one of them is the recent decision that seniors no longer qualify for home health care benefits solely on the need to have blood drawn. No; in North Carolina, we are—and I am sure in a lot of the rural parts of this country—are pretty far removed from lab technicians or people with the capability of withdrawing blood.

Now, I understand that this was done because of fraud. But HCFA has so far not identified to any Member of Congress how big the problem is of fraud here, and documented its abuse. Could you

do so? And what level of infraction is appropriate and compelling to stop this practice?

Secretary SHALALA. I would provide whatever we have free trade, Senator Faircloth. I think the rule was changed—it was eliminated as something that required a skilled practitioner, under the Medicare law. And I would be happy to provide whatever information that we had related to fraud and this issue to you for the record.

Senator FAIRCLOTH. All right. Well, if you would, have somebody send it over.

Secretary SHALALA. Yes, sir.

Senator FAIRCLOTH. Like as in the morning or this afternoon.

Secretary SHALALA. Right.

[The information follows:]

OPERATION RESTORE TRUST

During Operation Restore Trust, the 5-State demonstration jointly conducted by the Health Care Financing Administration (HCFA), OIG, and the Department of Justice, we saw numerous situations where beneficiaries who needed blood draws but did not need other skilled treatment, were nevertheless receiving a full array of home health services. Home health claims reviews under Operation Restore Trust uncovered clinical examples of the problems associated with venipuncture. Examples include patients with atrial fibrillation who were using a blood thinning drug, coumadin, but needed no other skilled treatment. Physicians ordered skilled nursing visits to draw blood for laboratory testing treatment. Physicians ordered skilled nursing visits to draw blood for laboratory testing (for adjustment of coumadin dose), and home health aide services for these individuals. In one case, even though there was no evidence that the patient needed skilled treatment, skilled nursing visits were prescribed 1–2 times per week, and a home health aide was ordered for 12 hours a day, 7 days a week to assist in showering, meal preparation, shopping, laundry, housekeeping, safety supervision, and escorting. The venipuncture provision targets this inappropriate use of home health services and ensures that individuals receive care that is medically necessary.

VIRUSES

Senator FAIRCLOTH. Here is one of those love in bloom statements, but it concerns. Incidentally, I thank you for your support for tobacco farmers. I was glad to hear you come out with that.

But there has been a lot in the news, in Time magazine, in different places about the speed with which very, very deadly and very new viruses can spread around the world. I do not know whether you read the report or not. But I do not remember the exact dates. But in World War II, it took roughly 90 days for the flu virus to encircle the globe. Of course, now it can do it almost immediately.

These potential epidemics are extremely challenging to everyone. And most people were absolutely shocked to learn that the first line of defense against these threats, the 3,000 health departments scattered across the United States, are in most cases not in any way linked with a computer setup. And only 40 percent of our health departments are online. The remainder need computer training, manpower, and all of those things.

What are we doing about that? And what should we be doing? And should we have the—can we demand—a lot of these are not funded by the Federal Government, these health departments. I mean, local funding is involved. Can we demand that they do it? I think it is totally necessary. When you read that, it is absolutely frightening how quick a catastrophe can move around the world.

Secretary SHALALA. What we are talking about is the public health infrastructure in this country, the core of which is State public health departments and State epidemiologists. I, in fact, just returned from a major meeting the CDC is hosting in Atlanta specifically on the subjects that you bring up. It is on emerging infectious diseases, on the new flus in particular, and the need to both rebuild and to strengthen the role of the epidemiologists and the public health infrastructure in this country. This is something we have been addressing since the beginning of this administration, including putting new surveillance systems in place that have quicker turnaround.

The story of Hong Kong, in fact, is a story of a very good health department that did the right thing from the beginning, that routinely took swabs from individuals who were willing. And when they found something they did not understand, they sent it immediately to the CDC. That is what good public health departments in the United States do. They send the sample immediately—if they do not have the capacity themselves to make the diagnosis, they send it immediately to the CDC.

In this budget is a new investment in the U.S. infrastructure, particularly. Some of it is related to food-borne illnesses, some of it is related to these emerging and infectious diseases. This is part of the effort to rebuild our ability to quickly identify an outbreak and to quickly contain it. But as you point out, it does us little good to make these huge U.S. investments unless we simultaneously have surveillance systems around the world. Ships come in, people come to visit; these diseases know no boundaries. And it is, in fact, significantly cheaper for us to deal with tuberculosis in India rather than deal with that same case here in the United States, where it might cost us $100,000, and $50 there in India. So these multiple investments of our international aid budget, plus the HHS investments for the CDC to rebuild and strengthen our oversight and our surveillance systems are, in our judgment, critical.

FLU OUTBREAK

The lesson of the 1918 flu outbreak is a lesson that it can happen again. We were frightened by Hong Kong. It turned out not to have human-to-human transmission, but Hong Kong has just started their flu season. And as far as I am concerned, we need to continue to make significant investments in the Centers for Disease Control and in our national systems. The States have to take this seriously at the same time, they have to make investments at the same time in their own public health structures.

Senator FAIRCLOTH. All right. If you will make the demands on them to do it. And I thank you.

And thank you, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Faircloth.

Madam Secretary, I want to cover a number of points with you that may deal more specifically with Dr. Varmus at NIH, but these are matters of real concern. I have heard from Dr. Varmus, in response to my letter, that NIH is not doing the so-called professional judgment budget, which represents an estimate for optimal funding levels, irrespective of economic conditions, that those have been done in the past, and the levels range from 20 to 30 percent higher,

sometimes as much as 50 percent, and what the NIH has done now is to balance extraordinary scientific opportunity against the budget limitations facing both the administration and the Congress.

When I talked to Dr. Varmus at Senator Hatfield's ceremony, dedicating the building at NIH for Senator Hatfield, I told him that this subcommittee wanted to see the druthers list. And we do want to see that.

The Senate went on record as favoring a doubling of the NIH budget over 5 years, in the sense of the Senate last year. When it came time for the budget, the health account was cut by $100 million. And Senator Harkin and I offered an amendment to increase NIH by $1.1 billion, which was defeated 63 to 37. But I believe there may be sentiment within the Congress to do more for NIH if we see exactly what NIH says can be done. And I am going to press Dr. Varmus for that professional judgment budget, so we have their judgment as to optimal funding levels, irrespective of economic constraints.

And my question to you is, will you recommend to him or instruct him, whatever you do, that he complies with that request?

Secretary SHALALA. Well, as you know, the National Cancer Institute and the Office of AIDS Research do this as a matter of statute. NIH did not do that for the 1999 budget. I think this may reflect the significant increase that they did get. But my view is that the National Institutes of Health and the rest of us ought to answer whatever questions Congress has. And while they have a very large increase, I am well aware that Congress may consider some additional funding. I think that you will find that the Director of the National Institutes of Health is quite enthusiastic about the budget the President did propose and about the range of opportunities that it provides.

Senator SPECTER. Well, I accept this enthusiasm for the President's budget. He has probably been enthusiastic about the previous President's budgets, before President Clinton, although he was not here before President Clinton. But I think he has been even more enthusiastic about what the Congress has done, in putting up more than the President has.

And that is our decision as to how we allocate the $1.7 trillion. So I appreciate your support, as you say, for getting us the information which the Congress wants.

Secretary SHALALA. Yes; though, Senator, you do understand that all of us that work for the President are expected to support the President's recommendations once we have our internal discussions within the administration. We have kept to that. I fully understand that the Congress has additional questions and will ask the scientists for their professional judgment. But I simply want to reiterate our own support for the President's historic recommendations that he made.

Senator SPECTER. Madam Secretary, I understand that you support what the chief executive officer has said, your appointor. But that is not really relevant to the congressional function to make an independent judgment as to how we allocate the resources. And that is why we want the judgment of NIH as to what is optimal. That is what we are asking for.

We know that he will support the President. We expect that. And sometimes I support the President, too.

Secretary SHALALA. I know that. And we appreciate it, Senator.

Senator SPECTER. We are going to press on this clinical aspect with Dr. Varmus, and I will not take up any time here. We have a tough issue on ergonomics, where I had written to Dr. Varmus concerning a study which had been requested by some on the House side.

ERGONOMICS ISSUE

Coincidentally, on February 4, a letter was submitted by other House Members, where Ms. Taylor, my deputy here, talked to Dr. Varmus. He said that he did not agree to this type of study. And the ergonomics issue has been debated very heavily in the committee. And we have an arrangement where no regulations were to be published in this fiscal year. And we are hopeful that we have put that matter to rest without having another very protracted study on the matter. But, again, we will take that up in detail with Dr. Varmus, unless you have any comment which you would like to make.

Secretary SHALALA. No; what I have said to Dr. Varmus is that until there is a resolution on this issue between both Houses of Congress, plans for any activity ought to be on hold. And I did see your letter to Dr. Varmus. So we will be happy to work with you, Senator.

Senator SPECTER. Madam Secretary, if the tobacco agreement is not reached, how are we going to fund the Department of Health and Human Services?

Secretary SHALALA. Senator, we believe that there is no reason why a bipartisan group of Members of Congress, working with the President, cannot agree on a comprehensive piece of tobacco legislation. We believe it is possible to get consensus on that legislation. We have outlined the major principles. We have already endorsed one bill on the Senate side, and are providing technical assistance. So we are very enthusiastic about this huge public health step, which will also obviously provide resources for some of the public health investments we want to make.

But what I have said consistently on the President's priorities—and NIH is clearly at the top of that list—is that if the resources that we have identified, whether they are user fees or whether it is legislation that must be passed, are not there, we are going to have to work with the committee to make sure that these priorities are passed.

Senator SPECTER. Are you prepared to give the tobacco companies immunity from future liability and class actions for the settlement?

Secretary SHALALA. Senator, the President has said that any legislation he will support must have a significant price increase, be comprehensive, change the behavior of the tobacco companies, leave FDA in place, work with the farmers and with their communications to make sure that they are not hurt by the legislation, and fundamentally change behavior and hold tobacco companies accountable. If all those things are in place, if there are other issues that are raised as part of an overall comprehensive piece of legisla-

tion, we will consider them. But until we see a bipartisan effort and a bill that is put together and has the support of the vast majority that we can endorse, we are not prepared to discuss additional issues.

Senator SPECTER. Madam Secretary, what you have articulated is a little bit of something for everybody, and make a lot of people happy. But the reality is there is not going to be a settlement unless there is a release of the tobacco companies from future liability and class actions. And unless someone is prepared to step up to the table and say yes, I am prepared to do that, I think that any inclusion of funds from the tobacco companies is really totally illusory.

Secretary SHALALA. Senator, what we have consistently said is that we are talking about a major piece of legislation that would be a huge public health step toward reducing youth smoking in this country. We are going to keep our eye on the ball. And if we see a comprehensive piece of legislation that has all of the elements the President has recommended—in particular, the price increase, which we know will have an effect on children smoking in this country—then we are prepared to discuss other issues.

CLASS ACTION SUITS

Senator SPECTER. Well, the best that I take from that answer is that you would not rule out a release from liability from class action suits in the future.

Secretary SHALALA. Senator, we will consider any other issue that anyone wants to put on the table once we see the comprehensive piece of legislation.

Senator SPECTER. Including release of liability from future class action suits?

Secretary SHALALA. Senator, we are not taking a position on anything specific, other than that on which we have already taken a position: a comprehensive piece of legislation that focuses on reducing children smoking. Once we see that comprehensive piece of legislation which we believe there is a bipartisan majority to pass, that will be a huge public health step, then we would be happy to discuss any additional issues.

Senator SPECTER. Including a release of liability for future class actions? [Laughter.]

If you repeat the same answer and do not answer the question, and you do not want to answer the question, I will not ask it again.

Secretary SHALALA. Senator, I think I have answered the question. The President will support a comprehensive piece of legislation.

Senator SPECTER. I know what you said.

Secretary SHALALA. If there are other issues——

Senator SPECTER. Like a release of future liability from class actions. [Laughter.]

Secretary SHALALA [continuing]. That could be discussed, we would be happy to look at them at that time. First, we want to see the public health package.

Senator SPECTER. Well, we cannot be happy to look at your budget when it has $1.9 billion which is predicated on what is really illusory and pie in the sky. But I think I understand your position.

Thank you very much, Madam Secretary.

Secretary SHALALA. Senator, if I may, since you are going to hear from Nancy-Ann Min DeParle, I want to make clear both my support for her and my enthusiasm about her willingness to take on the toughest job in the Department. We were lucky to attract a young woman like Nancy-Ann Min DeParle to take on this responsibility. I have full faith in her ability to lead the Health Care Financing Administration, and I think she is an outstanding professional. Thank you, Senator.

ADDITIONAL COMMITTEE QUESTIONS

Senator SPECTER. Thank you very much. There will be some additional questions which will be submitted for your response in the record.

[The following questions were not asked at the hearing, but were submitted to the Department for response subsequent to the hearing:]

DEPARTMENT OF HEALTH AND HUMAN SERVICES

ADDITIONAL COMMITTEE QUESTIONS

CLONING

Question. The adult-cell technique used to create the sheep "Dolly" is very powerful and could be used someday to meet legitimate medical needs, such as the production of scarce replacement organs, skin, or blood. FDA has said they hold regulatory jurisdiction over cloning. How will the agency assure that the technique is used for legitimate research and not for cloning of a human being?

If this cloning technique does support useful purposes, are there steps in the cloning process that could be monitored or regulated?

Answer. On March 4, 1997, President Clinton issued an Executive Order which prohibits federal financing of human cloning, and has repeatedly encouraged Congress to pass legislation to ban human cloning. In July 1997, President Clinton submitted legislation which would ban cloning of a human, whether publicly or privately funded, for a period of five years. In February 1998, Senator Feinstein introduced a similar bill with a 10 year ban on cloning a human.

Independent of future legislation regarding the cloning of humans, FDA has the jurisdictional authority to regulate human cloning, including cloning of organs, under the Public Health Service Act (regulating biological products) and the Federal Food, Drug and Cosmetic Act (regulating drugs). Under these statutes and implementing FDA regulations, clinical research on the creation of a human being using cloning technology may proceed only when an investigational new drug application (IND) is authorized by the FDA. Before such research may begin, the sponsor of the research is required to submit to FDA an IND describing the proposed research plan, to obtain authorization from an independent institutional review board, and to obtain the informed consent of all participating individuals. FDA may prohibit a sponsor from conducting the study (often referred to as placing the study on "clinical hold") for a variety of reasons, including if the Agency finds that "human subjects are or would be exposed to an unreasonable and significant risk of illness or injury," "the IND does not contain sufficient information required * * * to assess the risks to subjects of the proposed studies," or "the clinical investigators * * * are not qualified by reason of their scientific training and experience to conduct the investigation."

In the case of attempts to create a human being using cloning technology, there are major unresolved safety questions. Until those questions are appropriately addressed, the Agency would not permit any such investigation to proceed.

LIVER TRANSPLANT ALLOCATION POLICY

Question. Madame Secretary, you recently notified the Senate that HHS intends to change the current liver allocation policy. Now, donated livers are first offered to patients ranked on a local list prior to being made available nationally. I understand that your new policy will begin to implement a nationwide severity of illness policy. Could you elaborate on why the current liver allocation policy needs to be changed.

Answer. We continue to have a serious shortage of organs for transplantation, and indeed in recent years, the shortage has grown worse. We have also not yet achieved many of the important benefits of a national organ-sharing network that were envisioned by the National Organ Transplant Act of 1984 (NOTA). The most visible short-coming is the wide span in average waiting times for those on transplantation waiting lists. In some areas of our Nation, patients wait 5 times longer or more for an organ than in other areas. Less visible but more important are the resulting inequities in who receives organs. Where waiting times are shortest, organs may go to patients who are less ill; while at the same moment, in areas where patients wait longer, organs often are not offered to patients with greater medical need. In the worst case, patients die in areas where waiting times are long, while at the same time organs are being made available to less ill patients in areas with shorter waiting times. Even as technology has improved, making it possible to preserve organs longer and hence offer them over a wider geographic area, the allocation scheme of the Organ Procurement Transplant Network (OPTN) has continued to give preference to local use of organs even if such organs could be used to save the lives of sicker patients located further away.

Question. It is my understanding that the administration will soon issue new regulations regarding liver allocation policy. Can you share with us what will be the key elements?

Answer. HHS will establish broad performance standards and make clear the desired outcomes which will best serve the Nation. In preparing the regulation, we are developing performance and outcome standards which would be applied to the policies developed by the OPTN. The goal of the performance standards would be to make it possible for patients with the greatest medical need for transplantation to be more accurately identified by the national network and to be put at the head of the list for a suitable organ. This means the development of standard patient listing criteria and medical urgency categories that would enable our transplant network to reliably assess the medical condition and need of all patients awaiting transplantation. The regulation would look to OPTN to develop the specific, medically-sound policies for achieving goals such as uniform criteria among centers and the development of allocation policies that would make waiting times more equal in the various regions of the Nation. HHS does not seek to develop the policies and would not do so unless the OPTN failed to develop satisfactory policies of its own.

HEALTHY START INITIATIVE

Question. What have been the accomplishments of the Healthy Start program? In your opinion, is the program serving its core purpose of identifying the contributing factors to infant mortality and low-birth weights?

Answer. We believe that many important lessons were learned through the original Healthy Start communities and their successes should be passed on and replicated in other interested communities. The purpose of the Healthy Start Demonstration was to create and implement community-based strategy targeted at improving birth outcomes among underserved women. The demonstration phase of the Healthy Start Initiative concluded in September 1997. An interim report, Interim Findings: Impact of Healthy Start on Infant Mortality and Other Birth Outcomes, found that infant mortality declined substantially in the Healthy Start project areas between the baseline period prior to Healthy Start and the early years of Healthy Start. Across all of the projects in the interim evaluation there was a 21 percent reduction in infant mortality. There was also a 20 percent national decline in infant mortality over the same period. The Detroit Healthy Start program significantly reduced the infant mortality rate from 27.2 to 22.5 infant deaths per 1,000 live births, a 17 percent reduction. The Philadelphia Healthy Start program significantly reduced its post neonatal mortality rate from 7.7 to 4.5 postneonatal deaths per 1000 live births. The Healthy Start program was also associated with increases in the percentage of women who received adequate or better prenatal care.

In addition, the Healthy Start Communities have reported positive progress towards increasing the number of women entering prenatal care early, increasing utilization of services, increased public awareness of the contributing factors of infant mortality, and improved family and community support.

Question. How might the program be improved or extended in ways that would further the lessons learned up to now from the original 15 Healthy Start sites?

Answer. Fiscal year 1999 funding will provide for a continuing opportunity to reduce infant mortality by replication of successful Healthy Start models of intervention in urban and rural communities with high rates of infant mortality. In fiscal year 1999, $35 million will be awarded to up to 20 mentoring projects for continued support of successful strategies and the utilization of these projects as peer mentors

to new Healthy Start communities and other health care providers, thereby maximizing the lessons learned to date in the reduction of infant mortality and low birth weight infants. In addition, $51 million will be awarded to up to 42 communities which have begun to replicate successful strategies of infant mortality reduction in fiscal year 1998.

PRESIDENT'S COMMISSION'S CONSUMER BILL OF RIGHTS

Question. Last month the President issued an Executive Order which, among other things, directs HHS to ensure that Medicare complies with the Quality Commission's Consumer Bill of Rights by 1999, including providing access to specialists and ensuring adequate levels of beneficiary participation in treatment decisions. What specific steps does HHS plan to take to implement the Executive Order?

Answer. The President has directed all Federal agencies with jurisdiction over health programs to ensure that all of these programs come into compliance with the Consumer Bill of Rights by 1999. With regard to HHS implementation of this order for Medicare, our analysis shows that Medicare is already largely in compliance. Our current plan is to take the following steps to ensure compliance with the order for Medicare (there may also be areas where we will need additional statutory authority):

—Establish the new "www.medicare.gov" website as well as the Medicare Compare database included in the website. These innovations will help beneficiaries and relatives understand the options available under Medicare. This helps to fulfill the Information Disclosure Right. The website is live.

—HCFA will issue a policy directive, based on current statutory authority, that will ensure that health plans will be in compliance with the Access to Specialty Care Right.

—The BBA included a number of provisions related to complaints and appeals that will be applicable to Medicare + Choice plans, and we are in the process of implementing them. These provisions will strengthen Medicare's existing protections for managed care enrollees.

—HIPAA requires HHS to promulgate standards for a specified set of electronic health care transactions which is part of a broader effort to protect the confidentiality of medical records. We have undertaken this effort which will help to fulfill the Confidentiality of Information Right.

—Additional statutory authority is needed to bring the program into full compliance with regard to confidentiality and choice of provider rights.

Question. Has the Department estimated the administrative costs, if any, of implementing these changes?

Answer. While we have not made any formal estimation of the administrative costs involved with implementing these changes, we strongly believe that any costs will be minimal.

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

Question. Dr. Eisenberg, I understand that a conference was held in October 1997 which looked at "Early Childhood Caries." The conference concluded that in many low-income preschool children—dental caries is under-treated. First tell me, if you can, why this is the situation? Especially with the existence of such programs as the Child Health Insurance Program and the State Medicaid program.

Answer. Research conducted by the Agency's first dental Scholar-in-Residence, in collaboration with individuals from the National Center for Health Statistics and the Health Care Financing Administration, and by the National Institute of Dental Research has identified the sociodemographic distribution of pediatric dental caries (cavities) in different age, ethnic and income groups. Once an almost universal condition of childhood, extensive caries afflicts disproportionately more low-income children today. The prevalence of untreated dental decay is approximately 4 times higher for the poor as it is for children from economically comfortable families, a situation which exists for very young children, older children, and adolescents.

Care delivery issues are complex. Although both physicians and dentists have opportunities to prevent, intercept, and treat early childhood caries, oral health services are not well integrated with other services and assessments. Even if a physician detects the condition and refers the mother to seek dental care for her child, she faces other barriers to having her child actually receive care. Very young children present management challenges that reduce still further the number of dentists willing to schedule appointments for them. Low-income parents frequently have not experienced regular dental care themselves, and many have not developed the skills nor awareness that allow them to assume responsibility for appropriate visits and recall appointments. Painful emergency treatment experiences that are common for

low-income recipients of dental care often result in the development of permanent fears and avoidance of dental care.

The October 1997 Early Childhood Caries Conference recommended that more research is needed to identify effective means of preventing and treating this problem, and it is clear that health services, behavioral, and biomedical research each have a role in identifying solutions. Only multifaceted approaches to address this problem are likely to be successful. Solutions depend upon synthesis and transfer of research findings, provider and public education, expanded provider base through effective extender utilization, coordination with primary pediatric medical care, and development of quality performance measures for health plans and population-based oral health care. Evaluation of demonstration programs can identify elements associated with success. Development and implementation of improved quality measures to assess the performance of outreach and care delivery components of future programs should create incentives for providers and plans to engage in coordinated care and be held responsible for the outcomes.

Question. The Early Childhood Caries conference recommended that more research is needed to identify effective means of preventing and treating this problem. How much do you have in your 1999 budget to research this problem?

Answer. Although the Agency has not specifically designated a portion of its budget for dental health services research in general, or to early childhood caries in particular, research on children's health has been designated a priority area in the fiscal year 1999 budget. It is expected that up to $2 million will be devoted to improving the quality of children's health care. The general topic of quality also has been designated as a priority area in the fiscal year 1999 budget, including development and implementation of improved quality measures.

Research conducted by the Agency's first dental Scholar-in-Residence, in collaboration with individuals from the National Center for Health Statistics and the Health Care Financing Administration, has identified the sociodemographic distribution of pediatric dental caries in different age, ethnic and income groups. Care delivery issues are complex. Although both physicians and dentists have opportunities to prevent, intercept, and treat early childhood caries, oral health services are not well integrated with other services and assessments.

Question. As the U.S. population gets older, are there some special dental care problems faced by our senior citizens?

Answer. Despite appreciable gains in oral health, certain groups still carry an extensive burden of oral disease. Among these are older adults and minority populations. Older adults who were born and spent their early years without the benefit of fluorides and other preventive therapies and who became acclimated to a pre-World War II delivery system exhibit an oral health status different from that of younger adults. Similarly, these older adults' values, beliefs and behaviors, despite formal education and sufficient income, may make them more vulnerable to oral diseases and their sequelae. Addressing the dental care needs of the elderly population is becoming more complex, as younger cohorts have more, often heavily repaired, teeth than earlier cohorts, and the maintenance of this health presents different challenges.

The elderly have problems of untreated dental disease, problems with deterioration of previously repaired teeth and supporting structures, problems of complications of multiple chronic medical diseases, and problems associated with some of the treatments of those diseases, such as the many medications which cause "dry mouth" and increase the risk of dental diseases. The continued prevention and control of oral diseases and conditions in those groups of individuals who bear the burden of most of the problems requires a broad approach, involving numerous strategies, as well as the efforts and resources of many groups, organizations, and individuals.

Having a regular source of care and/or regular dental visits and improved oral hygiene practices appears to be a promising avenue for the promotion of better perceived and clinically evaluated oral health status among most older ethnic groups. New initiatives may be required to reach those who may never have had a pattern of regular dental care, particularly minority and low-income elderly. However, even those who enter their senior years following regular receipt of care face new challenges associated with income, mobility, and other social factors. Complicating their situation further is the fact that many common dental treatment procedures for older adults are rendered in the absence of comprehensive knowledge of their expected results along most dimensions of treatment outcome, which limits the information available to practitioners. At a time in their life when financial resources become limited, many senior citizens are faced with treatment options whose benefits, relative to the costs, are difficult to assess without this information. If patients

face financial barriers to receipt of necessary dental care, the outcomes of care for some medical conditions may be compromised.

Question. Does your research agenda include addressing the special dental care needs of the seniors?

Answer. In the early years of AHCPR, a series of studies was supported that addressed special dental care needs of the elderly, providing information for the health care professionals who care for them, and policy makers. Some studies looked at issues related to access to care, such as evaluation of a Medicare demonstration program to provide access to dental care for low income minority seniors, and evaluation of the effectiveness of a community-based geriatric nurse practitioner intervention targeting older-old adults (age 75+) to stimulate appropriate dental service utilization and improve oral health. Another study focused on methods to be used for outcomes research, specifically a self-reporting instrument to measure patient satisfaction and outcomes with dental implant procedures. Recently, findings were reported from a study addressing ethnicity, aging, and oral health outcomes, which included assessment of predisposing and enabling factors, dental care delivery systems, and sociodemographic population characteristics. This study suggests characteristics, such as an individual's care seeking attitudes, of people at highest risk for poor oral health outcomes and the kinds of policies that might improve those outcomes.

Further research is needed to determine which measures work best to prevent and treat dental diseases that disproportionately affect older adults, such as root surface cavities, as well as technologies and approaches to screen for early stages of oral cancer. Research addressing the value of treatment for oral conditions on the outcomes of care for medical conditions is also needed.

The Agency has funded NMES and MEPS providing important information on dental care. NMES and MEPS data are especially useful to better understand the dental needs for vulnerable populations such as children and the elderly. Specifically, NMES data collected in 1987 established a baseline level of use, expenditures and sources of payment for dental care for the U.S. population. MEPS data collected in 1996 and 1997 will be used to establish more current estimates for dental care utilization and make possible the identification of changes that have occurred during the previous ten years. Since NMES and MEPS are nationally representative data, analyses are very useful to describe dental access for vulnerable populations.

Analyses of MEPS data will make possible estimates of the impact of retirement on the use, expenditures and sources of payment for dental care. Since dentistry is generally not covered by Medicare, retirement can result in the loss of dental coverage for many Americans. The impact of this loss of coverage has been difficult to estimate because panel data for a sufficiently large population has not been available. MEPS is a panel survey with data collected over two years. Sample size permitting, analyses of MEPS will allow for a description of the elderly as they move in one year from working to the next year into retirement. Also, as the population ages it is important to update current data for older Americans of different cohorts. MEPS will provide the most current and comprehensive data for each cohort within the elderly population.

SUBSTANCE ABUSE AND MENTAL HEALTH ADMINISTRATION [SAMHSA]

BLOCK GRANT FORMULA

Question. Last year's Labor/HHS Appropriations Act prohibited SAMHSA from implementing a proposed change in the way it allocates block grant funds to the States and the Conference Report indicated that this Committee would not increase funds for either of the State block grants until the authorizing Committees, SAMHSA, and the substance abuse and mental health communities have implemented a consensus policy regarding block grant formulas.

What is the current status of the block grant formulas, and has a consensus been reached?

Answer. It should be noted that the Secretary has no authority to change the Block Grant formula, except that which is granted in section 1918 of the Public Health Service Act which applies only to the cost of service index. The House Committee on Commerce and the Senate Committee on Labor and Human Resources have jurisdiction over SAMHSA programs including the Block Grants, and they have the responsibility and authority to change the formula in statute should changes be necessary.

In an effort to help forge a consensus, SAMHSA met with majority and minority staff of both Committees and explained the changes that the Secretary was making. At the request of Senator Frist, we, along with GAO, briefed staff of the members

of the Labor and Human Resources Committee on the formula and the change from manufacturing to non-manufacturing that the Secretary had authorized.

On January 20 and 21, SAMHSA provided technical and financial assistance to a meeting of several State Directors of Substance Abuse and/or Mental Health Services to discuss the formula. In early February, we provided the same technical assistance to members of the National Coalition of State Alcohol and Drug Prevention and Treatment Associations at their annual conference. We have been and will continue to be available to brief any group who would like to become familiar with the formula and the issues involved.

While various changes are being considered in both the House and Senate, no consensus has been reached.

Question. If not, what are the major stumbling blocks?

Answer. As members review the formula, they are trying to balance the need of their home State for funds and what makes good policy. We have confidence that an agreement will be reached, especially since the President has requested an additional $200 million for the SAPT Block Grant.

Question. What do you believe is the most equitable way of implementing any new formula so that no State experiences an inordinately large decline in federal funding?

Answer. The Secretary has recommended to Congress that new statutory authority be passed to phase in the changes caused by the shift from the use of manufacturing to non-manufacturing wage data over three or five years.

Question. What assistance will SAMHSA provide to states which would lose significant funding?

Answer. As pointed out earlier, it is our hope that the Department will be given authority to phase the change from the use of manufacturing to non-manufacturing wage data in over 3 or 5 years. The advantage of this is that States will be able to plan how they will make up for the loss of Federal funds. SAMHSA will assist them in prioritizing their activities. Moreover, the additional $200 million requested for the Substance Abuse Block Grant program will help prevent significant funding losses.

KNOWLEDGE DEVELOPMENT AND APPLICATION [KDA] PROGRAM

Question. Madame Secretary, the new Knowledge Development and Application (KDA) program in SAMHSA is designed to identify and address policy and service delivery questions of national concern, as opposed to SAMHSA's previous policy of funding local substance abuse and treatment demonstration programs. Is there overlap in the new KDA's with existing programs?

Answer. The KDA Program is designated to identify and address policy and service delivery questions important to communities, and it does so in several different ways. For example, the State Incentive Grants (SIG's) are a major component of the HHS Secretary's Youth Substance Abuse Prevention Initiative and play a key role in helping to achieve the outcome targets associated with this Initiative. SIG's are competitive grants to Governor's office which help coordinate disparate funding streams and facilitate the development of proven effective, prevention strategies at the local level aimed at reducing drug use by youth. This program serves as an incentive for Governors to examine and synchronize State-wide comprehensive prevention strategy with private and community-based organizations. In the five states recently awarded a State Incentive Grant in fiscal year 1997, the Governors have committed themselves to becoming actively involved in substance abuse prevention by direct involvement and oversight of this project.

Another example is the Targeted Treatment Capacity Expansion Program designed to create and expand comprehensive substance abuse treatment services, promote accountability and enhance the quality of and access to treatment services. CSAT will support State, city, and/or other partners in efforts to identify gaps in the alcohol and other drug service delivery system, and where current capacity within a treatment modality is insufficient, provide for expanded access to treatment.

As these examples show, the KDA Program directs resources to improving service quality in communities. It does not duplicate any other federal efforts, and in fact, has been expressly designed by SAMHSA to complement existing programs. The program serves several distinct purposes: to ascertain whether approaches that have a basis in research are effective in actual service settings; to communicate best practice information through such mechanisms as treatment improvement protocols; to ensure that high quality services in targeted areas of national interest are implemented nationwide; and to translate knowledge into practice, in particular through the Block Grants and other service programs. In short, the program helps ensure

that SAMHSA and other federal efforts work in an integrated way at the community level.

An example of this is the relationship between federal research programs and SAMHSA KDA's. Research projects generally represent long-term studies of a wide variety of service topics, each inspired by an individual investigator. The results are of course immensely valuable in contributing to the knowledge base. However, given the variety and ever-changing dynamics of service delivery, practitioners may be unfamiliar with new research results, find them less relevant to their particular service needs, or be unable to change their practices for a wide variety of reasons. SAMHSA communicates continually with the field to assess their needs; an excellent example of how this is accomplished is through feedback from the extensive Block Grant technical assistance program. This feedback permits SAMHSA to design and develop shorter term, focused evaluations and knowledge application projects. They are coordinated to ensure that proven practices not only work when employed in public sector programs, but that these programs are implementing effective practices. No other federal programs have this as their mission. Similarly, other KDA-supported projects such as national clearinghouses and sponsorship of national information and public communication programs either represent a unique SAMHSA role, or are conducted jointly with other federal sponsors to prevent any overlap.

Question. How is demonstration funding being phased out and KDA funding phased in?

Answer. Consistent with the guidance received from the Committee, SAMHSA's former demonstration projects are being continued through their initial federal project period, which was up to five fiscal years. No new demonstration projects have been awarded since 1995. In the fiscal year following completion of a demonstration continuation project, a comparable amount of funds within the resource base is available to initiate new and more focused KDA projects targeted to the highest priority service issues. This phase in can of course be accomplished only if the overall KDA funding level remains level.

Question. Which demonstration grant programs still receive funding?

Answer. The Center for Mental Health Services (CMHS) will fund continuations for the Service System Improvement grants and AIDS Education I in fiscal year 1998. CMHS will fund only one Service System Improvement grant in fiscal year 1999. The Center for Substance Abuse Prevention (CSAP) will support 18 continuation grants funded under the Community Partnership program and 3 continuation grants funded under the old High Risk Youth program in fiscal year 1998. While we are phasing out the old High Risk Youth demonstration grants, the new High Risk Youth services grants will continue. For most of these projects, fiscal year 1999 reflects their last year of federal support for the grants.

The Center for Substance Abuse Treatment has four demonstration programs continuing in fiscal year 1998. These are the Residential Treatment Program for Women and Their Children (RWC–15 grants), the Pregnant and Postpartum Women and Children Program (PPW–3 grants), the Criminal Justice Treatment Networks (7 grants), and the Rural Remote and Culturally Distinct Populations Program (3 grants). The majority of the grants for the Women's programs (RWC and PPW) and all of the Criminal Justice Treatment Network grants are planned to continue in 1999. That will be the final year of funding for those programs.

Question. How are the substance abuse and mental health communities' needs and concerns taken into account by SAMHSA in developing the new KDA's?

Answer. Given the direct relevance of the KDA program to current service needs, continuing input from mental health and substance abuse service providers is vital to the success of the program. This is accomplished both through the active solicitation of input from the service field, as well as through information gained by the Agency as part of our continual involvement in service delivery issues. The former usually occurs through suggestions received from national organizations representing States, consumers and their families, service providers, and others. Their suggestions are factored into SAMHSA's agenda-setting process as potential grant announcements are considered each year.

The second, more indirect aspect of field input regarding needs and concerns occurs during SAMHSA's continual communication with the field throughout the year. Information from State Needs Assessments, concerns raised during technical assistance visits to help implement Block Grant programs, views expressed in national meetings, information clearinghouse inquiries, and a wide variety of other communications help identify the most salient issues. Since there are many more needs identified than resources to address them, the final KDA agenda represents SAMHSA's careful selection of issues deemed to be of greatest need and broadest value to the field.

Question. Do KDA's unnecessarily duplicate research efforts being conducted by the National Institutes on Drug Abuse (NIDA), Alcoholism and Alcohol Abuse (NIAAA), or Mental Health (NIMH)?

Answer. We do not expect that there will be any duplication of research efforts being conducted by the former ADAMHA research Institutes. Our KD projects are based upon specific situations where the fact that approaches have not been tested in certain service settings creates an important gap in knowledge. We would not expect that NIH research projects would be based upon such very specific, highly applied research questions; that would be inconsistent with the NIH approach, where specific research questions generally are investigator-initiated. In addition, we meet regularly with the staff of the three Institutes to share information and identify areas of mutual interest for collaboration.

Question. Would the purpose of the KDA's be better served by having the "development" portion administered by NIH instead of SAMHSA so that more of SAMHSA's discretionary funding could be used to provide direct assistance?

Answer. As expressed above, SAMHSA has a unique role to play in knowledge development and application because of its extensive, continuing link to day-to-day issues of service delivery. Agency staff understand community service delivery programs; barriers to developing better service integration and linkage; problems faced by State, city and local governments in developing and managing comprehensive prevention and treatment programs; challenges posed by co-occurring disorders, homelessness, HIV/AIDS, and similar problems; and numerous other impediments to quality improvement in the service system and to achievement of better system-wide outcomes. This knowledge is essential to effective "development" activities. It is particularly important since the service field is not as well developed as it is in some areas of primary health care. While NIH plays an important role in the mental health and substance abuse areas, it is a quite different one. It is unlikely that an organization with a strong research orientation can be as effective in translating knowledge into practice, if de-coupled from service delivery programs and the understanding which derives from managing them.

PROGRAMS IN RURAL/NATIVE COMMUNITIES

Question. A 1994 RAND Corporation study showed that living in a nonmetropolitan area was associated with higher needs for substance abuse treatment, especially in the areas of alcohol abuse. Substance abuse is a leading contributor to health problems among American Indians and Alaska Natives. Last year the Committee earmarked $10 million for programs in rural and Native communities. What steps is SAMHSA taking to address the special needs of rural and Native populations?

Answer. The fiscal year 1998 Senate Appropriations Report earmarked $4,000,000 for programs in rural and Native communities. CSAP has targeted these funds to provide continued substance abuse prevention support for ongoing native and rural programs. These programs constitute 10 percent of CSAP's continuation grant portfolio in fiscal year 1998. In addition, CSAP is providing targeted technical assistance and outreach to areas with rural and native focused programs, in particular Alaska, and encourage these programs to apply for new fiscal year 1998 substance abuse prevention initiatives.

CSAP's fiscal year 1998 appropriation and fiscal year 1999 Budget request also supports new awards under the State Incentive Grant (SIG) program. The SIG program calls upon Governors to develop a statewide comprehensive prevention system directed at reducing youth substance abuse, including under-served populations in rural and Native communities. The program is designed to coordinate, leverage and/or redirect as appropriate and legally permissible, all Federal and State substance abuse prevention resources directed at communities, families, schools and workplaces. Community involvement is key to the success of these grants. Eighty-five percent of the grant funds will be directed to community based programs. These programs will be required to utilize scientifically defensible prevention practices. CSAP has awarded 5 State Incentive Grants for fiscal year 1997: Illinois, Kansas, Kentucky, Oregon and Vermont. Approximately 15 more states will be funded in fiscal year 1998. The fiscal year 1999 budget request calls for an additional 2 new State Incentive Grants.

There are two new programs for 1998, Exemplary Treatment Programs and Targeted Capacity Expansion, which will target the additional $3 million for rural and Native American populations in the grant application process.

Question. Are health care professionals being trained to treat these needs, and is there sufficient access to care in these communities?

Answer. CSAT's Addiction Technology Transfer Centers (ATTC's) focus on the training needs most critical to the effectiveness of addiction treatment and recovery

programs within each ATTC catchment area. They all focus on developing practitioners who are qualified to work with one or more special populations groups.

While current routine reporting from the ATTC's does not include information on the number of trainees from rural or remote areas, the data indicate that nearly 220 Native Americans were trained in 1997. All of the ATTC's focus on reaching minority students and those individuals living in rural areas. In 1996, three ATTC's developed new training programs to address rural needs.

There is a need to increase treatment availability for all substance abusing populations. It is for this reason that the Administration has requested a $200 million increase for fiscal year 1999 in the SAPT Block Grant, in an effort to help close the treatment gap. Rural and Native populations present an array of challenges for service delivery including treatment availability and access and cultural differences. In order to address these and other types of treatment gap and comprehensive service issues, CSAT will continue the Targeted Capacity Expansion Program in 1999. This program allows States, cities and other governmental entities to create capacity and expand substance abuse treatment services where there are gaps in treatment availability. Rural and Native populations are being targeted for this program during the grant application process.

TOBACCO BUDGET PROPOSAL

Question. Elements of the tobacco settlement may involve major constitutional questions, especially with regard to advertising restrictions. If there is reason to believe that this proposed settlement may not pass or be sustained on a constitutional issue, then why should this Subcommittee base its important spending decisions on conditions that may not come to pass?

Answer. We fully believe that a comprehensive bipartisan tobacco legislative package will be enacted by Congress this year, and that this legislation will contain the revenues needed to expand NIH research and the health research of CDC and AHCPR. These increases are a priority of the President, and we will work closely with the Congress to assure that the revenue source we have identified, comprehensive bipartisan tobacco legislation, will be in place this year to fund the President's priority for research into the twenty-first century.

Question. If the tobacco settlement does not pass this session, which programs would you designate as your top priorities? How would you rearrange your priorities?

Answer. The budget request includes the largest increase ever proposed for the National Institute of Health—a $1.15 billion, or 8.4 percent, increase for fiscal year 1999. This is a long-term commitment. We propose to increase NIH funding by nearly half by 2003. Like every other priority of the President, we will work with the Congress to pay for these increases in spending. We fully believe that a comprehensive bipartisan legislative package on tobacco will be passed by the Congress, and that this legislation will provide the resources to expand NIH research spending, as well as the expanded health research efforts of CDC and AHCPR.

Question. A constituent of mine, Hilary Koprowski of the Biotechnology Foundation, proposed to establish a research effort into using tobacco plants for healthier purposes, namely the production of vaccines. I understand that he has met with several government officials, including those from your department. Do you believe that such a proposal may be worth investigating?

Answer. The field of biotechnology is expanding rapidly. Through advances in our understanding of genetic and other processes in molecular biology, there will soon be a variety of new products and new methods for producing useful products. Certainly a variety of plants, including the tobacco plant, should be examined in this research endeavor. Scientists like your constituent will ultimately provide information as to which plants will be most useful for vaccine development and other purposes. I would encourage your constituent to continue his research, in the hope that the tobacco plant, which has done so much harm to human health, could one day be used to promote health.

QUESTIONS SUBMITTED BY SENATOR LAUCH FAIRCLOTH

Question. Both the FDA tobacco regulation and the Synar Amendment are directed at reducing minors' ability to purchase tobacco products. The Administration repeatedly refers to these efforts as "complementary." Will you explain to the Committee why two federal agencies are needed to enforce the prohibition against state sales to minors?

Answer. It has been the intent of the Department for the SAMHSA and FDA efforts to provide a multi-level approach to addressing youth access to and availability

of tobacco products. The SAMHSA Synar regulation is one piece in a comprehensive effort to reduce youth tobacco use. For such an effort to be successful, the Department must address issues of tobacco access, availability and appeal. While the FDA and SAMHSA regulations both address access and availability, Synar is not an enforcement program and Synar monitoring is not substitute for active enforcement of the FDA rule. The HHS response to youth tobacco use provides resources for enforcement activities, as well as a method of monitoring the success of State and Federal efforts. FDA rule enforcement is required to achieve the Administration's goal of reducing, by 50 percent over the next seven years, the young people who use cigarettes and smokeless tobacco.

Under the Synar amendment States are required to conduct random, unannounced inspections of a representative sample of the State's tobacco vendors to assess their compliance with State access laws. States that fail to meet the goal of reducing violation rates to no more than 20 percent can lose a percentage of their federal Substance Abuse Prevention and Treatment Block Grant funds. The Synar activities are specifically designed to measure if stores are selling to minors, and this measurement provides SAMHSA with concrete evidence of the success of State enforcement efforts of their own State laws. The Synar provisions, although requiring the States to enforce their youth tobacco access laws, offer no specific financial support to States for such efforts.

The FDA rule makes it a federal violation to sell cigarettes or spit tobacco to anyone younger than age 18 and requires retailers to ask for photo identification from anyone younger than 27. FDA activities are designed to actually enforce, not measure. The FDA regulations complement on-going State and local activities and establish mandatory conditions on the sale and distribution of tobacco products. The State agency administering the FDA rule must be an agent of FDA and funds are needed to pay State agencies. FDA needs flexibility to select non-Synar agencies to act as FDA agents, especially in poorly performing States. Enforcement of the FDA rule can only be done through compliance checks separate from SAMHSA, backed by fines, administered through FDA.

Question. The Administration's budget calls for a $100 million increase in FDA funding for tobacco enforcement—and a $46 million increase for CDC's existing state tobacco-prevention activities. Please detail for the Committee the differences in these two programs, and what procedures HHS has in place to ensure that these programs are not duplicative?

Answer. FDA's tobacco programs seek to restrict access to tobacco products, while CDC programs are targeted to reduce the demand for cigarettes. As FDA fully implements the tobacco rule and expands their activities to the full extent of the law, there will be increased workload and a need for increasing appropriations, $100 million in fiscal year 1999. The fiscal year 1999 goals for the FDA tobacco program include a significant expansion of the outreach and enforcement activities initiated in fiscal year 1998. With this increased funding, FDA can ensure fundamental progress in all States, through partnerships with States and local authorities, to reduce use of tobacco products among our nation's youth. FDA will primarily engage in enforcement, outreach, and product regulation.

FDA has developed a general enforcement strategy aimed at conducting compliance checks in a significant percentage of the roughly 400,000 retail outlets that sell tobacco products. FDA will commission State and local officials to conduct unannounced purchase attempts using young people under the age of 18. FDA follow-up enforcement includes special monitoring projects, demonstration projects, and an enforcement strategy for national chains. Evaluation activities include an inquiries and reporting system and other legal requirements. The outreach activities include compliance outreach, trade advertising and direct mail targeted to retailers and clerks, advertising, and media and public education. A strong outreach program is one of the most effective ways of increasing compliance with this rule. In fiscal year 1999 FDA plans to intensify its advertising campaign and use community organizations, parent groups, voluntary health groups, and the media to raise awareness of the tobacco rule and encourage compliance. FDA will design and, to the fullest extent permitted under law, begin to implement a regulatory program for cigarettes and smokeless tobacco products under the Food, Drug, Cosmetic Act. This includes a procedure for the classification of devices to determine the level of controls required by the products' characteristics to provide a reasonable level of safety, a process of reviewing and analyzing ingredients used in cigarettes and smokeless tobacco, establishing a framework for the evaluation and review of new and existing cigarette and smokeless tobacco products, and beginning the inspection process by reviewing the practices of tobacco companies.

The CDC increase of $46 million for tobacco prevention programs will fund a nationwide program that recognizes prevention and reduction of tobacco use is a core

public health function. This will replace and expand CDC's Initiative to Mobilize for the Prevention and Control of Tobacco Use (IMPACT) program to include all 50 States and the District of Columbia. The IMPACT program funds a number of prevention and control activities which include training and programmatic support for school-based smoking cessation programs, national surveillance activities, state prevention and control plans to protect nonsmokers from exposure to environmental tobacco smoke, and state programs to address oral cancer in high risk populations. This will also replace the NIH's American Stop Smoking Intervention Study (ASSIST). Of the CDC increase, $22 million of the $46 million funds NIH had been granting to States through the ASSIST program.

QUESTIONS SUBMITTED BY SENATOR LARRY CRAIG

Question. It has been said that most states aren't using all of the monies they are allotted through the Child Care and Development Block Grants. Could you please comment on why you think the states aren't utilizing the money that is being sent to them? And in view of that, why is the Administration proposing an increase in spending in this area?

Answer. In fact, States are utilizing the money that is being sent to them and we do project that the States will spend virtually all of their child care funds. The State financial reports received thus far are very encouraging and show that States have obligated over 99 percent of the fiscal year 1997 child care funds available to them under the new welfare law. States have outlayed 90 percent of their child care funds for fiscal year 1997 and we project they will expend all their funds within the time frame allotted. The outlay rates for 1998 are also quite strong and we project that States will expend all their funds within the two years as required.

The passage of the Personal Responsibility and Work Opportunity Reconciliation Act made major changes in the funding for State child care programs, and it was expected that States would require some time to make the transition. However, despite these significant reforms in the program, States reacted quickly and have drawn down the vast majority of child care money.

There is a tremendous need for child care assistance, particularly among low income working families. While our most recent data from 1995 indicates that funds in that year allowed us to serve over about 1 million children, that is a small percentage of those eligible since there are approximately 10 million children eligible for the Child Care and Development Block Grant. Further, without assistance, working families with annual incomes under $14,400 who pay for care for children under five spend 25 percent of their incomes on child care—even then, it's difficult to find accessible, high-quality care.

Question. Doesn't the Administration's child care proposal amount to a return to categorical programs in essence saying we shouldn't trust the states with block grants? Does the Administration have a complaint with how the states are handling block grants?

Answer. The Administration's child care proposal does not return to categorical programs and we continue to support the consolidation of child care that took place in the Personal Responsibility and Work Opportunity Reconciliation Act. We do not have problems with how States are handling block grants, and that is partially why the President has proposed an increase in the block grant program of $7.5 billion over 5 years. We feel like States are working hard to provide child care for working families and continue to want to support them and provide for the additional funds they need.

The President's Child Care Initiative does not create a lot of new programs; it builds on three of its primary programs: Child Care Development Block Grant and child care entitlement money, Head Start, and Child and Dependent Care Tax Credit. All of the components of the President Initiative would be included in the Child Care Development Block Grant so that States have more funds to assist working families in finding and keeping higher quality child care. Over 95 percent of the funds in the President's initiative go to States, communities, businesses and families to support their choices.

Question. Data clearly show that low- and middle-income families are just as likely as, if not more likely than, higher income families to have one spouse in the paid work force and the other in the home. Stay-at-home spouses work full time as care givers, schedulers, travel managers, culinary experts, home repair engineers, and home economists and frequently volunteer many additional hours in school and community activities. In short, all moms work. Why, then, do the Administration's child care proposals target assistance to two-earner families, and neglect the one-earner families who are, if anything, more economically overburdened?

Answer. Our child care initiative builds on President Clinton's record of providing real choices and opportunities for parents—including the choice to stay home with their children. He has worked to enact: a $500 per child tax credit that provides $98 billion in tax benefits over the next 5 years for 26 million families with children including those with stay-at-home mothers; the Earned Income Tax Credit also helps stay-at-home mothers and gives 15 million working families $150 billion over the next five years in tax relief; health insurance for children; increases in the minimum wage; and the Family and Medical Leave Act. The Administration is committed to helping parents make the choices that are right for their families, whether that means working or staying home to care for their children.

The President's Child Care Initiative is primarily oriented toward families with a single parent who works or two parents who both work, usually for reasons of financial necessity. According to the March 1997 Current Population Survey, only 26 percent of families with children under age 14 have a stay-at-home mother. Seven out of every 10 mothers of children under age 6 spent some time in the labor force during the past year. The initiative is designed to ensure that children in these families receive quality care while their parents are working.

The President believes strongly, however, that we should support parents who have sufficient resources and who choose to stay home. The Administration's proposal includes provisions that will help parents who stay at home. It will support demonstration projects in States and communities to test policies to help new parents who choose to stay home to care for their newborns and newly adopted children. In addition, the President's Early Learning Fund supports parents who stay at home through home visits and parent education.

Question. Why did the President suggest that surpluses be dedicated to protecting Social Security when everyone knows that Medicare is facing a more imminent crisis?

Answer. The President is committed to addressing the long-term needs of the Medicare program and has worked hard to protect and strengthen this vital program. The Balanced Budget Act enacted last year by the President and Congress saves $150 billion over 5 years and extends the life of the Medicare Trust Fund for more than a decade.

In addition, the Medicare Commission agreed to as part of the Balanced Budget Act has begun its work and will present recommendations for addressing Medicare's long-term financing needs by the Spring of 1999. The President has appointed a distinguished group of individuals as his representatives to the Medicare Commission. The President is committed to working with the Commission to find ways for the program to meet the longer-term financing challenges that confront it.

At the same time we are addressing Medicare's future, the President recognizes the long-term needs of the Social Security program, which without any changes, will become insolvent after 2029. That is why in his last State of the Union address, he asked the Congress to set aside every penny of any budget surplus until the President and Congress deal with Social Security first In January of 1999, the President intends to convene the leaders of Congress to draft a plan to save Social Security. The Administration is encouraged by the favorable response from both parties in Congress to the President's call to address Social Security before spending any future surplus.

If we act now, we can ensure strong retirement benefits for the Baby Boom generation without placing an undue burden on our children and grandchildren. And, if we act now, any changes will be far simpler and easier than if we wait until the problem is closer at hand. For example, a $100 billion budget surplus, if used for Social Security, would add a year or more to the solvency of the Social Security Trust Fund with no other changes being made. Other changes enacted now could be phased-in over time, thereby minimizing their immediate impact. Small changes made now will have huge impacts in 30 years.

The President understands that there are many worthy programs and initiatives on which to spend any budget surplus. He welcomes such a dialogue. However, he believes that before a dime of any surplus is spent, the Administration and Congress should develop a plan to save Social Security for generations to come.

Question. Instead of dedicating potential revenues from a tobacco settlement to the immediate gratification of new domestic spending, wouldn't it be more responsible to set aside any new revenues in this area to the long-term need of protecting Medicare?

Answer. The President's investment priorities for tobacco legislation are aimed at protecting children from diseases and investing in their future through health care coverage, child care, and education; improving the lives of current smokers through health research and smoking cessation programs; and protecting farmers. The Administration believes that these investments have a natural link to tobacco receipts.

The President shares the Republicans' concerns about the Medicare program. No President has done more to protect and strengthen this vital program. Just last year, working with the Congress, the President signed into law a package of unprecedented savings—$150 billion over 5 years—and structural reforms that extended the life of the Medicare Trust Fund for the next decade. He recently appointed a distinguished group of individuals as his members of the Medicare Commission. The President is committed to working with the Commission to find ways for the program to meet the longer-term financing challenges that confront it.

QUESTIONS SUBMITTED BY SENATOR KAY BAILEY HUTCHISON

Question. Secretary Shalala, when do you anticipate that the final Temporary Assistance for Needy Families (TANF) regulations will be issued?

Answer. We are planning to publish final rules in August of this year.

Question. Proposed TANF reporting regulations would require States to make significant changes in their reporting and data collection systems, diverting limited resources from client services. Will the final rules ensure that only the minimum amount of data is required and that States be given an adequate time to come into full compliance with final reporting requirements?

Answer. We have received numerous comments on the proposed scope of the TANF data reporting. We are currently analyzing the comments we received. While it would not be appropriate to speculate on the nature of data collection under the final rule, we are re-evaluating each data element to determine if it is necessary to carry out our responsibilities under the statute to monitor the program, determine work participation rates, assess penalties, and provide information to Congress on the impact of welfare reform under the TANF program. We are aware of the burden this new data system places on States and will look for ways to streamline these reporting requirements.

Question. Many States, including Texas, operate their TANF programs under waivers approved by the Secretary. These States have relied upon the integrity of their waivers while setting overall program strategy and operational policies. Section 415(c) of the Personal Responsibility and Work Opportunity Reconciliation Act asserts that the Secretary "shall encourage" States to continue such waivers. Many States argue that the proposed rules actively discourage States from continuing waivers by narrowly defining waiver inconsistencies. Does the Department agree with the clear intent of the PRWORA to allow States to fully maintain their waiver-driven programs? Will the final rules reflect that legislative intent?

Answer. Section 415 of PRWORA allows States to delay applying provisions of TANF "to the extent such amendments are inconsistent with" their waivers. In drafting the Notice of Proposed Rulemaking (NPRM), we sought to propose rules defining waiver inconsistencies that would allow States the flexibility to continue IV–A program policies to the extent they were inherent to their waivers while assuring accountability to meeting TANF requirements established under the law.

The comment period on the TANF NPRM has just closed and we are in the process of reviewing the comments we received at this time. We will carefully consider comments like you have cited in making decisions concerning the final rules.

It is our intention to issue final rules that will be entirely consistent with the law and with Congressional intent. We are currently reviewing all the comments we received on the proposed rules and will give them full consideration as we draft final rules.

Question. States operating under an approved waiver may desire to gradually move their waiver-based initiatives and program rules closer to those found explicitly in federal statutes. Would the Department allow such a State to move gradually toward federal law on a voluntary basis without invalidating the rest of the State's waiver?

Answer. There is no mechanism for modifying IV–A waivers approved prior to a State's enactment of TANF.

However, we have advised States that they have full discretion concerning decisions to terminate any specific waiver at any time. For example, a State could choose to retain a waiver related to time-limited assistance, but terminate a waiver allowing a particular work activity not otherwise countable under TANF.

Similarly, we have advised States that they may unilaterally modify a specific waiver to the extent the modification brings the waiver into closer compliance with TANF. For example, they could decide that one of the classes of recipients now exempt from time-limited assistance under their waiver will henceforth be subject to the time limit; or, in conjunction with allowing devolution of program policies to

counties, allow counties to decide whether to continue to count a specific work activity allowed under the waivers.

On the other hand, they could not modify their waiver to exempt a new class of recipients subject to the time limit under their waiver as that would increase the inconsistency; nor allow waiver policies inconsistent with TANF approved for application in a pilot site to be expanded statewide, as this would serve to increase inconsistencies with TANF.

Question. Original communication from the Department indicated that States would be allowed to develop an alternative participation rate methodology to account for State initiatives that expanded TANF program eligibility. The proposed rules did not contain such a clause. Will the final rules ensure that States are not penalized in terms of their participation rates for TANF program eligibility expansions?

Answer. The comment period on the TANF NPRM has just closed and we are in the process of reviewing the comments we received at this time. We will carefully consider comments like the ones you have cited in making decisions concerning the final rules.

Question. In 1994, Congress authorized a Border Health Commission to address health problems that affect the population of the U.S./Mexico Border. In last year's Labor/HHS appropriations bill we appropriated $800,000 to fund this vital commission. When do you intend to move forward with establishing this commission?

Answer. I am pleased to inform you that we are moving forward toward establishing the U.S.-Mexico Border Health Commission. The Office of Public Health and Science's Office of International and Refugee Health has been working with the four U.S. border States to establish the U.S. side of the Commission. On March 3, the White House forwarded letters to the Governors of these States, requesting nominations of individuals to serve as Commission members. In addition, we are in the process of contacting the Health Commissioners of these States about also serving as members of the Commission. In fact, the Commission was discussed during a recent meeting between the Health Commissioner of Texas and the Assistant Secretary for Health/Surgeon General. We consider the Health Commissioners and their respective Border Health Offices to be key participants in the Commission's development process.

The primary goals of the Commission are to institutionalize a domestic focus on border health which can transcend political changes, and to create an effective venue for bi-national discussion to address public health issues and problems which affect our U.S.-Mexico border populations. To realize these goals, HHS has also proceeded on several fronts regarding Mexico's involvement: we have re-opened informal dialogue with officials from Mexico's Ministry of Health regarding their critical partnership in the development of the Commission, and we have formally requested the Department of State to initiate discussions with the government of Mexico regarding their potential participation in the Commission.

QUESTIONS SUBMITTED BY SENATOR TOM HARKIN

Question. Our fiscal year 1998 appropriations bill included additional funds for the Early Head Start program. I am glad to see that the President's budget also increases funding for Early Head Start. Madame Secretary, can you tell something about what you have been doing with those additional funds?

Answer. Early Head Start programs provide early, continuous, intensive, and comprehensive child development and family support services on a year-round basis to low-income families with children under the age of three and pregnant women. In fiscal year 1999 Early Head Start (EHS) spending will total $350 million, an increase of +$71 million over fiscal year 1998. This spending will be used to increase projected enrollment by an additional +10,000 children for a projected total of 49,000 children in fiscal year 1999. Funding will also allow EHS to focus on four cornerstones of providing quality programs: child development, family development, community building and staff development. EHS technical assistance includes on-site training for teachers and staff and regional office staff. In addition, Head Start will monitor all EHS programs in their first year of operation with teams consisting of experts in the field and Federal staff.

Question. Last year, this Committee provided an additional $50 million in the Child Care Block Grant to activities that improve the quality of care for infants. What has your Department done to make sure that those funds go to increasing quality and not just supply?

Answer. This March the Department has sent a letter to all Child Care Development Block Grant (CCDBG) State administrators explaining that in fiscal year 1998

Congress appropriated an additional $65.139 million for CCDF and that $50 million is earmarked for quality and $18.59 million for resource and referral activities. The letter included a table of State allocations, including the minimum amounts States must spend on quality and resource and referral activities. It was also noted that these funds are in addition to any expenditures necessary to meet the "not less than 4 percent quality requirement." While we cannot specify what type of quality activities are undertaken, we have also provided CCDBG Agencies with a list of suggestions for activities in such areas as monitoring of child care programs, training curriculum, child care networks, and scholarships/grants as well as a summary of innovative programs already in existence.

Question. As you know, the President's budget essentially pays for the NIH increase with tobacco proceeds. I have been saying for years that we need another source of funding for biomedical research. Madame Secretary, what advice do you have for us on how to get those tobacco proceeds available to this Committee to fund a NIH increase?

Answer. We fully believe that a comprehensive bipartisan tobacco legislative package will be enacted by Congress this year, and that this legislation will contain the revenues needed to expand NIH research and the health research of CDC and AHCPR. These increases are a priority of the President, and we will work closely with the Congress to assure that the revenue source we have identified, comprehensive bipartisan tobacco legislation, will be in place this year to fund the President's priority for research into the twenty-first century.

QUESTIONS SUBMITTED BY SENATOR HERB KOHL

Question. Secretary Shalala, one part of the President's budget that I am interested in is a demonstration project run by the Education, Health and Human Services, and Justice Departments that would coordinate Federal after-school programs. I understand that this initiative is to designate three to five pilot cities and show how we can coordinate all the various government programs that serve children after school. How will the pilot cities be chosen? Obviously, I believe Milwaukee would be a great site for this project. Will you help guide them through the process and make sure they receive serious consideration?

Answer. The initiative you are referring to was part of the Child Care Initiative announced by the President on January 7, 1998. The President announced at that time a collaborative effort involving numerous federal agencies to eliminate duplication and better coordinate existing federal funding for after-school programs in three to five pilot cities, including the District of Columbia. A working group within the Administration has been formed to put this collaborative effort in motion. It comprises of representatives from HHS, Department of Education, the Justice Department, as well as other interested federal agencies. This working group will be looking at previous collaborative efforts to gain some lessons learned as criteria is developed for considering other cities that may be included as part of this effort. The key goal of this initiative is healthy development and learning, and not custodial. I will communicate to the working group your interest to have Milwaukee be considered as one of the possible sites and your concern that this effort not be focused on custodial issues.

Question. Last year, the Milwaukee Journal-Sentinel ran a series of articles focusing on the prevalence of elder abuse by health care workers, many of whom had prior criminal histories. Similar stories have appeared nationwide, and abuse is not isolated to nursing homes. To respond, I have introduced and continue to work on legislation that would create a national registry of abusive long-term health care workers, and require criminal background checks for prospective employees of long-term care facilities. This will make sure that abusers cannot travel from state to state and continue to prey on vulnerable patients. Would you support such a proposal and work with me to push for its passage? Will you help me move this along this year by also looking for a way to do this administratively?

Answer. We would be happy to review your proposed legislation when it is completed. As you are aware, this Department is in the forefront of weeding out poor health care providers from the Medicare and Medicaid programs using the tools provided by Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Balanced Budget Act of 1997. We are currently working on developing the Healthcare Integrity and Protection Data Bank established in HIPAA which will eventually catalogue all health care providers with adverse actions against them. Regarding criminal background checks of health care workers, the HHS Office of Inspector General (OIG) performed two State audits with supplemental work in nursing homes and several other States to get a sense of the value of performing back-

ground checks for nurse aides. Based on the OIG's information which is not statistically valid for projecting nationwide, they believe that background checks may have merit and that their application to nursing home aides and perhaps others who have access to patients in long term care facilities should be seriously considered. A number of nursing home officials indicated that background checks were especially helpful in screening prospective employees. Further, they believed checks reduced instances of abuse by deterring applicants with criminal histories.

As you are also aware, nurse aide registries were established by OBRA 87. The law required that States maintain a registry of all nurse aides who have satisfactorily completed a nurse aide training and competency evaluation program. It also required that the registry should include specific documented findings by a State of resident neglect, abuse, or misappropriation of resident property involving an individual listed in the registry. The registry, however, is for nurse aides only, and does not apply to all long term health care workers. OBRA 97 also did not mandate criminal background checks for prospective employees of long term care facilities. We would be happy to discuss this important matter with you and your staff.

Question. The President's $20 billion child care proposal contains over $5 billion in spending that goes through this Subcommittee spending for programs like teacher scholarships, child care facility inspections, and after-school programs. Currently, that money is considered outside of our spending caps, and the President has suggested paying for it with part of the revenues from a new cigarette tax. Will the Administration still stand by its child care proposal if we are unable to reach agreement on a new tobacco tax?

Will you suggest some offsets to help this Subcommittee find the money to fund your child care priorities?

Answer. As the President has said, every initiative in his budget submission, including the child care proposals, will be paid for within the context of a balanced budget. The budget we send to Congress will have a number of proposals to pay for new initiatives like this one—including tax proposals and other spending offsets. The child care package is funded in a variety of ways—some on the mandatory side and others on the discretionary side of the budget. Of the President's 5 year, $21.7 billion request, $7.5 billion is funded out of expected tobacco revenue and is requested for a mandatory increase in child care subsidies.

The proposed $5.1 billion fiscal year 1999 program level for child care includes an appropriation request of $1.182 billion in discretionary funds, $2.167 billion in pre-appropriated mandatory funds for the child care entitlement, $1.755 billion in mandatory increases for subsidies and the Early Learning Fund. Of this $1.755 billion, $1.155 billion is for subsidies funded out of tobacco revenue.

Our budget does assume that Congress will pass tobacco legislation, and we believe that they will. It is a top priority for the President, and it has bipartisan support. We are committed to working with Congress to pass this important legislation.

As noted above, we support the Presidential priority of finding child care funds and will work with Congress to find other offsets if tobacco legislation is not passed.

Question. Last October, Time Magazine published a disturbing article describing how few nursing homes that are cited for deficiencies are actually penalized. I understand that the Administration is requesting $167 million for Survey and Certification activities, which are responsible for inspecting facilities to make sure they comply with health and safety standards; and impose penalties on those who violate standards. However, I am concerned that $62 million of this would be available only if legislation is passed to require user fees. Does the Administration have a contingency plan in the event that user fees are not accepted by Congress? Do you agree that we should make this increase a priority regardless of the passage of user fees?

Answer. In order to effectively perform Medicare survey and certification activities in fiscal year 1999, the Administration requests a program level of $167 million. This includes a $104.7 million appropriation request plus $62.3 million in proposed discretionary user fees. The full $167 million funding level is needed to provide the necessary resources for us to keep pace with the continuous growth in this program. More specifically, the request will support inspections of all facilities seeking to participate in Medicare for the first time as well as re-inspections of all currently participating nursing homes and home health agencies that are statutorily mandated. Also, the request supports inspections of a minimum of 10 percent of non-statutorily mandated facilities.

Full funding of our proposed discretionary user fees is crucial to our ability to maintain priority program operations, including survey and certification activities. Insufficient funding to conduct on-site inspections of health care facilities could jeopardize the quality of care provided and place beneficiary health at risk. Without a user fee to supplement our appropriations request, HCFA's ability to survey new providers will be compromised, as will its ability to perform all of the statutorily-

mandated surveys for those providers that are already participating in our programs. The Administration is eager to work with both this Committee and the authorizing committees to fully enact our user fee request.

Question. After the Time article was published, Senator Reid and I wrote to you expressing our outrage at the disparity between citations and penalties. To date, we have not received a reply. What has the Administration done to address the problems raised by the Time article?

Answer. HCFA is currently developing initiatives to respond to the Time Magazine article, including better ways to target current poor performers, prevent and penalize resident abuse, and develop more focused survey guidance on nutrition and hydration requirements. We believe these activities will greatly improve the nursing home survey, certification and enforcement process.

For the record, I have included a copy of the letter I wrote in response to Senator Reid; an identical copy of this letter was sent to your office as well.

[A copy of the letter follows:]

DEPARTMENT OF HEALTH AND HUMAN SERVICES,
OFFICE OF THE SECRETARY,
Washington, DC, March 10, 1998.

Hon. HARRY REID,
U.S. Senate,
Washington, DC.

DEAR SENATOR REID: Thank you for your letter of concern about nursing home enforcement. Let me preface my response by saying that I appreciate your deep concern for the nation's elderly nursing home residents and your offer to collaboratively improve the processes used to ensure quality care. I apologize for the delay in responding.

I, too, am disturbed by the allegations and information that appeared in the October 27, 1997, issue of Time magazine. The General Accounting Office is investigating these charges, and we will, of course, fully cooperate with this effort.

Regarding your broader concerns about the nursing home enforcement process, the Health Care Financing Administration (HCFA) is preparing a report to Congress that will examine these very questions. The report, which will be sent to Congress in the Spring, will include an analysis of the effectiveness of the survey and enforcement systems, a comparison of the current survey and accreditation process, and a discussion of the regulatory and non-regulatory incentives for improving care. The information in the report will provide us with a solid foundation for determining whether changes may be needed to the present survey, enforcement, and accreditation process, including any necessary Congressional action.

You ask why so few citations are acted upon and what procedures are in place to process citations and recommendations. Under the current process, when a survey occurs and a facility is found out of compliance with nursing home requirements, most nursing homes are afforded an opportunity to correct their deficiencies. If the nursing home is unable to make the corrections within three months of being found out of compliance, the law requires that a sanction be imposed. Most nursing homes are able to make corrections and achieve substantial compliance within that three-month period. However, if a nursing home's care represents an immediate threat to the health and safety of nursing home residents or otherwise is considered a poor performer, sanctions are put in place immediately. The procedures for sanctioning a nursing home only occur after the state makes a recommendation for HCFA to take an action. This usually occurs after the nursing home has been given an opportunity to correct the deficiencies but failed to achieve compliance. When this happens, HCFA sends out an official notice and sanctions become effective after the notice period (between 2 to 15 days after the date the notice is received).

In answer to your question about how decisions are made as to which facilities are sanctioned, the state survey agency (HCFA's agent) makes recommendations for sanctions based on its inspection of the nursing home and subsequent follow-up visits to the nursing home. The final decision is made by the state Medicaid agency for Medicaid-only nursing homes and HCFA for all others. HCFA and the state Medicaid agency impose sanctions at the third month after the date noncompliance was found, and terminate a facility at the sixth month after the date noncompliance was found if a nursing home fails to achieve compliance.

In addition, HCFA is developing initiatives that are aimed at specific issues raised in the Time magazine article. These initiatives include ways to target current poor performers, prevent and penalize resident abuse, and develop more focused survey guidance on nutrition and hydration requirements. We believe these activities will greatly improve the nursing home survey, certification, and enforcement process.

Thank you for your interest in this aspect of the Medicare and Medicaid programs. I look forward to continuing to work with you to improve quality of care and life for the nation's elderly. A similar letter is being sent to Senator Herb Kohl who co-signed your letter.

Sincerely,

DONNA E. SHALALA,
Secretary of Health and Human Services.

BALANCED BUDGET ACT

Question. Last year's Balanced Budget Act included significant changes to the Medicare program which will ensure Medicare's solvency for the short-term. Included in these changes was an increase in payments to HMO's and other private plans under the Medicare+Choice program. The new $367 payment floor and blended rates are an improvement, but Wisconsin counties still have the fourth lowest payment rates per Medicare beneficiary in the nation. This will seriously limit choices for seniors in Wisconsin, as few HMO's or other plans will participate in Medicare in a State where the payment rate is so low. Does the Administration have a proposal to address this problem?

Answer. As your question mentions, the new Medicare+Choice program, established under the BBA, changed the payment formula for managed care plans under Medicare. This change was an attempt to raise the payment levels in low-cost, mostly rural areas, in order to induce managed care companies to offer plans in these areas. Specifically, a new payment floor was established at $367 per member per month nationwide for 1998. This will mean that the lowest county payment has increased from $221 to $367 per month. This figure will be adjusted upward in future years, primarily according to the growth in per-capita Medicare spending.

In addition, a new blended county rate was also established under BBA. This new rate, as opposed to the old rate which was based 100 percent on local costs, will blend national rates and local rates over a six year period. By 2003, the blend will be fully implemented at 50 percent local and 50 percent national rates. Each local area will receive the highest of the possible rates produced by the payment floor, the 50/50 blend, or the minimum update for high cost areas. We believe that these higher rates for low-cost areas should have a positive effect on plan establishment in these areas. We will continue to monitor the developments in this area to see whether any recommendations to the Congress are warranted in the future.

Question. The Long-term Care Ombudsman program serves as an advocate for the elderly by pursuing cases of abuse and neglect. Often, it is the Ombudsman program that serves as the only voice for frail and elderly people. The Administration has requested flat funding for the Ombudsman program; yet, the programs already do not have enough staff or resources to respond to existing inquiries. Shouldn't the Administration place a greater emphasis on the Ombudsman program?

Answer. The Administration's funding requests are made within the context of the need to balance the budget and of larger funding priorities. Most of the funding for Ombudsman services comes from Title III monies which the State and area agencies commit to Ombudsman programs, rather than from designated Ombudsman money in Title VII. With the recent increase in total Title III funding, State and area agencies may commit additional funding to Ombudsman services, depending on their individual priorities.

The Administration on Aging (AoA) works in partnership with the States' Long-Term Care Ombudsman Programs to emphasize the significant role provided by Ombudsman staff and volunteers. Through the provision of on-going training, guidance and reviews of best practices, AoA consistently focuses on maintaining and improving the quality and effectiveness of the Ombudsman program, and recognizes its important on-going efforts for HHS's Operation Restore Trust. Finally, AoA has proposed a consolidation of the Title VII programs that serve vulnerable elders. A base amount of this consolidated funding would be earmarked for Ombudsman services, so that their continued significance would be ensured even under level-funding.

QUESTIONS SUBMITTED BY SENATOR ROBERT C. BYRD

VENIPUNCTURE

Question. A provision of the Balanced Budget Act of 1997 (BBA) eliminated qualification for home health care services based on the need for venipuncture, or blood draw, services. This provision has raised great concern in West Virginia and around the nation. Homebound, frail elderly Medicare beneficiaries are frightened that they will no longer receive the home health services they need to remain in their homes

and to remain healthy. While I support efforts to combat Medicare fraud and abuse, I am concerned that the venipuncture provision was not well thought out and that homebound, elderly Medicare beneficiaries' health will be jeopardized by this provision. In some rural areas of West Virginia we do not have "traveling labs" that will go back into the hollows and up winding dirt roads. What will happen to these beneficiaries?

Answer. These beneficiaries first should contact their physicians to determine whether, in the physician's medical judgement, they qualify for home health based on the need for another skilled nursing service besides venipuncture. The physician is responsible for assessing whether a patient requires Medicare home health care, and for establishing a patient's plan of care. The Health Care Financing Administration (HCFA) has stated that most beneficiaries will not be affected by the venipuncture provision because they require another skilled nursing service or physical or speech therapy.

However, if the physician determines that a beneficiary no longer qualifies for Medicare home health, there are several other ways the beneficiary can receive blood tests. Home health agencies can take a blood sample at a beneficiary's residence and bill Medicare for the service using the appropriate codes for specimen collection and travel. Furthermore, agencies may conduct some of the less complex blood tests themselves, receive the collection and travel fee, plus receive a fee for performing the tests. These are called the Clinical Laboratory Improvement Amendments (CLIA)-waived tests. The CLIA-waived tests include among others, glucose (tests blood sugar levels for diabetic patients), and cholesterol/triglyceride (checks lipid levels, used for patients with cardiovascular disease).

In addition to home health agencies performing venipuncture, a variety of other providers can take a blood sample at a beneficiary's home. The physician prescribing the blood tests can conduct a home visit for evaluation and management, and take a blood sample during the visit. The physician also can arrange for a nurse practitioner, physician assistant, or clinical nurse specialist to conduct a home visit and draw blood when they examine the beneficiary.

Question. Can you tell me how many beneficiaries will be affected by the venipuncture provision of the BBA?

Answer. HCFA does not have estimates on the number of beneficiaries affected by the venipuncture provision. Home health agencies report only to HCFA that a beneficiary qualifies for home health because s/he needs a skilled nursing service. Agencies do not specifically report which of the approximately 14 qualifying skilled nursing services the beneficiary needs.

However, HCFA believes that most beneficiaries will continue to qualify for home health because they need another skilled nursing service, such as observation and assessment, monitoring effects and compliance with complex medications changes, wound care, or others. For example, severe diabetics generally qualify because they need another skilled nursing service besides blood draws. Stroke victims also may qualify for home health because they require physical therapy or speech language pathology services.

Question. What assurances can you provide that the alternatives to care that HCFA has in place are sufficient to assist rural beneficiaries?

Answer. While we believe that most beneficiaries will have no problem having blood samples taken, there may be some areas of the country where blood specimens are more difficult to collect. HCFA is continuing to study this issue.

Question. What would be the cost of re-implementing the venipuncture benefit or of a grandfathering provision for those who received the benefit prior to February 1998?

Answer. Although no one has estimated the cost of a grandfathering provision, the Congressional Budget Office has scored reinstating venipuncture as a qualifying skilled service to receive home health. Their cost estimates for repealing the venipuncture provision are $1 billion for fiscal year 1999 to 2003 and $2.5 billion for fiscal year 1999 to 2008.

ALCOHOL

Question. Madame Secretary, would you please comment on the Department of Health and Human Services role in educating the nation about youth alcohol use and alcohol abuse?

Answer. I agree with you that young people, specifically those underage, need a clear message that consuming alcohol has serious consequences and can result in destructive behavior. As I have traveled throughout the country and met with young people, I have been very clear the dangers of engaging in a variety of risky behaviors the use of drugs, including alcohol; smoking; and sexual activity. In the case

of our message about the dangers of alcohol, we are still not getting through to thousands of older teens. We need to focus much more on early detection, timely intervention and comprehensive prevention.

In a recent major speech I gave to the Annual Meeting of the National Collegiate Athletic Association, I called for greater action on the part of the universities about the major public health problem of alcohol abuse. I asked the schools to begin the process of severing the tie between college sports and drinking—completely, absolutely, and forever. I asked that schools consider: no alcohol advertising on the premises of an athletic event; no bringing alcohol to the site of the event; no turning a blind eye to underage drinking at tailgate parties and on campus; and no alcohol sponsorship of sporting events. Research suggests that advertising may influence adolescents to be more favorably disposed to drinking. These voluntary guidelines would remove that advertising at intercollegiate sporting events.

In addition, the Center for Substance Abuse Prevention and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) are collaborating on a joint Request for Application (RFA) titles "Effects of Alcohol Advertising on Underage Drinking" in fiscal year 1998. The RFA will support five-year grants which conduct complex longitudinal research to determine whether alcohol advertising affects both initiation and continued consumption among youth. Grants are expected to explore short an long term relationships among exposure to alcohol advertising, alcohol expectancies and other mediating variables, and actual consumption among youth.

Another element of our education efforts is making available high quality materials that are used and accepted by young people, as well as adults. The NIAAA distributes brochures, helpful guides, video cassettes, and other types of information and materials on substance abuse through its National Clearing House for Alcohol and Drug Information. An especially popular publication has been Alcohol Alerts, covering such topics as "Alcohol and Tobacco," "Alcohol, Violence and Aggression," and "Youth Drinking: Risk Factors and Consequences." NIAAA also works with the Department of Education's Safe and Drug Free School Program—preventing and reducing alcohol use among college students and modifying college environments that are conducive to alcohol abuse.

APPALACHIAN LABORATORY FOR OCCUPATIONAL SAFETY AND HEALTH

Question. What is the number of Full-Time Equivalents (FTE) for the Division of Safety Research and the Division of Respiratory Disease Studies at this facility in fiscal year 1998 and the number projected for fiscal year 1999?

Answer. The fiscal year 1998 FTE projection for the Division of Safety Research (DSR) is 107 and is projected to be the same in fiscal year 1999. For the Division of Respiratory Disease Studies (DRDS), the 1998 plan is 135 with the same number projected for 1999.

Question. Please provide the funding level for the above-mentioned Divisions in fiscal year 1998, and the projected level for fiscal year 1999.

Answer. The current fiscal year 1998 allocation for DSR is $11.891 million and for DRDS $12.100 million. There are no changes for fiscal year 1999.

NEW OCCUPATIONAL SAFETY AND HEALTH LABORATORY

Question. How many FTE's are at this facility in fiscal year 1998, and what is the projected number of FTE's for fiscal year 1999?

Answer. By September 30, 1998, 280 full time staff are projected to be on board at the new laboratory. The full compliment of 303 full time staff will be hired by December 31, 1998.

Question. Please furnish the funding level required for staffing and research for fiscal year 1999 at this facility.

Answer. Our current estimated level of funding for this facility in fiscal year 1998 is $33.725 million. We estimate that this same amount would be required for staff and research in fiscal year 1999.

The fiscal year 1998 budget includes the funding for 23 FTE's. Strategic planning and targeted recruitment efforts to hire the top scientists and technicians in the field, where all recruitment efforts are necessary to compete with private industry, have somewhat delayed hiring processes. Since the FTE's are not yet on board, the fiscal year 1998 funding has been used for the one-time purchase of start-up equipment and other related costs for laboratories. Once on board, FTE's will be supported through the fiscal year 1999 funding as planned. No budget increases are being requested for fiscal year 1999.

HEALTH CARE FINANCING ADMINISTRATION

ADDITIONAL COMMITTEE QUESTIONS

COST OF GAO RECOMMENDATIONS

Question. Ms. DeParle, GAO and the Practice Expense Coalition have made a number of recommendations for your agency to further refine practice expense data during phase-in of the new fee schedule revision. Do you intend to implement these recommendations, and what will this cost?

Answer. We are studying the recommendations but have not made a final decision about the process we will use to refine practice expense relative values. Consequently, it would be premature to estimate any associated costs.

Question. Can these costs be financed within your agency's fiscal year 1999 budget request?

Answer. We are confident that the agency's fiscal year 1999 budget request includes the necessary resources for this process.

MEETING DEADLINES

Question. I understand that the GAO and the physician community have raised a number of concerns about HCFA's work to date. In response you note that you are considering the suggestions of GAO and you have held numerous meetings with physician organizations, although no consensus among physicians has been reached. With all of these unresolved issues, how can your agency publish a proposed rule on May 1st that responds to the mandates of the Balanced Budget Act of 1997, the recommendations of the GAO, and the concern of the physician community?

Answer. We believe that we will be able to publish a proposed rule on May 1, and fully intend to do so. This is not to minimize the task ahead of us. Developing a resource-based practice expense methodology is a complex undertaking, and with $20 billion of Medicare spending at stake, it is a responsibility we take very seriously. As the question notes, we will need to balance the mandate of the Balanced Budget Act (BBA) of 1997, the recommendations of the General Accounting Office (GAO) and the concerns of the medical community, along with our own obligation to ensure that our proposal is methodologically sound.

We were pleased to receive the recommendations from the GAO and were gratified by their general support of HCFA's work on practice expense to date and by their affirmation that generally accepted accounting principles were utilized. Most of the recommendations are medium to long range, and do not apply to our May proposed rule. The more immediate recommendations are still under consideration and are directly addressed, to some degree, by each of our optional methodologies. We also believe that whichever methodology we choose to propose in May will, to the maximum extent practicable, respond to the mandate of the BBA.

As your question also notes, no consensus has been reached among physicians as to the preferred methodology for determining practice expense relative values. Given that any change in the current system will result in some degree of redistribution, and given that we are operating under the constraints of budget neutrality, it is not surprising that one specialty's gain would be viewed as another specialty's loss. However, from the beginning of the practice expense initiative, we have sought maximum input from the medical community and have attempted to find ways to address their concerns. We are now considering optional methodologies to respond to comments and concerns that have been raised.

Question. If HCFA can't accomplish all that needs to be done by May, will you be able to complete your work by January 1, 1999?

Answer. The rule we will publish in May is a proposed rule, with a 90-day comment period. The final rule is due to be published by October 31. We expect a large volume of comments on our proposal and will, as appropriate, make the needed changes. This will entail a great deal of analytical work on the part of our staff, but we fully anticipate that the final rule will be published in time for implementation of the new practice expense values to take place on January 1, 1999.

Question. Dr. Day's prepared testimony suggest that the process for collecting physician practice expense information could be facilitated by convening a public/private partnership between HCFA and physician organizations. What do you think?

Answer. We certainly do want to work cooperatively with physician organizations, now and in the future, in order to develop and then improve our practice expense methodology. We agree with the GAO report regarding the recommendation of several medical specialty groups that HCFA base practice expense values on data obtained from physician surveys or on-site data collection. The GAO believes that

using such approaches as the primary means for developing direct expense estimates would needlessly increase costs and further delay implementation of the fee schedule revisions. We will, however, explore what additional data we will need for future refinements.

REFINEMENT PROCESS

Question. You state that you are currently developing plans for refining the new system, once it's in place. Have you made any final decisions about this process? Are the resources necessary for this refinement contained in HCFA's fiscal year 1999 budget?

Answer. We have not yet made any final decisions about the process we will use to refine practice expense relative values. To a large degree, the specifics of the process will depend on the option we finally choose to develop the initial relative value units. In addition, this is a topic on which we want to receive more input from the medical community, and we are planning to include in our proposed rule a specific solicitation of ideas, comments or advice on the refinement process. We believe that our fiscal year 1999 budget request includes sufficient resources for the refinement process.

ACCESS TO CARE

Question. You note that you will continue to monitor indicators of beneficiary access to care. I am very concerned that if physicians experience the same level of reductions as were proposed by HCFA last year, Medicare beneficiaries will experience access problems. How does HCFA intend to monitor this potential problem?

Answer. HCFA has a broad and varied approach to monitoring access to care. Much of our effort has focused on assessing the impact of specific program changes, such as implementation of the Medicare fee schedule (MFS), on access to health care services in the fee-for-service (FFS) sector. To date, our monitoring efforts have shown that implementation of the MFS has not negatively impacted on access. It is conceivable, however, that future program changes could negatively affect access. For this reason, we will continue to monitor the impact of program changes. As part of this ongoing effort, we will continue to monitor and report on the rate of referral sensitive surgeries, and the rate of hospitalizations for ambulatory care sensitive conditions, such as asthma and pneumonia. We will also use survey-based data, such as the Medicare Current Beneficiary Survey, to examine beneficiary self-reports of access problems. In addition, a major set of activities involves the development of new indicators for both Medicare and Medicaid. Examples include the development of clinically-based indicators of appropriate care for beneficiaries with chronic conditions, such as diabetes. Our analyses will focus on and highlight population subgroups for which there appear to be potential access problems.

Question. Given that many private insurers, as well as other government programs are also using the Medicare fee schedule are you monitoring access to care for all our citizens?

Answer. HCFA's current efforts to monitor access are not limited to the Medicare population. To illustrate, we are monitoring access for the Medicaid population. In particular, HCFA has 6 ongoing contracts to evaluate the section 1115 demonstrations. These evaluations examine the impacts of moving about 6 million Medicaid beneficiaries into managed care and expanding Medicaid eligibility in 12 States, and the District of Columbia. In each evaluation, a significant component is concerned with Medicaid beneficiaries' access to care. For the Medicaid population, we will examine such issues as the availability and use of primary care and specialty providers, travel and waiting time, and language barriers.

Similarly, as part of the Children's Health Insurance Program, States are required to describe in their State Plan the methods that will be used, including monitoring, to ensure access to covered services. Following review and approval of the State Plan, States will be required to report to HCFA on an ongoing basis on their monitoring efforts and performance in the area of assuring access to covered services.

Finally, attempting to monitor access throughout the entire health care industry demands comprehensive data sources. These issues are best addressed through national surveys of the entire population, such as those conducted by the Agency for Health Care Policy and Research (AHCPR). HCFA staff are actively working with private interests and other government agencies to establish additional standardized reporting efforts, such as Health Plan Employer Data Information Sets (HEDIS) and the Consumer Assessment of Health Plan Survey (CAHPS), which will give us new tools and different perspectives on access to care issues.

EQUIPMENT COSTS

Question. Many physician groups, according to GAO, state that HCFA's estimates greatly overstate the utilization of most equipment, which results in underestimating equipment expenses. Does HCFA plan to test the effects of different utilization rates on various specialties?

Answer. HCFA does plan to perform sensitivity analyses to test the effects of varying equipment utilization rates on the different specialties. It should be noted that in our notice of pre-rulemaking, published in the Federal Register on October 31, 1997, we requested data on actual utilization rates. Unfortunately, we received only a few comments on equipment utilization with information on only a few specific pieces of equipment. We will welcome any additional data that the medical community wishes to share with us.

WORK DONE IN HOSPITALS

Question. In last June's proposed regulations, your agency eliminated nearly all expenses associated with physician's staff, primary nurses, for work they do in hospitals. The rationale was that it is Medicare's policy to pay hospitals, rather than physicians, for these expenses.

What evidence is there that this policy results in a major absorption of costs for surgical specialists?

Answer. In comments and in our panels, many surgical specialty groups have complained about the elimination of most of the claimed expenses connected with work done by physicians' clinical staff in the hospital. In the same panels, many other physicians disputed the surgeons' claims that staff was typically brought into the hospital. The American Hospital Association conducted a survey of its members which indicated that, in the vast majority of hospitals, surgeons did not use their own staff with hospital patients. In addition, in the October 1997 notice of pre-rulemaking, we specifically requested information on this, asking commenters to send us the name of any hospital where this practice occurred. We did not receive the name of any hospital. However, we still continue to hear from surgical specialty societies that use of physicians' staff in the hospital is increasing. This may well be true, but we are not currently in receipt of hard evidence that indicates that our policy would result at this time in a major absorption of costs for surgical specialists. We will continue to collect as much data as we can on this for future refinement.

Question. Ms. DeParle, will this matter be corrected in the May 1998 regulations, or left for adjustments during the refinement process?

Answer. We have not yet made a final decision on our treatment of physicians staff used in the hospital. In part, it will depend on which alternative methodology we choose. Each of our suggested options treats clinical staff costs in a different manner.

MEDICARE + CHOICE

Question. Madame Secretary, you are requesting the full authorization level of $150 million for fiscal 1999 to administer the "Medicare+Choice" program enacted last year; this program greatly expands the options available to beneficiaries among fee-for-service and managed care plans. Why do you need an increase of this magnitude over the $95 million provided by Congress for the current fiscal year?

Answer. The 1998 user fee money is being used mostly for start-up costs and building infrastructure, whereas the 1999 user fee money will be used to actually operationalize the new Medicare+Choice program.

It is essential that HCFA receive the full $150 million authorization in fiscal year 1999. We expect most new plans will not be approved until after the fiscal year begins, which in turn will lead to an explosion of beneficiary inquires regarding their new plan choices.

The $150 million in user fees we request for fiscal year 1999 will be used to distribute revised information on Medicare+Choice plans that are approved after the initial comparative handbook has been published. This updated information will be distributed via mail, libraries, and the Internet. In addition, the money will be used to staff the expected increase in calls to the new toll-free hotline, conduct health fairs and other dissemination activities across the country, and to continue our marketing research on how best to get information to our diverse beneficiary population.

Question. Health plans invest considerable resources in becoming Medicare HMO's. It is not unusual for a plan to spend $100,000 to $150,000 just to prepare and submit an application to become a Medicare risk HMO. Today, 322 health plans participate in the Medicare HMO market. Assessing $37 million in new user fees

for initial applications and contract renewals represents an additional assessment of almost $115,000 on each of these plans. Wouldn't this user fee represent a significant barrier to entry for new organizations such as PSO's?

Answer. We estimate the cost per plan is much less than you state—for the processing of initial applications about $55,000 and approximately $41,000 per plan to renew and monitor existing plans. We do not feel that this will represent a significant barrier to entry for PSO's or any of the new Medicare+Choice plans. The proposed fee is to cover the costs of the Federal government associated with Medicare+Choice plans acquiring a Medicare contract; there is currently no charge for this benefit. These plans will directly benefit from the Medicare program and it is reasonable to expect them to pay the costs of doing business in the program.

Question. Wouldn't this user fee strain the resources of health plans that have already reduced some of their additional benefits for seniors in response to the new payment methodology under the Balanced Budget Act of 1997?

Answer. We believe that this user fee will not place too much of a burden on health plans. As beneficiaries options increase, competition amongst Medicare+Choice plans will continue to increase. The type of benefit package that plans offer will be used as a marketing tool. Plans will have a strong incentive to provide better benefit packages and a higher level of service to attract and retain Medicare beneficiaries.

Due to the enactment of the BBA, we believe that the number of Medicare beneficiaries enrolled in Medicare+Choice plans will increase at a pace faster than would have occurred under the old 1876 provisions. This will create a much larger market for these types of health plans. We feel that the overall impact on plan revenue will not have an adverse effect on the quality of services or benefit packages that plans provide.

Question. Please describe the status of HCFA's beneficiary education and information campaign. Under the Balanced Budget Act of 1997, a number of new health care delivery options become available to seniors in January 1999. Is HCFA's education campaign on schedule for informing beneficiaries regarding these options in a timely manner?

Answer. Yes, HCFA is on schedule with the various initiatives included under the Medicare+Choice beneficiary education and information campaign. HCFA's new consumer information Internet site, "www.medicare.gov," went live in March 1998. This web site includes "Medicare Compare," the interactive database with the HMO comparison chart on benefits, premiums, and cost-sharing.

We plan to have the majority of our implementation activities for the toll-free call center completed during fiscal year 1998, so the center can be fully operational in fiscal year 1999. This activity is very extensive and will require a lot of effort from HCFA and the private sector contractor which will operate the center. The call center will receive a lot of calls and it is crucial that representatives have adequate training to handle the different types of questions that Medicare beneficiaries will have.

Publishing and mailing the Medicare+Choice comparative information is on schedule for a fall mailing. Compiling this type of information for the first time and having the information for specific areas is an important and complicated task. HCFA and a contractor will continue to explore effective and efficient dissemination strategies.

HCFA has developed a plan for a national publicity and educational campaign to inform beneficiaries of their health plan options that will combine and coordinate the efforts of HCFA, including its regional offices, its partners and contractors, and community-based organizations throughout the country. The primary attributes of HCFA's campaign are: that it be interactive, i.e., that it will afford beneficiaries the opportunity to ask questions and/or obtain counseling; that it be conducted at local outlets that beneficiaries can access; and that it take place at the optimal time period of beneficiary information needs.

This plan will incorporate and build upon existing locally-based interactive activities currently sponsored by these organizations either individually or in cooperation with others. Further, HCFA intends to work with large employers to assist it in sharing information about Medicare+Choice with their retirees. These activities may include participation in "auditorium-type" benefits fairs, presentations to beneficiaries and other interested parties at beneficiary gathering places, interactive television shows, radio call-in shows, strategically placed interactive information kiosks, Internet chat and news groups, and newspaper question and answer columns. These community based activities will begin with awareness building and will take place in late summer and continue through the fall.

Question. HCFA has indicated that it intends to make the initial application process for existing Medicare health plans to convert to Medicare+Choice plans fairly

simple and "streamlined." At the same time, HCFA has requested $37 million in user fees from Medicare+Choice organizations for reviewing initial applications and contract renewals. Currently, HCFA does not charge an application or contract renewal fee. Please describe the initial application and renewal process for health plans wishing to become a Medicare+Choice organization and why that should necessitate $37 million in user fees.

Answer. The purpose of this fee is to recover the costs incurred by HCFA to allow a managed care plan to obtain a Medicare contract and thus become a Medicare+Choice organization. Because these plans will benefit from this program, it is reasonable to expect them to pay the costs of doing business in the program.

The costs associated with processing managed care plan applications, the annual renewal of contracts, and the monitoring of managed care plans, currently come out of HCFA's administrative budget. HCFA staff visit the organization to conduct a legal review of the entity and its administration. This includes monitoring for fiscal soundness and all other requirements that the plan must meet to participate in Medicare. We also conduct an in-depth review of the plan's health services delivery network, marketing materials, benefit packages, and enrollment and disenrollment procedures.

The rate of growth in the number of managed care plans has averaged almost 23 percent in recent years, and the number of plans we contract with will increase significantly with the implementation of the Medicare+Choice program. Obtaining the resources necessary to deal with this increasing workload from a user fee to be paid by those organizations that benefit directly from HCFA's activities, seems both prudent and reasonable. The proposed fee is to cover the costs associated with Medicare+Choice plans acquiring a Medicare contract for which there is currently no charge.

Question. Although HCFA currently conducts numerous beneficiary education and information dissemination activities, it has not elaborated on its plans to use its existing infrastructure in meeting the Balanced Budget Act requirements for a beneficiary education and information campaign. Will HCFA use some [of] its existing toll-free lines to offset the costs of its beneficiary education and information campaign?

Answer. HCFA is exploring the most customer-centered, cost-effective solution to this effort. As part of the legislation, the Secretary must make available a toll-free number for inquiries on Medicare+Choice options. In this light, HCFA is developing a plan to deploy a single 1–800 number service to meet the Medicare+Choice information needs of Medicare beneficiaries. The Medicare+Choice toll-free line will be used as part of, and as a supplement to, the beneficiary education and information campaign, and will address many questions related to Medicare+Choice. Current toll-free lines are designated to address issues related to claims processing and payment, quality of care, and beneficiary protections and insurance counseling and assistance. Information about Medicare+Choice will also be made available through these 1–800 services.

HCFA is also building an alliance network to enlist the aid of national, State, and local organizations in the public and private sectors. These organizations will be asked to serve as intermediaries—channels of transmission for program activities, messages, and materials in an awareness campaign and a large-scale national education effort. One objective of the alliance network is to leverage the existing expertise in the existing community based networks to lay the foundation of sustained support for a broad base of public, private, and volunteer community-level support. In addition to working with the States, advocacy groups, such as AARP, and some provider organizations, we are actively seeking employers to help share information about Medicare+Choice with their retirees—groups that share a common interest in informing and educating Medicare beneficiaries.

HCFA has embarked on a team approach, using our existing information intermediaries to ensure that beneficiaries will have access to a readily-available network that is capable of providing Medicare+Choice information through existing phone networks, printed material, educational fairs, and other outreach activities. This network includes: Medicare carriers, Health Insurance Counseling and Assistance program (HICAP) staff, peer review organizations, and other agents and partners. All of these sources of information dissemination will leverage community resources to foster the Medicare+Choice campaign.

Question. Has HCFA explored the capacity of some of its sister agencies that work with Medicare beneficiaries, such as Social Security Administration, in conducting education activities?

Answer. HCFA is building an alliance network to enlist the aid of national, State, and local organizations in the public and private sectors. These organizations will be asked to serve as intermediaries—channels of transmission for program activi-

ties, messages and materials—in an awareness campaign and a large-scale national education effort. As part of this alliance network, HCFA will work with its sister agencies such as the Social Security Administration, the Administration on Aging, the Office of Personnel Management the Agency on Health Care Policy and Research, as well as other parts of the Public Health Service.

Question. Does HCFA plan to work with State area Aging Organizations and other senior organizations as part of its beneficiary education and information campaign? The Balanced Budget Act of 1997 introduced a number of new health care delivery system options for seniors. How will HCFA educate State and senior organizations regarding these new options?

Answer. HCFA is building an alliance network to enlist the aid of national, State, and local organizations in the public and private sectors. These organizations will be asked to serve as intermediaries—channels of transmission for program activities, messages and materials—in an awareness campaign and a large-scale national education effort. One objective of the alliance network is to leverage the existing expertise in the community, as well as the existing community-based networks to lay the foundation of sustained support for a broad base of public, private and volunteer community-level support.

As part of this network, HCFA will work with these organizations and many others as part of its campaign. In addition to working with the States, advocacy groups (such as AARP) and some provider organizations, we are actively seeking employers to help share information about Medicare+Choice with their retirees—groups that share a common interest in informing and educating Medicare beneficiaries.

Extensive training of these organizations will be necessary to put these groups in a position to address beneficiary concerns. We plan to structure our overall campaign so it can be accessed by a variety of people, from a variety of sources, in a manner that will ensure reliable and accurate information is provided to beneficiaries.

Question. Several health plans that operate toll-free lines to field pre- and post-enrollment questions reported a $5.50 or less per call estimate including phone calls, training, staffing and other overhead. How does this estimate compare with HCFA's per call estimate for its proposed toll-free call centers?

Answer. There are many factors involved that will impact the cost per call of the Medicare+Choice Toll-Free Line, including: The length of time on the call; the degree of complexity of the incoming questions; and the cost premium associated with employing a highly skilled temporary workforce.

The Medicare+Choice Toll-Free Line is being designed to provide specific information on approximately 500 different managed care plans, as well as information on Medicare+Choice in general, to a population base of approximately 39 million beneficiaries; therefore, the cost per call could exceed many individual health plan call center cost estimates. We are working closely with call center industry staff and our contractor, Arthur Andersen, to establish accurate costs associated with this initiative. We are currently conducting a procurement for the work, and will distribute the information to you once the procurement is completed.

Question. You are requesting level funding of $10 million for fiscal year 1999 for the Health Insurance Counseling and Assistance Program, which is planned to be a part of the Medicare+Choice beneficiary information plan and which provides individualized counseling to Medicare beneficiaries mostly through a network of trained volunteers. In light of the high probability that the ICA program counselors will face substantial additional demands for individual counseling, do you believe this funding will be adequate in fiscal 1999?

Answer. HCFA currently provides $10 million as the basic level of effort for beneficiary health insurance counseling and assistance services. This volunteer-based program provides a cost-effective and essential tool in the educating and counseling of beneficiaries in vital areas such as health plan choices, fraud and abuse prevention, basic Medicare coverage, and Medigap insurance.

Due to enactment of the Medicare+Choice provisions of the Balanced Budget Act, HCFA will require additional resources to inform and educate beneficiaries about their available Medicare+Choice options. To meet this need in fiscal year 1998 and fiscal year 1999, HCFA will allocate an additional $5 million towards this effort. We expect that this need will continue and that the counseling role of our State partners will significantly increase. As awareness and interest in Medicare+Choice options increase, we anticipate that greater numbers of beneficiaries will depend on our State partners to assist them in making appropriate health plan choices.

USER FEES

Question. Congress has already enacted legislation authorizing up to $150 million in user fees for implementing the "Medicare+Choice" program in fiscal 1999, and you are requesting the full amount. You are also requesting $265 million in new user fees to help finance an expansion of Program Management activities. Further, you are requesting legislation to collect an additional $395 million in user fees to augment audit activities. That's $810 million in user fees to be imposed in fiscal year 1999, more than 8 times the current level. What reaction are you getting from health care providers which would bear the brunt of these extra costs?

Answer. We believe that charging these fees is reasonable and will not impose a burden on providers in light of the benefits they receive for affiliation/participation in the program. These fees will allow us to oversee the Medicare program, including the significant recent legislative changes, while minimizing the need for discretionary budget authority. The additional resources provided via these fees will also allow HCFA to greatly increase its fraud and abuse activities.

Question. Your budget request for Program Management of the Health Care Financing Administration assumes enactment of user fee legislation totaling $264.5 million. Without these proposed user fees your "current law" appropriation request is actually a cut of $65,066,000 below a freeze level. What would be the impact of a $65,066,000 cut?

Answer. A $65.1 million cut in HCFA's baseline funding is unrealistic. Not only would many aspects of the HIPAA and the BBA not be implemented, but the agency's existing workloads—including mandatory requirements such as annual surveys of nursing homes—would be seriously impacted. These fees are meant to fund some of the agency's existing workloads, thus freeing up resources to be used to support implementation of the HIPAA and the BBA.

Question. If the authorizing Committee does not enact your user fee legislation, what alternative would you propose?

Answer. If the authorizing committee does not enact our user fee legislation, HCFA will be unable to accomplish critical workloads. During my appearance before the House Appropriations Subcommittee on March 4, Chairman Porter suggested that he would consider inclusion of user fee language in the appropriations bill in the absence of another bill to which these proposals could be added.

Given the constrained discretionary budget environment we believed that funding the agency's required program level from user fees, charged to those individuals and organizations that benefit directly from HCFA's activities, is both reasonable and prudent.

COST OF NEW LEGISLATION

Question. According to your budget justification materials, you are requesting $30.5 million to cover costs of implementing new requirements under the Balanced Budget Act of 1997, and $15.5 million to implement recently enacted provisions of the Health Insurance Portability and Accountability Act. Why didn't you request user fees to cover this $46 million costs, instead of $264.5 million?

Answer. It was not our intent that the proposed user fees cover only the incremental need for implementation of the HIPAA and the BBA. Given the current constraints on discretionary budget authority, our goal was to have those individuals and organizations that benefit directly from the Medicare program pay the costs associated with the activities HCFA undertakes on their behalf. This, along with the requested appropriation level, will enable the agency to fund not only existing workloads, but new workloads associated with the HIPAA and the BBA, while minimizing the level of appropriated discretionary budget authority.

PATH AUDITS

Question. Last fall, I held a special hearing on the conduct of the Inspector General's PATH audit program (Physicians at Teaching Hospitals). In addition to representatives of the Office of Inspector General and the Health Care Financing Administration, I heard testimony from the Association of American Medical Colleges. How does HCFA intend to address the complaints from the teaching hospitals that they are being treated unfairly by overzealous auditors?

Answer. I have been assured by OIG that its auditors are aware of the importance of treating teaching hospitals fairly and physicians respectfully. The OIG has said that the PATH audits are both appropriate and fair. The OIG provides teaching hospitals with ample opportunity to respond to auditors' findings and to furnish additional documentation and information on any aspect of a PATH audit at any time

during the process. Nonetheless, if a hospital believes that it is not being treated fairly, it should make its concerns known.

Question. Do you believe there is a serious enough problem with hospital double-billing and overcharging Medicare to warrant nationwide, comprehensive audits?

Answer. Because the OIG has limited the PATH audits to locations where carriers, before December 30, 1992, issued clear explanations of the rules regarding reimbursement for the services of teaching physicians, the audits are limited in both scope and time. The OIG believes, however, that there is a serious enough problem to warrant targeted, comprehensive audits, and has the authority to pursue those audits under the Inspector General Act.

Question. What is your assessment of the allegations that the Inspector General's office is applying vague regulations retroactively?

Answer. The policy of the HHS Inspector General is to conduct PATH audits only where the Medicare contractor has provided long-standing (pre-Dec. 1992) unambiguous guidance to providers requiring the physical presence of the teaching physician.

Question. How much has been recovered to date from the PATH initiative?

Answer. To date, the government has recovered $67.6 million from the PATH initiative.

GAG CLAUSES

Question. In November of 1996, as the result of a hearing I held on quality of care issues under Medicare, the Health Care Financing Administration issued a directive specifically banning "Gag" clauses in all of its managed care contracts. Early in 1997, this ban was extended to Medicaid. However there is still no ban on efforts to restrict physician communication with patients about treatment options in the private health care sector. Do you support legislation to prohibit gag clauses in all health plans?

Answer. Yes, we do support legislation that would prohibit gag clauses in all health plans. The President's proposed "Consumer Bill of Rights" prohibits gag clauses in the administration and management of all Federal health programs. The Administration is strongly committed to ensuring that all Americans enjoy the protections outlined in the Bill of Rights. We would like to see legislation that transforms the Bill of Rights into real protections for all Americans.

Question. In a report issued by GAO in August 1997, about two-thirds of health plans were found to have had nondisparagement, nonsoliciation, or confidentiality clauses that providers might interpret as limiting communications about treatment options. How serious a threat are such contract provisions to restricting doctor-patient communications?

Answer. HCFA's Operations Policy Letter (OPL) 96.044 addresses this issue. This OPL basically states that Medicare beneficiaries enrolled in Medicare contracting risk plans are entitled to the same benefits that they would be entitled to under the fee-for-service program. Among the benefits to which the fee for service beneficiaries are entitled is the advice and counsel from their physician on medically necessary treatment options that may be appropriate for their condition or disease. Beneficiaries enrolled in managed care plans are entitled to the same advice and counsel.

The OPL continues to state that a physician providing care to a Medicare beneficiary who is enrolled in a Medicare contracting managed care plan may not be limited in counseling or advising the beneficiary on medically necessary treatment options that may be appropriate for the individual's condition or disease. The OPL then states that any contractual provisions that limit a physician's ability to do so are a violation of the law.

Whether the clauses that GAO discovered truly limit the communications about treatment options would depend upon the wording of the clauses and the interpretation placed on them. HCFA's routine oversight procedures investigate the content of provider contracts to ensure the availability of the medical advice and counseling benefit to the contracting managed care members. Any contract wording that is thought to limit this benefit is to be removed from the contract.

CAPITATION

Question. Secretary Shalala, I have had many health care providers tell me about major excesses and abuses under the payment system of capitation. The central focus of a health care system ought to be the doctor-patient relationship, but too often under managed care capitation, I have heard that the plan administration gets in the way and technicians interfere with medical decision making. What needs to be done to control the most serious abuses of managed care capitation, such as re-

stricting communication on treatment options, referrals to specialists, emergency care, and appeal rights?

Answer. These are very valid concerns regarding managed care versus the health care provider-patient relationship. One of the significant contributions to managed care of the BBA of 1997 is that for the first time, provider protections are addressed at the Federal level. Currently, most States have some form of protection in their laws governing managed care for the provider-patient relationship but none are as inclusive as the BBA of 1997. What has been done to address your concerns has been legislation, monitoring, and satisfaction surveys. Let me speak to each of these points:

Section 4001 of the BBA 97 "Establishment of Medicare+Choice Program" addresses provider protections.

—Anti-gag clauses are included so providers will not be restricted from discussing treatment options with their patients.

—Anti-discrimination of providers is addressed so providers treating high-risk, high-cost beneficiaries will not be penalized or prevented from participating in the plan.

—Prior plan approval for emergency services defined as emergent from a prudent layperson perspective is strictly prohibited.

—Patients and health care providers have appeal rights for adverse decisions made by the plan.

—Providers must be consulted in regards to medical treatment decisions and guidelines enforced by the plan.

—Access to a full range of health services is not only included in the BBA of 1997, but President Clinton's Consumer Bill of Rights.

Another significant difference in the BBA legislation is that HCFA is given a stronger monitoring role. Monitoring of these and other requirements will be done more frequently and more uniformly than in the past. Part of the monitoring process is interviewing providers who contract with a managed care plan. This is one of the most direct methods we have of ensuring these protections are adhered to. Another part of our monitoring process is a new set of monitoring standards much like standards set by accrediting organizations such as the Joint Commission on Accreditation of Health care Organizations. These Quality Improvement System for Managed Care (QISMC) standards will be monitored annually and include provider protection monitoring.

We have in the past and will continue to conduct provider satisfaction surveys of Medicare HMO's, as well as consumer satisfaction surveys. The results of these surveys will be used for public education on plan comparisons and will certainly have a positive influence on relationships between plans and providers which then hopefully influences provider-patient relationships. All Medicare-approved plans will have to conduct consumer satisfaction surveys.

Question. To what extent should Congress get involved in micro-managing managed care?

Answer. We don't believe that (nor have we proposed) any laws should be passed that involve micro-managing any form of health care. The Consumer Bill of Rights, which the President has endorsed, would establish consistent consumer protections for all Americans, regardless of where they receive their care or who pays for it. The rights that would be established involve ensuring appropriate access to specialists, ensuring access to emergency services should the need arise, and ensuring full information disclosure for consumers, among other important rights. We believe that these rights strike an appropriate balance between the health of patients and the ability of health care providers and insurers to treat patients in an efficient and appropriate manner.

MEDICARE CUSTOMER SERVICE PILOTS

Question. You are requesting $12.8 million for a Medicare customer service pilot program, which includes establishing toll-free telephone centers. How many customer service pilots do you intend to implement, and what will be the cost beyond fiscal year 1999?

Answer. We currently fund over 150 different toll-free telephone lines at our various agents and partners. This has resulted in a patchwork of telephone service which has contributed to a significant amount of confusion within the beneficiary community about exactly whom to call for Medicare help and assistance.

At the present time, we are conducting a limited one State (Maryland) pilot test referred to as the Medicare Customer Service Center (MCSC). Through the establishment of systems interfaces with all the multiple information systems containing data about a given beneficiary and their use of Medicare, we are testing the feasibil-

ity and implications of offering a single point of contact for Medicare. Our fiscal year 1999 request envisions expanding the geographic area covered by the MCSC's so that by the end of fiscal year 1999 it will be able to cover approximately half of the Medicare beneficiary population. The costs included in our request include the necessary hardware and software to support this expansion of the MCSC Pilot.

Beyond fiscal year 1999, additional funds will be needed to purchase the hardware and software to cover the rest of the Medicare population, excluding any funding to cover additional requirements related to Medicare+Choice customer service requirements.

Question. Why couldn't you use the existing Social Security Administration teleservice center?

Answer. While we appreciate the marketing advantages of trading on a well established and widely known 1–800 telephone number, our experience has been that the missions and programs of the Social Security Administration (SSA) and HCFA are too diverse to benefit from a shared support arrangement, such as a common call center. Indeed, SSA's independence from the Department of Health and Human Services on March 31, 1995 evidences this diversity. Experience has indicated that the technical complexity of both agencies' programs, when combined, is well beyond the commonly accepted expectations and capacity of an average customer or teleservice center representative. Further, a separate and distinct systems infrastructure would have to be built at the SSA teleservice center to support the Medicare workload, offsetting any of the benefits gained from collocation.

In that our existing toll-free lines are currently operated by our contracted agents and partners, we had envisioned continuing to contract for our telephone customer service activities. If we were to expand the SSA teleservice centers, we would be forced to request between 1,500 to 2,000 additional FTE's to handle the more than 17 million calls our agents currently receive annually, as well one-time funding to pay the contract termination and severance costs incurred by our current contractors.

ATTENDANT CARE DEMONSTRATION PROJECT

Question. Madame Secretary, the Conference Report on the fiscal year 1998 appropriations bill earmarked $2 million for Medicaid attended care demonstrations. I see no mention of this matter in your fiscal year 1999 budget justification material. What is the status of conducting attendant care demonstration projects for persons with disabilities as an alternative to institutional care?

Answer. During testimony on the MiCASA bill on March 12, we announced that we will soon be asking States to submit proposals to develop research designs for projects that would identify individuals who could successfully move out of nursing homes into the community and provide the services needed to support these individuals in the community. This solicitation is in response to the commitment made by President Clinton on this issue and to the report language accompanying the fiscal year 1998 Labor-HHS-Education appropriations bill. We believe that we will be able to fund research in 3 to 5 States. If further funding for discretionary activities is needed in fiscal year 1999, we would expect to look to our general research request in the fiscal year 1999 President's Budget as a source for these funds.

CHILDREN'S HEALTH INSURANCE

Question. The State Children's Health Insurance Program (S-CHIP) was established in the Balanced Budget Act of 1997 as a State-federal partnership with $4.295 billion in federal funds authorized in fiscal year 1998 to provide health insurance for children not covered by Medicaid, but whose families cannot afford private insurance.

A number of uninsured children now receive health care through community health centers, community mental health centers, or through the Maternal and Child Block Grant. The fiscal 1999 budget requests $841 million for community health centers (one-third of health centers revenue) and $683 million for the Maternal and Child Health Block grant. What impacts will S-CHIP have on funding and target populations served by these programs?

Answer. The State Children's Health Insurance program (S-CHIP) represents a tremendous advance in serving the health care needs of underserved children. In 1996, 43 percent of the roughly 10 million patients seen by Health Centers and the National Health Service Corp (NHSC) providers were children, of whom, moreover, approximately 30 percent—or 1.3 million—were uninsured. We estimate that fiscal year 1999 sources of funding for Health Centers will include $29 million through S-CHIP. This is still a very rough estimate, however; the extent and nature of S-CHIP's impact on Health Centers will depend in large part upon decisions taken

by the individual States and the Health Centers themselves. Most States have not yet submitted—or even finalized—their S-CHIP plans. Ongoing and intensified outreach and educational efforts, in particular, will be necessary to assure that all the children who are eligible under S-CHIP are enrolled. More than 3 million of the over 10 million uninsured children prior to S-CHIP's passage were eligible for, but not enrolled in Medicaid. This was, and remains, largely due to enrollment barriers or lack of awareness.

S-CHIP will impact the health insurance coverage of low-income children in the U.S. but is not likely to have a substantial impact on the mission of the Title V program, the Maternal and Child Health (MCH) Block grant. The MCH Block Grant is at its core a public health program that reaches across economic lines to improve the health of allwomen and children. Within broad State discretion, State Title V programs use appropriated, formula grant funds for resource development, capacity and systems building, and population-based functions such as public information and education, knowledge development, outreach and program linkage, technical assistance to communities and agencies, provider training, evaluation, implementation of model programs, support for newborn screening, lead poisoning and injury prevention, and promotion of health and safety in child care settings. Special efforts are made to build community capacity to deliver such enabling services as care coordination, transportation, home visiting, and nutrition counseling and where no services are available, States also use Title V funds to subsidize or provide direct care.

The S-CHIP program, as well as the Medicaid program, is a health insurance program that pays for a defined set of benefits for low-income women and children who are in families meeting specific eligibility requirements. These programs, being payers rather than providers of services, rely on the public and private sectors to organize and provide the services for which they reimburse. Historically, State Medicaid programs have relied on State MCH programs for assistance in enrolling eligible women and children, developing policies, procedures and practice standards that help providers and other agencies work more effectively with Medicaid, and organizing and providing services not available or accessible in the private sector.

The OBRA–89 amendments to Title V made clear that Congress did not intend to use these public health dollars to pay for direct services already covered by Medicaid or private insurers. Similarly, the S-CHIP funds available for Title V-type activities is strictly limited by a Congressionally imposed cap. States can only use 10 percent of the benefits spending under their S-CHIP for outreach, public health initiatives, administrative costs, and direct services. States have objected that this Cap is already too restrictive. Therefore, we believe that the Title V funds will continue to play an important role in protecting the health of the American public. However, S-CHIP may relieve some of the financial drain on Title V by insuring a group of previously uninsured children thereby allowing the funds to be refocused on needed public health capacity and resource building activities.

Question. How will funding and services be coordinated between S-CHIP and these alternative sources of health care for uninsured children?

Answer. Both the Title V Maternal and Child Health Block Grant and Community Health Centers (CHC) coordinate health and related services for children in Medicaid and WIC and provide outreach to enroll children in these programs. In addition, the MCH Block Grant also coordinates these and other related services for children with special health care needs. Both programs, working closely with Medicaid and the private sector, are already studying ways to expand and, in some cases, have already begun to expand of their outreach and coordination functions. HRSA has been coordinating with the regional, State, and local Title V and CHC programs, Primary Care Associations, as well as Federal and regional HCFA offices since the inception of the S-CHIP plans in order to assure coordination between programs to increase the interaction of these programs at all levels around S-CHIP. HRSA staff have also brought into these meetings contacts in disability, welfare, education, and WIC programs to further enhance cooperation at all levels. State MCH Directors have been meeting with their State Medicaid offices and the people responsible for developing the State CHIP applications to assure coordination of funds and services.

Question. Will S-CHIP displace the need for some portions of these programs?

Answer. S-CHIP is going to make a significant difference in the health coverage status of low-income children, but it will not displace a substantial portion of the services provided through the Title V, MCH Services Block Grant Program as well as Community Health Centers. The S-CHIP program enables States to fund services for uninsured children who are also low-income. The two groups of children left unserved by the S-CHIP program and still, therefore, requiring services supported through HRSA programs are (1) the partially or poorly insured who may have no usual sources of care and who seek publicly funded care on a regular basis; and (2)

those children with special health needs whose insurance is nonexistent or inadequately covers those special needs necessary for them to function and learn successfully.

While S-CHIP is a major advance, building capacity to provide medical and enabling services in underserved, low income communities is necessary to make the new insurance coverage a reality. Health Centers currently reach only one-fourth of the 43 million Americans who are identified as medically underserved. The number of Health Center patients seen increased from 5 million in 1980 to over 9.5 million in 1995. More than half of the 2,091 U.S. counties identified in 1996 as having primary care access problems, moreover, remain unserved by a Health Center or an equivalent provider. In addition, in most States, a minority of Title V dollars are spent on services that can be financed under Title XXI. Both Federal and State Title V funds are already being used to leverage other funds and coordinate and administer State activities that further develop a seamless, comprehensive, system of care for children through initiatives which include technical assistance, resource support, and performance measurement, without which State CHIP plans will not be able to achieve their goals. The challenge of providing adequate primary health care to the underserved is greater than ever.

Question. Are states being encouraged to include community health centers and community mental health centers as potential delivery sites in the health networks they establish for S-CHIP enrollees?

Answer. While States are not required to included Community Health Centers and Community Mental Health Centers as potential delivery sites, HRSA in response to this historic opportunity, has charged every State and Regional Primary Care Association—non-profit membership organizations that Health Centers—with the responsibility of working with their members to ensure that: HRSA-supported programs in their States are effective participants in the design, development, implementation and operation of S-CHIP; HRSA-supported programs provide high-quality, cost-effective care to low-income and uninsured children; and, HRSA-supported programs serve significant numbers of children covered by S-CHIP.

To assist Primary Care Associations (PCA's) in attaining these objectives, HRSA has implemented two primary initiatives. The first is the Five-State PCA S-CHIP Initiative. HRSA will work with PCA's in the five States receiving the largest S-CHIP allotments to assess S-CHIP opportunities, to collect and disseminate information and data about HRSA-supported programs and their services to children, and to document the impact of the S-CHIP design/implementation on HRSA-supported programs. Effective strategies for ensuring HRSA-supported program participation in S-CHIP will be identified, shared, and, as appropriate, replicated in other States. One of the designated PCA's, in Texas, was recently selected to coordinate all S-CHIP outreach efforts in the State. In fiscal year 1998, HRSA has also implemented a $1 million pilot program to expand the capacity to establish out-stationed Medicaid and S-CHIP eligibility workers in Health Centers.

SUBCOMMITTEE RECESS

Senator SPECTER. Thank you. The subcommittee will stand in recess to reconvene at 2 p.m., Wednesday, March 18 in room SD–138. At that time we will hear testimony from Hon. Alexis Herman, Secretary of Labor on the 1999 budget request.

[Whereupon, at 3:30 p.m., Tuesday, March 10, the subcommittee was recessed, to reconvene at 2 p.m., Wednesday, March 18.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1999

WEDNESDAY, MARCH 18, 1998

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 2:08 p.m., in room SD–138, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.

Present: Senators Specter, Faircloth, Bumpers, and Kohl.

DEPARTMENT OF LABOR

OFFICE OF THE SECRETARY

STATEMENT OF HON. ALEXIS HERMAN, SECRETARY OF LABOR

OPENING REMARKS OF SENATOR SPECTER

Senator SPECTER. Good afternoon, ladies and gentlemen. We will commence the hearing of the Appropriations Subcommittee on Labor, Health and Human Services, and Education. Today we have the opportunity to hear from the distinguished Secretary of Labor, the Honorable Alexis Herman, on the fiscal year 1999 appropriations requests.

The Labor Department's budget totals $11.1 billion for discretionary programs. This is a net increase of $425 million or 4 percent above fiscal year 1998. In addition, the Labor Department has responsibility for administering a $3 billion multiyear Welfare-to-Work Program, with funding provided under the historic balanced budget legislation enacted last year.

PREPARED STATEMENT

Madam Secretary, we have a chart which we have shown to Secretary Shalala and others, Secretary Riley, showing a $1.9 billion gap in funding which is supposed to be accommodated by tobacco funds, which so far are tobacco in the sky, pie in the sky, we do not know where they are coming from, and unauthorized user fees. So that is a matter of real concern.

Without objection, my full statement will be made a part of the record.

[The statement follows:]

PREPARED STATEMENT OF SENATOR ARLEN SPECTER

This afternoon, the Subcommittee on Labor, Health and Human Services and Education will hear testimony from Secretary of Labor Alexis Herman on the fiscal year 1999 appropriations requests.

The Labor Department's budget totals $11.1 billion for discretionary programs. This is a net increase of $425 million or 4 percent above fiscal year 1998. In addition, the Labor Department has responsibility for administering a $3 billion multi-year Welfare-to-Work program, with funding provided under the historic Balanced Budget Act legislation, enacted by Congress last year. I have asked the Secretary to pay particular attention to the challenges imposed by this major new effort, which I intend to closely monitor. In the coming months, Madame Secretary, it is my hope that we can work together, with the Department of Health and Human Services and other agencies with responsibilities for certain welfare reform activities, to make sure this program is a resounding success.

You can see from the chart to my right the difficulty facing this Subcommittee by the President's assumption that savings will be realized through enactment of user fees or new taxes.

In fiscal year 1997, discretionary spending for this subcommittee totaled $74.4 billion.

In fiscal year 1998, discretionary spending increased to a total of $80.4 billion.

For fiscal year 1999, the President has requested $84.5 billion, but $1.9 billion of this amount would be financed by new user fees and assumed receipts from tobacco legislation.

Madame Secretary, the Administration's budget request has put us in a real spot, basically $1.9 billion in the hole, and I fully expect that you will work closely with this Committee as we try to resolve this dilemma.

Madame Secretary, due to scheduling conflicts, we didn't have the opportunity to have you appear before the Subcommittee last year, although I must say we had occasion to meet in Pennsylvania on vital issues, including a conference on women in nontraditional occupations, and the announcement of job training support for the re-opening of the Philadelphia ship yard. I know we can continue to count on your cooperation and you can count on ours, in the year ahead.

Madam Secretary we will be pleased to hear your opening remarks at this time.

SUMMARY STATEMENT OF HON. ALEXIS HERMAN

Senator SPECTER. We are pleased to welcome you here, Secretary Herman. You are the 23d Secretary of Labor. As President Clinton characterized you, quote, she understands the needs of workers and understands the challenges they face as we approach the 21st century. Welcome, and the floor is yours.

Secretary HERMAN. Thank you very, very much, Mr. Chairman. I would like to ask that my full statement be submitted for the record. If you would permit me to make a few brief opening comments before responding to questions.

Senator SPECTER. That is entirely acceptable. Without objection your entire statement will be made a part of the record, and we look forward to your highlighting it.

Secretary HERMAN. Thank you very much. I am very pleased to be here today to discuss the work of the Labor Department and our fiscal year 1999 budget request.

This is certainly an exciting and historic period for all of us who care about improving the lives of America's working families. Working together with Congress, we have made enormous strides. We have the healthiest economy in a generation. The misery rate—the combination of the unemployment rate and the inflation rate is at a 31-year low. And just this month the Labor Department reported that our economy has created over 15 million new jobs in the last 5 years. We are entering the 21st century truly with opportunity on our side.

But where there is opportunity, there also is challenge. I believe our challenge is to help every American not only secure the economic future that they so deserve, but to help them also to manage change for the better, to help transform change from an obstacle to an opportunity, from something to avoid to something to embrace. I see my job today as Labor Secretary as making sure that the Labor Department is an effective, efficient partner in helping Americans manage change that is inherent in today's global economy. As we do that, I want to make sure that our initiatives are results oriented and bottom line.

The Department of Labor has made a lot of progress since our team came into office 10 months ago. We played a role in bringing together labor and management to settle the UPS strike. We attacked fraud and abuse in pension and health care plans, and recovered more than $360 million for hard working Americans.

We are proud to report the fatality rate for coal mining injuries for 1997 was the lowest ever recorded. Similarly, the injury and illness rate in general industry for 1996, the latest year for which data is available, was the lowest since the Bureau of Labor Statistics began collecting the information 23 years ago.

Because we know that a paycheck is, in fact, the passport to dignity, we have worked diligently to make sure that the welfare recipients that we are working with today are integrated into the work force development system. As a result, we now have $3 billion in grants to distribute to help long-term welfare recipients secure lasting unsubsidized employment.

Let me pause here briefly to say that our work force development reform is about fundamentally changing how we look at the future in a way that is good for workers and good for business. We are very hopeful that Senate bill 1186, the Workforce Investment Partnership Act, will be considered this week and that it will move quickly to conference. Our hope is to see a bill enacted before July 1, 1998. Let me say that I am pleased with the bipartisan support that this bill has received within Congress. As you know, the President has made public statements in support of this bill. I hope that you will agree with us, Mr. Chairman, that now is the time for action.

DOL STRATEGIC GOALS

But now, in working to establish a unified Department of Labor, I have established three strategic goals which bridge the Department's many agencies and programs that serve the common purpose of helping America's workers meet the challenges they face today and in the future.

The first goal is a prepared work force that enhances opportunities for America's workers. With the strategic goal of a prepared work force, the Department is committed to creating an environment where those new to the labor market or those wishing to improve their potential are provided the assistance and tools needed to achieve success in today's market, and where policy and decisionmakers and those seeking employment have access to information for making sound economic decisions.

Our second strategic goal is a secure work force. We seek to promote the economic security of workers and families by protecting

workers' hours, wages, and other conditions when on the job, providing unemployment and compensation benefits when workers are unable to work, retraining and adjustment services for workers who are permanently laid off from their jobs to help them return to work, and expanding, enhancing, and protecting workers' pension, health care, and other benefits.

Our third and final strategic goal is quality work places that are safe, healthy, and fair, meaning free of discrimination. Since today's workplace is increasingly affected by global markets, we will increase our commitment to addressing core international labor standards and also child labor issues.

Our fiscal year 1999 budget request of $11.1 billion and 17,012 full-time equivalent staff is only 4 percent above the fiscal year 1998 level. This modest increase in our budget will allow us to build on what we are already doing to achieve my strategic goals that cut across the Department's agencies to serve the common purpose of helping American workers achieve economic security and manage change for the better.

PREPARED STATEMENT

Mr. Chairman, I will be happy to discuss today the welfare-to-work issue that you raised in your letter, as well as any other questions from you or members of this committee. I thank you for the opportunity to appear before you today.

[The statement follows:]

PREPARED STATEMENT OF ALEXIS M. HERMAN

Mr. Chairman and distinguished members of the subcommittee: I am pleased to be here today to discuss the work of the Labor Department and our 1999 fiscal year budget request.

Managing Change in the 21st Century

We have made great progress in helping America's working families build a better future for themselves. The President's budget is a truly historic document. It gives the American people the first balanced budget in 30 years. Because of tough choices and fiscal discipline, our deficit has gone from over $350 billion 5 years ago, to about $10 billion today, and with this plan it will be zero in the next fiscal year.

And these are also historic times. Thanks to the hard work of the American people, we have the healthiest economy in a generation. The misery index—the combination of the unemployment rate and the inflation rate—is at a 31 year-low. And just this month, the Labor Department reported that our economy has created over 15 million new jobs in the last five years. We are entering the 21st century with opportunity on our side.

But where there is opportunity, there is also challenge. The workplace and the workforce are changing before our eyes. In the 1950's, the workforce was 20 percent professional, 60 percent unskilled and 20 percent skilled. By 1996 it was 20 percent professional, 60 percent skilled and 20 percent unskilled. Education and training matter as never before.

The workforce of the future is changing in other ways. It will be older and more diverse. Our workplace is also changing. We are utilizing more technology, and more of us are using that technology. The proportion of workers using computers has more than doubled in the past ten years alone. And every day we are becoming more globally integrated—in the next 10 years up to half of all manufacturing jobs will be export-related.

Our task is to help prepare every American worker for this changing world. And our challenge is to help every American manage change for the better. I know confronting change is never easy. I've faced a lot of change in my life. I've had many different jobs. I've lived in a number of cities. I've had a lot of obstacles thrown my way. But I also had something else—a solid foundation from which to draw strength—my faith, family, values.

Just as that kind of support structure is integral to managing change in our own lives, it is also critical in our national life. Because it's that kind of support structure that transforms change from an obstacle to avoid to an opportunity to embrace.

I see my job as making sure the Department of Labor is an effective, efficient partner in helping Americans manage the change that is inherent in today's global economy. And as we do that, I want to make sure our initiatives are bottom-line and results-oriented.

The Department of Labor has made a lot of progress since our team started 8 months ago. We helped play a role in bringing labor and management together to settle the UPS Strike.

We attacked fraud and abuse in pension and health plans and recovered over $360 million for hard working Americans.

We were proud to report that the fatality rate for coal mining injuries for 1997 was the lowest ever recorded. Similarly, the injury and illness rate in general industry for 1996, the latest year in which data are available, were the lowest since the Bureau of Labor Statistics started collecting that information 23 years ago.

And because we know a paycheck is the passport to dignity, we have worked diligently to make sure that welfare recipients are integrated into the workforce development system. As a result, we now have $3 billion in grants to help long-term welfare recipients secure lasting, unsubsidized employment.

We want to build on our record and our progress in helping American workers manage change for the better. And that's why the President is now proposing this year to do things such as raise the minimum wage, expand the Family and Medical Leave Act, and work closely with Congress to pass legislation to enact his GI Bill for America's Workers that will reform the entire job training system so anyone looking for work will be able to get the service and assistance they need to find and keep good jobs.

This is all a part of fulfilling the Department of Labor's fundamental mission—to assist workers in their efforts to achieve economic security, with rising wages, pensions, health benefits and opportunities—and to improve their skills in safe and healthful workplaces free of discrimination.

In order to succeed in this mission, the Department has developed an effective strategy for improving the lives of America's working families. It has been developed within the context of the Government Performance and Results Act (GPRA) and is reflected in the Department's fiscal year 1999 Annual Performance Plan which is tied directly to our budget request. This Performance Plan reflects a substantial revision and improvement on the Department's September Strategic Plan which was largely developed prior to my arrival. In working to promote a more unified Department of Labor, I have established three strategic goals which bridge the Department's many agencies and programs that serve the common purpose of helping America's workers meet the challenges they face today and in the future. Those three strategic goals are: A Prepared Workforce—to enhance opportunities for America's workforce; A Secure Workforce—to promote the economic security of workers and families; and, Quality Workplaces—to foster quality workplaces that are safe, healthy and fair.

With the strategic goal of a Prepared Workforce, the Department is committed to creating an environment where those new to the labor force, or those wishing to improve their potential, are provided the assistance and tools needed to achieve success in today's job market. And where policy and decision-makers, and those seeking employment, have access to information for making sound economic decisions.

With the strategic goal of a Secure Workforce, we seek to promote the economic security of workers and families by protecting workers' hours, wages and other conditions when on the job, providing unemployment and compensation benefits when workers are unable to work, retraining and adjustment services for workers who are permanently laid off from their jobs to help them return to work as quickly as possible, and expanding, enhancing, and protecting workers' pension, health care, and other benefits.

With the strategic goal of Quality Workplaces, we will direct attention toward fostering workplaces that are safe, healthy, and fair. Today's workplace is increasingly affected by global markets so we will continue to address core international labor standards and child labor issues as they affect American workers. The Department is committed to working with employers to help them maintain safe and healthy workplaces. However, we will maintain a credible, targeted enforcement program to catch and punish the bad actors.

This vision cannot be accomplished overnight. To accomplish these goals, we must make critical investments over a period of years that will promote programs to support the President's goals and accomplish this vision. Investments that begin with this fiscal year 1999 budget will move the Department toward accomplishing these

goals for American workers, retirees and their families. Investments will continue over many years, but this budget request takes the first step on that journey.

Our fiscal year 1999 budget—which amounts to $38.1 billion—will allow us to build on what we are already doing and begin new initiatives to meet these goals. The amount before the committee includes $12.7 billion and 17,012 full-time equivalent (FTE) staff. Each of the initiatives in our budget was developed to achieve my strategic goals that cross-cut the Department's agencies, programs and activities to serve the common purpose of helping American workers manage change for the better.

I would like to discuss my initiatives arrayed by the goal they support.

A PREPARED WORKFORCE—ENHANCE OPPORTUNITIES FOR AMERICA'S WORKFORCE

The fiscal year 1999 request includes a continuation of a $250 million advance appropriation for the Opportunity Areas for Out-of-School Youth program for Program Year 2000. With your leadership, Mr. Chairman, this Sub-Committee provided in the fiscal year 1998 appropriation, a $250 million advance appropriation for the program for use in fiscal year 1999, contingent upon enactment of authorizing legislation. The Administration is working closely with Congress to enact job training legislation containing this authorization in early 1998. These resources will be used to provide competitive, matching grants to 15 to 20 high poverty urban and rural communities including Empowerment Zones and Enterprise Communities, to train an estimated 50,000 youth for jobs, as an alternative to welfare and crime.

This is a high priority for me and a challenge that I have devoted a good part of my life to addressing. Almost thirty years ago, I worked for Catholic Charities in my hometown of Mobile, Alabama. I helped young men from the housing projects find apprenticeships and job opportunities in the shipyards near Pascagoula, Mississippi.

There is one statistic that really sticks in my mind from twenty years ago when I was working at the Department of Labor. At that time, the unemployment rate for African-American teenagers was over 30 percent. Two decades later, I am back at the Labor Department, and the unemployment rate for African-American teens is at 30 percent. This Department is about the work of moving a fact like this from the statistics books to the history books.

What is the out-of-school youth initiative all about? Let me tell you about Hector Hernandez.

Hector is from Bellflower, California, one of the barrios of Los Angeles. He grew up in one of the toughest neighborhoods in the country. His mom was a high school drop-out and survived on welfare. His dad—who he hardly ever saw—sold drugs.

To Hector, school never really seemed important. And so he dropped out and joined a gang. One thing led to another, he committed a crime, got arrested, and served three years before he was paroled. As a condition of his parole, Hector was required to attend the Community Youth Corps program in Norwalk, California. This is a Job Training and Partnership Act (JTPA) initiative that provides education, training and job placement services to out-of-school youth.

In January of 1997, he began courses for a GED. Hector worked hard—and earned his GED last May. Today he works full-time as a security guard at a local Nissan plant—and part-time at UPS. Last month, he enrolled in Cerritos Community College and hopes one day soon to work with youth in the California prison system.

This story is one of many that demonstrates the kind of success we are having by investing in opportunity for our young people. The resources that the President's fiscal year 1999 budget contains for youth funding will allow us to build on that kind of success, reduce unemployment levels for the youth of our country, and make a real difference in the lives of young people and the life of our nation.

The Summer Jobs Program gives hundreds of thousands of urban and rural disadvantaged youth their first work experience. The budget proposes $871 million which is sufficient to finance as many as 530,000 job opportunities for the summer of 1999 if local areas use all of these resources for summer jobs. The budget also includes $130 million for the year-round program to help low-income youth, many of them in families on public assistance, who have dropped out of school or are at risk of doing so. The proposed budget would continue to permit local service delivery areas that receive both types of these funds to shift resources between the summer and year-round program, as local needs dictate.

Another of our important programs for youth is the Job Corps, which will provide intensive skill training, academic and social education, and support to an estimated 69,700 seriously disadvantaged participants at 118 centers in fiscal year 1999. An increase of $61.4 million for fiscal year 1999, brings the total for the program to

$1.3 billion. This increase includes funds to complete five new centers and to maintain the current program. Funds are also requested to continue the multi-year quality improvement initiatives to enhance Job Corps performance.

The Welfare-to-Work Jobs initiative is already funded at $1.5 billion in mandatory funding in each of fiscal year 1998 and fiscal year 1999. This initiative was enacted with bipartisan support in the Balanced Budget Act of 1997. The program provides formula grants to States; and Federally-administered competitive grants to Private Industry Councils, political subdivisions of States, and private entities to assist hard-to-employ welfare recipients to secure lasting, unsubsidized employment. Its success, however, depends on the formation of partnerships to allow leveraging of additional resources at the local level.

I completed a national fact-finding welfare-to-work tour to put a human face on the framework we have developed to move people from welfare to work and have reported my findings to the President.

There are a number of innovative programs out in the field that are making a real difference. Let me tell you about them.

The Community Occupational Readiness and Placement Program (CORPP) Inc. serves people young and old, and even homeless, to help them realize their strengths and interests. CORPP provides a variety of programs to enable Philadelphia's urban poor gain employment. Over 90 percent of all program graduates have gained employment and the retention rate is above 95 percent. Employed graduates are working an average of 33 hours per week with an hourly wage between $6–$8 per hour. CORPP gives participants the tools to take their first steps into the world of work.

After having her first child at the age of 14, Sheree Smith enrolled in CORPP and was successfully placed in a job working as a receptionist for a State Senator earning $16,500 per year. She stayed for two years but continued to use the skills she learned at CORPP and to grow in her job. Last June, she went to work for a non-profit organization where she is the office manager for 16 employees and earns over $28,000 per year. I am pleased to report that Sheree is doing her part to contribute to the economy—she recently purchased a home.

There are so many good programs, like those in South Carolina, Texas, Washington, Wisconsin, Iowa and Arkansas that have similar and innovative approaches to assisting people in moving from welfare-to-work.

The Bridges to Work program in Baltimore, Maryland provides a transportation link between welfare recipients living in job-poor inner cities and suburban employers. But the program provides a lot more for their clients. Bridges, whose clients must be job-ready welfare recipients, helps their clients find jobs, counsels them once they are placed, and provides assistance with child care and other needed services. They help them manage the vital logistics of their lives.

Transportation is a key link. Over the last decade, Baltimore has lost over 50,000 jobs to the suburbs, while the nearby suburban counties have added at least 70,000 jobs. The story is the same in Chicago, St. Louis, Milwaukee and Denver—other sites where Bridges runs this innovative federal demonstration project. The job creation boom is not taking place in the inner cities, it is taking place in the suburban corridors, while there is still chronically high unemployment in the inner cities. Recent figures from the Department of Housing and Urban Development reveal that 97 percent of new businesses in the U.S. were created in the suburbs between 1990 and 1993. Most inner cities across the country, like Philadelphia, are recognizing the need for transportation alternatives that offer reverse commutes so that those people who want to work and in many cases have worked hard to get the skills to get into the job market, have the access to take those jobs.

Promise Jobs in Iowa represents the coordination necessary among agencies to successfully move people from welfare to work. This program is jointly operated by local offices of the Iowa Workforce Development and JTPA grantees. It operates in each of the State's sixteen Service Delivery Areas and funds are provided through contractual agreements with the State Department of Human Services. The Dubuque-Delaware Consortium regularly uses multiple programs to support the self-sufficiency plans of its participants. As they did in the case of Susan, a 30-year old single mother of 4 children, ranging in age from 1–7 years old, with limited work history. The Consortium put together tuition, education, child care, transportation and job placement services, and Susan reached her goal of becoming a registered nurse. She is now making $12.50 an hour and is completely self-sufficient and off the welfare rolls.

It is the dignity of work, as we move people from the welfare rolls to the payrolls, and the efforts of innovative programs and companies across the country, that will help to make the Welfare-to-Work initiative a success.

Related to our Welfare-to-Work program, the budget proposes to extend, for one year through April 30, 2000, the Welfare-to-Work Tax Credit, which the President and Congress created as part of the Taxpayer Relief Act of 1997. It focuses on long-term welfare recipients by allowing employers to claim a tax credit of 35 percent on the first $10,000 of eligible wages in the first year of employment and 50 percent of the first $10,000 in the second year of employment for workers they hire who were long-term welfare recipients. The budget also includes an extension of the Work Opportunity Tax Credit through April 30, 2000, which provides a credit of 40 percent on the first $6,000 of wages paid to members of eight target groups.

Adult Training Grants provide formula grants to communities under authority of Job Training Partnership Act (JTPA) Title II–A for employment and training assistance to economically disadvantaged adults. This program also aids in our welfare-to-work efforts since two of every five participants is a welfare recipient. An increase of $45 million, or nearly 5 percent above the fiscal year 1998 level, is proposed for fiscal year 1999 bringing the program's funding up to $1 billion to support an estimated 401,100 participants.

Legislation will be proposed in conjunction with the President's Budget that would authorize the Department of Veterans Affairs to transfer to the Department of Labor $100 million for the JTPA Veterans Employment program to reimburse activities designed to train, retrain, and provide employment assistance for unemployed and dislocated veterans. The program will provide outreach, assessment, counseling, on-the-job or classroom training, placement assistance and supportive services to help these veterans rejoin the American workforce.

The Learning Anytime, Anywhere initiative is a joint Department of Education and Department of Labor program to emphasize the use of new technologies to enhance post-secondary learning by increasing access to and improving the quality of education and training delivery. The Department's $10 million request for fiscal year 1999 will allow the Department to explore removing some barriers faced by learning in non-traditional settings, such as uncertainty as to quality, the value of certificates or degrees, and the limited availability of some training. The Department will provide an Internet-based system (America's Learning Exchange) linking providers of and customers for training and education and including: a library of courseware, a database of education/training opportunities, and a directory of learning opportunities.

A net increase of $18.3 million is proposed to support and improve economic indicators. New this year is a proposal for $3.3 million to start the National Job Opening and Labor Turnover Survey. Currently there is no economic indicator of the demand for labor with which to estimate labor shortages in the U.S. labor market. Information on labor shortages can only be inferred indirectly using labor supply information, such as the unemployment rate. Developing a demand-side indicator of labor shortages at the National level would greatly enhance policy makers' understanding of imbalances between the demand and supply of labor.

As part of this increase, the Department also proposes an additional $9.1 million for the second year of the multi-year Consumer Price Index Improvement initiative. Last year this Subcommittee supported the launching of this effort, for which I am grateful. This initiative allows the Department to continue undertaking a series of steps to improve the CPI's timeliness and accuracy by strengthening the statistical and methodological infrastructures supporting the current CPI program.

The Department proposes $1 million to continue the work of a Presidential Commission on Workers and Economic Change in the New Economy. This initiative is an important component of a comprehensive set of initiatives announced by the President last Fall to help ensure that all Americans share the benefits of free and open trade. As the new economic forces change the standards for economic competition, they also affect organizational structures, skill requirements, and jobs. As part of the Administration's effort to help workers and those not in the job market to take advantage of the opportunities of expanded trade, this Commission will explore a variety of strategies for upgrading the skills of existing and future workers.

The Department is requesting $2.4 million to establish a National Task Force on the Employment of Adults with Disabilities. According to the Census Bureau 74 percent of persons with severe disabilities 21 to 64 years of age were not employed as of the last year surveyed (1994). The Task Force would be charged with the development of a national policy to bring adults with disabilities into gainful employment at a rate that is as close as possible to that of the general population. The Task Force will study the barriers to employment faced by disabled individuals and report its findings and policy recommendations to the President on a periodic basis over its four-year life.

In the area of worker retraining, our budget includes an increase of $100 million, or 7 percent above last year's level, for a total of $1.45 billion to support an estimated 685,800 participants in the Dislocated Worker Assistance Program.

With the support of this Committee, the funding for this program has doubled since the President took office. The President is committed to tripling it over the next five years. This is a high priority because we know a fundamental element of a secure workforce—and helping workers manage change—is providing access to training and assistance to those workers when they need it. We want to build on the success we've had with our rapid response teams to move this goal forward.

Back in August, the Fruit-of-the-Loom company announced that about 4,800 workers in plants in Louisiana, Texas, and Kentucky would face layoffs in 60 days. Our Dislocated Worker Unit Rapid Response teams immediately contacted the plants in their States—and within 48 hours made arrangements for on-site strategy meetings—in partnership with state and local economic development, workforce development, and elected officials—to begin the full range of rapid response assistance.

The layoffs were announced on August 7, by August 11 meetings were held in Louisiana with all the various players—and the next day our dislocated worker staff was meeting with the workers.

Layoffs are always painful. But the rapid response team mobilized quickly, got in place, and helped workers look ahead and plan for their future. They set up worker assistance workshops that covered everything from résumé writing to interviewing skills. They set up job fairs, training (including community college courses), direct placement, and related skills and remedial assistance.

This year's budget increase will not only allow the Department to continue to provide this type of rapid response but it will also increase the number of people to be served (40,000 or more) and allow us to provide training and income support for laid-off workers in secondary industries doing business with primary firms affected by trade.

As the President said in his State of the Union address, we should provide the same response when a factory closes as we do when a military base closes. This Department is at the forefront of making that happen. And I am absolutely committed to increasing job placement and wage replacement for workers who permanently lose their jobs in a plant closing or mass layoff.

In the North American Free Trade (NAFTA) and Trade Adjustment Assistance (TAA) programs, legislation will be proposed to extend the programs for 5 years; expand eligibility for TAA to those who lose their jobs due to a shift in production abroad, similar to shifts in production to Mexico and Canada covered under NAFTA–TAA; increase the training cap; make the requirements linking training and income support more consistent across both programs; and finally, create a contingency funding provision to assure that resources are available to pay for any unexpected increase in benefit costs to eligible workers. The fiscal year 1999 request, including the legislative proposal, is a $108 million increase over the fiscal year 1998 appropriation.

The Unemployment Insurance (UI) System also needs to be reformed in order to meet the challenges of a new economy. The President's Budget anticipates legislation for a UI Safety Net to assure the availability of benefits for more of America's workers in the event of a recession, to make the program more accessible to low-wage unemployed workers, to improve the solvency of the State Trust Funds, and to improve State administrative operations.

In addition to this legislative proposal, the fiscal year 1999 budget includes a request for $91 million to strengthen the integrity of the Unemployment Insurance System, as authorized in the Balanced Budget Act of 1997. Tight budgets for unemployment insurance administration over the past several years have caused State agencies to cut back their investments in program integrity activities which affect benefit payment accuracy, detection of overpayments, collection of overpayments, and collection of under-reported taxes. Funding this proposal will reduce unemployment insurance errors and overpayments, improve State tax collections, and result in anticipated savings of well over $100 million to the Unemployment Trust Fund in 1999 alone.

The fiscal year 1999 Unemployment Insurance budget also proposes $8 million for the one time cost of transition to the North American Industrial Classification System. This will allow the exchange of data among North American countries as well as provide for increased precision in identifying industries as a result of utilizing six rather than four digit codes. Similar investments were made in BLS for this project in fiscal year 1997 and fiscal year 1998.

Another important part of promoting economic security for workers is to provide pensions. I can't overemphasize the importance of retirement security. Today Americans are living longer and are more concerned about saving enough money to maintain their standard of living throughout retirement. One of the basic problems is information and education.

Many workers do not have access to basic retirement and savings information that can help improve their understanding of steps they can take for long-term financial security. We want to change that. That's why, working with the public-private American Savings Education Council, we have launched a Retirement Savings Education Campaign to inform Americans about the importance of saving for retirement and to encourage employers to establish pension plans for their workers. We already have over 250 campaign partners representing federal agencies, trade and professional associations, labor unions, community groups, financial entities, and private sector employers.

I have held a series of roundtable discussions with owners of small business around the country to discuss barriers and the options available in offering retirement plans to workers. In Dallas, I met with women small business owners. There is no doubt that small business has a big role to play in improving the retirement security of workers. Our nation's small businesses employ 40 percent of the workforce—and 32 million workers in small businesses do not have an employer-sponsored pension plan.

I wanted to hear from these women about the obstacles they thought they faced to offering plans and to listen to some of the tips they picked up and lessons they have learned as small business owners. The goal of our education campaign is to change the way the American public thinks and acts about retirement needs. Americans need to reconsider how their personal finances are managed, begin saving early for retirement, save more and select retirement savings options that offer them the fullest advantage.

With the funding provided in the President's fiscal year 1999 Budget, the Department will develop new public service announcements for our targeted audiences, produce a video for small businesses to identify pension plan options and encourage them to establish a employer-sponsored plan and, of course, we will work in partnership with the President, members of Congress, and our private and public sector partners to conduct a National Summit on Retirement Savings this summer.

All of this will help expand pension coverage to many of the 50 million workers not covered by pension plans and enhance the security of pension plans already in existence. We must protect pensions and make them more portable.

The Administration will be proposing legislation to expand pension coverage to some of the more than 50 million American workers who are not earning these benefits on their job by making payroll deduction arrangements more widely available, offering a tax credit for small businesses to defray the costs of starting a new plan, creating a new and simpler defined benefit plan for small businesses and requiring that workers more rapidly be vested in their employer contributions to 401(k) accounts. These proposals will also enhance the security of pensions by requiring that better information be provided to workers about their benefits, improving the audit of plans, and extending the Federal government guarantee for certain types of plans.

The Department's fiscal year 1999 request includes an increase of $7 million for pension plan protection activities. This includes an increase of $4.5 million for the transition to the new Form 5500 ERISA Filing Acceptance system (EFAST). For the past 2 years, this Committee has supported the Department's efforts to develop this new system, which will soon be in operation. Securing pension benefits, in part, occurs when plan officials and service providers understand the requirements of the Employment Retirement Income Security Act (ERISA) and meet their responsibilities under the statute, including their responsibility to file annual reports with the Department. With these funds, the Department will also establish a "help desk" operation and develop a program for direct filing entities. The new system will improve the quality and accuracy of processed data and speed their use in safeguarding pensions. The investment in the new system will yield a projected net savings to the Federal government of approximately $57 million over the 5-year life cycle of the system.

The Department also proposes an increase of $1.6 million for the Pension Plan Service Provider Investigative Probe to be conducted by the Office of Inspector General. This initiative will enhance retirement security by identifying and investigating racketeers and criminal enterprises who manipulate the investment of pension fund assets for their own benefit.

The Department also has a role in private health benefit regulation. The fiscal year 1999 budget proposes $4.6 million to administer the Department's responsibil-

ities related to implementation of health care reforms in the new health care laws. The Health Insurance Portability and Accountability Act of 1996, the Newborns' and Mothers' Health Protection Act of 1996, and the Mental Health Parity Act of 1996 establish many new protections for employee health benefits. These laws added new provisions to the Employment Retirement Income Security Act (ERISA) and demand additional regulatory, interpretative, enforcement, and disclosure efforts. The Department is working in conjunction with the Departments of Health and Human Services and Treasury on the implementation of these new laws.

The President has proposed legislation to allow early retirees to buy into Medicare. The Administration is concerned about the plight of older workers who unexpectedly lose their health benefits when they lose their jobs or retirees whose benefits are eliminated. Too many Americans who have worked hard all their lives suddenly find themselves losing their health coverage just at the time when they need it most and can afford it least. The President's proposal would provide dislocated workers with an option to continue coverage under Medicare by buying into the program for as long as they need it, or until standard Medicare coverage becomes available. Retirees who lose their benefits will also be able to extend COBRA benefits in order to maintain access to the health care that is essential for them.

There are several new proposals, totaling $17.2 million, in the Department's Workers' Compensation Programs in fiscal year 1999 to be drawn from the benefit funds established for these programs. One proposal is for an expansion of $3.2 million in the Periodic Roll Management (PRM) program that supports the Federal Employees' Compensation Act (FECA) program. This proposal is designed to reduce the costs of the Federal government's workers' compensation program by re-evaluating long-term disability cases. Also, there is a proposed financing shift of $3.5 million from general revenues to the fair share collections in the Special Benefits account. Funding the PRM from these employer-supplied "Fair Share" funds in the Special Benefits account properly ties these staff investments directly to the account which will accrue the resulting savings. With the expansion of the PRM project, the total estimated savings in benefit payments by the Federal government from fiscal year 1992 through fiscal year 2002 will be approximately $672 million. The Office of Workers' Compensation Programs has also proposed an additional $3.3 million for the Black Lung program to facilitate Year 2000 conversion.

QUALITY WORKPLACES—FOSTER QUALITY WORKPLACES THAT ARE SAFE, HEALTHY, AND FAIR

The Administration proposes $37 million for a multi-faceted initiative to fight abusive child labor, both internationally and domestically. I would particularly like to recognize Senator Harkin's national leadership on this issue over the past 4 years.

As America takes its place in the global economy, international labor standards, particularly prohibitions on forced labor and exploitative child labor, benefit all economies. To provide additional support for the International Labor Organization's International Programme for the Elimination of Child Labor (IPEC), the Department requests $27 million, increasing the total amount available in grants to $30 million. This increase would ensure continuity, expansion and sustainability of existing IPEC programs. This increased funding would allow the ILO to include more countries in their technical assistance programs, and conduct more detailed analyses of issues of child labor and exploitative labor practices worldwide. These additional funds would expand the program in a way that is consistent with the lead role the United States plays in the fight against child labor exploitation worldwide.

We can't lead internationally unless we do all we can at home. Domestically, there has been considerable progress in reducing illegal child labor. However, problems persist—particularly in agriculture where working families face additional problems resulting from inadequate child care and illiteracy. An increase of $5 million in Job Training Partnership Act Pilots and Demonstrations is proposed to develop new models for work and learning opportunities, including mentoring, for young migrant farmworkers so that they may qualify for other job opportunities with career potential.

The Department also proposes $4.1 million to increase compliance in targeted industries, including garment manufacturing, agriculture, health care and other low-wage industries. While maintaining planned education and outreach among agricultural employers and a near term focus on "salad bowl" commodities, these additional resources will enable the Department to double its current level of effort and specifically target those crops and regions where the data and experience suggest the prevalence of child labor violations. Also included in this amount is an additional

$800,000 for expansion of the National Agricultural Workers survey to include significant data on child labor.

In another area of child labor enforcement, the Department proposes a $1 million increase for a review and update of child labor hazardous occupational orders, which pertain to child safety in the workplace. These hazardous orders, the last of which were issued in the early 1960's, will be updated to take into account new industries and technologies and address the needs and dangers of today's workplaces as they relate to young workers.

Worker safety and health is essential to a quality workplace. The budget proposes $355 million, an increase of $18 million, for workplace safety and health programs. An increase of $2.8 million is proposed to support workplace safety and health enforcement in fiscal year 1999. This initiative builds upon the Department's commitment to focus on inspections on worksites with the highest lost work day injury and illness rates, either through the Cooperative Compliance Program or an alternative mechanism. Proposed funding will support front-line compliance officer penetration and expand the level of compliance assistance offered to employers choosing to partner with the Department. The Department also will highlight the construction trade in an effort to focus on the leading causes of fatalities in that industry. An increase of $1.3 million is included to enable State partners to meet new challenges and complement Federal program strategies. The budget proposals also include $4 million to enhance training capabilities offered by the Department and to direct outreach materials towards specific industries, work processes and localized safety and health issues. These funds also will allow for augmentation of state consultation programs which provide free on-site consultations to employers upon request.

Continuing the work of the New OSHA which emphasizes a cooperative approach, balancing enforcement with compliance, is already making a big difference. You can talk with the owners and workers of EZ Paintr in Milwaukee, Wisconsin about that. Through its cooperation with OSHA in Wisconsin, EZ Paintr, a paint roller manufacturer, reduced its workplace injuries and illnesses by nearly 60 percent and cut its workers' compensation costs by more that 80 percent (from 1991 to 1994).

When OSHA inspected EZ Paintr in 1992, the company had a lost workday injury rate of 13.9; by 1996, it had dropped to 5.1. As the owners of EZ Paintr have noted, "working together with our employees to provide a safe workplace makes monetary sense." Throughout the process, the company also worked closely with the United Steelworkers Union. Continuing on this common sense, cooperative approach will truly help us achieve my goal of reducing accidents, injuries and illnesses in the workplace.

The budget also proposes $211 million, an increase of $8 million, for mine safety and health programs. To address concerns about the effectiveness of a major component of the Federal program to protect miners from exposure to respirable coal mine dust and quartz, the Department took steps in fiscal year 1997 and fiscal year 1998 to increase Federal monitoring of exposure limits to aid in restoring confidence in the Federal program. In fiscal year 1999, an increase of $2.7 million is proposed to target sampling inspections at coal mines.

The Department is also proposing to increase resources by $1.2 million for the analysis and resolution of difficult compliance problems for targeted hazards, while taking a cooperative approach with mine operators to encourage long-range solutions for a safer and healthier work environment.

A fair workplace is also essential for a quality workplace. The Department proposes $67.8 million, an increase of $5.5 million, to implement a compliance assistance strategy in civil rights enforcement and to expand its Fair Enforcement Initiative to support the Administration's efforts to strengthen enforcement of civil rights laws. The compliance assistance strategy will implement technical assistance and training guides for contractors; encourage Federal contractors to self evaluate their EEO performance; and develop and deliver grass root technical assistance seminars. This proposal will help contractors comply more easily with their EEO obligations. The Fair Enforcement Initiative will increase the number of contractors brought into compliance while reducing burdens on contractors, such as paperwork requirements. This proposal allows the Department to continue a Fair Enforcement strategy which includes a tiered review process, upgraded information technology capabilities, and paperwork reduction.

Finally, the Department proposes a $5 million Child Care initiative which will support the President's proposal to greatly improve the quality of services provided by day care providers. Quality child care service goes hand in glove with having an adequate supply of competent, professional child care providers. In fiscal year 1999, the Department proposes to expand the registered apprenticeship system using these funds to assist States in building their infrastructures and replicate—based on a nationally recognized West Virginia model—training for skilled Child Care De-

velopment Specialists in at least 10 States. This initiative provides industry-recognized certification and development of career ladders in the child care field.

GOVERNMENT PERFORMANCE AND RESULTS ACT [GPRA]

Under my leadership, since my arrival in May, the Department has taken GPRA very seriously and I believe we have made considerable progress in meeting both the legal requirements and the spirit of the Act. We realize, however, that there is more work to be done as the Department continues to refine its strategic plan to move further toward an outcomes focus. The performance plan recently submitted with the budget request reflects my budget and program priorities, arrayed by the strategic goals, to achieve the results planned for the Department in fiscal year 1999. This Plan also responds to concerns raised by the Government Accounting Office (GAO) and Congressional staff during their review of the Department's Strategic Plan that it did not adequately reflect the integrated and cross-cutting nature of the Department's programs and activities. We are committed to working with the Office of the Inspector General (OIG) and GAO to improve our management systems and procedures. The OIG has agreed to work as a partner with the Department to provide the Congress and me with advice on how to attain the highest possible results from program performance.

One of the primary aims of the Department's fiscal year 1999 Annual Performance Plan is to advance the Department toward achieving my vision of an integrated Department, one in which component agencies work together to achieve common goals. This plan represents a major step in that direction, as capitalizing on the commonalities and linkages between DOL's agencies is critical for successful plan accomplishment.

A major management challenge in fiscal year 1999 will be to establish a process aimed to assure the Department's performance and level of accountability for program results. To oversee implementation of the Department's fiscal year 1999 and subsequent Performance Plans, and coordinate all the Department's programs as a unified Department of Labor, I will institutionalize a strategic management process to maintain a central focus and accountability of the Department's many programs and activities. This is in addition to current efforts designed to better align performance-based information systems, including a unified capital planning evaluation process for information technology systems, financial management integrity to obtain a clean audit opinion of the Department's Financial Statement on an annual basis, and human resource utilization.

I believe that the fiscal year 1999 Annual Performance Plan, which is directly tied to my budget request, sends the American public a clear message of the purpose and mission of the Department and represents a commitment to the achievement of my strategic goals—a prepared workforce, a secure workforce, and quality workplaces. The Plan presents the programs, activities, and achievements that DOL will strive to accomplish in fiscal year 1999, the means by which its performance will be evaluated, and the standards to which it will be held accountable by Congress and the American public.

I look forward to working with the committee and I thank you for the opportunity to appear before you. I will be happy to respond to any questions.

JOB TRAINING PROGRAMS

Senator SPECTER. Thank you, Madam Secretary. I thank you for coming to Philadelphia shortly after you were confirmed and sworn in, where we took a look at one of the very important job training programs. There is an enormous need in America today for job training. We have a low unemployment rate, but within that group there remain people who could undertake work if they had the training and also if they were located in the right spots. So the transit bill which we passed last week with the reverse commute from, say, center city Philadelphia to Montgomery County, a suburban affluent county, and to Reading, PA, in Berks County, taking people from areas where people have no jobs to areas where they do have jobs, is a very important component.

The tax break, where there is a fringe benefit which is not taxable where people can get transit fare up to $780, I just was dis-

cussing this with my distinguished colleague, Senator John Chafee, the author of that bill, could be very, very important.

With respect to the Welfare-to-Work Grants Program, I would like to go over with you some of the components. But first could you share with the subcommittee what you have learned from your tours of local projects around the country? What are the biggest problems, and how successful have we been in involving the private sector?

Secretary HERMAN. Let me respond to the question on two levels, Senator, first, as a result of my tour what were the key learnings, and second, what can we do more to involve the private sector. With regard to the tour, it was a 10-city tour for me commencing in October of last year and just ending in February of this year. Coming away from that tour I believe that we have several challenges if we are going to ensure that welfare-to-work is successful for the long haul this time around. If you would permit me for just a few moments to expand on some of those challenges.

Senator SPECTER. By all means.

WELFARE TO WORK

Secretary HERMAN. The first I believe is a recognition that these individuals who are making the transition from welfare to work really want to be treated as workers. I call them new workers, especially today, because it is clear to me that they are suffering from the stigmatization of being labeled as ex-welfare recipients, and, therefore, they do not feel as though they have the ability to leave their past behind them and to really begin anew, and to really get a firm toe hold, if you will, in the labor market today with all of the rights and protections that other workers are entitled to. So I think a recognition, first of all, of these individuals as a new source of talent, as a new labor supply, is very important for us psychologically as a country, and not to label them under the old traditional stereotypes.

Second, I repeatedly saw in all of the cities that I visited the three biggest barriers to maintaining a job today—child care, transportation, as you so correctly just pointed out, and housing. But I would have to say the biggest barrier is, in fact, child care, and then transportation. We are going to have to do a lot more to make sure that we can move workers to where the jobs are since we know today that three out of four jobs are in suburban communities. Two out of three of these individuals who are trying to make the transition are in inner cities, so there is a clear mismatch between where the workers are oftentimes and where the jobs are. So innovative strategies around transportation, as well as child care support, are going to be very important.

Third, I would say historically we put a lot of emphasis on getting jobs. We have not put enough emphasis on keeping jobs. I believe that in order for this population, especially the hardest to serve that remain, to be successful we are going to have to do a lot more to stress mentoring and coaching and other kinds of support services to enable individuals to stay on the job, and to follow them for longer than the prescribed periods that we have in the past.

I would also add parenthetically that while there is much that is being said today about the decrease in welfare roles, that I believe the biggest challenge really remains because the hardest to serve really still remain on the rolls, those with multiple barriers, poor work histories, low to no educational experience or work histories. I believe that we do not have a lot of experience, quite frankly, with serving that population.

Last, I would just comment on a need for a focus on fathers. So much of our welfare attention has correctly been placed on mothers who are largely raising these children alone in their own families, but not enough is being said about fathers. While we have certainly beefed up our efforts in the criminal justice system to enforce child care payments, you need a job in order to pay child support. We have got to do a lot more, I believe, to bring fathers into the loop, to be responsible parents as well, as a part of this welfare-to-work initiative.

WELFARE TO WORK COORDINATION

Senator SPECTER. Madam Secretary, with respect to developing a plan to coordinate welfare implementation with other departments, Transportation, HUD, HHS, it is projected that HHS Secretary Shalala will have the chief oversight policy. When will you finalize your plans, and tell us, if you can, how it will function coordinated with those departments and perhaps the Department of Justice, particularly in the area for training for juvenile offenders who will have unique needs for shaping what they can do in the workplace?

Secretary HERMAN. With regard to the coordination, we do have a staff working group representing various agencies who have responsibilities for the welfare-to-work initiative, looking at better coordination and how we can work more closely together to ensure success of our welfare-to-work initiatives. Specifically with the responsibilities that Congress gave to the Department of HHS and Secretary Shalala for the overall evaluation of this effort, we are working very closely with the HHS team on the inputs into that evaluation so that we can make sure that we are going to appropriately measure the right outcomes, the right results for this initiative. I am confident that the close relationship that we have with HHS is going to result in better coordination in the field as a result of it.

As we look in particular at our efforts to coordinate with departments like Justice on juveniles, we see as you know, Senator, that many of these young kids today come from families who are on public assistance. So our efforts on the out-of-school youth initiative, as well as what we are doing to more intensely work with these young people, will also be coordinated.

I was particularly struck by recent data which suggests that when we look at our out-of-school youth population, that we are focussed on as a part of welfare-to-work, that generally 12 percent of them are juvenile delinquents. If you look in particular at African-Americans in this population, you are talking about 34 percent of that particular group. So we have to have greater coordination, in my view, if we are going to be successful in this area, with the Justice Department.

YOUTH OFFENDER DEMONSTRATION GRANTS

Senator SPECTER. Madam Secretary, in the Judiciary Committee we are wrestling with a juvenile crime bill. We have had quite a battle, and we split 9 to 9 on whether the lion's share of the funding should be in prisons or whether there ought to be rehabilitation. My views are that we have to divide the criminal element into two parts, the career criminals, those are people who have committed three or more major offenses, and isolate them from society with life sentences. But as to others, where they are going to be released, and especially with juveniles, I believe we have to approach it with a so-called seamless web to try to move them through the educational process, and if they become delinquents to have literacy training and job training. If you release a functional illiterate without a trade or a skill, that individual goes back to a life of crime.

Now, I am pleased that we were successful in providing your Department with $12,500,000 for youth offender demonstration training grants for the new program which starts July 1, 1998. Have you made any of those grants, and what do you project for the future on that subject?

Secretary HERMAN. We have not made grants to date, Senator. The funds will be available, as you said, July of this year. We have been working, however, on developing the competitive guidelines that will go to States to make the appropriate requests for those funds. As a part of the guidance that we will be giving in this area, we intend to work very closely not only with our State and local work force development boards but also with correctional institutions and facilities to be able to target this population in particular.

Senator SPECTER. When you move ahead on that program, Madam Secretary, I would be interested in your Department's evaluation as to what funding is really necessary on the training grants for juvenile offenders. My sense is that if we really were serious about violent crime, that we could cut it by about 50 percent, if we trained, literacy training and job training, those people who are going to be released. It is for public safety, No. 1, but obviously for the quality of life of those individuals. It has always seemed to me just ridiculous that we have not allocated the resources necessary for that kind of realistic rehabilitation.

So as you work through the program, the subcommittee would appreciate it if you would give us your appraisal as to what really is necessary on a nationwide basis to do the job.

We have been joined by the distinguished Senator from Arkansas, one of the distinguished Senators from Arkansas, one of the most distinguished Senators in the body, Senator Bumpers.

REMARKS OF SENATOR DALE BUMPERS

Senator BUMPERS. Thank you very much, Mr. Chairman. Secretary Herman, Tuesday morning my chief of staff and I were driving to work and I was telling her that during a speech I made the night before to 300 or 400 Arkansans who were in town, mostly business men and women, that as I closed out my remarks I talked about what a great country this was. I remarked on how fortunate we were to live in a civilized society under the magnificent organic

law we call the Constitution, and how wonderful it was to know that when we sat down to eat we knew that the food had been inspected and was pure, that when we took medicine we knew that medicine had been tested over and over again, when we got on an airplane we knew that we were being handed off by a computer in Oberlin, OH, to a computer in Memphis, TN, and the security one feels with all of that.

I grew up in the South, poor, during the Great Depression, and was the beneficiary of tremendous Government assistance. But while I was talking I saw a husband and wife in the back of the audience who were demonstrating through their facial expressions their contempt for what I was saying. When you have made as many speeches as I have you can pretty much tell what is on people's minds and whether they are agreeing or disagreeing with what you are saying. These two people were obviously disagreeing just by their motions and actions.

She said is it not amazing how many people are irrational about their contempt and hatred of Government, and I said yes, but this guy may have just had a terrible experience with the IRS. He may have had a terrible experience with somebody else, like OSHA. It may be that while he thought he was running a good plant, treating his employees well, trying to comply with the laws as best he could, OSHA inspectors swooped down on him and the first thing you know he is being fined. After 3 months of harassment he is being fined, he is being abused, linguistically, as well as financially, and he thinks it is an unnecessary and unwarranted intrusion into a business which he feels he is running well and serving everybody's purposes.

TRAINING OF OSHA INSPECTORS

Such was the case as far as I am concerned with Hudson Foods in Noah, MO. I am sure I do not know all there is to know about that, and I blame the Department of Agriculture for forcing the sale of Hudson Foods, which I believe was as innocent as innocent could be. The E.coli came into that plant from another federally inspected plant, but the owner of Hudson Foods bore the brunt of the whole thing. He had no choice. His name was in lights all over the Nation for 1 month, and his sales declined to nothing. He had no choice but to sell, and he sold the corporation for $300 million less than it would have brought 2 days before this happened.

So if Mr. Hudson and his wife had been in the audience and they had been making those faces, I would have understood, whether I was talking about food inspection service or whether I was talking about OSHA.

Just let me ask you this. What kind of training do these OSHA inspectors get so far as their conduct in a plant is concerned, not their technical skills at picking out violations of safety standards, but just their conduct, their attitude? I ask you this in the utmost good faith as one who has championed and voted for strict OSHA regulations ever since I have been in the Senate, and even when I was Governor and charged with the responsibility of administering a lot of them. What kind of instructions do these people get before they go into a plant about their conduct and their attitude toward the people in the company?

Secretary HERMAN. Thank you very much for your comments and your questions, Senator Bumpers. They do get classroom training and they do get training in terms of how to approach businesses today. As you know, this is my second tour of duty at the Department of Labor. I was there 20 years ago, and I can honestly say that one of the things that has impressed me the most about coming back to the Department 20 years later is the attitude and the spirit of what I call the new OSHA, and the culture changes that OSHA really is trying to bring about today in terms of how it does business. That culture change involves the way it goes in today to conduct an inspection.

If you will recall the old OSHA, they had random surveys. They were not necessarily targeted on the most hazardous industries. In the old OSHA you did not get any prenotification even that someone was coming in. It was always the surprise factor. In the old OSHA you had no chance to correct a finding or violation, the way you do now under the new OSHA with many of the changes that have been put in place.

But the changes, the culture changes that are taking place in the new OSHA do require that we provide substantial training of our employees and of our inspectors, so that this new way of doing business, if you will, is felt more broadly in the organization. So I want you to know that we are on the road, I believe, to making positive changes for the better. I think we are working much more cooperatively with businesses, with small businesses in particular, and we have beefed up our own training requirements. That includes not only classroom training for our inspectors but on-the-job training as well.

Senator BUMPERS. Secretary Herman, I see my time is up, Mr. Chairman, and I am going to have to leave, but let me just remind——

Senator SPECTER. If you would like to take a little longer, Senator Bumpers, go ahead. I am sure Senator Kohl would yield to you his time. [Laughter.]

TARGETING OF POULTRY INDUSTRY

Senator BUMPERS. Thank you, Senator Kohl. Let me just say that I believe the stories I heard that came out of that plant about OSHA's conduct for 3 months. They were there for 3 months. Not only did they check the payroll records, they checked everything. Bear in mind that this was a 2-year-old, state-of-the-art, $11 million plant. I saw some of the pictures of the things that were considered to be violations. I suppose from a superficial standpoint maybe that would stand up, but it certainly did not look to me like anything that would warrant 3 months of activities by so many people in that particular plant.

My closing question is this. At some point during Robert Reich's tenure as Secretary preceding you, there was an understanding, and you could never convince the poultry industry any differently, that they were being targeted by Labor because a lot of these plants are not unionized. You have seen those stories.

Secretary HERMAN. Yes, I have, Senator.

Senator BUMPERS. They had no reason not to believe them. I am not sure exactly what Secretary Reich's statement was, but it was

something to the effect that they were targeting this group. I am going to tell you something. I do not believe in targeting. I do not believe an entire industry in the United States deserves to be targeted. If you have a legitimate complaint that you consider credible from a credible source about violations in any kind of a plant, you will never hear a complaint from me if you investigate. But to take on the steel industry or the poultry industry or the beef industry or any other industry simply because you have heard rumors to a certain effect is absolutely unacceptable to me.

You do not even have to respond to that, but I would like for you to respond to whether or not the Department of Labor has, in fact, started a lot of investigations based on the idea that this particular industry ought to be targeted?

Secretary HERMAN. Well, I can certainly say, Senator, in regard to the poultry initiative, that I believed very strongly that we should engage in consultation, that I was not someone who wanted to play the "gotcha" game or have surprise raids, if you will. That is why we have reached out to the poultry industry. We did meet with more than 50 producers in the industry to talk about what the issues were and what the concerns were.

Where we are at this point is that we have come back with a series of findings and recommendations, and the staff is presently engaged in putting those findings and recommendations back into the field so that everyone has the benefit of that knowledge and information to decide on appropriate steps and recommendations. I think, quite frankly, Senator, a lot of us were surprised at some of the information that did come back that I believe in the end will help not only the industry but all of us who are concerned about safety issues in the poultry industry. We are making that information generally available so that we all have the opportunity to see it and to examine it, and to ask ourselves what are the best corrective actions.

One of the things, just parenthetically, that we found that was contributing to the most injuries in the industry were slips and falls resulting in back injuries that actually had to do with the chicken fat that was on the floor. That is not something that one would have thought would have manifested itself as the greatest finding in terms of the injury and accident rate, but that is one of the findings, for instance, that came out of the survey.

But we are putting all of that information back into the field, and what we want to do is to continue to consult as to what we should do to correct these findings.

Senator BUMPERS. Well, it would be OK with me if you started a crash course over there on teaching some of those people what civilized conduct is.

Secretary HERMAN. I can appreciate those comments, Senator.

Senator BUMPERS. Thank you, Mr. Chairman.

Senator SPECTER. Thank you, Senator Bumpers. Senator Kohl, you have your full time, of course.

REMARKS OF SENATOR HERB KOHL

Senator KOHL. Thank you, Senator Specter. Ms. Herman, I wanted to ask you about retiree health care coverage. In Milwaukee the employees of the Pabst Co., are not alone in this, but they, as you

know, had their health care coverage eliminated by the employer as a result of a contract loophole. They were left stunned and disappointed, and in many cases unable to handle their health care coverage because their company, which had promised them in writing that their coverage would be maintained as retirees, simply decided it had become too expensive and they eliminated that benefit to these people.

My question is what can you do for those people at the Pabst Co., and at other companies who have had this happen to them? And beyond that I would like to ask you whether or not there is legislation that you or we need to propose and enact to ensure this retiree health coverage?

Secretary HERMAN. Thank you very much, Senator, for your question. President Clinton in his most recent announcements on Medicare buy-in took into consideration not only the issue of what happened with the workers at Pabst, but as you have correctly pointed out, other workers who have had promises broken to them by their employers for their health coverage as a part of their retirement benefits package. As you know, the Department has been a friend of the court in the Pabst situation, as with other situations, to try and get employers to maintain and to keep those promises.

Recognizing that that is not happening, the President has proposed that we allow those workers, such as the workers in the Pabst Brewing Co., who had promises to them broken, to be able to purchase COBRA coverage for up to 125 percent of the average cost of active employees, and to have the option of extending that COBRA coverage until they are eligible for Medicare. The other consideration that the President put forward is the ability to buy into Medicare if you are 55 years of age and older, if you have been dislocated from your job so that you have that as a bridge, as a fall back, as some of these workers were also dislocated as a result of the actions that have been taken there and in other communities.

So I am hopeful that both of these provisions will actually help workers, one, those who have had promises broken, and two, those who have been dislocated from their jobs, to have the ability to continue some kind of health coverage for themselves.

PABST RETIREE HEALTH CARE COVERAGE

Senator KOHL. Is there anything in particular that you can offer these employees at the Pabst Co., now?

Secretary HERMAN. Right now what we are looking at as a part of our own beefed up dislocated worker assistance program is going in with rapid response teams that are not only working to certify workers for new job situations, but also to look at what the benefit packages can be as a part of those new job environments that we are doing job search and job assistance with. This will not help the Pabst workers, but certainly it was instructive for us to see what those workers experienced, to know that we have to go in on a much faster pace to be able to act as an intermediary in the labor market and to be a bridge for them to other employment situations to get other opportunities, and not have the time lag in such a way that by the time that we do move in oftentimes we have either lost

contact with the workers or certainly they have given up on any viable alternatives being available to them.

Senator KOHL. I appreciate that. I know it is a knotty problem without an easy answer, but, you know, to those people in particular, and we are here to help people one by one, if we do that then we help everybody. Those people in particular at the Pabst Co., are out of luck right now. They are out of pocket and they are not able to cover their health insurance. The legislation that is being proposed, hopefully, will get passed, but it is not there right now.

Is there something that you can suggest that your Department and we, working together, can devise to help those people?

Secretary HERMAN. What I would be very interested in trying to do, and I have asked our team at Labor to look into this, is to actually go back and to track those workers basically to see where are they right now and what is the current state. We just had a very successful experience with that kind of an effort in the State of Louisiana with Fruit of the Loom plant closings there, because we were able to go back in with a better data tracking system to bring those workers, if you will, back into a matrix so that we could help facilitate not only training assistance but job search and job placement assistance. I am pleased to report that almost 70 percent of them have now been served, and I am hopeful that we will be able to get the other 30 percent. What I would like to do is to go back and to take a look as well as to what has gone on with those workers in Milwaukee.

Senator KOHL. I would appreciate that opportunity to work with you and your Department for those people to see if we cannot help them to get some kind of coverage.

Secretary HERMAN. We will take a look at it, Senator.

Senator KOHL. I do appreciate it. Thank you so much. Thank you, Mr. Chairman.

Senator SPECTER. Thank you, Senator Kohl.

[The statement follows:]

PREPARED STATEMENT OF SENATOR HERB KOHL

Thank you, Mr. Chairman. Madam Secretary, it is always a pleasure to see you. Thank you for giving us this opportunity to delve into some priorities addressed in the 1999 budget.

In this new era of balanced budgets there are tight restraints on spending initiatives. Yet even though there are fewer funds to go around, the pressures of globalization on today's workers and businesses continue. While America leads the way in many industries, in other sectors consolidation is taking place and workers are being downsized. These people need to be given the skills to move from industries of the past to the technology of the future. The key to rising wages in today's economy is mastering innovative technology.

Whenever I speak to young people I always stress to them the importance of learning a skill. Whether they go to college or vocational school, they have to enter the job market with a skill that the marketplace values. The job training opportunities offered by the Federal government are important tools used by many young people to gain these skills. I look forward to hearing how the Department of Labor's budget intends to expand opportunities for young people.

While we are enjoying this time of economic growth, we must not forget those who have been left behind. Unemployment may be low, but it continues to burden too many individuals and families. Some of these workers have a long work history and will only be dislocated for a short period. Others, for instance those moving from welfare to work, are trying to find a job after being out of the work force for many years. These folks are the hardest and most expensive to serve. At the same time, the labor market is very tight and they have the best chance in a long while of finding a job. The stakes are high because if we cannot help these people find a job now,

what will happen to them during an economic downturn? We have to do all we can to get them the job experience and skills they need so that when a recession occurs they have what it takes to keep their jobs and weather the storm.

REMARKS OF SENATOR LAUCH FAIRCLOTH

Senator SPECTER. Senator Faircloth.

Senator FAIRCLOTH. Thank you, Mr. Chairman, and thank you for holding this hearing. Thank you, Madam Secretary, for being with us.

I was elected to the Senate to create workfare and not welfare. That was what I ran on, and I notice that in Wisconsin Gov. Tommy Thompson says he has written his last welfare check. I hope he is right, because everyone who receives benefits now is required to work for those benefits. I am a great admirer of Governor Thompson and what he has done over the years. As a founder of the Senate to preserve a real welfare reform working group, I am particularly interested in hearing about your plans to successfully implement the new welfare-to-work programs so that we stay the course on welfare and not lapse into the old system.

In your Department, $3 billion will be spent over the next 2 years to provide grants for on-the-job training, job placement, job vouchers, and private sector wage subsidies. Most of these ideas have been tried many times before with very little success, as you well know. I would like to hear what you propose to do differently to make them work this time. I agree that the key is not only finding jobs, but in keeping them. I am very much aware that transportation and child care are two of the biggest obstacles facing workers today, and new workers entering from possibly a welfare role.

But more and more jobs require basic skills in computer knowledge and training. This is one of the reasons that I have championed the community college tax credit last year. Community colleges and I have worked with them over the years and running the North Carolina Commerce Department, have been the best job training program we have ever had in the Nation, much more successful than Federal job training programs. Welfare caseloads are dropping, 30 percent in North Carolina alone, but I understand that your Department is seeing an increase in the number of people on welfare 3 years or longer, and an increase in those who have been on welfare before and are returning.

I would be very much interested in your response when we get back to the question part of it, and I again thank you for being here.

Secretary HERMAN. Thank you very much, Senator Faircloth.

EMPLOYEE RETIREMENT INCOME SECURITY ACT

Senator SPECTER. Thank you very much, Senator Faircloth. Madam Secretary, there has been a lot of concern about the question of responsibility of HMO's for precluding ill people from getting certain specialist care because of their evaluation that the care was not needed. President Clinton recently made a reference to a specific case in speaking before the American Medical Association last week about a 12-year-old boy stricken by cancer who had his leg amputated after his managed care insurer balked at paying for

the alternative treatment that might have saved the limb. Under 1974 Federal legislation, the young man and his parents were barred from suing the health plan for damages and have no case against the doctor because he urged the leg saving procedure.

You are a member of the President's commission which is looking into the need for legislation to protect patients' rights under managed health care plans. This may be a little too early for you to make an assessment, this is a big question. I want to give you fair warning, because it is a very big question——

Secretary HERMAN. It is a big issue.

Senator SPECTER [continuing]. To impose liability on the HMO's, changing the Employee Retirement Income Security Act. It is a very unusual provision of Federal legislation to preclude a State cause of action, but that is where we are. Would you care to make a comment?

Secretary HERMAN. We spent a great deal of time, Senator, examining this issue as a part of the work of our commission, and I believe that while there was general agreement and recognition that we have to do something to provide greater protection for patients, for citizens, in this area, since ERISA plans are not subject to remedies under State laws and, therefore, citizens do not have the right to sue, if you will, under State law because of ERISA preemption. Exactly what is the appropriate response is an issue that the commission itself did not reach a conclusion on. What it did say in its recommendations to the President was that we needed to have a national dialog on this issue, that it was important to begin this debate in earnest, that we had to have a balanced approach that took into account not only a patient's legitimate right for redress but the obvious employer concerns of the costs that would be attendant to expanding ERISA as one option, or just a whole question of what you do to impose remedies in this area.

COST OF EXPANDING ERISA

I know that this is also something that the Congressional Budget Office is looking at in terms of scoring, as a part of our own recommendations to the President. They have not yet come back with whether or not increased remedies would necessarily be a burdensome cost to plans, and I know that we are all waiting to get a better handle on that cost data. But there have been other studies that have been done, and I see the red light is on, there have been other studies that have been done that do suggest that strengthening remedies in this area does not necessarily suggest that it would result in increased costs to plans, but we have not reached a formal recommendation in this area yet.

Senator SPECTER. That is a splendid answer which would win you plaudits from any diplomatic post in the world.

Secretary HERMAN. Thank you, Senator.

Senator SPECTER. But what do you think?

Secretary HERMAN. I think, speaking for the Department of Labor, that we have to have strengthened remedies in this area.

Senator SPECTER. We have to have what?

Secretary HERMAN. Strengthened remedies in this area. I think the loopholes that presently exist are loopholes that have to be closed in some way. I am not prepared, of course, to say exactly

what is the best way to do that, but I do think that when you look at the loopholes that are there, that we have to have increased remedies in this area.

Senator SPECTER. Well, it is going to be expensive beyond any question. I think there is no doubt about that. But the question is what is fair here? What this subcommittee is going to do, we are going to convene a hearing on this subject alone. This has received a lot of attention and a lot of notoriety. In my open house town meetings I hear the question all the time about the gag rule about capitation, and there is no doubt about the increase in cost. As the increase in costs go up, we also know the people lose their health benefits. So there is a tradeoff here, but I think it requires some greater analysis. I also think that if there were a little sharper focus in public attention, that there would be a little more care exercised by the HMO's in denying the extra care.

This is an area where I think the President's bully pulpit, the Secretary's bully pulpit, you have a powerful bully pulpit, Madam Secretary, and so does Senator Faircloth, so we may just have to call some of that into action.

Secretary HERMAN. I certainly would agree with you, Senator, and I would look forward to any efforts on the part of your work here to give greater attention to this issue because I think the more we can focus public attention and public debate on it, you are right, it does also build in I think more responsible actions.

Senator SPECTER. We are going to submit quite a number of questions on this for the record. I will give Senator Faircloth the last word.

Senator FAIRCLOTH. I did not understand in your second answer to Senator Specter that you are going to have to have stricter what?

Secretary HERMAN. He asked me what did I think personally, and I was making the statement on the part of the Department of Labor and not speaking broadly for the administration, because the President has not taken a position on this issue, but I said I thought we needed to have increased remedies, strengthened remedies in this area, but I was not prepared to say what those remedies, what form those remedies would take.

NORTH CAROLINA FORMULA GRANT WAIVER

Senator FAIRCLOTH. One question that pertains to my home State. I will ask that, and then I will be through. My State, North Carolina, submitted their plan recently, and in it we asked you to grant a waiver to allow us to administer our formula grant through our local job service employer committees rather than through the work force development boards. North Carolina is not trying to exclude work force development boards. We have been directed by State law passed by General Assembly to use our local employers, the job service employer committees. Do you have the authority to grant this waiver?

Secretary HERMAN. Presently, Senator, I am very much aware of what has just happened in the State of North Carolina with regard to the actions that the State legislature took there. We are presently in consultation with the individuals in the State now, trying to determine exactly what is possible in terms of what has hap-

pened in North Carolina. This is the first time that this has happened. We have had 16 States that have come before us that we have approved their plans for formula grants. The legislation does require that the States work through the work force development boards. We have not had, quite frankly, a situation like this occur, and I must admit that I am not in a position at this point to answer the question directly because we are just beginning that consultation with the State now.

Senator FAIRCLOTH. Well, I was hoping you did have the authority to grant the waiver, and I think North Carolina should have the flexibility to set up a program that puts welfare recipients into jobs, and it not get hung up in the inevitable hang ups we can produce here in Washington, as you are well familiar with. If the law is not clear, then I would like to look at maybe offering a rider to the budget bill or somewhere to make it clear, because this is authority you should have. If you would please, in just the next few days, by the first of the week at least, if you or someone in your office would give me a call and tell me where we stand on this.

Secretary HERMAN. I would be happy to get back with you on it, Senator, or have someone on our staff be in touch with your office.

Senator FAIRCLOTH. If you could this week, because they are pushing me on it in the State. Thank you so much.

NLRB BUDGET REQUEST

Senator SPECTER. Madam Secretary, one final question. Last year Congress froze funding for the NLRB which was nearly $12 billion below the agency's request. Now this year the NLRB is the subject of a request for nearly a $10 million increase. From your perspective as Secretary of Labor, please give me your assessment of the workload and budgetary needs of the NLRB. Do you really need that increase?

Secretary HERMAN. Well, Senator, as you know, the Department of Labor does not have direct responsibility for the NLRB, but I do know that the administration has put in a request of $9 million or $10 million, or a 5-percent increase in funding, due to the tremendous backlog of cases that the NLRB is experiencing. It was precisely because the budget of the NLRB was frozen in 1997, staff were laid off, that this backlog has now resulted. So, yes, I do believe that additional resources to the NLRB would certainly help with the tremendous administrative problems they are having right now in managing that backlog.

ADDITIONAL COMMITTEE QUESTIONS

Senator SPECTER. Madam Secretary, in addition to the questions we have asked for the record, would you provide the subcommittee with the details on backlog and the necessity as you see it for this increase? We would like to have some back up verification of that request.

Secretary HERMAN. Yes, Senator, we would be glad to do that.

[The information follows:]

NATIONAL LABOR RELATIONS BOARD—FISCAL YEAR 1999 FUNDING

PRESIDENT'S REQUEST: $184,451,000

Background: Limited funding and reduced staffing have led to growing backlogs

Funding has not kept pace with inflation: The current funding level, adjusted for inflation, is 8.7 percent below the 1995 level and 10.6 below the 1993 level; The requested amount, adjusted for inflation, would still be 7 percent below the 1993 level; and Current funding has imposed stringent limitations on Agency activities (see below).

Agency staffing has been reduced to meet funding limitations

By more than one-third since 1980—from about 2,950 to 1,900 projected this year.

By more than 15 percent since 1990 and more than 30 percent since 1984.

Field professional staffing has been reduced by 6 percent since 1990, managerial staffing by 13 percent, and clerical staffing by 20 percent.

The staffing level (FTE) for fiscal 1996 and 1997 were the lowest since 1962, yet the case intake was nearly 60 percent higher.

While intake has remained steady, workload has grown

Because of reduced staffing, each employee must now handle 22 percent more cases than in 1988 and almost 33 percent more than in 1985.

Cases have grown more complex due to corporate and workforce restructuring and other factors, increasing demands on resources. Information Officer program has also filtered frivolous charges, so that cases filed are more complex.

Despite efforts to prioritize and be more efficient, case backlogs are growing

Cases are piling up in the Regional Offices at the initial, investigative stage, where two thirds are dismissed or withdrawn:

Situations pending initial investigation in regional offices

September 30, 1988	2,891
September 30, 1993	3,858
December 31, 1997	7,151

Cases are taking longer to investigate:

Overage cases (more than 45 days) pending initial investigation

	Percent
September 30, 1988	3.8
September 30, 1995	21.2

In 1996, to cope with rising backlogs, a new case prioritization program was implemented (see page on "Impact Analysis" below). Time targets were extended for lower priority cases. But even under new time targets, as of December 1997, 27.4 percent of all cases were overage at the investigative stage. Of the highest priority cases (14 percent of all cases), 17.4 percent were overage (pending more than 7 weeks).

Delay in court enforcement of Board decisions has increased because of a shortage of attorneys to handle the cases.

Issuance of complaints, review of Regional Director dismissals of unfair labor practice charges, and computation and collection of backpay are taking longer.

Agency has taken extensive steps to operate more efficiently (see below). Without these, backlogs would be even greater.

Funding at the administration requested level would reduce backlogs, promote efficiency

Steady growth in backlogs would be halted.

Backlogs would begin to be reduced by up to 10 percent or more.

Hiring of more field staff, so that cases could be investigated quicker, yielding faster complaints, settlements, and dismissals.

More consistency in ability to hold timely elections and promptly certify results.

Improved quality of case handling from enhanced training in investigation and litigation.

The NLRB promotes stable and productive labor relations. It is most effective when it can resolve disputes quickly. Budget reductions have led to growing case backlogs. Efficiency measures have slowed the growth of backlogs, but adequate funding is necessary to provide effective service and to invest in further improvements.

Actions taken to meet current funding freeze

Hiring freeze (Agency expects to lose 80 or more staff through attrition this year); Planned cancellation of all trials in September; Elimination of all training; Travel for elections, trials and other case handling drastically cut; Computer and other equipment acquisitions sharply reduced; and Automation program stretched out beyond 2000.

"Impact analysis" program to maximize benefit of available resources

Impact Analysis was implemented in 1996 to cope with rising inventory of uninvestigated cases, to ensure that more prompt attention and staff resources go to the cases with greater public impact.

Under Impact Analysis, cases are classified at initial intake to determine time frame for investigation and resources to be applied. Previous system was essentially first-in, first-out.

Cases receiving highest priority involve alleged unlawful activity having a demonstrable impact on the general public through disruptions of business activities, or significant impact on many employees.

Cases are recategorized if necessary as investigation proceeds.

Time targets for completion of investigative stage (previously 45 days for all cases):

Category	*Weeks*
III	7
II	11
I	15

NLRB AUTOMATION PROGRAM FOR FISCAL YEAR 1999

Program is behind schedule due to funding limitations in fiscal year 1998; automation budget was scaled back from $11 million to $5 million.

On-time completion of system requires investment of $6.9 million in fiscal year 1999 to pay for:

—Upgrading of desktop PC's capable of running new software;
—Fileservers for database storage in headquarters and field offices Fileservers will also meet other data storage needs;
—Installation in field and headquarters offices;
—Continued development of software necessary to implement the system; and
—Complete implementation of Year-2000 modifications.

In addition to addressing the Year-2000 problem, new system will improve accuracy and availability of information for reports to Congress, public inquiries, GPRA compliance, FOIA compliance, internal management

Failure to implement system as planned will necessitate increased costs in future years to solve Year–2000 problem

Steps taken since 1994 to restructure and streamline NLRB operations

Reduction of rental space by closing/reconfiguring field offices. Since 1994 and especially during the 1996 space reduction initiative, we reduced space in 28 field locations, including the Division of Judges. We also closed the El Paso, Texas Resident office and moved the D.C. Resident Office into Headquarters. The 1998 planned reductions include 4 regional offices and Headquarters. Our end of year space assignment is expected to be 721,269 square feet—a more than 10 percent reduction from the 1994 level of 801,991 square feet. This represents a rental savings of $2.25 million.

Streamlining of supervision throughout the Regional Offices and in the Headquarters divisions to reduce layers of review, delegate decisionmaking to the lowest practicable level, utilize supervisory staff flexibly to perform direct casehandling; and increase the ratio of line employees to supervisors. Field office supervisory positions have been reduced from 155 in 1994 to 123 today.

Significant increase in the identification and transfer of "portable" work such as decision writing and telephonic investigations from a temporarily understaffed or backlogged region to one that can better handle the increased workload or to Headquarters. Savings come from moving work, not people.

Streamlining oversight of Regional Offices by reducing the number of districts in the Division of Operations-Management at Headquarters by one-third, reducing the number of managers and increasing the managerial responsibility of each remaining district manager by 50 percent in 1995.

Eliminating administrative clearances and reviews. Delegation of additional casehandling and administrative authority to Regional Offices, eliminating requirements for clearance or approval from Washington.

Reduction of investigative travel costs by asking parties who file ULP charges (charging parties) and are situated within a 120-mile radius of a field office to come to that office to provide their evidence; by increased use of affidavits taken by telephone and of questionnaires or requests for statements of facts; by clustering cases so that multiple cases can be handled on a single trip.

Use of resident agents, working out of their homes in cities where there is no field office but where there is steady casehandling activity. Currently there are 3 resident agents, with one additional position posted and one more under consideration.

Increasing the use of information technology (IT) to facilitate casehandling and management. In recent years, the Agency has made enormous strides in automation of all work processes. Computerized word processing and quantitative analysis and electronic communication have permeated the Agency's culture. Current projects include legal research, forms, case tracking, greater use of Internet technology.

Streamlining of Office of Appeals by reducing layers of review, establishing time targets, and screening of cases. Case processing time reduced by more than half.

Restructuring of compliance program by emphasizing more efficient methods of backpay computation and collection and improving coordination between Headquarters and Regional Offices.

Reduction by 20 percent of FTE devoted to Board staff supervisory functions.

Adoption of rules governing proceedings before ALJ's, designed to facilitate the expeditious resolution of unfair labor practice proceedings—including assigning judges to convene settlement conferences and permitting judges to dispense with full written briefs and to deliver "bench decisions" in some cases.

Adoption of a "Speed Team" procedure to reduce amount of staff time devoted to cases where the Board is adopting recommended decisions of ALJ's.

HIGHLIGHTS OF STEPS TAKEN SINCE 1994 TO REFORM AND PRIORITIZE-CASE PROCESSING

Impact Analysis.—Implemented in 1996 to cope with rising inventory of uninvestigated cases, to ensure that more prompt attention and staff resources go to cases with greater public impact. Cases are now classified at initial intake to determine time frame for investigation and resources to be applied. Investigative approaches to cases can now be differentiated based on the categorization of the case. Previous system was essentially first-in, first-out.

R case reinvention program.—There was an extensive examination of Regional Office practices to identify and resolve impediments to prompt union representation elections. All aspects of R-case processing were given higher priority. Particular attention is now paid to cases that take longer than average time to hold election. As a result, preelection issues are resolved sooner, whether by agreement or hearing/decision; time to holding elections has been reduced. Half of all elections are now held in 42 days compared to 50 days before reforms; 87 percent of elections are now held in 57 days compared to 75 days before.

10(j) Program.—The goal has been to promote uniform application of NLRA injunction provisions. A manual was produced and distributed to all field offices; training was conducted, with subsequent refresher sessions. Each Region named a 10(j) coordinator. Cases are now reviewed for 10(j) potential early in investigation.

Compliance Program Reform.—Regional Office procedures for computing, collecting backpay and obtaining other remedies were extensively reviewed. The manual was updated and expanded. Regions may now use sampling, estimating techniques to simplify backpay computation. Compliance cases now prioritized under Impact Analysis principles.

ADDITIONAL COMMITTEE QUESTIONS

PROGRAMS FOR WOMEN REENTERING THE WORKFORCE

Question. Secretary Herman, what are your plans to provide training, technical assistance and resources on displaced homemaker services to employment and training programs that deal specifically with women re-entering the workforce.

Answer. The Department of Labor's Women's Bureau has a long history of helping women, especially displaced homemakers, re-enter the labor force. This was the case during my tenure as Director of the Women's Bureau and continues under the leadership of Acting Director, Ida Castro. For fiscal year 1997, the Women's Bureau provided a grant for the continuation of training and technical assistance services to approximately 1,300 programs that work to assist close to 400,000 displaced homemakers re-enter the workforce. The Women's Bureau is continuing funding for this program in the current year and has requested $600,000 to continue the program in fiscal year 1999.

Eligible displaced homemakers, welfare recipients and other low-income women can access job training and related services under the Job Training Partnership Act (JTPA). About 40 percent of all participants in the JTPA Adult Training Program are welfare recipients. The Department of Labor's planning guidance for the JTPA program for economically disadvantaged adults identifies displaced homemakers as one target group whose needs should be addressed. To ensure that this occurs, the Employment and Training Administration (ETA) monitors JTPA State grantees each year. States and local communities have addressed the needs of displaced homemakers for many years. The Department also has funded a series of demonstration projects to explore ways to help displaced homemakers re-enter the labor market.

Question. What actions will the Department take to help returning women workers enter occupations in the information technology field?

Answer. The assistance the Department of Labor provides to job seekers, including women who are seeking new or better jobs, ensures that they have appropriate and relevant information about labor markets, job opportunities, and skill and other hiring requirements. The Department is responsible to make sure that the job training system it administers with State and local partners is responsive to the skill needs of the job market, including the information technology field.

For example, the Department of Labor is helping States and local communities build One-Stop Career Center systems, and an integral part of One-Stop is the creation of America's Labor Market Information System (ALMIS). ALMIS is intended to help women and men exercise informed choice in their workforce decisions and to ensure that training is linked to occupations that are in demand in the communities in which they reside. Among its components are the America's Job Bank, which is the largest and most frequently visited job bank on the Internet, with 750,000 job openings posted daily; and America's Talent Bank, which allows registered employers to search a data-base of electronic résumés to find suitable candidates for their job openings. Many women will continue to benefit from these services. In addition, the Women's Bureau directly provides women returning to the labor force with information on occupations, projections, required education and training, and employment opportunities in the global economy.

Job training programs are another avenue for providing American women with the skills they need for good jobs. The Women's Bureau will focus its Women in Apprenticeship and Non-Traditional Occupations Act (WANTO) technical assistance grants on community-based organizations that work with employers and labor unions in non-traditional industries, particularly computer-based industries in information technology and other computer-based manufacturing processes. Coordinated with the Bureau of Apprenticeship and Training, the effort will focus on women who are former welfare recipients who live in empowerment zones and enterprise communities and their employers. The Women's Bureau also plans to look for information technology and related employers and labor unions who want to work with community-based organizations that will deliver technical assistance services.

In addition, Congress is currently considering legislation that would streamline and consolidate the web of job training programs and better prepare the American workforce for the 21st century. This legislation reflects key principles proposed by the President in his G.I. Bill for America's Workers. This job training reform will empower women with resources and information, helping those who seek training or retraining with control over their own careers. This empowerment will make the job training system more responsive to the skill needs of the market, including the information technology field.

Finally, the Department also recently issued a solicitation for training individuals in high technology fields. We anticipate that a large number of women will benefit from job training under these grants.

MINIMUM WAGE

Question. The President's budget proposes raising the Federal minimum wage, which now stands at $5.15 per hour, to $6.15 over the next two years. Would you expect this higher minimum wage to apply to welfare recipients engaged in work under the new welfare law.

Answer. The minimum wage and other provisions of the Fair Labor Standards Act (FLSA) apply to working welfare recipients just as they apply to all other workers. If welfare recipients are employees under the FLSA's broad definition, and their job is covered by the FLSA, they must be paid the Federal minimum wage.

Question. Do you expect the minimum wage requirement to act as a deterrent to employers' willingness to hire welfare recipients?

Answer. As people move from welfare to work, one of the most important lessons they can learn is that work pays. Raising the minimum wage is a signal that the nation should reward—and not hold back—people who try their best to work hard and play by the rules. Welfare recipients should not be excepted from that deal.

New block grant rules and declining caseloads have resulted in many States having more flexible resources and additional funds available per welfare household this fiscal year. A report by a House Ways and Means subcommittee shows that last year the typical State received a 56 percent increase in available funding per recipient family over 1994 levels. In addition, States may use their State-only welfare funds to serve a variety of needs and special populations. States have substantial available resources.

The President proposed and won passage of the Welfare-to-Work Jobs Challenge which will make $3 billion available over the fiscal years 1998 and 1999 to States and localities for the purpose of helping the hardest-to-serve recipients secure lasting, unsubsidized employment. The President also proposed and won passage of a "super" Work Opportunity Tax Credit (WOTC) for long-term recipients. Employers could receive a credit equal to 35 percent of the first $10,000 in wages in the first year and 50 percent of the first $10,000 of second year wages, making for a maximum credit to private sector employers of $8,500 as opposed to $2,400 under the regular WOTC.

In light of these additional resources and incentives to employ welfare recipients, it will be difficult to argue that a modest increase in the minimum wage would act as a deterrent to employer's willingness to hire welfare recipients.

JOB STABILITY

Question. A recent research study found that from half to two-thirds of the welfare recipients who leave welfare to work lose their first job within a year. Sixty percent of the job losses were initiated by the employees, in response to problems either on the job or at home.

What have you learned about problems facing these former welfare recipients that need to be addressed to promote job retention?

Answer. Krista Olson and LaDonna Pavetti of the Urban Institute estimate that almost 90 percent of welfare recipients between the ages of 27 and 35 experience at least one of five major potential barriers to employment—low basic skills, substance abuse, a physical health limitation, clinical depression, or a child with a chronic health problem. They estimate that almost half of welfare recipients experience a severe form of one of these barriers. Low basic skills is the most common of these barriers—about a third of welfare recipients score in the bottom decile of the women's distribution of the Air Force Qualifying Test (AFQT), and another third score in the 10th to 25th percentiles.

About 10 percent of welfare recipients report having physical health problems that prevent them from seeking work; 22 percent report being depressed over 3 days a week; 5 percent report a serious drinking problem; 9 percent report heavy cocaine or crack use either currently or at some point in their life; and 21 percent have a child with a chronic medical condition. Of these various barriers, low basic skills appears to be a particularly strong barrier to employment—only 44 percent of welfare recipients who score in the bottom decile of the AFQT report working at all in the current or previous year.

Olson and Pavetti note that while welfare recipients with barriers to employment often work despite these barriers, these recipients seldom work for a full year. Of welfare recipients who worked despite having a serious barrier to employment, only 11 percent reported working the entire year. Olson and Pavetti suggest that a particularly at-risk group of welfare recipients are those that have a potentially serious barrier to employment and have no recent work experience. About a quarter of the welfare population fits this description. Further, because welfare recipients with serious barriers to employment seldom work throughout the year, Olson and Pavetti estimate that half of the welfare population will need fairly intensive levels of services if they are to fare well over the long-term.

All of this suggests that it will be very difficult for a fair proportion of welfare recipients to maintain employment. Realistically, it will be extremely difficult for all welfare recipients to attain self-sufficiency, and perhaps the key issues as welfare reform plays itself out over the next few years are what proportion of welfare recipients may not be able to become self-sufficient and how States and the federal government deal with these persons and their children.

To maximize the proportion of welfare recipients who maintain employment, there are four elements that can be built into welfare-to-work programs. First, there probably needs to be strong case management component that provides follow-up serv-

ices for at least two years. Butte County has perhaps the strongest results in the California GAIN evaluation, and its program has a strong emphasis on case management. Second, part-time jobs may be a good compromise for welfare recipients who cannot maintain a full-time job. Third, work experience in the non-profit sector may also be appropriate for welfare recipients not ready for employment in the private for-profit sector. Finally, welfare-to-work programs could include a health component to address physical, mental, and family health problems that are barriers to sustained employment.

UPDATE ON WELFARE-TO-WORK

Question. Concerns have been raised that placing welfare recipients in jobs would hurt the working poor. What is your assessment of this problem?

Answer. We do need to be sensitive to the effects of welfare reform on the low wage labor market, but it is likely that the low wage labor market will be able to absorb the numbers of welfare recipients entering it.

—In addition, we anticipate that creative State and local efforts (spurred by the broad flexibility of welfare-to-work (WTW) grants and the additional resources they are expected to leverage) will produce new and sustainable relationships (in areas such as public housing, transportation, child care and other support services) which will benefit the working poor as well as welfare recipients. Many innovative welfare reform efforts have already extended child care to the working poor to reduce the high marginal tax rates on low income individuals leaving welfare.

—Both the Earned Income Tax Credit and transitional benefits such as child care, health care and transportation assistance can ease the difficult move into self-sufficiency. One of the assumptions of transitional benefits is that earning progress and job-related benefits will lessen the need for the transitional benefits.

—The Department of Labor will encourage service providers, employers and other interested parties to avoid having low-wage American workers displaced by those who are hired from the welfare roles. Current low-wage workers need opportunities to acquire the skills necessary to move up the career ladder and make room at the entry level for job candidates who are on welfare.

—Making this kind of room is the result of extensive job development not only for entry level jobs but for jobs on the rungs just above the working poor.

—The Department and our State partners are taking steps to ensure that the products under America's Labor Market Information System (ALMIS) are available to welfare recipients and the working poor. One-Stop Career Centers and employment service offices have a strong network of contacts with employers providing jobs in the initial third of the labor market.

Question. The Department recently issued a solicitation for the competitive grant process. Could you explain how much money is available, who is eligible to apply, and what is the expected outcome from these grants?

Answer. The amount of money for the competitive grants is 25 percent of the total appropriation, after the set asides (for the Indian program, the Health and Human Services (HHS) evaluation, and, in fiscal year 1999, the performance bonuses to States) have been taken out. In fiscal year 1998, there is a total of $368.25 million, split between two separate solicitations. In fiscal year 1999, there will be approximately $343.25 million, split between two or more solicitations.

—Eligible applicants include Private Industry Councils (PIC's), political subdivisions (cities and counties), and private entities, which can include community development corporations, community-based and faith-based organizations, disability community organizations, community action agencies, and public and private colleges and universities. Private entities are required to apply "in conjunction with" the PIC or political subdivision. [Note: Public colleges are included as private entities for the purposes of this program].

—In addition to the general performance goals set forth for the overall WTW program (the primary being placement of individuals into unsubsidized jobs with good career potential for self-sufficiency) the expected outcomes of the competitive grants are two-fold—

  —First, these grants are targeted to the special needs of local communities. While WTW formula grant funds are distributed according to a general formula applied across the country, competitive grant funds are meant to address issues specific to local areas, as described by the community in its grant applications.

  —A second major goal particular to the competitive grants is expansion of the knowledge base on effective welfare-to-work strategies. Innovation is an im-

portant factor in evaluating competitive grant applications. Replication and dissemination of best practices will be a critical activity for the Department and its grantees.

Formula Grants

In regard to WTW formula grants, the majority of States are very eager to begin implementation. As of March 18, twenty State plans had been received. The Department of Labor and Health and Human Services Regional Offices continue to work closely with States to provide assistance in developing their plans. Since States are at various stages of readiness, the Department will continue to accept formula grant plans until June 30, 1998.

Most of the States who have not yet submitted plans will do so, once they are able to complete their State and local planning processes and establish the appropriate linkages and partnerships necessary.

Question. I've also heard that not all States have submitted plans for the formula funds. Could you explain why some States have opted out of the program?

Answer. To date, very few States have informed the Department that they will opt out of the WTW program in fiscal year 1998. These States are, for the most part, small Western States with relatively low welfare caseloads. They have told the Department that they feel they can effectively serve their welfare caseload with the funds available to them under the Temporary Assistance for Needy Families (TANF) program. These States have also indicated that they may be interested in participating in fiscal year 1999.

Question. What impact has welfare reform and the welfare-to-work initiative had on the workforce development system? Are they working together or competing?

Answer. DOL anticipates that welfare reform will put more pressure on States and local areas to use JTPA funds to serve higher proportions of welfare recipients relative to other JTPA target groups. However, it is still too early to pick up such changes in administrative data. It also is much too early to tell how the welfare-to-work initiative will affect the broader workforce development system. DOL expects that welfare-to-work efforts will complement rather than compete with the broader workforce development system because in many local areas the same agency will operate both the JTPA and the WTW programs. Currently, 63 percent of low income adults and 57 percent of JTPA's welfare recipients who leave the program are employed three months later, although half of the welfare participants have little if any work experience at program entry.

Although administrative structures and levels of integration vary across States, the workforce development system has been working hard to incorporate welfare reform into its services structure. The Interstate Conference of Employment Security Agencies (ICESA) recently conducted a survey that indicated that:

—In almost two-thirds of States, Employment Security Offices have agreements with welfare/social service agencies to provide employment services to job ready welfare recipients.

—At least three States have enacted major legislation to put workforce development and welfare within the same agency.

—Many other States indicated that they are planning to integrate services through their One-Stop system, and the majority have established Human Resource Investment Councils to integrate a variety of workforce and welfare programs and services.

—Given the emphasis at the Federal, State and local level directed towards system integration, coupled with the flexibility provided by WTW grants, we see the workforce development and welfare infrastructures moving towards seamless service provision versus client competition.

SUCCESS OF WELFARE-TO-WORK

Question. The new welfare law provides a total of $3 billion over the next three years to help transition public assistance recipients into self-sufficient wage earners. Is this funding, coupled with existing Job Training Partnership Act resources, going to be enough to reach the requirement that 50 percent of adult welfare recipients obtain jobs by the year 2000?

Answer. The 50 percent requirement you refer to appears to be the ''minimum participation rate'' of all TANF participants in work mandated in section 407 of the Act. The 50 percent participation is applicable in fiscal year 2002 and after. Minimum participation rates for fiscal year 2000 and fiscal year 2001 are 40 percent and 45 percent, respectively. The $3 billion available for WTW in fiscal years 1998 and 1999 are targeted at helping some of the hardest to employ TANF recipients successfully make the transition from welfare to work. These resources alone, or coupled only with JTPA resources, are not, nor were they intended to be, sufficient to

achieve the 50 percent participation rate. Success in this area is dependent on a comprehensive strategy which utilizes WTW, JTPA, and TANF resources combined with TANF maintenance of effort resources, WTW matching funds, and other community resources to successfully move individuals from welfare to productive employment.

Question. What happens after the year 2000, when the Welfare-to-Work program terminates, but States are still required to transition 50 percent of welfare recipients into jobs?

Answer. Because WTW funds are available for expenditure for a three year period from the date provided to a State, the WTW program will continue to operate at some level in most States through fiscal year 2001.

PERFORMANCE BONUS

Question. The welfare reform legislation sets aside $100 million in "bonuses" to be distributed to States in fiscal year 2000 for successful performance. What criteria have been established on the basis for awarding performance bonuses?

Answer. The Department has not yet finalized its performance bonus criteria but will do so before the August 1998 deadline. Performance bonus criteria will, as the statute and regulations require, be based primarily on the success of WTW programs in placing participants in unsubsidized employment, retention of participants in employment for at least 6 months, and participant earnings gains.

Question. How do you intend to insure that States don't substitute federal welfare-to-work grant funds for activities that would otherwise have been supported with State and local funds?

Answer. A number of provisions are included in the statute and WTW regulations which guard against such substitution of federal funds for already existing State and local program funding. First of all, the WTW program requires the expenditure of $1 in State or local funds on allowable WTW activities for each $2 in WTW grants funds received by a State. Second, the statute and WTW regulations limit the use of WTW funds to the provision of services which are not otherwise available in the community. Finally, the statute and WTW regulations prohibit the use of WTW grants funds or funds used as match for WTW grants funds as match for other federally-funded programs. The Department believes these safeguards are sufficient to guard against the substitution of WTW grants funds for pre-existing State and/or local program funding.

EVALUATION

Question. Critical to successful implementation of a welfare-to-work program is evaluation of what is effective, and making changes to improve performance. What efforts are being taken to make sure there is an effective monitoring and evaluation system for the Welfare-to-Work program?

Answer. The Department will assign a Grant Officer's Technical Representative (GOTR) to be responsible for monitoring of and technical assistance to each WTW formula and competitive grantee. Most of these GOTR's will be located in the regional offices. All GOTR's will be thoroughly trained in their responsibilities. In addition, the Department is developing programmatic and financial/administrative management review guides to aid GOTR's in monitoring WTW programs. Finally, the Department has worked closely with the Department of Health and Human Services (HHS) to develop a comprehensive approach to evaluating the effectiveness of the WTW program.

Question. The degree of this program's success may also depend significantly on what you decide to measure as indicators of success. What emphasis do you plan to put on going beyond the simple measures of "persons served" and "placed in jobs", to stress the quality of jobs, retention and employment, and increased earnings?

Answer. The Department is committed to measuring the success of the WTW program based on outcomes rather than process. To that end, job retention, increased earning and other similar measures will be important factors in evaluating the program.

Question. The welfare law places primary responsibility for performance data reporting with the Secretary of Health and Human Services. What impact has the Labor Department had on developing data to be collected from States?

Answer. The Department is working closely with HHS and OMB to develop the data collection/reporting strategy for the WTW program.

Question. What data collection issues remain to be resolved?

Answer. Outstanding issues include agreeing on the precise data elements to be collected and how the data flow from the grantee to the federal level.

Question. Madam Secretary, the Welfare reform legislation gave you responsibility to implement the $3 billion work program, but gave the Secretary of Health and Human Services responsibility for data collection and evaluation. Is this assignment of evaluation responsibility to HHS a concern to you?

Answer. It is very rare for one agency to have responsibility for program operations while another agency is responsible for the evaluation of the program. I am confident, however, that the two Departments can work together on this.

Question. What role does the Labor Department have, working with HHS, to monitor and evaluate the welfare-to-work effort?

Answer. In addition to the longitudinal analysis planned by HHS in its national evaluation, HHS invited staff from DOL as well as other agencies affected by welfare reform such as Housing and Urban Development (HUD) to be part of the overall team designing the welfare-to-work evaluation. DOL's Assistant Secretary for Employment and Training met with HHS Policy and Evaluation administrators on the design of the evaluation. DOL's Assistant Secretary and staff also have worked closely with HHS in resolving evaluation issues with OMB. DOL included in its competitive Welfare to Work grant announcement bonus points for local sites willing to be part of the random assignment component of the HHS evaluation.

Question. Will the evaluation system provide data on how many former welfare recipients achieve economic self-sufficiency?

Answer. In addition to the longitudinal analysis planned by HHS in its national evaluation, HHS is providing competitive grants to a number of States to provide follow-up data on persons leaving the welfare rolls. This will include data both on persons who leave welfare on their own, and persons who reach welfare time limits. States will provide matching funds for such grants and will design their own follow-up data collection.

AMERICA'S JOB BANK

Question. I have heard such great reports about the success of America's Job Bank, an Internet site that allows the public to look at what jobs are available throughout the country. How are you building on this success to meet the growing demand for this type of information?

Answer. America's Job Bank (AJB) has been achieving solid month to month gains in job seeker and employer usage. The Department projects that approximately 55 million accesses to the AJB website will be recorded in March 1998, easily eclipsing the previous monthly high. With daily access to over 750,000 jobs, the AJB ranks as the largest Internet job bank in the world. Increasing numbers of firms are placing job orders on the service, with growth rates between 10 percent and 30 percent registered each month in the number of listed job vacancies. Some large employers, including IBM and NationsBank, have begun placing all of their job openings on AJB.

A long-standing Federal-State partnership recognizes the tremendous potential of the Internet to improve the functioning of the nation's labor markets. Working closely with the State Employment Security Agencies, the Department has developed America's Talent Bank (ATB) under the One-Stop initiative. Through the Internet, job seekers can post their résumés from One-Stops and other publicly-funded institutions (community colleges, public libraries) or from home. In April 1998, a new version of AJB will integrate the ATB. Under this combined system it will be easier for job seekers to apply for employment.

Two other initiatives also should be mentioned. Customers who desire information on the operation of local, State, regional and national labor markets can access America's Career Information Network (www.acinet.org). The Department is also beginning the development of America's Learning Exchange (ALX), which should help support the investment in new skills the nation will need in the next century.

LEARNING ANYTIME, ANYWHERE

Question. Explain the Administration's "Learning Anytime, Anywhere" initiative. I know that ED has the lead, but what is DOL's component?

Answer. The Administration's Learning Anytime, Anywhere initiative emphasizes the use of new technologies to improve postsecondary learning by increasing access to education and training, and improving program quality. This initiative will make it easier for Americans who live in remote rural areas, and have a disability, or cannot take advantage of traditional learning because of competing family and work demands to access quality learning "anytime, anywhere." This initiative requests funding for both the Department of Labor ($10 million in fiscal year 1999) and the Department of Education ($30 million in fiscal year 1999).

The overall leadership for this initiative is coming from the National Economic Council and the Office of Science and Technology Policy. The initiative has the following broad objectives:

—To enable adult learners to find information easily on the skills they need to advance in or change careers, and compete for higher-wage jobs.

—To expand opportunities for lifelong learning for all adults by creating pathways for them to tap into learning on demand delivered by a variety of institutions using new technologies such as the Internet, CD–ROM, interactive TV, and satellite.

—To advance the use of technology through the use of existing grants, loans, and tax credits in the learning on demand environment.

Under the Department of Education's (ED) proposed Learning Anytime, Anywhere Partnerships, ED will offer competitive grants to foster the development of high quality learning content where new learning technologies are used as a means for delivery. In addition, ED has proposed in its Higher Education Act authorization to broaden opportunities for distance learners by expanding institutional and student aid eligibility, eliminating the different treatments in cost of attendance between distance learners and on-campus learners, while ensuring quality through accreditation.

The Department of Labor's (DOL) primary responsibility under the Learning Anytime, Anywhere initiative is to develop an Internet-based component of America's Labor Market Information System (ALMIS) that would serve the same "public broker" function for the training market that America's Job Bank (AJB) and America's Talent Bank (ATB) currently offer for the labor market. This new service, known as America's Learning Exchange, or ALX, would fulfill two primary functions: (1) to serve as a public conduit for information about, and access to, education and training resources, and (2) to foster the emergence of a coherent, efficient electronic marketplace for these resources. ALX has five primary customers: individuals, employers, education and training providers, education and training developers, and workforce development professionals.

Secondarily, the DOL is also working with the Department of Defense to advance their Advanced Distributed Learning initiative and to move new learning technologies, e.g., the Intelligent Tutors, developed in Defense laboratories into use by the public workforce development system.

Several Federal Departments and agencies are involved in this initiative. The Department of Education is working to remove restrictions on Pell grants for use in a distance learning environment, and, if their budget request is approved, will offer challenge grants to foster the development of high quality learning content where new learning technologies are used as a means for delivery. The Department of Defense is pursuing a procurement strategy to foster a new training development environment, Advanced Distributed Learning, which is based on creating the capability to combine and recombine basic training building blocks, called learning objects, using metalanguage descriptors. The National Science Foundation, as part of their Advanced Technology Program, is offering challenge grants to develop new learning technologies.

Question. How will this initiative be managed?

Answer. The approach agreed upon to develop ALX, similar to that used successfully to develop other ALMIS products, was to form a consortium of States and other organizations which had aligned interests. Minnesota agreed to lead such a consortium, and it was formed at an initial meeting in the summer of 1997. It has met four times since then, and now includes representatives from 16 States, 2 Job Training Partnership Act Service Delivery Areas, 5 nonprofit organizations, and 3 Federal agencies. Additional partners are being sought. The ALX Consortium is augmented by a core staff component: 2½ full time Federal staff on detail from the National Occupational Information Coordinating Committee and 4½ full time contract staff paid for by Minnesota.

The Consortium is organized into five operating committees: Design, Content, Taxonomy, Collaboration, and Marketing, each addressing a different substantive component of the initiative. To ensure effective management and coordination of the project, there is also a Planning Committee, composed of consortium core staff, the lead person for the Federal partner, the lead person for the State partner, and the Chairs of the five committees. Workplans have been developed for each of the five operating committees.

The Consortium has also established a virtual workspace on the Internet (www.excelgovt.org). This space is being hosted by one of the Consortium's non-profit partners, the Council for Excellence in Government. In it, Consortium members can take part in "threaded" topical discussions, post documents for comment and input, and send or receive e-mail from any member or all members of the Consor-

tium. Additionally, there are monthly working meetings of the full Consortium and weekly conference calls of the planning committee.

STIGMA OF WELFARE RECIPIENTS

Question. I share your concern about the stigma that is often attached to welfare recipients. That is why Congress established tax incentives for employers to hire former recipients. Nevertheless, based on HHS data, a large portion of welfare recipients are over 40. Many former recipients may face other cultural biases such as age discrimination. How does the Department expect to monitor these cases?

Answer. Both the WTW statute and the implementing regulations contain nondiscrimination protections for WTW participants. For example, all WTW participants are covered by Federal, State and local laws prohibiting discrimination including: The Age Discrimination Act of 1975; Section 504 of the Rehabilitation Act of 1973; The Americans with Disabilities Act of 1990; and, Title VI of the Civil Rights Act of 1964. Complaints alleging discrimination in violation of any applicable Federal, State or local law will be processed in accordance with those laws and the implementing regulations. Questions or complaints alleging discrimination in violation of the laws enumerated above may be directed to the Civil Rights Center in the Department. In addition, the regular program monitoring of State and local operations, which will be conducted by our regional office staff, will be able to identify cases of discrimination.

SCHOOL-TO-WORK

Question. Some parents and interested groups are concerned that school-to-work programs steer students away from college and tracks them into specific jobs. What evidence do you have to the contrary?

Answer. School-to-Work (STW) is designed to enhance any student's education regardless of whether they're going to college or straight to the workplace. The STW initiative stresses academic achievement, preparation for college, and exposure to a wide variety of career options. It is designed to broaden opportunities for students. Internships help students understand the relevance of academic subjects and how to apply academic concepts at work and in everyday life. Mentors share knowledge, focus, and commitment to one's work while they provide extra adult support and encouragement to students. Local STW partnerships of parents, employers, community organizations, and educators work together on school improvement and enriching programs for out-of-school youth.

Initial evidence from local communities suggests that schools that have adopted school-to-work principles have experienced increased attendance, reduced drop-out rates and increased college admission among students. STW learning experiences help students gain a realistic appreciation for what a "day in the life" of a career/occupation is really like, which aids in college planning and making better decisions about postsecondary education. Adria Steinberg writes in the March 25, Education Weekly, "not surprisingly students in such [STW] programs often identify the internship, and their connection to adult mentors outside of school, as providing them with their most meaningful, and rigorous, learning experiences".

We can look to one of the first school-to-work initiatives, Boston's Pro-Tech program for early evidence. Sixty-nine percent of Boston's Pro-Tech class of 1995 went on to college as opposed to 51 percent of students in Boston's public schools overall. In Philadelphia, the graduation rate (from high school) of STW students was 97.6 percent, compared to 85.8 percent of other students in the district. Good School-to-Work systems have become "better college prep than college prep" according to Robert Riordan of The Big Picture Company (a network of urban schools).

Question. What steps is the School-to-Work Office taking to ensure parents that school-to-work programs won't preclude or discourage their children from going to college?

Answer. Through technical assistance, grant monitoring, and public outreach, the National STW Office works closely with State and local grantees to ensure that the objectives of the Act are met. This includes making sure that partnerships designing State and local STW systems represent all appropriate parties including secondary and postsecondary educators, employers, parents, community leaders, students, and others who are concerned about the education and future of our youth. These partnerships are in place to develop and implement STW efforts that reflect local needs and community values.

Question. The School-to-Work Opportunities Act aims to provide "seed money" or "venture capital" to leverage funds from private and public resources to promote broad-based school reform. Are you concerned that federal funds are not leveraging

sufficient non-federal funds to sustain school-to-work programs as federal support declines and ends?

Answer. States have been strongly encouraged over the past four years to consider how existing federal, State and local funding can support School-to-Work once their five-year implementation grant ends and/or the School-to-Work Opportunities Act (STWO) sunsets. In the first year after the STWO Act became law, data from the first eight States (implementing STW) indicated that for every Federal dollar invested, $2 was leveraged from other public and private funds. These included new contributions, funds redirected from other programs, or in-kind contributions, such as staff or facilities. The next assessment on funds leveraged from public and private sources will be made in late Spring 1998, when data from the latest Progress Measures survey (the instrument used to collect this information) will be available. This survey is expected to include responses from the 37 States that have had implementation grant funding for at least one year.

Nevertheless, the leveraging of sufficient non-STW funds to sustain a fledgling system is a significant challenge. Implementing STW is a complex task, and significant time and resources are required to create sustainable systems that support education reform, workforce development, and economic development. The Departments of Education and Labor will work closely with all States to support their efforts to develop strategies for sustaining their STW initiatives. Our most pressing priority now is to ensure sustainability in the eight States who are entering the last year of their implementation grant in 1998. We will keep the Congress apprised of these efforts.

YOUTH OPPORTUNITY INITIATIVE AND JOB CORPS

Question. Madam Secretary, we understand one of your top priorities in the coming fiscal year is to create opportunities for out-of-school youth through the Opportunity Areas for Out-of-School Youth program. We know there is a tremendous need to address the training and employment needs of young people who are no longer part of the mainstream—and this Committee included $250 million in the Department's fiscal year 1998 funding for this program, if it's authorized.

Can you share with us how you see the Job Corps program working in concert with this initiative? What role does the Department see for Job Corps in the Opportunity Areas for Out-of-School Youth program?

Answer. The Job Corps program and the new Opportunity Areas initiative will have an interactive relationship that will include several elements. First, Job Corps outreach/admissions counselors will conduct active recruitment in Opportunity Area program sites, making presentations to parents, guardians and potential participants and discussing the opportunities for training and post-program job placement through Job Corps. Second, Job Corps students who are unable to complete their Job Corps training and whose homes are in communities where an opportunity area program operates will be referred to that program. Third, non-residential Job Corps programs located in communities where opportunity area programs operate will offer enrollment opportunities for eligible youth, allowing them to live at home while participating in education and training.

JOB CORPS EXPANSION

Question. Madam Secretary, in fiscal year 1998 this Committee supported the appropriation of $4 million to begin the site selection process for the continued expansion of Job Corps. We are pleased to note that the Department acknowledged the Committee's request and has asked for an additional $33 million in fiscal year 1999 to continue this process and establish 5 new facilities. Madam Secretary, can you share with us the Department's long-term plans for the incremental expansion of Job Corps?

Answer. Because Job Corps has a proven track record of effectiveness in serving this Nation's most at-risk youth, the Department hopes to continue to expand the program on an incremental basis over the next several years. We are not in a position to quote specific numbers at this time, but I can assure you that each year we will explore the feasibility of increasing Job Corps capacity and enrollment levels, while ensuring that the quality and effectiveness of the existing program is maintained.

WORKER PROTECTION LAWS

Question. During last year's debate on the Welfare-to-Work initiative, there was a great deal of discussion about applying worker protection laws to the welfare-to-work program. How are States dealing with the reality that the Fair Labor Standards Act does apply to these jobs?

Answer. States are successfully creating employment activities for welfare recipients, including work experience, that comply with provisions of FLSA.

To this end, in May 1997, prior to the implementation of the WTW program, the Department provided guidance to the States concerning how the Fair Labor Standards Act (FLSA) applies to welfare recipients. Names of regional contacts from the Employment Standards Administration (ESA) were also provided to the States to answer questions and provide technical assistance.

Question. What assistance is the Department providing to States to meet the requirements of the Fair Labor Standards Act as States move welfare clients into work experience?

Answer. During the implementation of the WTW program, the Department increased its technical assistance efforts to States to assist them in developing WTW State formula plans which comply with the provisions of FLSA. In addition to the on-going guidance and assistance from regional contacts, the Employment and Training Administration (ETA) maintains a continuously updated Internet home page on WTW which includes answers to commonly asked questions such as "How does FLSA apply to WTW participants?". Regional WTW training sessions also were provided to State staff on the WTW regulations and program design and included presentations and materials from ESA staff concerning the applicability of FLSA. Following the training sessions, as States began developing their plans for the State formula grant program, ETA regional staff with the assistance of staff from ESA have worked successfully on a one-to-one basis with several States to create WTW program designs that assure compliance with FLSA.

UNEMPLOYMENT INSURANCE INTEGRITY ACTIVITIES

Question. You are asking for $91 million to strengthen the integrity of the Unemployment Insurance System, which you say will save well over $100 million in 1999 alone. What specifically would these funds be utilized for, and how did you arrive at your savings estimate?

Answer. The fiscal year 1999 President's budget request for enhanced integrity activities includes additional funding for the following functions: Eligibility Review Program (ERP), Benefit Payment Control (BPC), Tax Field Audit, and detection of separation issues.

The Department estimates that this investment will save trust fund dollars of about $120 million in fiscal year 1999, and about $160 million annually in the outyears. The savings will accrue from additional investments in: detection and collection of benefit overpayments, ensuring proper eligibility for UI benefits at the beginning of a claim, work search review, and collection of taxes.

Data show that attention to four integrity activities: tax field audits, eligibility reviews, benefit payment control, and separation issue detection, has eroded over time. The savings estimate was developed by examining each of the integrity activities and determining the amount of funds which could be retrieved or retained in the trust fund given the addition of resources to the activity.

For example, according to available information a determination can be made as to the average reduction in benefit payments due to errors detected in an eligibility review. Knowing how many eligibility reviews a reviewer can make per year, the savings per additional reviewer was calculated. Given average salary rates and the total dollars available for eligibility reviews, the number of additional reviewers was computed and the result multiplied by the savings per reviewer to calculate the savings attributable to the additional ERP's. Similar calculations were made for each of the other categories and in all cases conservative assumptions were used.

The $91 million figure was authorized in the Balanced Budget Act of 1997. For the purpose of determining savings from each of the four integrity activities, the $91 million was allocated among the four categories in the proportion to the amounts allocated in the fiscal year 1997 base grant. Thus, the savings calculation is conservative since States will in fact be able to target their funds in activities with the biggest payoffs.

REQUEST FOR CHILD LABOR INITIATIVES

Question. Your budget proposes $37 million for child labor initiatives, of which $27 million is for overseas activities. Shouldn't we be spending more to correct child labor problems here at home than in foreign countries?

Answer. As background, the Administration's Child Labor initiative includes the following four components: (1) $30 million for international programs against child labor, including the increase of $27 million identified above; (2) $50 million for the Migrant Education Program; (3) $5 million for a JTPA Migrant Youth Job Training

demonstration program; and (4) $4 million to increase enforcement of child labor laws in the agricultural sector.

This Administration is dedicated to fighting abusive child labor wherever we find it, here at home as well as around the globe. In fact, this initiative is proof that we intend to step up our efforts here at home even as we are building upon and increasing existing efforts to eliminate abusive child labor worldwide. The President's child labor initiative comes to almost $90 million. Most of this budget, essentially two thirds of this request, is targeting at correcting child labor problems here at home.

According to ILO estimates, there are 250 million children between the ages of 5 and 14 youth working world-wide, of whom at least 120 million work full-time. Tens of millions of these children work under extremely exploitative conditions. The depth of this problem requires our increased level of support, and thus we hope to commit one third of our child labor initiative to helping the millions of children around the world being terribly abused in the workplace.

CHILDREN'S INITIATIVES

Question. You are requesting $9 million under the Job Training Partnership Act pilot and demonstration authority for a child labor initiative and an apprenticeship child care initiative. Please provide for the record a detailed description of how these initiatives would work, including the background justification for them.

Answer. Following are descriptions of the two initiatives:

Child Labor Initiative

In conjunction with the President's Child Labor initiative, the Department is requesting $5 million under the JTPA pilot and demonstration authority to foster new work and learning opportunities to help young migrant farm workers (ages 14–18) qualify for other job opportunities with career potential.

The justification for this request is straightforward. Agricultural work stretches the limits of child labor standards by requiring long hours of stoop labor and exposure to hazardous chemicals. Because of the pressing economic needs of migrant families, their young people must often work in the fields rather than attend school, resulting in high drop out rates. As generations of families stay in agriculture, the future of its youth is bleak: continuing poverty, low educational achievement and inability to progress in an increasingly technical workplace.

As a demonstration program, this initiative will allow us to test the efficacy of a combination of subsidized non-agricultural work experience and educational enrichment in expanding the horizons of migrant youth, breaking the generational cycle of migratory agricultural labor, and combating the violation of child labor statutes.

The demonstration will be geared specifically to the special needs of farmworker youth. This will include an annual plan of action which will follow participants throughout the year. Through coordination and partnerships with schools and service providers across the country, participants will be provided with a planned sequence of work experience and educational enrichment opportunities as they follow their families through the migrant stream.

The educational enrichment component of the demonstration will utilize the School to Work approach of contextual learning. This integrates mentoring, "hands on" learning, and credentialing as supplements to traditional classroom instruction. The subsidized non-agricultural work experience component would focus on exposure to professional and technical careers (e.g., banking, teaching, health occupations, et. al.). This combination of educational enrichment and work experience would maintain the participants' contribution to family income and allow them to complete their requisite annual academic credits without the usual disruption that the migrant stream engenders.

After project implementation and completion (18–24 months), we expect an evaluation of outcomes and impact on the economic future of farmworker youth.

Child Care Initiative

On October 3, 1998, President Clinton hosted the White House Conference on Child Care to focus the nation's attention on the importance of addressing the need for safe, available, affordable quality child care. Also on October 3, Secretary Herman signed the Quality Child Care Targeting Agreement, which is designed to expand the utilization of the Registered Apprenticeship System by the child care industry.

The initiative is designed to provide the child care industry with locally-owned collaborative partnerships to establish a structured, formalized credentialed edu-

cational system for child care providers by utilizing the National Apprenticeship System.

Building on successful models will be one of the cornerstones of the initiative and to this end the Bureau of Apprenticeship's (BAT) West Virginia office has developed a very successful model for training Child Care Development Specialists. This child care apprenticeship statewide system incorporates training based on the 13 nationally recognized functional competencies of developmentally appropriate practices and experience. This and other models, like the Maine model, will be blended to meet the needs of those States that adopt the apprenticeship system of training for this occupation.

To facilitate the initiative, BAT will convene 7 to 8 regional meetings during fiscal year 1998 to introduce the concept and foster partnerships needed for implementation on a national basis. Each meeting will be broadly inclusive. Participants will include child care experts, apprenticeship representatives, health and human services providers, educational specialists, and other interested parties.

The major attributes of this initiative will begin in fiscal year 1998 with the concentration of building an infrastructure and local ownership of the statewide system. BAT will provide guidance, leadership, and technical assistance to the process every step of the way and act in the capacity of liaison to foster collaboration among all parties involved.

The fiscal year 1999 budget request includes $5 million for this initiative. $4 million will be utilized for seed grants in a variety of locations from urban to rural areas. With this request the Department can provide assistance to a minimum of 10 States during fiscal year 1999. An additional $1 million in the Program Administration account will be used for 10 FTE to address the increased workload associated with building a sustainable child care infrastructure.

By utilizing the apprenticeship strategy we have established a career path for child care providers that includes reduced turnover, increased wages, and potential educational opportunities.

The Department of Labor has been approached by Chrysler, Ford, and General Motors (GM) to expand the BAT child care program to their employees. This would be a collaborative effort between the corporations and the United Auto Workers (UAW) union. Because the corporations already have existing apprenticeship programs established in other fields, they are comfortable with the model. They would like assistance from DOL in using the apprenticeship model to train providers in an effort to expand and enhance existing on-site child care centers. GM's initiative would include 20 States while Ford's and Chrysler's would include 10 States each. Regional meetings with the corporations and the UAW are tentatively scheduled for late April or May.

BLS JOB VACANCY SURVEY

Question. The Department's request includes what appears to be the development of a new economic indicator, the vacancy survey. Could you explain why this survey is needed and how it can be used and by whom, and when it will be available? How does this proposal relate to the job vacancy survey initiative incorporated in last year's House report, which was intended to pilot test the development of local information about job vacancies at the local level?

Answer. Presently, there is no effective way for policy-makers to assess labor shortages in the United States. As a result, the existence of labor shortages can be inferred only indirectly using labor supply information, such as the unemployment rate. National data on job openings and labor turnover can serve as demand-side indicators of labor shortages. The availability of unfilled jobs is an important measure of the tightness of labor markets.

Development of job openings and labor turnover data at the National level would greatly enhance policy makers' understanding of imbalances between the demand and supply of labor. Job openings and labor turnover statistics considered in conjunction with information on unemployment also would be helpful to analysts and policy makers interested in monitoring wage rates.

High vacancy rates signal unmet demands for labor, just as high unemployment rates signal unused supplies of labor. Information on labor turnover would be of value, among other purposes, for diagnosing whether high or rising vacancy rates reflect increased difficulty in filling positions as opposed to increased hiring activity. Further, comparisons of the aggregate number of job openings to the number of unemployed persons can be expected to be useful in understanding increases or decreases in labor market mismatch. Estimates of the number of job openings by major industry group would enhance the diagnostic value of the vacancy information.

The survey plans call for the first publication of an experimental series in late 2001.

As we understand the pilot initiative undertaken by the Employment and Training Administration (ETA) based on last year's House report, it was intended to provide information on the number of vacancies by occupation at the local level for planning purposes.

While the BLS initiative included in this year's budget request is not directly responsive to the House report, BLS sees these two efforts as complementary and is committed to working with ETA to insure comparability to the extent possible.

STATUS OF WELFARE-TO-WORK COMPETITIVE GRANTS

Question. Of the $1.5 billion provided for the welfare-to-work program in fiscal year 1998, $368 million are for competitive grants awarded directly by DOL to localities and entities working with localities. A solicitation for the first round of grant awards was published in the Federal Register on December 30 and were due to DOL by March 10, 1998. Unlike the formula grants, which are to be administered at the local level by Job Training Partnership Act (JTPA) Private Industry Councils (PIC's), competitive grants may also be administered by cities, counties, other localities, and private entities. (While private entities are permitted to apply for welfare-to-work competitive grants, the requests for proposals states that profits are not an allowable use of grants.)

How would you characterize the responses you received for the first round of bids for competitive grants in terms of: (1) the number of responses, and (2) the types of entities that responded (e.g., PIC's, cities, rural counties, private entities)?

Answer. The Department received over 500 grants applications in response to the WTW competitive Solicitation for Grant Applications (SGA) that closed on March 10. Applications were received from almost every State in the country and from all of the types of organizations identified as eligible in the SGA, including PIC's, cities, counties, community-based, faith-based and other nonprofit organizations, private for-profit organizations, private employers, transportation and housing authorities, and private employers.

Question. Were the PIC's that responded in States that also have or intend to apply for formula grants?

Answer. Proposals were received from PIC's in States who have received or are planning to apply for formula grants, as well as in States that have opted out of the formula program in Program Year 1998.

Beyond these general characteristics, there is no information available at present regarding the types of applicants who applied for funding in this round. At present, the Department is in the process of evaluating the applications. We expect this process to be completed by the end of April.

Question. Why did DOL, in its request for grant proposals, prohibit "profits" as an allowable use of funds when the law permits for-profit entities to participate in the welfare-to-work competitive grant program?

Answer. The Department views WTW competitive grants as an opportunity for private for-profit entities to collaborate with non-profit organizations as well as public agencies to provide effective services for hard-to-employ welfare recipients. To a certain extent, competitive grant funds will subsidize the normal research and development activities of for-profit entities, enabling them to test experimental employment strategies at no cost to themselves. For-profit entities are welcome to use the knowledge and experience they gain in profit-making enterprises funded through other sources, but the Department feels it is reasonable to disallow the earning of profit on competitive grant funds.

Question. How would you estimate the effect of this prohibition on the response rate of for-profit entities?

Answer. During this first round of grant solicitation, the Department received some questions as to the disallowance of profits under competitive grants. We received no indication, however, that private for-profit entities chose not to apply as a result of the prohibition on profit. Since applications from private for-profit entities were received by the Department, we must assume that the impact of the prohibition was minimal.

Question. What percent of responses were from for-profit entities?

Answer. As indicated above, we have not yet performed an analysis of the types of applicants and grant applications received. We expect to be able to perform this analysis by the end of April.

HEALTH AND HUMAN SERVICES DATA REPORTING

Question. Under the 1996 welfare reform law, States are required to report case-level information for families receiving assistance under the Temporary Assistance to Needy Families (TANF) program, including their characteristics and benefits and services they receive. The Balanced Budget Act, which added the welfare-to-work program to the new TANF program, also added some data elements to describe welfare-to-work services by TANF families served with welfare-to-work funds. These data are to be reported to the Department of Health and Human Services (HHS). However, the law requires HHS to consult with the Department of Labor in defining these data elements. This data report is separate and different from the data reporting system under the JTPA.

Has HHS consulted with you concerning data collection for the welfare-to-work program? Please describe the nature of the consultation.

Answer. The Department is working closely with HHS and OMB to develop the data collection/reporting strategy for the WTW program. Outstanding issues include agreeing on the precise data elements to be collected and how the data flow from the grantees to the federal level.

Question. What type of coordination between the State agency administering the TANF program and the local PIC's is required to collect welfare-to-work data?

Answer. Coordination between the PIC's, the State WTW administering entity and the State TANF administering entity will be required in order for the data to be reported to HHS. We do not expect the DOL/HHS reporting instructions will mandate a particular organizational structure within which this coordination must occur. States will have the flexibility to develop reporting systems that best meet State and local needs, within the statutory requirements.

Question. Do you have any concerns about the ability of the States and the local PIC's to coordinate and collect these data?

Answer. The Department does not have major concerns about the ability of the PIC's, other local entities, and the States to collect and report WTW data. The PIC's and most State WTW agencies have for many years worked closely together to administer and report on the JTPA program. We expect the system to draw on this experience to minimize WTW reporting problems.

Question. When will you have and expect to make available data on welfare-to-work recipients?

Answer. Only about 20 States have begun operating the WTW program by the end of the January-March quarter. Most of the activity in these States has involved program start-up. As a result, the Department does not expect significant financial or program data to be reported until the end of the April-June quarter. As reports are due 45 days after the end of a quarter, data will not be available until September or October, 1998.

OUTCOME DATA

Question. The interim welfare-to-work regulations permit, but do not require, PIC's to voluntarily submit information about welfare-to-work recipients under the JTPA data reporting systems. This is outcome information at the time a recipient leaves the program. The voluntary submission would be in addition to information required under the TANF data reporting system, which is caseload information while a recipient is in the program. The interim regulations note that the DOL may require the submission of outcome information in the future.

Why did DOL decide not to require PIC's to submit outcome information through the JTPA reporting system for welfare-to-work recipients?

Answer. The interim final WTW regulations indicated that the Department would pursue modifications to the Standardized Program Information Report (SPIR) to permit PIC's to use this reporting system for internal management purposes. However, the SPIR, as a termination based reporting system, cannot be used in its current configuration as a vehicle to report the transaction-based information required for the WTW program. We are working closely with HHS and OMB to develop the optimal reporting system for WTW recipients.

Question. Will DOL obtain outcome information on the program? If so, how?

Answer. DOL will obtain outcome information from the participant data reporting system being developed jointly with HHS.

Question. How useful will the voluntarily reported data be to DOL in determining how to improve the program since some PIC's will be reporting it while others will not?

Answer. The Department is exploring modifications to SPIR to permit its use by PIC's for internal WTW management purposes. Data for program improvement and evaluation purposes will be reported through the official WTW reporting system.

Question. How will the effectiveness of the program be evaluated?

Answer. The evaluation of the welfare-to-work program will encompass extensive implementation reports covering both year one and year two administrative data on participant characteristics, services received, and wages at placement. The data will be generated through indicator surveys of all formula and competitive grantees and site visits to 35 programs. The evaluation will also include formal random assignment studies in eight to ten sites to determine the effectiveness of alternative types of employment and training services, and in-depth case studies of welfare-to-work programs in 13 to 15 sites.

Question. What are the respective roles of HHS and DOL in evaluating the welfare-to-work program?

Answer. Congress assigned the Department of Health and Human Services the responsibility for evaluating the Welfare-to-work program, in consultation with DOL and HUD. DOL staff have worked with HHS in designing the evaluation, and will continue to work with HHS through the implementation of the evaluation.

FINANCIAL DATA

Question. The interim final rule notes DOL will develop a form for financial reporting of welfare-to-work expenditures by States and localities. Welfare-to-work funds may be spent on work or work-related activities and supportive services.

Has the Department developed a form for reporting welfare-to-work expenditures by States and localities? What categories of expenditures will be on the form? Will there be a breakout of expenditures for work and work-related activities versus supportive services?

Answer. The Department has developed financial reporting instructions for both WTW formula and competitive grants, which will be issued shortly. The reporting instructions require expenditures for each allowable WTW activity (e.g. OJT, support services, post-employment services, administration) to be reported separately.

WELFARE-TO-WORK PERFORMANCE BONUS

Question. The welfare-to-work program includes a $100 million set-aside from fiscal year 1999 funds for a performance bonus for States that achieve success in their welfare-to-work programs. The law requires the Secretary of Labor to consult with the Secretary of the Department of Health and Human Services, the National Governor's Association, and the American Public Welfare Association to develop a formula for awarding these bonuses. The formula must be developed by August, 1998.

What consultations or activities has the Department undertaken toward the development of the formula for awarding welfare-to-work performance bonuses?

Answer. The Department is currently meeting with Health and Human Services, the National Governor's Association, and the American Public Welfare Association to develop a fair and comprehensive performance bonus system. In addition, a workgroup will meet this spring, and will include stakeholders, as well as federal, State and local partners representing employment and training, and welfare agencies. This workgroup will assess various measurement options and give us vital feedback on how to best award performance bonuses. We expect the performance bonus system to be in place by the statutory deadline, August 1998.

OPPORTUNITY AREAS FOR OUT-OF-SCHOOL YOUTH

Question. The fiscal year 1998 appropriation included $250 million in advance funding for a new Opportunity Areas for Out-of-School Youth (OASY) initiative for fiscal year 1999. (October 1, 1998 through September 30, 1999). This funding is contingent upon enactment of authorizing legislation by July 1, 1998. The program would award grants to high poverty communities to provide training and other assistance to out-of-school youth for the purpose of raising their employment rate. The President is requesting $250 million in advance funding for Program Year (PY) 2000 (July 1, 2000 through June 30, 2001).

In the DOL budget justification, you state that you are requesting an advance appropriation for OASY for PY 2000, so that it is consistent with JTPA programs (which are funded on a program rather than a fiscal year basis). However, funds from the current appropriation may be obligated only through September 30, 1999. Since PY 2000 starts July 1, 2000, it appears that the program would not be funded for the 9 month period of October 1, 1999 through June 30, 2000. Please explain this apparent gap in funding.

Answer. It is correct that we will experience a nine month gap in funding from October 1, 1999 through June 30, 2000. This switch to program year funding will make the funding consistent with the language contained in the pending workforce development legislation. As a result of this gap, we are planning on having the $250

million advance appropriation from fiscal year 1999 carry us for the entire first 21 months (the fiscal year plus the nine month gap) of the program. Due to budget restraints, we did not request an additional nine months of transition funding.

We expect to award the first round of multi-year grants (funded with the advance fiscal year 1999 appropriation) in March of 1999. The grant award documents will contain language clarifying that the second year of funding will not be available until July 1, 1999—giving the grantees a planning period of approximately 15 months.

Question. If you anticipate that fiscal year 1999 funds would be used to cover the period October 1, 1999 through June 30, 2000 (contingent on the provisions of authorizing legislation), then couldn't the program still be forward funded in the fiscal year 2000 budget, which could cover the Program Year July 1, 2000 through June 30, 2001?

Answer. Yes, the Opportunity Areas for Out-of-School Youth Initiative could be funded out of the fiscal year 2000 budget since we are planning on the fiscal year 1999 advance to carry the activities through June 30, 2000. However, it is critically important that we assure continued funding for this initiative. Therefore, we would not want this initiative "zeroed-out" in the fiscal year 1999 budget.

Question. If funds are needed for the period of October 1, 1999 through June 30, 2000, then wouldn't your request need to be for only 75 percent of the amount requested (i.e., $250 million)?

Answer. We will be able to stretch the fiscal year 1999 advance appropriation of $250 million over the initial 21 months of the initiative since it often takes grantees several months to begin full implementation. The advance fiscal year 2000 appropriation of $250 million is needed to finance activities from July 1, 2000 through June 30, 2001. This represents the full amount needed to finance the program year's activities, and the amount needed every year thereafter.

SUMMER YOUTH PROGRAM AND YOUTH TRAINING GRANTS

Question. The budget proposal would retain language allowing service delivery areas to transfer 100 percent of the funds appropriated to either SYEP or Youth Training Grants between the two programs. This language has been in appropriation bills since fiscal year 1996.

To what extent have service delivery areas taken advantage of the authority to transfer funds between SYEP and Youth Training Grants?

Answer. Service Delivery Areas have fully utilized the authority to transfer funds in their youth programs. Our data show that in 1996, States transferred about $130 million from the Summer Youth Employment Program to the year-round Youth Training Program. In 1997, preliminary data indicates that approximately $102 million was similarly transferred from the summer program to the year-round program. Only a handful of States did not use the transfer flexibility. We expect States to continue to make significant transfers inasmuch as they have been doing so since the year-round program was reduced in 1995.

Question. What kinds of improvements, if any, in the delivery of services to youth have you observed as a result of this authority?

Answer. The 100 percent transfer authority between the summer and the year-round program enables local operators to customize and integrate their programs to better meet specific needs, i.e., target groups, length of program, and number of youth served. The Department also believes that flexible funding between the two programs enables the States and localities to sequence services over a longer period of time. This specifically meets the needs of those with substantial skill deficits.

JOB CORPS ZERO TOLERANCE POLICY

Question. In PY 1994 the Department instituted its "Zero Tolerance Policy for Violence and Drugs". According to the Department's Job Corps Annual Report for Fiscal Year 1996, the dropout rate in PY 1995 increased to 38 percent from a fairly constant rate of about 31 percent in previous years as a consequence of full implementation of the policy. The Annual Report states that the dropout rate has leveled off at 34 percent in PY 1996 indicating a successful adjustment to the policy.

What is a reasonable dropout rate and why?

Answer. One must look at dropout rates in other programs to provide a context in assessing turnover rates in Job Corps. Data from the U.S. Department of Education's National Center for Education Statistics, published in 1992, showed a dropout rate for post-secondary, nine-month vocational certificate programs to be 49.5 percent. Further, in a report covering the 1992–93 school year, the Educational Testing Service indicates that one in four urban school districts experienced four year dropout rates of greater than 35 percent.

Another way to look at the same issue is to review findings of an impact evaluation by Abt Associates on four Youth Conservation and Service Corps programs funded under Subtitle C of the 1990 National and Community Service Act. The study was published in August, 1996. These were programs that were intended to improve the educational and employment prospects of participants and enhance their personal development. They served a population similar to Job Corps. The Abt Study found that only 33.3 percent completed the program, whereas the Job Corps vocational completion rate for students entering vocational training was 61 percent in PY 1996.

In these contexts, the Job Corps turnover rate compares well. It must also be kept in mind that nearly 80 percent of Job Corps students have already dropped out of the regular school system.

Question. What steps are you taking, if any, to reduce the dropout rate?

Answer. We understand that having some participants leave Job Corps within one or two months is a cost to the program and Job Corps must do what it can to minimize the extent to which it occurs. However, reducing the turnover rate is an extremely difficult challenge. The turnover rate has remained relatively constant in Job Corps since its inception. We have initiated many strategies in attempts to impact this particular area. These have included requiring applicants to sign letters of commitment, conducting behavior checks with the criminal justice system, identifying and addressing health issues, carefully assessing applicants' capabilities and aspirations to participate in Job Corps, assuring that child care needs are met, making sure that applicants understand Job Corps' policy of zero tolerance for drugs and violence, and thoroughly informing applicants about what to expect when they arrive at a Job Corps center. In May of this year we will be convening a conference with all outreach and admissions counselors to discuss these and other approaches to reducing the early dropout rate. Particular attention will be paid to strengthening the process of assessing an applicant's capabilities and aspirations, a primary concern identified in a recent GAO audit.

With respect to center programs, we have developed and implemented an intergroup relations program to accommodate the diversity that exists on Job Corps centers. We are also implementing a new social skills training program to teach students how to deal with anger and conflict, dress properly, get along with one another and work together in a team setting. A recently-instituted refinement to our occupational exploration program is designed to better match students with available vocational training. Taken together, these address factors which can contribute to students leaving centers early.

Question. One criticism of Job Corps has been that students do not always feel safe at Job Corps centers. Do you have any indication that as a result of the zero tolerance policy that students perceive Job Corps to be a safer environment?

Answer. The Office of Job Corps is committed to ensuring that students perceive Job Corps centers as safe places. According to a recent student feedback survey, 89 percent of Job Corps students nationally perceive their centers to be safe.

Question. What indication do you have, if any, that Job Corps has become a safer environment as a result of this policy?

Answer. Anecdotal information indicates that center staff believe that Job Corps centers have become safer environments as a result of the zero tolerance policy.

JOB CORPS TRAINING RELATED JOB PLACEMENTS

Question. According to the Department's Job Corps Annual Report for PY 1996, 62 percent of all students placed in employment found jobs that matched the training received in Job Corps. (In PY 1995, 53 percent of students obtaining employment were placed in jobs matching their training.) In its October, 1997 report on Job Corps, the General Accounting Office (GAO) stated that the training-related placement measure is flawed, because placement contractors have a wide latitude in deciding whether a job placement is a job-training match. The GAO report also states that Labor is developing a new system to more accurately determine job-training matches.

In light of the GAO criticism of the training-related placement measure, how would you assess the accuracy of your reported 62 percent training-related placement rate?

Answer. With regard to job training match (JTM), we share some of the GAO's concerns about how job training matches are determined. References were made by GAO as to the wide latitude and possible matches under the current job training match process. While such matches are possible, there are no empirical data to suggest they occur to any significant degree. GAO's examples of possible egregious matches were hypothetical only. We remain confident in the reported JTM data.

Question. What steps have you taken to more accurately determine job-training matches?

Answer. In accomplishing the objective of strengthening the JTM process, we will work with available coding systems. In this regard, and as acknowledged by GAO, Job Corps is moving to a new system based on the Occupational Information Network (O*NET) system. This replaces the current system which relies on the Dictionary of Occupational Titles and encompasses more than 14,000 codes. The new O*NET system will be more accurate, and easier to maintain and monitor in terms of egregious matches. The job training match issue is one of the primary projects addressed by the National Vocational Operations Committee, which was established by Job Corps to improve the quality of vocational outcomes.

GOVERNMENT PERFORMANCE AND RESULTS ACT [GPRA]

Question. How are the agency's annual performance goals linked to the agency's mission, strategic goals, and program activities in its budget request.

Answer. DOL's work is organized around three strategic goals which are outlined in the fiscal year 1999 Performance Plan. These goals bridge the Department's many agencies and programs linking them to the DOL mission.

Goal 1. A Prepared Workforce: Enhance opportunities for America's workforce.

Goal 2. A Secure Workforce: Promote the Economic Security of Workers and Families.

Goal 3. Quality Workplaces: Foster quality workplaces that are safe, healthy and fair.

For each of the three strategic goals there are supporting outcome goals in the fiscal year 1999 Performance Plan that refine and further focus the strategic goals. For each outcome goal, there are supporting performance goals that set specific and measurable target levels of performance for DOL Agency programs for the fiscal year. Linkage to the budget is provided in the DOL Annual Performance Plan by cross referencing DOL budget activities to the Department's three strategic goals. Specific linkages between individual Agency goals and program activities are provided in the individual Agency Performance Plans.

Question. Could you describe the process used to link your performance goals to your budget activities?

Answer. Our current efforts focus on assuring the Department's Annual Performance Plan has a well defined program structure supported by performance goals that capture the core purpose of each program or activity. We will then work with OMB to propose to the Congress appropriate budget restructuring recommendations. While the current budget structure aligns closely with our performance plan goals in many program areas, some budget program activities may have to be restructured to achieve the necessary alignment of programs, performance measures, and resources.

Question. What difficulties did you encounter and what lessons did you learn?

Answer. We have made significant progress in this area but much remains to be done. As noted above, we view GPRA implementation as an iterative process. Our fiscal year 1999 Annual Performance Plan includes measures for key program activities in the DOL budget. Our experience shows that to develop good measures for all budget activities will take both time and resources to accomplish. We need to analyze programs for representative measures of core work, test the measures, and establish reporting systems to capture the data in a timely and accurate manner. While our fiscal year 1999 Annual Performance Plan includes a number of good measures, we need to systematically assess all our programs to identify good measures that are representative in terms of the effectiveness, efficiency and impact of the work being performed.

Question. Does the agency's performance plan link performance measures to its budget?

Answer. Yes, the DOL Annual Performance Plan cross references all DOL budget activities to the Strategic goals of the Department. Individual DOL Agency performance plans link Agency budget activities to Agency performance measures.

Question. Does each account have performance measures?

Answer. The WCF does not have performance measures, however, the activities which it funds (OASAM & CFO) have performance measures.

PERFORMANCE PLAN STRUCTURE VS. ACCOUNT ACTIVITY STRUCTURE

Question. To what extent does your performance planning structure differ from the account and activity structure in your budget justification.

Answer. The DOL program and financing (P&F) schedules include a hybrid of budget activities. Some DOL Agencies are closely aligned with their performance

planning structure while others have a mixed alignment. In ETA, grants and program dollars are aligned to separate program based P&F schedules, and S&E dollars for staff in these programs are allocated on a functional basis in a separate P&F schedule. Similar variations exist in other DOL Agencies.

Question. Do you propose any changes to your account structure for fiscal year 2000?

Answer. At this time fiscal year 2000 considerations are premature. We will be assessing such changes with the development of the fiscal year 2000 budget.

Question. Will you propose any changes to the program activities described under that account structure?

Answer. As noted above, fiscal year 2000 considerations are premature. We will be assessing such changes with the development of the fiscal year 2000 budget.

ESTABLISHMENT OF PERFORMANCE MEASURES

Question. How were performance measures chosen?

Answer. With the Department's three strategic goals in mind, Programs developed performance goals and measures appropriately supportive of the goals and generally focused on capturing: (1) the core purpose of the program (e.g., OSHA: reducing injuries/illnesses in high hazard industries); (2) implications of timeliness and accuracy for the program (BLS: produce and disseminate timely, accurate, and relevant economic information), and, (3) project-oriented goals to improve programs and service delivery (e.g., OASAM: One-hundred percent of mission systems will process Year 2000 dates correctly).

Overall, we believe we have good measures in many programs, but we also have other programs which will require further study to establish measures of performance that are meaningful and cost-effective in terms of data collection, reporting, and analysis.

Question. How did the agency balance the cost of data collection and verification with the need for reliable and valid performance data?

Answer. Several areas in DOL, ETA for example, have comprehensive program data collection systems in place which are regularly audited by the DOL Inspector General. These data have proven reliable over time. We are now in the process of identifying baseline data needs to measure outcomes. In this process, we will weigh the relative cost and paperwork burden against the benefits of developing and implementing better performance measures.

Question. Does your plan include performance measures for which reliable data are not likely to be available in time for your first performance report in March 2000?

Answer. Given DOL projections for the implementation and refinement of data collection and reporting systems, we fully expect to report data which is reliable in the first DOL Annual Performance Report. A key exception, from a timeliness perspective, is the data reported under the Job Training Partnership Act (JTPA).

The JTPA Program Year (PY) corresponding to fiscal year 1999 is July 1,1999–June 30, 2000. The performance data for PY 1999 will be available in December 2000, or 15 months after fiscal year 1999 ends (September 1999). Thus, for the DOL Annual Performance Report for fiscal year 1999, DOL will have reliable JTPA data that reflects PY 1998 performance. This information will cover the period July 1, 1998 through June 30, 1999, which includes nine months of fiscal year 1999.

Question. What are the key performance goals from your fiscal year 1999 Annual Performance Plan that you recommend this subcommittee use to track program results?

Answer. The Department's Annual Performance Plan includes 43 program performance goals and 8 measures of management effectiveness. These goals were selected from over 233 performance and management goals included in 15 DOL Agency Performance Plans. We believe that they are representative of the core aspects of DOL programs for fiscal year 1999 and appropriate for tracking to assess DOL program results.

Question. For each key annual goal, indicate whether you consider it to be an output measure ("how much") or an outcome measure ("how well").

Answer. Of the 51 goals in the DOL Annual Performance Plan, 25 are outcome goals and 26 measure output.

PERFORMANCE GOALS RELATIONSHIP TO DOL STRATEGIC PLAN

Question. State the long-term (fiscal year 2003) general goal and objective from the agency Strategic Plan to which the annual goal is linked.

Answer. Each of DOL's three strategic goals has supporting outcome goals which focus Departmental programs and activities on specific areas of emphasis encom-

passed by the broader strategic goal. Outcome goals for each DOL Strategic Goal are listed below.

Strategic Goal: A Prepared Workforce: Enhance opportunities for America's workforce.—Increase Employment, Earnings and Assistance; Assist Youth in Making the Transition to Work; Provide Information and Tools About Work; Provide Information and Analysis on the U.S. Economy.

Strategic Goal: Secure Workforce: Promote the economic security of workers and families.—Increase Compliance with Worker Protection Laws; Protect Worker Benefits; Provide Worker Retraining.

Strategic Goal: Quality Workplaces.—Reduce Workplace Injuries, Illnesses and Fatalities; Foster Equal Opportunity Workplaces; Support A Greater Balance Between Work and Family; Reduce Exploitation of Child Labor and Address Core International Labor Standards Issues.

Performance goals measuring program performance within the broader outcome goals areas are listed in Appendix D to the DOL fiscal year 1999 Annual Performance Plan.

OUTCOME AND OUTPUT MEASURES

Question. In developing your Annual Performance Plan, what efforts did your agency undertake to ensure that the goals in the plan include a significant number of outcome measures?

Answer. Departmental guidance has consistently focused on achieving results. The Secretary of Labor has held two retreats with DOL's Senior Management Team which centered on Managing for Results. Top management's emphasis on measuring the results of our programs was heeded by DOL Agencies. Nearly 50 percent of the measures in the Department's fiscal year 1999 Annual Performance Plan are outcome measures.

Question. Do you believe your program managers understand the difference between goals that measure workload (output) and goals that measure effectiveness (outcome)?

Answer. The Secretary of Labor has held two retreats with DOL's Senior Management Team (a total of six days) that focused on the Department's Strategic Plan and its fiscal year 1999 Annual Performance Plan. During the retreats the both plans and the measures which comprise the plans were discussed. The Senior Management Team then formulated plans for informing all DOL employees on the plan's contents and for integrating performance requirements into the day to day activities of employees at all levels.

Question. What are some examples of customer satisfaction measures that you intend to use? Please include examples of both internal and external customers?

Answer. While our Departmental plan includes no measures of customer satisfaction, the 15 Agency plans include a number of such measures. Here are some examples:

ETA/UI measure.—Meet or exceed the Secretary's standards for promptness in paying worker claims for UI and deciding appeals.

PWBA measure.—Respond to all requests (from the public) for benefits plan documents, annual reports and other information maintained for pubic disclosure within an average of 10 working days.

PWBA measure.—Provide timely assistance to participants and beneficiaries. Respond to 90 percent of written requests within 30 days. Respond to 99 percent of telephone requests by c.o.b. the next business day.

ESA measure.—Increase overall rating of satisfaction ("fair" to "very good") among workers seeking Wage and Hour division services to 70 percent.

ESA measure: Increase customer satisfaction with the OWCP's Longshore and Harbor Workers Program service by 4 percent over the baseline.

OSHA measure.—Establish baseline and interim performance goals for strategic measure: 95 percent of stakeholders and partners rate their involvement in OSHA's stakeholder/partnership process as positive.

OASAM Measure.—80 percent of DOL managers and employees evaluate (OASAM) services as meeting or exceeding expectations. (This is an internal DOL measure that assesses customer (employee) satisfaction with the personnel, financial, and other support services provided by the Office of the Assistant Secretary of Administration and Management.)

MEASURABLE GOALS VS. FISCAL YEAR 1999 BUDGET

Question. How were the measurable goals of your fiscal year 1999 Annual Performance Plan used to develop your fiscal year 1999 budget?

Answer. Internal guidance to agencies in the budget formulation process required that requests for new budget initiatives be related to Departmental strategic goals and include a discussion of expected outcomes with proposed measures and projected cost.

Question. If a proposed budget number is changed, up or down, by this committee will you be able to indicate to us the likely impact the change would have on the level of program performance and the achievement of various goals.

Answer. As noted above, where there is a correlation, on a historical basis, of program performance data and funding, we are obviously better able to assess the impact of varying resource levels on program performance. Prediction of program performance with new measures, where the agency has had no experience with the data, would, of course, be tenuous.

Question. Do you have the technological capability of measuring and reporting program performance throughout the year on a regular basis, so that the agency can be properly managed to achieve the desired results.

Answer. DOL's capability to capture GPRA performance data and report it in a timely manner varies significantly among our programs. With a large number of new performance measures being tracked in fiscal year 1999, we are in the process of revising or updating existing systems to capture the necessary data, so it may be reported in a timely manner and used to manage.

DOL has also requested $1.159 million for contractor assistance to develop and refine a set of program performance measures for use at the Department level. These performance measures would use data from the various programs to establish a set of performance indicators at a fairly high level of aggregation to measure effectiveness in the broad and diverse programs that support the Department's three broad strategic goals. The key will be to develop these indicators using advanced analytical techniques, statistical analysis and correlation. The funding would also support identification of any baseline data needs across the Department from which to establish more concrete measures of program effectiveness, and assure efficiency in data collections and information technology improvements.

Question. If so who has access to the information—senior management only, or mid- and lower-level program managers too?

Answer. The capability of our agencies to provide ready access to program performance data varies markedly. Programs are currently assessing their systems for reporting program performance data with a view toward upgrading or implementing new systems which will provide more timely collection and reporting of data to all levels of DOL management.

Question. Are you able to gain access easily to various performance related data located throughout your various systems.

Answer. Data from the states needs to be reported in a more timely manner. Another short fall in this area, as discussed in the previous question, focuses on new program performance data requirements generated by GPRA. DOL data reporting systems needs to be expanded to support this larger data collection effort.

ACCOUNT STRUCTURE MODIFICATION

Question. The Government Performance and Results Act requires that your agency's Annual Performance Plan establish performance goals to define the level of performance to be achieved by each program activity set forth in your budget.

Many agencies have indicated that their present budget account structure makes it difficult to link dollars to results in a clear and meaningful way. Have you faced such difficulty?

Answer. Some DOL areas are closely aligned with their performance planning structure while others have a mixed alignment. Several DOL Agencies, for example, currently have budget decision units for overhead or staff based activities whose operations support multiple program performance measures. There may be cases where tying dollars to programs and program measures would be useful, and we may want to explore this and realign as necessary.

Question. Would the linkages be clearer if your budget account structure were modified?

Answer. Our current efforts focus on assuring the Department's Annual Performance Plan has a well defined program structure supported by performance goals that capture the core purpose of each program or activity. As noted above, we may want to explore realignment of the budget structure in terms of tying dollars to core programs and measures in certain areas.

Question. If so, how would you propose to modify it and why do you believe such modification would be more useful both to your agency and to this committee than the present structure?

Answer. The Department believes that our current appropriations structure, which has not been updated in many years, may not reflect the optimal display of resources which would permit better estimates of the total cost of our programs.

When this structure—essentially budget activities—was first developed, its purpose was mainly to describe the types of programs and activities being funded. Although the Department always has been attentive to results in its programs, the GPRA provides an opportunity to re-examine how we budget to help us assess program impacts.

In order to revise the current descriptive budget structure to a new presentation focused on results, it may be useful to realign the budget activity structure to reflect the program structure. The advantages would include a capability to assess the total program costs and the costs of achieving programmatic outcomes or results where these costs are a significant feature of the program.

Another goal of restructuring would be to reduce the number of budget activities to provide more flexibility within DOL agencies for utilizing funds made available by the Congress. For example, Job Corps has experienced growth in the number of centers and in the number of students, but there has been a serious decline in funding in the staffing account for staff to manage the centers and allow the most efficient and effective operation. Staffing directly related to the Job corp program could be integrated in order to relate operations support activities to results and to reflect the total cost of the program and outcomes. Similarly, the Solicitor's Office works to support the Department's regulatory agencies in several areas and plays an integral part in helping to achieve the Department's goals. We now include requests for Solicitor staff when we make resource allocation decisions for legal support to OMB and then to Congress. We may want to explore additional ways of linking those activities in the regulatory agencies.

The Department believes that a new activity structure could minimize the disconnect between programs and the resources needed to carry them out, and could better link total costs of the programs to the results. We will continue to explore the feasibility of realignment and may propose changes in the DOL budget structure in the preparation of the fiscal year 2000 budget.

Question. How would such modification strengthen accountability for program performance in the use of budgeted dollars?

Answer. Our goals cut across several budget activities, each contributing to the goal. In several cases, the overhead account for an entire agency represents overhead for all of the budget activities and contributes to each of the goals. Flexibility in determining what percentage of that account applies to each of the goals would be helpful in determining actual costs.

MANAGERIAL COST ACCOUNTING

Question. Spending significant resources on performance measurement systems appears to be a wasteful exercise if this information is not linked to: (1) real data about what it costs to perform various government functions; and (2) how to allocate agency resources to perform these functions.

Could you comment on your agency's cost accounting expertise and plans to link GPRA to the budget process?

Answer. Linking cost information to program performance measures and indicators is key and Departmental discussions have been underway for the last year. We are running a pilot program this year for two of our Agencies to test our cost accounting system. This effort is a major CFO initiative and it is related to the GPRA provision on performance budgeting.

Question. Under one of the new accounting standards recommended by the Federal Accounting Standards Advisory Board (FASAB) and issued by OMB, this year for the first time all Federal agencies are required to have a system of Managerial Cost Accounting. The clearly preferred methodology for such a system, as stated in the standard, is the one known as "Activity-Based Costing", whereby the full cost is calculated for each of the activities of an agency. What is the status of your agency's implementation of the Managerial Cost Accounting requirement, and are you using Activity-Based Costing?

Answer. The Department is making good progress in its effort to implement a framework for managerial cost accounting. We have already modified our core accounting system to capture cost information, and we have established a Department-wide workgroup to develop implementation strategies in conformance with the direction taken in the Department's recently issued fiscal year 1999 Performance Plan. We are on target and expect to be able to provide cost data for fiscal year 1999. Given the range of activities undertaken throughout the Department, we

share the view taken by the FASAB that a variety of appropriate cost accumulation approaches will be needed.

Question. Will you be able in the future to show to this committee the full and accurate cost of each activity of each program, including in those calculations such items as administration, employee benefits and depreciation?

Answer. In addition to the modifications which have been made to facilitate cost accumulation in the Department's core accounting system, a financial analysis software package has also been acquired to be used in allocating overhead costs to direct program activities. The "full cost" of the Department's programs, which will include an appropriate share of overhead expenses, will ultimately become part of the Department's financial statement presentation.

Question. By doing so, would we then be able to see more precisely the relationship between the dollars spent on a program, the true costs of the activities conducted by the program and the results of these activities.

Answer. Once full costing is implemented throughout the Department at the program activity level, it will be possible to provide a full and accurate distribution of the dollars spent on programs within the Department, the true cost of the activities conducted within each program and the results of these programs.

Question. Will you be able to show us the per-unit cost of each activity and result?

Answer. There is much work to be done in determining the relevant unit cost information throughout the Department's activities, as well as in determining precisely which activities are appropriate for cost accumulation. As the Department moves ahead with these analyses, its system should be able to provide the per-unit cost of each activity and result.

Question. To what extent do dollars associated with any particular performance goal reflect the full cost of all associated activities performed in support of that goal? For example, are overhead costs fully allocated to goals?

Answer. We expect to report the full costs for a particular goal in a manner that will fully reflect the activities within that goal and the overhead associated with that goal.

Question. Please identify any significant regulatory reform measures that have been put in place by your agency in conjunction with the development of the agency's performance plan.

Answer. No rules or regulations have been processed or initiated specifically related to the development of the Department's performance plan.

EXTERNAL FACTORS INFLUENCE ON PERFORMANCE PLAN

Question. Does your fiscal year 1999 performance plan—briefly or by reference to your strategic plan—identify any external factors that could influence goal achievement?

Answer. Section 5 of the DOL Annual Performance Plan includes a section on Cross-Cutting Programs and Issues. Several of the issues or planning considerations addressed in this section relate to working with other government Agencies to achieve the Department's three strategic cross-cutting goals. Each of the outcome goals in the Performance Plan also address means and strategies. In addition, the Department's Strategic Plan identifies key external factors that may affect performance.

Question. If so, what steps have you identified to prepare, anticipate and plan for such influences?

Answer. In the DOL Strategic Plan areas have been identified where external influences could impact performance. The Plan also identified strategies to achieve goals.

Question. What impact might external factors have on your resource estimates?

Answer. Most of our external factors are related to economic or employment shifts and pending or new legislation. These changes would most likely cause a change in how we target our resources causing an adjustment in our priorities or a retargeting of our programs within the broad scope of the Departmental mission.

Question. Through the development of the Performance Plan, has the agency identified overlapping functions or program duplication? If so, does the Performance Plan identify the overlap or duplication?

Answer. We have not identified overlap or duplication but have identified other programs that are complimentary to ours.

Question. Should agencies address management challenges and potential duplication and overlapping functions in their GPRA plans, and if so, how?

Answer. The Department's Performance Plan does address management challenges and the coordination efforts with other federal agencies that have complimentary programs.

Question. To what extent has GPRA been used by agency leadership to guide decision making? Will this use increase in the future and if so in what ways?

Answer. The Department has traditionally been focussed on results and this has been reflected in the internal process for budget decisions. GPRA implementation in the Department has continued on this path. Internal guidance to agencies in the budget formulation process required that requests for new budget initiatives be related to Departmental strategic goals and include a discussion of expected outcomes with proposed measures and projected cost.

GPRA principles will be used in many key decisions in the future. We are establishing a Management Council to monitor the execution of the Department's fiscal year 1999 Performance Plan and subsequent plans, and to provide central coordination of all of the Department's programs.

MATURITY OF PERFORMANCE MEASURES

Question. Future funding decisions will take into consideration actual performance compared to expected or target performance. Given that:

To what extent are your performance measures sufficiently mature to allow for these kinds of uses?

Answer. We are currently assessing systems for reporting program performance data with a view toward upgrading or implementing new systems which will provide more timely collection and reporting of data to all levels of DOL management. The capability to provide ready access to program performance data varies markedly. Many of our performance measures are sufficiently mature, however, many programs will be setting baselines in fiscal year 1998 and 1999.

Question. Are there any factors, such as inexperience in making estimates for certain activities or lack of data that might affect the accuracy of resource estimates?

Answer. Many programs will be setting baselines in fiscal year 1998 and 1999 and they have used educated estimates in the interim.

Question. Are you requesting any waivers of non-statutory administrative requirements?

Specifically, are you requesting any relaxation of transfer or reprogramming controls in return for specific accountability commitments?

Answer. We are not requesting any additional transfer or reprogramming controls in return for specific accountability commitments.

REVISIONS TO STRATEGIC PLAN

Question. Based on your fiscal year 1999 performance plan, do you see any need for any substantive revisions in your strategic plan issued on September 30, 1997?

Answer. The Departmental Strategic Plan, submitted to Congress in September 1997, outlined six strategic goals. The fiscal year 1999 Performance Plan consolidates those goals into three strategic goals. These goals support my vision, facilitate increased coordination, and foster greater cohesion within the Department. The revision also responds to concerns raised by external reviewers that the DOL Strategic Plan did not adequately reflect the integration and cross-cutting nature of DOL's programs. However, because we need to clearly align our strategic planning with these three goals, we plan to revise the Departmental Strategic Plan soon.

PROPOSED REGULATIONS REGARDING THE BLACK LUNG BENEFITS PROGRAM

Question. It is my understanding that there has been significant delay in the promulgation of new black lung regulations by the Department of Labor. What has caused the delay in final action on these regulations?

Answer. To make possible the fullest public participation in the rulemaking process, the period for the submission of written comments was twice extended, to a total of seven months. Two public hearings were also held, in Charleston, West Virginia and Washington, D.C. This process resulted in over seven hundred pages of hearing testimony and several thousand pages of written comments and related exhibits. Every major substantive and procedural aspect of the ninety-eight page proposal, as well as its possible economic impact on the coal industry, drew significant and highly diverse comments.

Question. When will the Department issue these regulations?

Answer. The Department is carefully reviewing the testimony and comments and will move forward with the process in a manner which will take into account the views of all of the affected groups, including claimants, large and small coal mine operators, insurers, attorneys, physicians and other health care providers.

EMPLOYEE STOCK OWNERSHIP PLANS

Question. The provisions of the Employee Retirement Income Security Act (ERISA) set standards to ensure that employee benefit plans are properly maintained, and that recordkeeping is accurate and current. It is my understanding that the Department of Labor has the fiduciary responsibilities of enforcing rules governing the activities of Employee Stock Ownership Plans (ESOP's). Title I, Part 5 of ERISA gives your department the authority to bring a civil action to correct violations of the law.

While I am certain no two cases are alike, please indicate to me, in general, the criteria your department needs to begin an audit of a company's ESOP.

Does the department ever conduct random audits? If so, please explain how the department would choose to conduct such an audit.

Answer. The Department has very broad investigative authority under the Employee Retirement Income Security Act to conduct investigations to determine whether any person has violated or is about to violate ERISA. The initiation of an investigation is at the discretion of the Pension and Welfare Benefits Administration, the agency within the Department responsible for the enforcement and administration of ERISA. Generally, PWBA initiates an investigation of an employee benefit plan based on information that a violation has or may have occurred, or is likely to occur.

PWBA does not follow a practice of conducting random audits. With over 700,000 pension plans and 2.5 million health and welfare plans subject to ERISA, random audits are not an efficient use of PWBA's limited investigative resources, which currently consist of approximately 350 investigators. PWBA selects plans for investigations based on a variety of sources and methods, including complaints received from participants of plans and other members of the public; computer targeting based on analysis of the database of Form 5500 annual report filings; referrals from other government agencies; and, media reports.

Question. Approximately how many audits does the department conduct each year?

Answer. During the past three fiscal years, PWBA's enforcement program has had the following activity and results:

	Fiscal year—		
	1995	1996	1997
Civil cases:			
Investigations opened	4,746	4,528	5,310
Investigations closed	3,840	4,201	4,506
Assets recovered (in millions)	$340.3	$407.4	$363.4
Criminal cases:			
Investigations opened	104	119	143
Investigations closed	102	96	85
Indictments	101	82	105
Convictions/guilty pleas	32	46	45

Question. Of the audits conducted by the department, what is the approximate percentage of ESOP's that are found to have irregularities?

Answer. During the past three fiscal years, PWBA's enforcement program closed 431 ESOP investigations. Fiduciary violations were found in approximately 3 percent of those cases resulting in the recovery of approximately $2.8 million. Another $1.1 million monetary recovery was obtained in a case where completion of investigative work is still pending.

Other violations that were less serious and may not have resulted in quantifiable monetary harm to plans were found in about 25 percent of the cases.

Question. What is the approximate cost on the part of businesses to comply with the federal government regulations in the administration of ESOP's?

Answer. An employee stock ownership plan (ESOP) is a defined contribution plan. Because most ESOP's are tax qualified, they are regulated by both the Department of Labor and the Treasury Department. Thus, costs borne by businesses to comply with regulations are based upon provisions of the tax code as well as ERISA. Most costs associated with ESOP compliance are attributable to tax qualification, but there are some costs associated with the reporting and disclosure requirements of ERISA (the tax code also requires annual reporting to the Federal government).

These costs may be paid by an employer or paid directly by a plan out of plan assets.

There is currently no reliable data on costs that would support such an analysis. Based on the way plans are designed and drafted, the cost of administering a plan may be paid directly by a plan out of its trust assets or paid in full or in part by the plan sponsor (e.g. corporation which establishes the plan). Although Federal regulation does result in some additional expense to plans, including ESOP's, any valid estimate would have to determine the extent to which an expense relates to Federal regulation as opposed to routine business operations (e.g., plan design and drafting expense, accounting and auditing fees, etc.). ERISA requires most employee benefit plans, including ESOP's, to file an annual report Form 5500 with the IRS and DOL, and if there are more than 100 participants in the plan a financial audit must be performed. In addition, ESOP's must have stock valuations performed to facilitate purchases, sales and distributions of benefits to participants, if the underlying employer stock is not publicly traded.

Question. How often would the department audit an ESOP beyond the statute of limitations? What action does the department take if this occurs?

Answer. ERISA's statute of limitations with respect to fiduciary breaches provides no action may be commenced after the earlier of six years from the date the breach or violation occurred, or three years after the earliest date of actual knowledge of the breach or violation. In the case of fraud or concealment the statute is extended to not later than six years after the discovery of the breach or violation.

The statute of limitations acts as a bar to legal action with respect to a fiduciary's breach of a responsibility, duty or obligation in violation of the law. This is a factual question which is usually determined during the course of an investigation as information is developed which indicates that a violation did in fact occur. Generally, if it is known before the investigation commences that a potential fiduciary breach has been committed and is beyond the statute of limitations, an investigation of that issue would not be pursued unless there was a specific reason to do so, such as the development of evidence regarding additional, subsequent or continuing violations which might be actionable. It is not uncommon for an investigation to disclose multiple acts or transactions which give rise to potentially multiple fiduciary breaches and thus multiple statutes of limitation, which must be analyzed carefully to determine whether the Department can take enforcement action to address the violation(s).

Question. Does the department provide information and advice on ESOP compliance requirements?

Answer. The Department has a formal procedure which has been codified, ERISA Proc. 76–1, to answer inquiries of individuals or organizations affected directly or indirectly by ERISA as to their status under ERISA and as to the effect of certain acts and transactions. The answers to such inquiries are categorized as "information letters" and "advisory opinions." Also, each of PWBA's Regional Offices and the National Office in Washington have customer service representatives who respond to written, telephone and in-person requests for technical assistance and information regarding employee benefit plans. Information and advice on ERISA-related topics, including ESOP's, may be obtained through the more formal written ERISA Proc. 76–1 process or through our customer service contacts.

In addition, as part of our outreach efforts, PWBA representatives often speak publicly at seminars, conferences and programs sponsored by educational and trade organizations on a variety of employee benefit related topics, which may include ESOP related matters.

QUESTIONS SUBMITTED BY SENATOR THAD COCHRAN

FEDERAL ACQUISITION REGULATIONS

Question. Secretary Herman, what is the substance and the timing of the blacklisting regulations promised to the AFL–CIO by Vice President Gore over a year ago, regulations that would give the executive branch discretion to "de-bar" any company from engaging in federal business if an unfair labor complaint has been filed against the company with the National Labor Relations Board?

Answer. The Federal Acquisition Regulatory Councils, and not the Department of Labor, are responsible for developing proposed changes to the Federal Acquisition Regulation (FAR). FAR changes are made through notice-and-comment rulemaking. Once proposed FAR changes are published in the Federal Register, the public—including all interested stakeholders and Members of Congress—will have the oppor-

tunity to comment on the proposal. No proposal has been published yet, and I am not aware of any precise timetable for the process.

Question. Secretary Herman, although these regulations will be issued by the Office of Procurement, and not the Department of Labor, is it not true that the procurement system is merely the vehicle for pushing through this radical reshaping of labor policy in this country?

Answer. I do not believe that the possible changes in Federal Acquisition Regulation (FAR) under consideration would have the effect that you suggest.

QUESTIONS SUBMITTED BY SENATOR KAY BAILEY HUTCHISON

PROPOSED ERGONOMICS STANDARD

Question. Can you describe the present status of the draft ergonomics regulation within OSHA, and do you believe that there should be an independent, peer-reviewed analysis of the scientific foundation for enacting such a regulation?

Answer. Currently, we plan to publish a proposed rule in fiscal year 1999. OSHA is developing a draft regulatory text for the rule, which will be shared with stakeholders later this year. OSHA is also examining all available scientific and medical studies related to the rule; these will contribute to other sections of our proposal.

We believe that it may not be necessary to have an independent peer-reviewed analysis as part of the process, since the scientific and medical evidence upon which any ergonomics rule will be based is peer-reviewed. In addition, we intend to rely heavily on NIOSH's analysis of more than 600 epidemiological studies, all of which were peer-reviewed. We expect the rulemaking process to provide additional information and that during the course of hearings and public comment, ample opportunity will be offered to challenge any and all of the evidence in the rulemaking record.

SAFETY STANDARDS FOR SMALL BUSINESS

Question. This week, I received a response to a letter I sent in December to OSHA Assistant Secretary Jeffress expressing concern that inappropriate safety standards may be applied to two specific industries: arborists and tower erectors. What efforts is the Department undertaking to ensure that appropriate and specifically tailored safety standards are being applied to these and other smaller industries? Specifically, do you believe it makes sense to apply commercial logging standards to residential tree pruners?

Answer. In accordance with the Regulatory Flexibility Act, the Paperwork Reduction Act, the Administrative Procedure Act, and the Small Business Regulatory Enforcement Fairness Act (SBREFA), OSHA conducts numerous analyses of its proposed rules to consider their potential impacts on small businesses and on specific industries. Following these procedures closely ensures that our safety standards are appropriate to the industries covered by the standards. For example, if these analyses show that significant adverse impacts are anticipated, OSHA takes steps to minimize those impacts. These steps may include lengthening compliance deadlines, reducing paperwork requirements, or making material modifications to the rule.

Throughout the rulemaking process, employers and industry groups, as well as workers, unions, and interested members of the public, have opportunities to review the proposed rule and submit comments to OSHA, including the opportunity to testify at public hearings. OSHA then addresses these comments in the preamble to the final rule. Under SBREFA, small entities are given special consideration through the Small Business Advocacy Review Panel process, if the rule is determined to have a significant impact on a substantial number of small entities.

In the case of the Logging Operations Standard (29 CFR 1910.266), arborists and their industry representatives participated in the public hearings during the rulemaking process, and OSHA addressed their concerns in the preamble to the final Logging Operations Standard. OSHA also issued a memorandum to its field offices concerning how the Logging Operations Standard should be applied to tree pruners. Residential tree pruners face many of the same hazards that the Logging Operations Standard was designed to address: being hit by heavy tree branches; being caught in or crushed by tools and equipment, such as chain saws, axes and chippers, that pose hazards whenever they are used; and exposure to dangerous environmental conditions, such as heavy rain, snow, lightning, strong winds, and extreme cold. OSHA has determined that the combination of these factors presents a significant risk to employees.

OSHA's intention in promulgating the Logging Operations Standard was to address the hazards associated with cutting trees, wherever those hazards are found,

including commercial tree trimming and cutting operations. OSHA believes that the equipment requirements, safe work practices, and training provisions included in the Logging Operations Standard will significantly reduce the risks that workers face, and will reduce the number and severity of the injuries that occur as a result of exposure to the hazards associated with trimming and cutting trees.

With respect to tower erection, the National Association of Tower Erectors (NATE) has raised a number of issues with OSHA relating to fall protection, employee access to towers, and gin pole safety. Our Towers Task Force is engaged in an intensive effort to identify specific tower construction safety procedures that will adequately protect employees. Once identified, these procedures will be spelled out in compliance directives.

Our Task Force has learned that we are in the midst of an extraordinarily active period of tower construction. NATE members constructed approximately 16,000 towers in 1997. They expect to build large but steadily declining numbers of towers in the next few years: 12,000 in 1998, 10,000 in 1999, and fewer thereafter.

OSHA is actively considering formal rulemaking tailored to this industry. However, the standards promulgation process can be lengthy, and the bulk of the towers planned for the foreseeable future may well be built before that process could be completed. OSHA is keenly aware of the need to resolve these issues in a much shorter time frame than rulemaking may be able to accommodate, and is confident that, through the efforts of the Towers Task Force, it can expeditiously identify safety procedures that are workable, effective and timely and disseminate this information to the industry.

WORKFORCE DEVELOPMENT

Question. As you know, the State of Texas has been a national leader in enacting broad-based workforce development reform, in anticipation of the federal government doing the same. However the State is concerned that many of its reform and consolidation efforts may be undone or undermined by federal legislation now pending in Congress that ostensibly seeks to achieve the same goals as the Texas and other State reforms have sought.

Do you support legislation, and will you support regulations under such legislation, that allow proactive States like Texas to implement their own versions of workforce development, so long as those plans are consistent with the general purposes of the federal law?

Answer. The workforce development reform legislation pending before Congress (S. 1186, the Workforce Investment Partnership Act, and H.R. 1385, the Employment, Training and Literacy Enhancement Act) builds upon ongoing reform efforts at the State and Federal level. In order to honor State-initiated reforms that are consistent with Federal law, the Senate legislation contains provisions that would allow States that have enacted workforce development legislation prior to December 31, 1997 to retain certain elements of such legislation. These provisions would remain in effect for the entire five years for which the bill is authorized. We have determined that approximately 22 States have enacted legislation that potentially could be grandfathered under this provision, including Texas.

We believe that the grandfathering provision should apply to the following areas, as provided for in the Manager's Amendment to S. 1186, the Workforce Investment Partnership Act:

—Human Resource Investment Councils (HRIC) in accordance with title VII of JTPA to carry out many of the same activities that would be carried out by the Statewide partnership under the bill;

—Regional and local boards with composition different from the local partnerships under S. 1186 or JTPA. (Texas, Iowa, Utah and New Jersey have done so);

—Designation of workforce development areas based on the regional planning areas in the State rather than the criteria in S. 1186; and

—Authority to impose financial sanctions under certain conditions on local areas that are continued poor performers.

Question. Would you please indicate why the Department has failed to allow States like Texas the option of contracting-out the delivery of Employment Service to responsible, high quality providers? Such providers have the potential, do they not, of providing more services to more people at a lower cost?

Answer. First, since 1993, the Department has worked with States, such as Texas, to forge workforce development systems that better serve job seekers and employers. States have implemented local One-Stop centers that provide job seekers and employers with a wide menu of services, without contracting-out Employment Service (ES) services. Federal funding under the Wagner-Peyser Act supports a national system of public employment services. For sixty-four years, with the knowledge and

approval of Congress, the Department has required States to run their Wagner-Peyser ES programs with merit system personnel.

The question of which public employment services, if any, should be available for States to contract-out at State option has national implications, and should be decided as a matter of a national policy. Moreover, this policy should not be decided in an ad hoc way, with each State determining which services are appropriate for contracting-out and which are not. The resulting patchwork of delivery system approaches could undermine the system's national character and national objectives. The Department plans to issue policy guidance after resolution of the merit staffing issue before the federal court in Michigan, and after a national dialogue on this issue to decide which functions authorized under the Wagner-Peyser Act may be construed as "commercial" and therefore available to be delivered by private vendors at States' options.

Second, the Department has not analyzed whether private vendors might provide more services at a lower cost. Currently, the national Wagner-Peyser Act cost per entered employment for job seekers is $230 and the entered employment cost in Texas is $154. Over the next several years, the Department will engage in a study to better understand the variations in services and costs among States. However, States now have considerable flexibility in managing the delivery of employment services consistent with the merit-staffing requirement. This flexibility is encouraged as an aspect of One-Stop system-building and, in this regard, we note that One-Stop system-building with a full range of services is proceeding well under a merit-staffed delivery system for ES in the great number of State workforce development settings.

Question. With regard to workforce development, do you support consolidating federal job training programs? Which programs, if any, do you believe should not be consolidated into a larger funding stream, and why?

Answer. Both the House-passed H.R. 1385, and the Senate-reported S. 1186, take great strides toward consolidation of job training programs. The House bill would integrate some 60 training and employment programs into a streamlined and consolidated workforce development system, while the Senate bill incorporates over 50 programs in the workforce investment titles. However, we do not believe this should become a numbers game about how many programs are consolidated. There are many forms that "consolidation" can take, including elimination of programs, incorporation of programs into a new, simplified structure (for example, summer youth programs are authorized, but not a separate program), linkages among programs (for example, the Employment Service is closely linked to the new workforce development system), or "street-level" consolidation through the one-stop access to a wide range of workforce development related information and services. Both House and Senate bills reflect each of these types of consolidation.

There are reasons why it may not be appropriate to consolidate a particular employment and training program into a block grant. Some programs have been created to address the needs of special populations, such as the disabled, Native Americans, or veterans. The administrative structures and systems for the delivery of services may be unique and therefore inappropriate to consolidate. Furthermore, the Congress created these programs with the intention of assuring that the needs of these special populations were addressed, and this could not be assured under a block grant. The important thing is to assure access to employment and training services for these populations through one-stop or "full service" centers, which the House and Senate bills will ensure.

Question. Could you please clarify the exact nature and scope of, and any details you can provide regarding the implementation of the "Work-Flex" waiver recently granted to Texas?

Answer. The Work-Flex designation is implemented through a modification to the grant the State of Texas has with the Employment and Training Administration for administration of the JTPA programs. A proposed modification has been formally sent to the State and after informal discussions, we believe that all the State questions have been answered.

The Work-Flex modification describes the authority granted to the State and also provides examples of material not subject to waiver under this authority. As indicated to the State in this material, we expect this authority to be extended to June 30, 2002. However, since grants are issued annually, the authority for Work-Flex will have to be extended in each annual grant.

QUESTIONS SUBMITTED BY SENATOR ROBERT C. BYRD

NATIONAL MINE HEALTH AND SAFETY ACADEMY

Question. Please provide the amount of revenues received by the Academy for the use of its facilities and for classes for fiscal year 1996, fiscal year 1997, fiscal year 1998, and the projected amount for fiscal year 1999.

Answer. The National Mine Health and Safety Academy raises revenues for deposit to the General Fund of the Treasury by charging tuition and lodging fees and selling training materials. The Academy has raised the following amounts:

Fiscal year	Tuition and lodging fees	Training materials sales
1996	$186,251	$99,641
1997	240,876	79,800
1998[1]	240,000	79,999
1999[1]	240,000	77,000

[1] The projected amount to be collected is based on past history.

Question. Please provide the staffing levels at the Academy for those same years.

Answer. The numbers below reflect end-of-year staffing levels.

	Full-time-permanent	Other
Fiscal year:		
1996	60	.....
1997	63	3
1998[1]	[1] 65	[1] 1
1999[1]	[1] 67	[1] 2

[1] Projected.

Question. Please advise how many requests have been made for the use of the Academy, how many were granted, and how many were turned down for fiscal year 1996, fiscal year 1997, and the numbers that are available for fiscal year 1998.

Answer. The Academy received 877 requests in fiscal year 1996, 836 requests in fiscal year 1997, and a projected 950 requests for fiscal year 1998. All the requests received have been granted, and we expect to honor all the requests estimated for fiscal year 1998.

Question. Does the use of the Academy by other Federal agencies result in expanded benefits and cost savings to the taxpayer?

Answer. Other Federal agencies are offered the use of Academy facilities. The Academy does not charge federal agencies for the use of classrooms, conference rooms or the auditorium. In fiscal year 1997, Academy space was used 115 times by other federal agencies such as the Department of Agriculture, Veterans Administration, Bureau of Prisons and the Department of Health and Human Services. In fiscal year 1998, we are projecting other federal agencies will request the use of the Academy 125 times.

Additionally, safety and health training is provided for industrial hygienists, engineers, and local government officials not only for MSHA and other federal agencies, but for educational institutions, State Department of Mines, State Grant Recipients, and Contract trainers. Also, space is made available to state and local government agencies upon request.

Question. Has the training provided at the Mine Academy led to a significantly reduced number of mine-related deaths across the nation?

Answer. We believe the Academy's training has contributed to the reduction of mine-related fatalities. The Academy develops current accident-focused course curriculum and accident prevention and occupational health awareness programs. Also, it responds to requests for specialized safety and health training programs and materials from the mining industry. Academy on-site training is provided to both mine inspectors and interested industry personnel. Off-site training is also provided to the mining industry and MSHA districts throughout the country. This training is directly related to improving the health and safety of all miners. During fiscal year 1998, the National Mine Health and Safety Academy will provide 550 course days of training to ensure that MSHA's mine inspectors, other federal and state employees, and mining industry personnel are trained to recognize, eliminate and prevent

hazardous conditions in the mining environment. The Academy continues to increase the number of training courses and available printed materials to inspectors and the mining industry, in general, and has increased the number of off-site training opportunities.

It is universally recognized that training saves lives and prevents injures and illnesses. Unfortunately, the training rider added to MSHA's appropriation language prevents the agency from enforcing basic statutory safety and health training for miners at more than 10,000 nonmetal mines employing more than 125,000 workers. Removal of the rider would facilitate much needed safety and health training for this sector of the industry. The training rider is an impediment to MSHA's ability to reverse the upsurge in fatal accidents in the metal and nonmetal mining sector. In 1997, 75 percent of the deaths at metal and nonmetal mines occurred at operations where MSHA cannot enforce basic safety and health training for miners. Also, more than 60 percent of the victims had received little or no training.

The positive effects of training have helped reduce mining fatalities from a total of 247 in 1977 (which was the first year training was mandated for all miners) to 90 fatalities in 1997.

CHARLESTON JOB CORPS CENTER

Question. Pursuant to the opening of the new Job Corps center in Charleston, West Virginia, I would like to know how many employees are currently working in the new facility and how many are projected for fiscal year 1999; in addition, please provide staffing levels for the previous facility for fiscal year 1996, fiscal year 1997, and fiscal year 1998.

Answer. The new Charleston facility is budgeted for 139 full-time equivalent (FTE) staffing positions. According to the most recent report from the center contractor, 129 of these positions were filled as of February 28, 1998. We anticipate that the budgeted staffing level of 139 FTE will be maintained for the foreseeable future. Before the Charleston Job Corps center was relocated to its new facility in the Fall of 1997, the old facility was budgeted for 137 FTE. The budgeted FTE staffing levels at the end of the 4 fiscal years mentioned in your question are as follows:

Fiscal year:	
1996 old facility	137
1997 old facility	137
1998 new facility	139
1999 new facility (planned)	139

Question. If possible, please estimate the total annual economic impact on the area, including salaries and other purchases, for fiscal year 1999.

Answer. In fiscal year 1999, approximately $7 million will be spent by Job Corps in Charleston, West Virginia and the surrounding vicinity. These federal expenditures will be in the form of staff salaries and benefits, local purchases of goods and services, and allowance payments to the students at the Charleston Job Corps center.

Question. Please also advise me how many students the new facility can accommodate and how many students are currently enrolled.

Answer. The new facility can accommodate 400 students at a time. According to the most recent attendance report (for March 18, 1998) 363 students are currently enrolled. Steps are being taken to bring the center to its full enrollment capacity of 400 students in the very near future.

COOPERATIVE COMPLIANCE PROGRAM

Question. I have noticed that the Department has requested an increase of $2.8 million and 23 FTE's to increase on-site safety and health enforcement in highly hazardous workplaces by continuing the implementation of Cooperative Compliance Programs nationwide.

Given the recent court-imposed stay on the implementation of these programs—and their uncertain future—what contingency plans does the Department have should the federal Court of Appeals prevent or significantly alter their implementation?

Answer. OSHA does have a contingency plan for inspection scheduling, but there is not a contingency program for the cooperative aspect because this is one of the issues in the case brought against the CCP. We expect the court to eventually rule in OSHA's favor and the Cooperative Compliance Program (CCP) will then continue. In the meantime we will continue to work on cooperative efforts through local initiatives, OSHA consultation programs, OSHA voluntary protection programs (VPP), and compliance assistance.

Prior to the CCP, past targeting systems were often and regularly criticized by industry and employee groups for inspecting employers with good safety and health records instead of concentrating on employers that failed to protect their workers. All interested parties agreed that OSHA needed some sort of system to target. The previous system only provided for inspection targeting based upon industries with elevated injury and illness rates, as opposed to targeting establishments with high rates. Consequently, when OSHA arrived at a work site the agency did not know if the establishment had a high or a low rate. Regardless of the individual employer's injury and illness rate, OSHA did an inspection.

The new system that the CCP is based upon targets individual worksites with elevated rates. As a result, our resources are directed at employers most in need of an OSHA intervention. Regarding the stay of the CCP, we do not expect the court to rule until at least December 1998 or January 1999. Therefore, the new program is essentially on hold. In the meantime, we have proposed an alternative targeting system, based upon site specific injury and illness data from the OSHA Data Initiative. This program, due to the stay, does not have a cooperative component. On April 6, 1998, the court ordered that the stay on the CCP program does not encompass OSHA's contingency plan for inspection targeting thereby allowing us to use this alternative system.

The interim OSHA targeting plan uses BLS data for 1996 to identify the one hundred industries, as characterized by four-digit SIC Codes, with the highest lost workday injury and illness (LWDII) rates, excluding construction, agriculture, mining, and public administration. For those four-digit SIC Codes for which BLS did not report LWDII rates at the four-digit level (such as non-manufacturing), OSHA attributed the rate reported by BLS for the three-digit SIC's. Eight SIC's were not included in OSHA's 1996 data survey, and there are therefore no establishment-specific LWDII data for them. The final listing of industries containing establishments to be inspected therefore excludes those eight SIC's and includes the 99 four-digit SIC's with the highest LWDII's for which OSHA has establishment specific data.

For each four-digit SIC on the list, each establishment with an LWDII rate at or above the average LWDII rate for that four-digit industry will be subject to an inspection with the exception of establishments in SIC 8051, "Skilled nursing care facilities," SIC 8052, "Intermediate care facilities" and SIC 8059, "Nursing and personal care not elsewhere classified." Those three industries contained many more establishments than the other SIC's on the list. To avoid over-concentration on inspections in those three industries, only the top 20 percent of the establishments in those SIC's with LWDII's above the industry average will be subject to inspection. All establishments subject to inspection will have an equal chance of being inspected. The national office will provide each area office with a list of establishments within the area office's jurisdiction that are subject to inspection under the plan.

Question. In particular, how would the additional $2.8 million requested for federal enforcement activities under this program be spent if the Department were not able to implement the Cooperative Compliance Program?

Answer. The budget request for 23 FTE and $2,750,000 is tied to the agency's efforts to enhance construction expertise in OSHA as well as to provide additional resources to help implement the Cooperative Compliance Program (CCP). The CCP is OSHA's current approach to addressing high-hazard industries and workplaces and offering partnerships with participating employers. Even if the courts should rule against OSHA's current CCP scheme, we would still use the requested resources to focus on high-hazard areas and to generate partnership opportunities with employers to reduce workplace exposure to hazards.

TRANSFER OF CERTAIN ADMINISTRATIVE SERVICES OF PART B OF THE BLACK LUNG PROGRAM FROM SSA TO DOL

Question. The conference report accompanying the fiscal year 1998 Department of Labor, Health and Human Services, Education and Related Agencies Appropriation Bill included language directing the Inspectors Generals (IG) of the Department of Labor (DOL) and the Social Security Administration to provide annual, joint reports to the Committee on Appropriations on the Memorandum of Understanding (MOU) between the DOL and the SSA which transfers certain administrative services of Part B of the Black Lung Program from the SSA to the DOL. The purpose this report is to help Congress monitor whether the terms of the MOU are being followed.

What is the status of the transfer of certain administrative services under the MOU?

Answer. The Memorandum of Understanding (MOU) between the Social Security Administration (SSA) and the Office of Workers' Compensation Programs (OWCP)

of the Department of Labor concerning maintenance activities for beneficiaries under Part B of the Federal Black Lung Program was signed September 26, 1997. Under the terms of the MOU, the Department has assumed responsibility for all routine maintenance activities associated with the Part B claims. The Social Security Administration (SSA) retains responsibility for taking applications on Part B claims and forwarding them to the appropriate DOL office for processing and also the responsibility for conducting Administrative Law Judge (ALJ) hearings to resolve contested issues, including overpayment issues, arising from Part B claims. SSA also retains the responsibility for considering appeals taken from ALJ decisions. Instances of possible fraud or abuse are also referred to the SSA OIG for investigation and possible prosecution.

OWCP has devoted 17 FTE and 10 contract mail and file and data entry staff to Part B case work and SSA has agreed to pay the Department $2,475,970 for administrative services being performed in fiscal year 1998. However, negotiations with SSA have not been completed for the administrative costs for fiscal year 1999. The program currently estimates its Part B needs at $2,551,000 for fiscal year 1999.

While the OWCP Division of Coal Mine Workers' Compensation is responsible for coordination and consultation in implementing the Memorandum of Understanding, ultimate responsibility for the policy, conduct, and administration of the Part B Black Lung program, including the services provided by OWCP, continues to rest with SSA.

SSA delivered its electronic records for those beneficiaries to OWCP during the first week of October 1997. Benefits for the October entitlement period were prepared by OWCP and issued on November 3, 1997. OWCP will have processed $350 million in monthly disability and survivors benefits to over 100,000 households, as of May 3, 1998.

Typical claims maintenance actions are being performed by OWCP in one week or less from receipt of the necessary information from the beneficiary. Overall, the transfer has proceeded very smoothly with a high level of service being provided to the beneficiaries.

Question. Has the DOL received any complaints from beneficiaries on the implementation?

Answer. The initial mailing by the Social Security Administration to the beneficiaries, informing them of the transfer of administrative services and of which OWCP office would be responsible for their individual claims in the future, resulted in a large volume of inquiries to the nine OWCP offices' 800 numbers. The great majority of those telephone calls were inquiries rather than complaints. In those instances where the beneficiaries identified problems, they were addressed in the individual cases. Very few of the beneficiaries have felt it necessary to seek Congressional assistance to help resolve their individual problems. In December 1997, 22 Congressional inquiries were received in the nine OWCP claims servicing offices. In January 1998, there were 13 such Congressional inquiries; in February, only 8. When compared to approximately 104,000 monthly beneficiaries, these numbers are very small and the trend is clearly moving in the right direction.

Question. What is the status of the report the DOL IG is compiling with the IG of SSA?

Answer. The initial planning phase of the audit requested by the Committee has begun with various preliminary activities. The OIG has met with staff from the Black Lung Program to obtain appropriate data necessary to perform the audit. In addition, we will be meeting with staff of the Social Security Administration OIG to coordinate and define the role of each office in the project. We anticipate allocating time over the next several months to data collection and coordination activities. In order to assess information through the end of fiscal year 1998, as requested by the Committee, the bulk of our audit work will be started in October 1998. Our final report will be issued on, or before, March 31, 1999, as required.

YEAR 2000 COMPUTER PROBLEM AT DOL

Question. What efforts are being made by the Department to prepare for the year 2000 computer problem?

Answer. The Secretary of Labor has made Year 2000 compliance a top Departmental priority and has taken the necessary steps to accelerate progress in reaching the Department's target goals for Year 2000. The Deputy Secretary meets with each agency head on agency Year 2000 progress. The Chief Information Officer (CIO) meets with agency heads to resolve problems and keeps the Deputy Secretary informed of progress weekly. The Office of the CIO has just completed an in depth review by agency of Year 2000 preparations to assure that the Department is prepared and has its computer systems ready for the Year 2000.

In a memorandum dated December 31, 1997, the Secretary of Labor outlined to the DOL executive staff the steps to be taken to accelerate progress in reaching the Department's target goals for Year 2000. In this memorandum, the Secretary made it emphatically clear that Year 2000 conversion is not to take the backseat to any other competing program initiatives—it is top priority.

Management tools used to track progress and manage the effort include a quarterly internal report used to assess system needs and to track progress against established goals. A monthly exception report has been established, beginning February, 1998, requiring a report of any deviations from their Year 2000 plan. This report provides an "early warning" of potential issues needing attention and reduces risk.

Should a system fall behind schedule, deviate from plans or encounter unforeseen problems, an "early warning" is received on a monthly basis through meetings of the Deputy CIO with Year 2000 managers. The monthly exception report is used to advise the CIO, the Deputy Secretary and the Secretary of deviations.

The CIO is hiring a Year 2000 contractor to provide additional support to CIO functions and to provide assistance to the agencies where needed. The CIO has entered into a partnership with the Inspector General to assist in Year 2000 matters by attesting to the viability of agency plans, progress and reports.

The Department has taken aggressive measures to meet the new OMB mission critical target dates. Systems activities have been accelerated to meet the new deadlines. Acceleration has been achieved by increased resources, repairing rather than replacing systems and making year 2000 modifications a top priority.

The Department continues to show substantial progress in meeting Year 2000 mission critical objectives. The number of mission critical systems becoming Year 2000 compliant has increased from 16 percent to 21 percent as reported in the most recent quarterly report to OMB. DOL management has demanded that Federal programming and contractor staff establish and follow aggressive schedules to convert and test applications/systems, including menus, sub-routines, programs, etc. Work on the remaining mission critical systems has been accelerated to meet the new government-wide goal to complete implementation by March 1999.

Other Year 2000 initiatives are listed below.

—FTS2000 is the primary telecommunications service used by the Department and all host mainframe facilities are provided under other contracts. The Department is currently reviewing all non-FTS2000 data and voice grade telecommunication systems for Year 2000 compliance. Plans are being developed to upgrade/replace systems as necessary.

—The Department is currently analyzing its facilities and embedded systems for Year 2000 implications to ensure all Departmental facilities, laboratory training equipment and computer products with embedded systems chips are compliant or have "work around" capability. Plans are being developed to solve any Year 2000 problems found within internal systems used to control, monitor or assist the operation of equipment, machinery or building maintenance which include HVAC, elevators, security systems, network hardware and telecommunications with embedded computer chips. The process of contacting contractors and supply vendors to determine the current level of compliance in their equipment and to prepare schedules for upgrades and replacements, as well as testing plans, is on-going.

—The Department has emphasized approaching the compliance issue for facilities on a mission-focused basis. Primary emphasis is placed on those facilities and equipment that impacts the essential missions such as providing workplace safety and health, critical infrastructures needed to carry out the Department's mission as well as the infrastructure needed for employees to do their work. Toward that end, the laboratory and testing facilities of the Department have been surveyed to determine what equipment is at risk. Manufacturers and vendors are being contacted to determine whether equipment contains date sensitive embedded chips, whether upgrades can be obtained or whether replacement equipment must be purchased. All micro-computers and LAN/WAN facilities either are now compliant or resources have been dedicated to ensure timely compliance.

—The Department identified over 3,000 data exchanges with States and other partners. In February of this year, the Deputy CIO visited the CIO for the Commonwealth of Pennsylvania to review State interfaces as a quality check for the exchange of information data process. These materials were also sent to the States of Washington and California for further review.

—The Department's host mainframe provider has successfully tested a Year 2000 compliant Logical Partition Region. This significant milestone allows for compliance testing of renovated host systems.

In summary, the Office of the Chief Information Officer continues to work to identify and resolve potential problems relating to the Year 2000 should they arise.

Question. Should the Department fail to address the issue in time, how might black lung beneficiaries and those applying for benefits be affected?

Answer. Sensitive elements in the legacy Automated Support Package (ASP) are being renovated to make them Year 2000 compliant. This will accelerate the scheduled implementation date for these elements for Year 2000 to March 1999. Work will continue concurrently on the fully Year 2000 replacement system. This decision to repair the mission critical functionality resolves a potential issue related to a delay caused by the late execution of the contract for system replacement.

This system tracks the status, history and location of claims filed for black lung benefits. It also generates payment of medical and compensation for eligible recipients and maintains a history of benefits paid, accounting and financial data.

The Department's Year 2000 contingency policy requires contingency plans for all mission critical systems. These plans are scheduled to be completed by July 1998. Contingency plans have already been developed under previous guidelines for certain targeted systems. Such is the case for the Black Lung ASP system.

The renovation actions referenced above should preclude any type of system failure which might affect beneficiary payments, medical reimbursements to health care providers, result in overpayments or cause delays in responding to inquiries.

QUESTIONS SUBMITTED BY SENATOR HERB KOHL

RETIREE HEALTH CARE COVERAGE

Question. Every day around the country more companies inform their retirees that they are unable to continue to provide health care coverage that they promised in past agreements. Between 1988 and 1996 availability of retiree health coverage declined by 8 percent among businesses with 500 or more employees. Too late, retired people find out that in the small print of their contracts a loophole allows the employer to end coverage if it gets too expensive. As I am sure you are aware, this happened to the employees of the Pabst Brewing Company in late 1996. They were left stunned and feeling lied to both by the company and the government who they thought had insured their benefits. What can the Department of Labor do for workers in this situation?

Answer. Retiree health benefits, like other employment based benefits, are subject to the protections of Title I of the Employee Retirement Income Security Act (ERISA). Unlike defined benefit pension plans, however, these benefits are not guaranteed by the Federal Government.

In 1993, the Department of Labor began looking for opportunities to offer its view of the law to support the legitimate expectations of employees who believed that they had been promised lifetime retiree health benefits. Since then we have filed several amicus briefs attempting to clarify benefit terms and help preserve the health benefits of the retirees involved. We filed five amicus briefs in the Pabst case, including a brief recently filed in the Seventh Circuit Court of Appeals, and have participated in several other cases. We have also published a brochure to assist retirees in understanding the terms of their health plan in order to better assess their options in the event of a termination or reduction of benefits.

Question. Is legislation necessary to provide further protection under the Employee Retirement Income Security Act (ERISA)?

Answer. The Administration proposed, and Senator Moynihan and Rep. Stark subsequently introduced, legislation that would amend ERISA to require that retirees, age 55 or older whose retiree health benefits are cut, be allowed to buy into their former employers' plans for active employees at a price not greater than 125 percent of the average cost for the group (S. 1749 and H.R. 3470). The legislation would also offer displaced workers aged 55 to 62 who lose benefits access to affordable coverage by buying into Medicare, and offer individuals aged 62 to 65 access to Medicare benefits under a special program until they become eligible for the traditional Medicare program.

OSHA PARTNERSHIP INITIATIVES

Question. Many voices in Congress are calling for OSHA reform. They are pushing for, and I support, an OSHA that focuses on consultation and working with employers to improve safety instead of just levying fines. In the last few years OSHA has responded to these demands and begun to change its focus, it is now encouraging employers to work with them for safer workplaces. I am proud to note that the Vice President and the Department of Labor just recently honored Wisconsin Box Co. for

its exemplary participation in OSHA's Cooperative Compliance Program (CCP). Has this program moved OSHA away from being an organization that employers fear as too arbitrary and authoritarian, to one they can work with to improve workplace safety?

Answer. OSHA has sought a variety of ways to work with employers in achieving improved safety and health conditions in the workplace. The CCP effort was specifically intended to address conditions at those worksites with elevated injury and illness rates by offering partnership opportunities for employers and OSHA to work together to reduce those rates. We would like to think that the nearly 90 percent of employers that chose to participate in the CCP did so because they believed that they could successfully work together with OSHA to improve workplace safety and health. The experience of Wisconsin Box Company is testimony to the positive effect this type of program can have in improving working conditions.

STAY ON CCP

Question. The Chamber of Commerce and National Association of Manufacturers are challenging the CCP program in court, halting the program. Does the Department of Labor have a back-up plan to make sure that cooperation and consultation continues?

Answer. OSHA does have a contingency plan for inspection scheduling, but there is not a contingency program for the cooperative aspect. We expect the court to eventually rule in OSHA's favor and the Cooperative Compliance Program (CCP) will then continue. In the meantime we will continue to work on cooperative efforts through local initiatives, OSHA consultation programs, OSHA voluntary protection programs (VPP), and compliance assistance. OSHA consultation programs have been and will continue to be a major part of OSHA's cooperative efforts. The court stay does not affect or alter these efforts.

DISLOCATED WORKERS

Question. Our economy today is the healthiest it has been in decades. Unemployment rates in recent months have remained very low while inflation has been stable. While this is all good news, factories continue to close and some workers are still without jobs. All the sunny statements about the economy don't mean much to someone who has just been laid off. The President mentioned in his State of the Union address creating a program to aid communities after plant closings similarly to what the government does after a military base is closed.

While I understand that some of this effort would be coordinated with the Department of Commerce, how will the Department of Labor be involved?

Answer. The Title III dislocated worker program requires States to initiate rapid response assistance within a short period of time (preferably 48 hours or less) after notice/information is received by the State Dislocated Worker Unit of an impending mass layoff or plant closure. The purpose of this assistance is to begin to share information with the workers and the employer regarding the type of readjustment assistance that is available in the community, including federal funds to provide reemployment services and facilitation in forming a labor-management committee to determine what types of assistance the workers at a specific dislocation are expected to require.

In order to address some of the concerns regarding communities that are being especially hard-hit by dislocations of unskilled workers with limited re-employment options and as part of the President's initiative, the Department of Labor is currently collaborating with the Departments of Commerce and Treasury to find ways to assist such local communities in responding to closures and downsizing. This is particularly critical in communities needing to actively grow or attract new businesses. In this regard, important elements of rapid response assistance include: providing or obtaining appropriate financial and technical advice and liaison with economic development agencies and other organizations to assist in efforts to avert worker dislocations; and assisting the local community in developing its own coordinated response and in obtaining access to State economic development assistance.

Strategies developed by the Departments of Labor, Commerce, Treasury and other agencies are expected to provide opportunities for local communities to enhance such planning envisioned by rapid response, and to encourage the formation of community transition committees to respond to mass layoffs and plant closures.

Question. On a slightly different note, how do you see the Workforce Investment Partnership Act that is currently awaiting consideration by the Senate, helping the dislocated worker?

Answer. The Workforce Investment Partnership Act would help the dislocated worker by:

—Maintaining a separate funding stream for dislocated workers, not only ensuring current resources, but retaining the ability to request increased funding based upon the needs of this targeted population. This is a major improvement over the provisions contained in the consolidation bills considered in the 104th Congress.
—Maintaining a viable National Reserve Account (National Emergency Grants) to allow the Secretary of Labor to respond to mass layoffs, plant closures, and natural disasters.
—Continuing the requirement that States conduct rapid response: the provision of onsite assistance to workers as soon as news of a layoff or plant closure is received. This is a valuable early intervention tool through which workers are provided information they need to start the transition process to new employment. Their need for services to regain employment is assessed and access to such services is facilitated.
—Continuing to allocate funds to carry out dislocated worker research and demonstrations from the national level, as well as technical assistance for continuous improvement of dislocated worker services.

In addition, dislocated workers will benefit from the other reform elements contained in the bill. Establishing One-Stop centers as the framework of the new system would improve dislocated workers' access to quality labor market information and services, and proposed skill grants and training performance information, or the Individual Training Account system, would enable them to make informed choices about training opportunities with qualified vendors.

JOB TRAINING REFORM/YOUTH OPPORTUNITY AREAS

Question. The Congress will again try to pass a job training reform bill this year. This time however, there is even more pressure for swift action than in the past. Last year this committee appropriated $250 million for Opportunities for Out-of-School Youth that cannot be used unless authorizing legislation is signed into law by July 1st of this year.

If Congress does not consider this legislation soon, and fails to meet the July 1st deadline, what would be some possible effects?

Answer. The Youth Opportunity Area initiative is designed to boost the employment rate of out-of-school youth ages 16 to 24 in high-poverty areas from current levels of less than 50 percent to a level of 80 percent. The pervasive joblessness that now exists in high-poverty neighborhoods is an underlying cause of the poverty, crime, youth gangs, drug abuse, welfare dependency, and family breakdown that characterize these communities. The effect of losing the $250 million will be to lose a chance to significantly change these communities and improve the lives of youth who live in them.

Question. Could this group be served by another program? Does the Department of Labor have a "back up" plan?

Answer. Apart from the small-scale Youth Opportunity Area pilots the Department is conducting in six communities with plans to expand the number of sites in PY 1998, there is no other DOL employment and training program that is strictly targeted on high-poverty urban and rural areas. DOL very much wants to implement the $250 million Youth Opportunity Area initiative. DOL will continue to work with Congress toward enactment of Workforce Development legislation in time to trigger the $250 million advance appropriation. We believe that the bill will be signed into law by July 1.

SUBCOMMITTEE RECESS

Senator SPECTER. Thank you very much, Madam Secretary, that concludes the hearing. We appreciate your being here. The subcommittee will stand in recess until 2 p.m., Wednesday, April 1, when we will meet in room SD–192 to hear from Dr. Harold Varmus of the National Institutes of Health.

[Whereupon, at 2:57 p.m., Wednesday, March 18, the subcommittee was recessed, to reconvene at 2 p.m., Wednesday, April 1.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1999

WEDNESDAY, APRIL 1, 1998

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

The subcommittee met at 2:20 p.m., in room SD–192, Dirksen Senate Office Building, Hon. Arlen Specter (chairman) presiding.

Present: Senators Specter, Cochran, Faircloth, Bumpers, and Kohl.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

STATEMENT OF HAROLD E. VARMUS, M.D., DIRECTOR

ACCOMPANIED BY:

RUTH KIRSCHSTEIN, M.D., DEPUTY DIRECTOR, NATIONAL INSTITUTE OF HEALTH
RICHARD KLAUSNER, M.D., DIRECTOR, NATIONAL CANCER INSTITUTE
CLAUDE LENFANT, M.D., DIRECTOR, NATIONAL HEART, LUNG, AND BLOOD INSTITUTE
HAROLD SLAVKIN, M.D., DIRECTOR, NATIONAL INSTITUTE OF DENTAL RESEARCH
PHILIP GORDEN, M.D., DIRECTOR, NATIONAL INSTITUTE FOR DIABETES AND DIGESTIVE AND KIDNEY DISEASES
AUDREY S. PENN, M.D., ACTING DIRECTOR, NATIONAL INSTITUTE OF NEUROLOGICAL DISORDERS AND STROKE
ANTHONY S. FAUCI, M.D., DIRECTOR, NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES
MARVIN CASSMAN, M.D., DIRECTOR, NATIONAL INSTITUTE OF GENERAL MEDICAL SERVICES
DUANE ALEXANDER, M.D., DIRECTOR, NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT
CARL KUPFER, M.D., DIRECTOR, NATIONAL EYE INSTITUTE
KENNETH OLDEN, M.D., DIRECTOR, NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES
RICHARD J. HODES, M.D., DIRECTOR, NATIONAL INSTITUTE ON AGING
STEPHEN I. KATZ, M.D., DIRECTOR, NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES
JAMES F. BATTEY, M.D., DIRECTOR, NATIONAL INSTITUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS

STEVEN E. HYMAN, M.D., DIRECTOR, NATIONAL INSTITUTE OF MENTAL HEALTH

ALAN I. LESHNER, M.D., DIRECTOR, NATIONAL INSTITUTE ON DRUG ABUSE

ENOCH GORDIS, M.D., DIRECTOR, NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM

PATRICIA A. GRADY, M.D., DIRECTOR, NATIONAL INSTITUTE OF NURSING RESEARCH

FRANCIS S. COLLINS, M.D., DIRECTOR, NATIONAL HUMAN GENOME RESEARCH INSTITUTE

JUDITH L. VAITUKAITIS, M.D., DIRECTOR, NATIONAL CENTER FOR RESEARCH RESOURCES

PHILIP E. SCHAMBRA, M.D., DIRECTOR, FOGARTY INTERNATIONAL CENTER

DONALD A. B. LINDBERG, M.D., DIRECTOR, NATIONAL LIBRARY OF MEDICINE

JACK WHITESCARVER, M.D., ACTING DIRECTOR, OFFICE OF AIDS RESEARCH

DENNIS P. WILLIAMS, DEPUTY ASSISTANT SECRETARY, BUDGET, DEPARTMENT OF HEALTH AND HUMAN SERVICES

OPENING REMARKS OF SENATOR SPECTER

Senator SPECTER. Good afternoon, ladies and gentlemen. The Subcommittee on Labor, Health and Human Services, and Education will now proceed.

I regret our late start. We had a vote scheduled for 2 o'clock, and if I am there to vote at 2 o'clock, I can get out at 2:01 and be here to have the minimal interruption with the hearing. But the 2 o'clock vote was postponed to 2:10, and then 2:15, and then 2:17. Then they decided to do that because they scheduled a vote right behind it. That 30 second explanation does not tell you about the proceedings in the Senate. I value your time very highly. I know this is an extraordinary assemblage of talent. As the saying goes, there is more talent in this room since President Kennedy dined alone—and I had better be careful of what I say here. [Laughter.]

The National Institutes of Health, as I so frequently say, in my opinion is the crown jewel of the Federal Government. Besides that, you are good. [Laughter.]

It may not take too much to be the crown jewel of the Federal Government, but the National Institutes of Health has set a mark in what you have accomplished and I am a total supporter.

We have a Federal budget of $1.7 trillion and if we set our priorities in order, there will be no problem in increasing your funding tremendously.

We give lip service to doubling the NIH budget over 5 years. It unanimously passed last year, 97 to 0. With Senator Harkin and I working together, crossing party lines—I learned a long time ago if you want anything done in Washington, you have to cross party lines and get bipartisan support—we tried to put the money into it by $1 billion plus budget amendment because the health account had been cut by $100 million, and it was defeated 63 to 27.

We have readied an amendment for $2 billion extra. We are talking about doubling, which would be more than $2.5 billion, but we are talking about a $2 billion addition.

I know that there are many grants not funded, and we would like to open up those doors if we possibly can.

So this having been said, Dr. Varmus, we welcome you. We welcome your colleagues.

We will have to vote again in a few minutes, so we are under time constraints, as usual. That is nothing extraordinary for the Senate and this distinguished panel is used to that as well.

So let us set a 5-minute time limit. Your full statements will be made a part of the record and, to the extent you can summarize, we would appreciate it.

SUMMARY STATEMENT OF DR. HAROLD VARMUS

Dr. VARMUS. Mr. Chairman, thank you very much. I appreciate those warm welcoming remarks. I will be extremely brief so that we can get on with the questioning.

INCREASE FUNDING

I am here for the fifth time representing the NIH. I am very pleased to be here to present an extraordinary budget by the President for 1999 of $14.797 billion, an 8.5-percent increase over our 1998 level, and a projected increase over the next 5 years up to a $20 billion final budget, a 50-percent increase.

In our view, this is a wonderful time for such an increase. Research in biology and medicine is moving at an unprecedented pace. The public health needs continue to be great, both here, as the population ages, and abroad, and especially in our minority populations.

I am going to omit a litany of our accomplishments, the great promises that new technologies offer, and simply mention, very briefly, four of the ways in which the Institutes and centers would spend this unprecedented $1.15 billion increase. Then we can get into some questioning to talk about specific projects they have in mind.

First, with this year's budget, we would fund an unprecedented number of research grants, with a healthy success rate and adequate levels of support for individual grantees, allowing us to pursue the many exciting initiatives that are described in the NIH areas of emphasis package.

Second, we would be able to implement many new, innovative components in our clinical research enterprise—recruitment of clinical investigators, training, career awards, clinical trials—as outlined in a letter that I recently sent to you in response to your question about our clinical research activities.

The third area of focus is to help develop the environment in which research is done by developing new instruments, purchasing shared instrumentation, supporting more bioengineering research, and in other ways, enriching the environment for doing research.

PREPARED STATEMENTS

Finally, we want to recruit and train more effectively in all fields, providing a stable environment for performing research in which investigators have a reasonable chance of being supported over many years, increasing stipends for our trainees, encouraging

transdisciplinary work, and doing a variety of other things that make it clear that science that benefits health is a very broad enterprise, which reaches from mathematics, computer sciences, and engineering, to medical research in the clinic.

I would be pleased to answer any questions you might have about the specifics of the plans we entertain for this coming year.

Thank you.

[The statements follow:]

PREPARED STATEMENT OF HAROLD E. VARMUS

OFFICE OF THE DIRECTOR

Mr. Chairman, Members of the Committee, we are pleased to be here today to discuss the fiscal year 1999 budget request for the Office of the Director (OD). As you know, the OD provides leadership, coordination, and policy direction for the overall extramural and intramural medical research activities across NIH, and for special programs specifically established within the OD. The office also provides management leadership and centralized support functions essential to the operations of the entire NIH.

The President in his fiscal year 1999 budget has proposed that the OD receive $212.9 million, an increase of $11.8 million over the non-AIDS portion of the fiscal year 1998 appropriation. Including the estimated allocation for AIDS in both years, total support proposed for the OD is $254.7 million, an increase of $13 million over the fiscal year 1998 appropriation. Funds for OD efforts in AIDS research are included within the Office of AIDS Research budget request.

The NIH, as a federation of research Institutes and Centers, (or IC's), conducts a vast program of medical research with the goal of advancing medical knowledge to improve health. Furthermore, NIH aims to develop the complex infrastructure of facilities needed to conduct this research. Attainment of these goals results in improved health for all Americans, enhancing the quality of life for our citizens, and benefitting the Nation's economy.

As has often been expressed during these hearings, NIH is in a position to achieve great strides in the prevention, diagnosis, and treatment of disease and has undertaken an ambitious program of medical research emphasizing such themes as genetics and neurosciences, new approaches to the origin and development of disease, and new prevention and treatment strategies. The OD mission is to provide the program means—policies, priorities, processes, and procedures—wherein the research IC's can conduct their activities in the core program areas of research, research training and career development, and support of research facilities. The OD provides a structure and framework for the conduct of the activities of the IC's in a manner that is responsive to promising research opportunities and technologies, yet addresses public health needs. Specifically, the OD guides and supports research by setting priorities; allocating funding among these priorities; developing science policies on the use of research subjects and materials; maintaining peer review processes; administering grant and contract award functions; communicating health information to the public; facilitating the transfer of technology to the private sector; and providing fundamental management and administrative services such as financial accounting and personnel, property, and procurement management, administration of equal employment practices, and plant management services, including environmental and public safety regulations of facilities. The principal OD offices providing these activities include the Office of Extramural Research (OER), the Office of Intramural Research (OIR), the Offices of Science Policy, Communications, Legislative Policy and Analysis, the Office of Equal Opportunity, and the Office of Management. This request contains funds to support the functions of these offices.

To further influence research activities and to address targeted public health needs and specific components of medical research, the OD maintains several trans-NIH offices and programs that focus on a particular aspect of research and foster and encourage research in that particular area. These OD offices address a variety of health needs and research areas, including programs to improve the health of women and minority populations, the use of complementary and alternative (CAM) therapies, activities to examine the use of dietary supplements, research related to social and behavioral patterns in the maintenance of health, and efforts to promote research on rare diseases. I will now discuss the budget requests of these trans-NIH offices in greater detail.

OFFICE OF RESEARCH ON MINORITY HEALTH AND THE NIH MINORITY HEALTH INITIATIVE

Minorities at all stages of life suffer poorer health and higher rates of premature death than does the majority population. To address these disparities from a trans-NIH perspective, NIH established the Office of Research on Minority Health (ORMH) to promote medical research aimed at improving the health status of minority populations throughout their lifespan; and to expand the ability of minority scientists to participate in all aspects of medical research. As such, the budget request is in support of numerous collaborative activities with the IC's in the core program areas of research, and in research training and career development. Specifically, ORMH will support research activities by providing grant supplementation for research on diseases that disproportionately affect minorities, such as lupus, asthma, and hypertension.

The NIH Minority Health Initiative (MHI) sponsors specific projects to develop therapies for sickle cell disease, address diabetes among Hispanics and Native Americans, and treatment for hypertension among Asian and African Americans, support initiatives to decrease injury and death due to violence in minority youth, reduce unintended pregnancy in minority women, and support initiatives to reduce infant mortality in inner city populations.

Research training programs such as the Bridges to the Future program, the Minority International Research Training (MIRT) program, and the Comprehensive Partnerships for Mathematics and Science Achievement (CPMSA) program are also supported. The Bridges to the Future program links two-year colleges with four-year colleges offering baccalaureate degrees in science; while an M.S./Ph.D. component of the program links institutions with terminal master's degree programs with schools offering Ph.D.'s in science. These activities help to ease the transition for students as they pursue each higher level of their education. The MIRT program encourages minority students to continue to pursue careers in medical research by providing exposure to global medical research issues and concerns through links with foreign scientists at established domestic medical research centers and with research institutions located abroad. Finally, the CPMSA program provides standards-based math and science curriculum development, teacher training, and research experiences for students in the K–12 sector to encourage young students to consider careers in science.

In addition, the ORMH represents the program means that NIH maintains to stimulate and foster minority research activities among the IC's, and to evaluate these activities and assess attainment of NIH goals in the area of minority health. To this end, the ORMH sponsors a number of community outreach and review functions including the convening of advisory committee meetings, and support of workshops, conferences, caucuses, and symposia designed to promote and assess minority health issues. In this respect, I am happy to report the establishment of the Advisory Committee on Research on Minority Health as a standing committee to advise the Director, ORMH, and the NIH Director on medical research activities pertinent to minority health issues. The Committee will hold its first meeting in April 1998.

OFFICE OF DISEASE PREVENTION

Within the OD, the Office of Disease Prevention (ODP) has several program offices that strive to place new emphasis on the prevention and treatment of disease. Chief among these is the Office of Alternative Medicine (OAM). OAM pursues studies of improved disease management through evaluation of complementary and alternative medicine (CAM) therapies. In the United States, it is estimated that some 61 million Americans, spending an estimated $13.7 billion annually, use CAM to treat varied conditions, both for preventive and for treatment purposes. The OAM, using its own program announcements and requests for proposals, will solicit applications and proposals in several promising research areas, including osteoarthritis, cardiovascular disease, and drug addiction. The OAM will continue funding Clinical Research Centers that have been established jointly with the IC's for the purpose of conducting research on alternative and complementary medical modalities. The Centers sponsor a number of clinical trials including examining the efficacy of herbal products for treating HIV-associated anemia, uterine fibroids, and alcohol dependence; examination of the use of acupuncture for treating drug withdrawal and addiction, dysphasia in stroke, and postoperative pain after oral surgery. Also underway are trials of Ginkgo biloba to treat stroke and traumatic brain injury; trials investigating supplementation to the diet with garlic on plasma lipoproteins levels; and acupressure and massage therapy in the management of asthma. In addition, the OAM will further enhance its dissemination efforts with the expansion of databases of CAM topics. Finally, the OAM will continue to explore methods to improve inves-

tigation and validation of promising CAM therapies through collaborations with other Institutes and agencies that perform long-term field studies.

Continuing to pursue improved prevention methods, the Office of Dietary Supplements (ODS) stimulates research on the use of dietary supplements, particularly regarding health benefits and impact on disease prevention. The ODS will continue to support investigator initiated research protocols through Research Enhancement Awards Program (REAP) awards and joint program announcements with the ICD's. These address areas such as thaimine deficiency, use of vanadium salts and antifolates; and protocols that investigate the effect of dietary supplements on antibiotic-induced hearing loss and loss of bone density in athletes. In the area of education and information dissemination, ODS will continue to maintain databases and Internet information pages to provide the public with information on such supplements, and to conduct conferences and workshops to encourage new research initiatives in this field.

To address unrecognized public health needs, the ODP's Office of Rare Diseases develops and disseminates information on rare diseases and conditions and links investigators with ongoing research activities in this area. The ORD supports workshops and symposia to stimulate research interest and to identify research opportunities related to rare diseases. These workshops have resulted in a determination of research priorities, the development of research protocols, and criteria for diagnosing and monitoring rare disorders such as head and neck cancers, AIDS related malignancies, sleep control, hereditary ataxias, and unusual palsies and dysplasias. The results of these workshops are fully documented in a report on the outcomes of ORD sponsored scientific workshops and symposia to be provided to Congress.

OFFICE OF BEHAVIORAL AND SOCIAL SCIENCES RESEARCH [OBSSR]

The Office of Behavioral and Social Sciences Research (OBSSR) was established to address the role of health behaviors and social factors in the prevention and management of disease. The OBSSR increases the scope of, and support for, behavioral and social science across all of NIH. The office develops initiatives to stimulate research in these areas and to ensure that findings from this research are disseminated to the public. In one such initiative, the OBSSR, in collaboration with sixteen IC's and the American Heart Association, will sponsor an RFA on disease prevention through behavioral change that targets the risks of tobacco use, lack of exercise, improper diet, and alcohol abuse. Additionally, OBSSR plans to organize a trans-NIH initiative designed to fund research on the influence that socioeconomic factors have on health and disease.

OFFICE OF RESEARCH ON WOMEN'S HEALTH [ORWH]

Responding to the health needs of women, the Office of Research on Women's Health (ORWH), as the focal point for women's health research at NIH, strives to ensure that NIH supported research addresses health issues of concern to women, that women are appropriately included as subjects in research protocols and clinical trials, and that women are encouraged to pursue careers in medical research. Working from a comprehensive research agenda that approaches women's health across the life span, ORWH will use its budget to stimulate, initiate, and expand women's health research by supporting research grants, RFA's, PA's, and REAP Awards in priority areas identified during public hearings and workshops held during the ORWH conferences: Beyond Hunt Valley: Research for the 21st Century. These efforts will be focused in the following areas: diabetes prevention, Hormone Replacement Therapy and lupus, arthritis and chronic pain, heart disease, alcohol and drug use, reproductive health, and urologic and kidney conditions.

OTHER OD ACTIVITIES

In addition to the offices previously mentioned, the OD sponsors a number of additional NIH programs that promote scientific research and enhance research career development.

The OER coordinates the Academic Research Enhancement Award (AREA) program that provides grants to institutions that award degrees in health sciences but are not major recipients of NIH grant funds. These awards enable students to participate in a research project and encourage them to the possibility of careers in medical research. OER also sponsors the Extramural Associates Research Development Award (EARDA) program that provides competitively awarded grants to institutions that offer medical research programs but have a significantly under represented minority enrollment. The grants are designed to provide faculty at these institutions with skills needed to become more competitive in obtaining Federally sponsored research funds.

The NIH, through the Office of Intramural Research (OIR), maintains loan repayment and scholarship programs as important instruments for recruiting high quality candidates in basic and clinical research positions. The request contains funds for the NIH Clinical Research Loan Repayment Program and the Undergraduate Scholarship Program, both for individuals from disadvantaged backgrounds; and for the Loan Repayment Program for General Research. Each program provides for the payment of educational costs in return for specific commitments of service in NIH's intramural research facilities.

The Office of Science Policy coordinates several science education activities that benefit both students and teachers and encourage students to consider careers in research.

The request also contains funds to support the Foundation for the National Institutes of Health to facilitate its transition to a self-sufficient entity able to support the mission of NIH through funds which the Foundation raises from private sources. Limitations are to be placed on the use of these appropriated funds, and their availability is contingent upon certification of a plan for self-sufficiency of the Foundation by the Secretary.

The request also includes funds for a Discretionary Fund to permit the Director to respond to new and emerging high priority research opportunities such as vaccine study, gene mapping and imaging.

WOMEN'S HEALTH INITIATIVE [WHI]

We are proposing to transfer the Women's Health Initiative (WHI) to the NHLBI, where it will function as a consortium among NHLBI, NCI, NIA, and NIAMS. We believe that by placing the WHI in an Institute, we can provide the best opportunity for success as it operates as a large-scale research project similar to others in the Institute. We recently conducted a detailed review of the WHI programs and contract costs in preparation for this transfer, and found that recruitment efforts had to be expanded beyond the original levels, special efforts to retain enrollees had to be put in place and increased emphasis on studying minority women was necessary. Expanding the sample size by 10,000 was necessary to ensure that we had participation from women of all demographic groups. But these increased recruitment and retention costs can noticeably diminish the financial resources for the other study components, and increasing the sample size will also increase the costs for follow-up. Therefore, an increase of $13.4 million is being requested by the NHLBI as a way to bring the WHI operation in-line with the long-standing program objectives. This increase is requested in the NHLBI budget along with the original funding request for the WHI.

MANAGEMENT IMPROVEMENTS

Seeking to maximize administrative effectiveness, NIH, at the request of the Subcommittee, undertook a comprehensive review of the agency's administrative structure and costs to document the effectiveness of current practices and identify areas for future improvements. After considering the major recommendations that emerged from this review, we will focus implementation efforts on a number of high priority areas including: accounts payable; property management; personnel delegations; procurement; an automated time and attendance system; and information technology management. In addition, an overall assessment of security services will be initiated. Other initiatives to be pursued include better management of the decentralized delivery of administrative services; strengthening the partnership between the scientific and administrative staff; and establishing increased administrative accountability throughout the NIH. In addition, in response to Subcommittee concerns, the NIH is initiating review of regulations governing the conduct of extramural scientific research in an effort to identify and alleviate any unnecessary administrative burden these regulations may impose.

The fiscal year 1999 budget request for the Office of the Director is $212.949 million. I will be pleased to answer questions.

The activities of the OD are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

BUILDINGS AND FACILITIES

I am pleased to present the President's budget request for the Buildings and Facilities (B&F) Program. The President in his fiscal year 1999 budget has proposed that the B&F receive $218.9 million, an increase of $12 million (or 5.8 percent) over the fiscal year 1998 appropriation. Including the estimated allocation for AIDS, total support proposed for B&F is $225 million, an increase of $18 million (or 8.7 percent) over the 1998 appropriation. Funds for B&F efforts in AIDS research are included within the Office of AIDS Research budget request.

ROLE IN THE BIOMEDICAL RESEARCH MISSION

The B&F Program plays an essential role in supporting the biomedical research mission of the NIH and has a critical and exciting impact on shaping and defining the NIH campus. The Buildings and Facilities appropriation provides funds for the design, construction, improvement, and major repair of clinical, laboratory, and office buildings, as well as supporting facilities, essential to the mission of the NIH.

MASTER PLAN

Armed with an updated master plan that was approved by the National Capital Planning Commission (NCPC) in February 1996 for the Bethesda campus, the NIH is moving forward with a new blueprint to guide future development on the campus. The new comprehensive master plan identifies programmatic requirements in terms of personnel and physical facilities; establishes concepts for future development and land use, buildings, utilities, open space, circulation and traffic management for the next twenty years; and illustrates how needs for laboratory and clinical research, administrative, and support space can be accommodated. An updated Master Plan for the NIH Animal Center in Poolesville was completed in the Fall of 1996.

The NIH is, however, challenged with an aging, deficient physical plant. The majority of the infrastructure systems are 20 to 40 years old and beyond their design life. To address this problem, which has major occupational and environmental safety implications, two major strategies have been put in place. First, NIH has integrated all corrective construction programs into a comprehensive Facilities Revitalization Program. Its objective is to support laboratory and clinical research by providing safe, functional, modern, and adaptable facilities that are program effective and cost efficient over their expected life. The second strategy is the upgrade of the NIH utilities infrastructure, most of which is obsolete, beyond its useful life, and needed to meet the demands of modern research.

MARK O. HATFIELD CLINICAL RESEARCH CENTER

In recent years, the NIH has placed the highest priority on the renewal of the Clinical Center (CC) hospital and related research laboratories. Ever since its construction in 1953, the CC has been the core of the Intramural Program, the training site for thousands of the nation's biomedical scientists, and home for the most prestigious clinical research program in the world. The power of this program is intimately linked to the diversity and quality of laboratory sciences present on the NIH campus, especially those practiced in space immediately adjacent to the clinical wards. With nearly half of the country's research beds, a large ambulatory care research unit, a coordinated training program, and over 1,000 protocols conducted with patients from throughout the nation and the world, the CC has fostered important work on diseases ranging from the well-known (e.g., cancer and AIDS) to the rare and obscure.

The Clinical Center complex contains approximately 40 percent of the laboratory research space on the Bethesda campus, and about one half of the federally supported research beds for clinical research. However, the utility systems within the complex are deteriorated, outmoded, obsolete, and insufficient to support modern research. Numerous distinguished review groups, including the U.S. Army Corps of Engineers and the External Advisory Panel established by the Congress and chaired by Drs. Paul Marks and Gail Cassels, have confirmed the increasingly dangerous deficiencies in the physical condition of the existing Clinical Center and proposed the construction of a new research hospital. More recently, the DHHS Secretary's review of the Clinical Center confirmed the recommendation for a new facility and noted that its proposed operational changes can only be fully realized in a building with a modern design. In accordance with the advice of the Marks-Cassell Panel, the Administration and the Congress has supported the NIH plan to design and construct what is now the Mark O. Hatfield Clinical Research Center (CRC), a state-of-the-art research hospital with 250 beds, allied clinical facilities, and adjacent research laboratories for work that is closely intertwined with patient research activi-

ties, a traditional strength of the existing CC. It will be located to the North of the existing Building 10 complex and ambulatory care research building. The research hospital will be approximately 600,000 gross square foot (gsf) and will be served by an additional 250,000 gsf of new space dedicated to laboratory and program support. It is estimated that construction for the new CRC will take five years to complete and will be ready for occupancy in 2002.

Funds provided in the fiscal year 1995 appropriation of $2,500,000 were used to investigate and evaluate different project development approaches and design options for the new facility. They were also used to pay for a design concept competition. The CRC project was initially funded in fiscal year 1996 when funding of $23 million was provided for architecture and engineering design and design development for the project. The fiscal year 1997 and fiscal year 1998 B&F appropriations included $90 million in each fiscal year for the construction portion of the Mark O. Hatfield Clinical Research Center. In accordance with the intent of Congress, the project is being planned at full scope to completion. The fiscal year 1999 request of $90 million will continue the course of the project. The total planned budget for design and construction of the CRC is $333 million. The proposed appropriations language specifies $90 million for fiscal year 1999 and requests advanced appropriations for $40 million in fiscal year 2000 for the construction of the CRC, which will remain available until expended.

The CRC is currently being fast-tracked, i.e., as segments of the project design are completed, the construction will start while the remaining design is being developed. Since September 1997, site preparation work for the CRC has been underway. This includes demolition of existing structures on the site of the CRC; modification of the existing south entrance to the Clinical Center to facilitate construction of the new CRC on the north side of the Clinical Center; and relocation of utilities and roadways. In the next year and a half, significant progress will be made: the design will be fully completed; the site preparation will be substantially completed; and the building foundation and structure will be in place.

HIV VACCINE FACILITY

Another highlight of the fiscal year 1999 request for B&F is funding for the construction of an HIV Vaccine Facility. With President Clinton's announcement of another important new NIH AIDS vaccine initiative in May 1997, the NIH is moving forward to develop a Vaccine Research Center (VRC). The VRC will bring together in a single location scientists engaged in all aspects of vaccine research, integrating modern immunological science with detailed understanding of the pathogenesis of HIV infection, development of immunogens and vectors, and new approaches to vaccination. The VRC will be housed in a Vaccine Facility which has been initiated with $17 million appropriated in fiscal year 1998 to accelerate design and begin construction. Funding to complete construction of the Vaccine Facility, totaling $9.1 million, is included in the fiscal year 1999 B&F budget request of $3 million and $6.1 million made available in the Office of AIDS Research request.

ESSENTIAL SAFETY AND HEALTH IMPROVEMENTS

The NIH continues to place a high priority on the essential safety and health requirements of its facilities. In addition to the CRC, the Essential Safety and Health Improvements initiatives address the infrastructure upgrades to existing NIH facilities to meet critical occupational and environmental requirements to protect and support ongoing research programs, including the safety and health of NIH employees and patients. Supporting utilities need to be modernized and improved in order to meet safety and health requirements in support of the NIH research mission.

The Infrastructure Modernization Program (IMP), initiated in fiscal year 1991, is in the final year of a nine-year program to replace and expand central utility equipment and distribution systems. A critical situation had developed where sufficient and uninterrupted services to research and patient care activities could not be ensured due to obsolete, deteriorated systems, overburdening from growth, and increasing program requirements. The IMP is critical to ensure the infrastructure capability to carry out the NIH mission and remove the possibility of a catastrophic failure of the central utility and distribution systems. This request includes funds to complete construction of the central power plant expansion that will house equipment such as secondary pumping apparatus, several chillers, and areas for maintenance and spare parts.

Other funds included in the fiscal year 1999 request for the Essential Safety and Health Improvements initiatives are for; the systematic and phased removal of asbestos-containing materials from various NIH buildings; the implementation of the plan to correct fire and life safety deficiencies in NIH buildings on the campus and

at the NIH Animal Center; the elimination of barriers to persons with disabilities; a multi-year program to address indoor air quality concerns at NIH facilities; the modernization of Building 6; the construction of the upgrade of the utility infrastructure at the NIH Animal Center, Poolesville; the ongoing rehabilitation of NIH animal research facilities; and initiation of the environmental assessments/remediation program. All of these projects are driven by federal and local regulations, policies and national accreditation requirements.

REPAIR AND IMPROVEMENT PROGRAM

The Repair and Improvement (R&I) program represents essential ongoing preventive maintenance, and major repairs and rehabilitation/upgrades to the physical plant that supports the main NIH campus in Bethesda, as well as to field stations that are the responsibility of the NIH. The R&I program covers projects of a recurring nature including roofs, roads, structures, and building utilities, as well as other projects that are unpredictable, and are one-time occurrences that require immediate attention that are critical to the continuing operation of our research facilities.

RENOVATIONS AND SYSTEM UPGRADES

This fiscal year 1999 B&F request also provides funds for the renovation of the basement of Building 30; safety upgrades within Building 37; and upgrades to NIEHS mechanical systems.

FISCAL YEAR 1999 BUDGET SUMMARY

The fiscal year 1999 request for Buildings and Facilities is $218.9 million. The request is highlighted by $90 million for the Mark O. Hatfield Clinical Research Center, the third of four planned funding increments to complete construction; and $3 million to complete construction of the Vaccine Facility to house the VRC. The NIH, through the Office of AIDS Research budget request, has also made available $6.1 million in the fiscal year 1999 to support the Vaccine Facility project. The request totals $55.1 million for essential safety and health improvements composed of $7.5 million for the final year of funding of the site infrastructure modernization program at the NIH; $5.5 million for the phased removal of asbestos from NIH buildings; $3 million for the continuing upgrade of fire and life safety deficiencies of NIH buildings; $500,000 for the elimination of barriers to persons with disabilities; $1.5 million for implementation of an indoor air quality improvement program; $8.8 million for the modernization of Building 6; $16 million for the construction of the upgrade of the utility infrastructure at the NIH Animal Center, Poolesville; $11.3 million to continue the rehabilitation of animal research facilities; and $1 million to initiate a program of environmental assessments and remediation. In addition to the essential safety and health improvements, the fiscal year 1999 request includes: renovation projects amounting to $4.4 million for the basement of Building 30; $17 million for the mechanical/life safety upgrades to Building 37; and funding of $9.1 million to upgrade mechanical systems at NIEHS. The fiscal year 1999 request also includes $40.2 million for the continuing program of repairs, improvements, and maintenance that is the true keystone of the B&F program.

My colleagues and I will be happy to respond to any questions you may have.

PREPARED STATEMENT OF JACK WHITESCARVER

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the AIDS research programs of the National Institutes of Health for fiscal year 1999, a sum of $1,730,796,000, an increase of 7.7 percent above the comparable fiscal year 1998 appropriation.

The activities of the OAR are covered by the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and linked to the HHS GPRA Strategic Plan that was transmitted to Congress on September 30, 1997. The OAR is anxious to meet the challenges set forth in this plan, and we look forward to continued support from Congress that will facilitate our achieving these goals.

The role of the Office of AIDS Research (OAR) is to plan, coordinate, and evaluate NIH AIDS research and to develop this budget request, assuring that the nation's investment will be used to address the most compelling scientific opportunities and priorities that will lead to better therapies and prevention for HIV infection and AIDS.

AIDS EPIDEMIC IN THE UNITED STATES

If I were to summarize where we stand after 16 years of pitched battle against the AIDS pandemic, I would say, with apologies to Charles Dickens, that it is the best of times; it is the worst of times. Here in the United States, remarkable research progress has brought about longer and better quality of life for many HIV-infected individuals. New combination therapies of protease inhibitors and other antiretroviral drugs can reduce the amount of virus in the blood to undetectable levels. Death rates, hospitalization, and rates of new infections are decreasing in many populations. Drug regimens have dramatically reduced the number of infants born with HIV.

But even here in the United States, the news is not all good. The new drugs are not a silver bullet. We do not know how long their benefit will last or whether immune function of treated individuals can be restored without additional interventions. There are many for whom the new drug regimens have not been effective or for whom the side-effects are not tolerable. We are now beginning to identify adverse metabolic effects that may be the result of long-term use of antiretroviral therapies. Drug-resistance and the transmission of drug-resistant HIV is a very dangerous reality. And many patients, particularly in our minority communities, simply do not have the means to access these life-extending therapies.

AIDS is actually a series of individual epidemics, and although overall statistics are down in the U.S., the epidemics in many groups are increasing. AIDS cases continue to rise among women and minorities in our country. According to the CDC, in 1996 new AIDS cases increased by 19 percent among heterosexual African American men; 12 percent among heterosexual African American women; 13 percent among Hispanic men; and 5 percent among Hispanic women. CDC recently announced that AIDS is on the increase in another group in our nation—people over 50 years of age. Since 1991, AIDS cases in the 13 to 49 age group increased 9 percent; but cases in people over 50 increased 22 percent during that same time.

WORLDWIDE PANDEMIC

The news around the world is far worse. The World Health Organization and the Joint United Nations Programme on HIV/AIDS (UNAIDS) recently released new data demonstrating that the deadly march of the pandemic had been underestimated. They now estimate that 2.3 million people died of AIDS in 1997—a 50 percent increase over 1996. Nearly half of those deaths were among women, and nearly half a million were children under 15 years of age. The total number of people living with HIV and AIDS worldwide has been revised upward to more than 30 million adults and children, with 16,000 new infections each day. WHO estimates that more than 90 percent of people with HIV live in the poorer countries of the globe, as the epidemic continues its unabated spread through Africa, Asia, and now Eastern Europe.

Thus, we face two great dichotomies in our progress against AIDS. One, the disparity that exists even among different populations within our own country; and the disparity that is exponentially greater between the industrialized and the developing worlds.

NIH COMPREHENSIVE RESEARCH PLAN AND BUDGET

The NIH AIDS research program is addressing these unacceptable dualities with a comprehensive research plan and budget that balances the need for new therapies that are more effective, less expensive, and in less complex dosage regimens with the need for a safe and effective vaccine that can be used worldwide. To gain the most expert advice and to achieve scientific consensus on the goals and objectives to be achieved, the OAR has established a unique and collaborative planning effort involving hundreds of individuals: NIH Institute Directors, scientists and program staff; non-government experts, including scientists from academia, foundations, and industry; and AIDS community representatives. The plan itself is unique in that it serves as the framework for the development of the budget and defines those research areas for which AIDS- designated funds may be allocated.

IMPLEMENTING THE LEVINE REPORT

The plan has also been shaped by the recommendations of the Levine Report, the comprehensive evaluation of the NIH AIDS research program. The recommendations of this landmark Report have had a lasting effect on almost every aspect of the AIDS research program—in setting the scientific agenda, refocusing priorities, and shaping the AIDS research budget. The report has had a profound impact in helping to establish the appropriate balance within the AIDS research program in

two critical areas. The first area is the balance between investigator-initiated research grants and targeted, directed science. Before embarking on the evaluation process, OAR already had identified the need to place greater emphasis on investigator-initiated science and to increase the proportion of funding devoted to basic research. The Levine Report confirmed these priorities. Between fiscal year 1994 and this budget request, OAR has increased the number of new and competing research grants by 50 percent, thus encouraging innovation from a wider group of investigators.

The second area of impact is the balance between research to develop treatments for those who are already infected and research to prevent infection. Vaccine research is a key priority of the Levine Report, and a specific challenge from the President. This budget request reflects an unprecedented commitment to this critical area of research. NIH has taken a number of steps to move the science in this area forward. Nobel Laureate David Baltimore now serves as chair of the NIH AIDS Vaccine Research Committee providing leadership and guidance to this effort. A new program of "innovation grants" was initiated by that Committee. A new center is being established on the NIH campus devoted to vaccine research with an AIDS vaccine as its first major goal.

The Levine Report also challenged NIH to develop a Prevention Science Agenda. OAR established a Prevention Science Working Group that has established other priority areas of prevention research, including topical microbicides and other female-controlled barriers, treatment and prevention of sexually transmitted diseases, and prevention of mother-to-child transmission.

NIH programs are pursuing the search for newer and better drugs and therapeutic regimens with increased potency, less complicated treatment regimens, and fewer toxic side effects. The second generation of protease inhibitors is now in development and moving rapidly through the drug development pipeline. NIH-sponsored researchers, in collaboration with industry, are working to identify, design, and evaluate new agents that interfere with other targets in the HIV life cycle with the goal of inhibiting HIV infection, disease progression, and transmission. NIH clinical trials will continue to identify and evaluate the most effective ways to use these drugs in combination.

BENEFITS OF AIDS RESEARCH TO OTHER DISEASES

Mr. Chairman, the nation's investment in AIDS research is also providing major benefits in our ability to understand and treat a wide spectrum of other infectious, malignant, neurologic, autoimmune and metabolic diseases. For example, the drug known as 3TC, developed to treat HIV infection, now has been shown to be the most effective therapy for chronic hepatitis B infection. The drugs developed to prevent and treat many of the opportunistic infections in HIV-infected patients also promise real benefit to those undergoing cancer chemotherapy or receiving anti-transplant rejection therapy. Researchers recently published a report suggesting that there is a link between the Kaposi's sarcoma-associated virus and multiple myeloma, a blood cancer. This finding may lead to new treatments or a vaccine, and additional information about the link between viruses and cancer. And, the study of the immune systems of HIV-infected individuals is providing new insight into changes that occur during the normal aging process.

In a very real sense, AIDS has also revolutionized the way that we conduct research at the NIH for all diseases, empowering patients, particularly women and minorities, to participate in clinical trials and in the design and implementation of research protocols. This is progress that also will benefit people with all diseases and disorders.

In closing, I would like to return to "A Tale of Two Cities," Dickens' story of the French Revolution, and read from its famous first sentence: "It was the best of times, it was the worst of times; it was the age of wisdom, it was the age of foolishness; it was the epoch of belief, it was the epoch of incredulity; it was the season of Light, it was the season of Darkness; it was the spring of hope, it was the winter of despair * * *." For those of us in the battle against this awful disease, that quote captures the roller-coaster of emotion. There is darkness and light. There are advances and then new problems. We cannot be complacent because death rates are down. We have succeeded in keeping some people alive longer, but we are already seeing the many limitations of the new therapies. The epidemic has brought about a revolution in science and in public health, but the battle is far from over.

The budget authorities provided to the Office of AIDS Research, that allow us to direct resources to the most important scientific priorities, are even more critical today as these opportunities constantly change. The Nation has invested major resources in the NIH AIDS research program. I believe that the steps taken by OAR

over the past few years and the scientific progress that has been made, demonstrate that the Nation's investment is indeed well spent. We are grateful to the Committee for your continued support for AIDS research.

My colleagues and I would be pleased to respond to any questions you may have.

PREPARED STATEMENT OF RICHARD D. KLAUSNER

Mr. Chairman and Members of the Committee: I am pleased to appear before you for the third time as Director of the NCI. The President in his fiscal year 1999 budget has proposed that the NCI receive $2.536 billion, an increase of $215 million (or 9.27 percent) over the non-AIDS portion of the comparable fiscal year 1998 appropriation. Including the estimated allocation for AIDS, total support proposed for NCI is $2.776 billion an increase of $229 million (or 8.99 percent) over the fiscal year 1998 appropriation. Funds for NCI efforts in AIDS research are included within the Office of AIDS research budget request. This will allow us to both continue and accelerate the progress I believe that we are making.

Last year, we reported what we believed to be a historic observation—the first sustained, significant decrease in cancer mortality rates since such statistics were collected in the 1930's. We agreed then, in collaboration with the American Cancer Society and the National Center for Health Statistics of the Centers for Disease Control and Prevention, to issue an annual report card on cancer statistics. This year's report card, using numbers updated through 1995, was presented at a press conference on Thursday, March 12, and I can tell you that the encouraging trends continue. This year, we have added incidence trends as well. From 1973 to 1990, overall cancer incidence rates increased by 1.2 percent per year. Since 1990, they have decreased by 0.7 percent per year. This drop includes three of the most common cancers: lung, colorectal, and prostate. Breast cancer rates, after increasing by 1.8 percent per year, are now flat. Non-Hodgkin's lymphoma had been rising at the extraordinary rate of 3.5 percent per year. While it is still rising at 0.8 percent per year, the slowdown in the rate of increase is significant.

Likewise, overall death rates continue to decrease by 0.5 percent per year, after rising 0.4 percent per year. For white males, this drop is 0.9 percent per year, while for black males, the mortality rate drop is 1.3 percent per year. Quite significant changes in incidence, mortality and pattern of disease rates for prostate cancer, the most common cancer in men, are currently being carefully analyzed. Overwhelmingly, due to the continuing increase in tobacco-related cancer deaths for women, the drop in their mortality rates is less than for men, 0.1 percent per year in whites and by 0.2 percent per year in blacks. Not captured by the above statistics are prolonged survival and improved quality of life for many of the millions of cancer survivors in this country.

CONTROL AND PREVENTION

This year, I received reports from two outstanding blue ribbon panels advising the Institute on critical opportunities and needed approaches in cancer control and cancer prevention. We are now engaged in implementing the many recommendations of these groups, expanding our activities in these areas. Our response has included the formation of two newly configured divisions of the National Cancer Institute, the Division of Cancer Prevention and the Division of Cancer Control and Population Sciences. These new divisions will strengthen our efforts in both cancer prevention and cancer control. This past year, in cancer prevention, we completed the accrual of 13,000 women at increased risk of developing breast cancer to a critical clinical trial to determine whether the anti-estrogen, tamoxifen, can actually prevent this disease. The development of new so-called "designer estrogens" is creating new possibilities for very selective hormone manipulation for cancer prevention and we are actively evaluating clinical trials to examine this. The NCI is currently sponsoring 85 chemoprevention trials for breast, colorectal, lung, prostate and other cancers, a growing number of these based upon a real understanding of the mode of action of the interventions. Twenty-five new prevention trials are to be implemented over the next year.

Identifying populations and individuals at high risk for cancer is a growing focus of the NCI. The Cancer Genetics Network, will involve eight different centers throughout the U.S. The goal is not only to identify new genes that predispose to cancer but also to learn better ways to counsel people, help them cope with the sequelae of genetic testing, and apply cancer prevention and early detection strategies in high risk individuals. Evaluating the efficacy of surveillance and prevention in high risk groups is the subject of several initiatives. One such population is the 8–9 million cancer survivors in the U.S. who are at an increased risk for the devel-

opment of second cancers. In fiscal year 1998, we have invested five million new dollars to put in place a growing research portfolio under the coordination of our Office of Cancer Survivorship to address the many issues facing this population. Our goals include not only decreasing the risk of second cancers but also improving quality of life among our survivors.

INCREMENTAL ADVANCES

Advances in treatment often are incremental and they take time to have an effect on cancer mortality. It is this incremental progress that, in part, explains the mortality trends for numerous cancer sites. We have had few dramatic therapeutic breakthroughs in cancer research. We have, however, developed a clinical trials system to test and optimize often complex therapies. Over the past 12–24 months, we have completed clinical trials that have established new standards of optimal therapy for women with node-negative and locally advanced breast cancer, for women with advanced ovarian cancer, for patients with nasopharyngeal cancer, for melanoma, and for childhood renal cancer.

A major explanation for the incremental nature of progress in treatment is that, with the exception of hormonal manipulation, our therapies have not been designed to target the machinery of cancer. This brings me to focus on dramatic changes in the National Cancer Program.

FRUITS OF RESEARCH

Thirty years ago, Peyton Rous in his Nobel Lecture said, "Tumors destroy man in a unique and appalling way, as flesh of his own flesh which has somehow been rendered proliferative, rampant, predatory and ungovernable * * * yet despite more than 70 years of experimental study, they remain the least understood * * * What can be the why for these happenings?" Three decades later, Dr. Rous would be amazed. With dizzying speed and growing precision, we are mapping the inner workings of the tumor cell, explaining how it behaves and how it assures an accepting and nurturing host. The black box cell of Dr. Rous seen in Figure 1 is being replaced by the intricate circuitries of Figure 2. The cancer genes so frequently reported in the news are altered relays in this circuitry. Viruses, carcinogens and radiation all act by altering one or more of these specific pathways. Each circuit suggests a rational target for prevention or therapy of cancer as shown in Figure 3. Dozens are being developed. Ten years ago, 60 drugs were entering clinical trials for cancer. Today, that number is about 320.

Let me illustrate one. Thirty-five percent of breast cancers overexpress a protein called HER–2, a crucial link in one of these growth-controlling circuits. These cancers tend to be more aggressive, and clinical trials have shown that women with such cancers require more intensive therapy to achieve the same outcome as women with tumors that do not overexpress HER–2. Last December, Genentech announced the results of the first clinical trial using an agent targeted specifically to HER–2. That agent, when added to taxol, showed a clinical response rate three times greater than with taxol alone in women with advanced metastatic breast cancer. New clinical trials will rapidly build on this result for breast and other cancers that overexpress this cancer gene, such as a proportion of ovarian and lung cancers.

In one of the more exciting tests of our new knowledge of cancer biology, we now know that altered circuits in cancer cells result in the production of molecules that stimulate the growth of blood vessels that nourish the growing tumor. Without these, the tumor will die or never grow beyond a microscopic size. Over the next year, we plan to have the first potent anti-angiogenesis agents into clinical trials for cancer. Knowledge about these cancer circuits will profoundly affect our approach to therapy although I believe they will also have a major impact on prevention.

THE CHALLENGE

To maintain this remarkable momentum of discovery, with the President's budget proposal, we can continue to increase the success rate for the funding of individual investigator-initiated research. We will continue to build on the infrastructure of the Cancer Genome Anatomy Project, which I introduced to you last year, to speed the discovery of the pieces of the machinery of cancer and especially to give us new molecular tools for early detection. This year, we will add to that project by beginning to catalog the natural variations in genes which will likely explain why different individuals respond to environmental, genetic and other causes of cancer so differently. This proposed budget will allow us to support a number of new initiatives which are aimed at bridging the gap between the explosion of discoveries in basic

science and the need to translate these advances to our ultimate goal of reducing the burden of cancer for people.

Among these are:

—Develop chemistry-biology centers to capture revolutionary new approaches to the generation of millions of small molecules and to couple this with so-called "smart assays" in order to target these newly defined cancer circuits.

—Build a new program for Rapid Access to Interventional Development, or RAID, which will allow the best new preclinical ideas in cancer intervention from investigators throughout the country to become available for clinical testing in an accelerated way.

—Build a re-designed, informatics-based clinical trials system to expand access to prevention, detection and treatment trials, to improve the speed and value of the trials and to allow the growing number of compelling ideas to be rapidly tested.

—Build a new imaging research network to rapidly evaluate emerging technologies in tumor imaging, both for early detection and staging and for image-guided therapy.

—Fund new clinical training pathways and fund mid-level and senior clinical investigators to protect their time to engage in both clinical research and mentoring.

—Improve our cancer surveillance system so we have a better understanding of the burden of cancer and where we need special efforts to control cancer.

The activities of the NCI are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

I will be happy to respond to any questions you may have.

PREPARED STATEMENT OF CLAUDE LENFANT

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Heart, Lung, and Blood Institute (NHLBI) for fiscal year 1999, a sum of $1,646.8 billion, an increase of $124.3 million above the comparable fiscal year 1998 appropriation. Total support proposed for AIDS is $68 million, an increase of $4.4 million over the 1998 appropriation. Funds for NHLBI's efforts in AIDS research are included within the Office of AIDS research budget request.

This year, it is a particular pleasure to appear before the Committee. The NHLBI is celebrating its 50th anniversary, and we have much reason to be proud of our past and optimistic about our future. Since it passed the National Heart Act in 1948, the Congress has appropriated more than $23 billion in support of this remarkable enterprise. I want to thank you—and the American taxpayers—for this support and to tell you how richly rewarding this public investment in medical research has proven to be.

NHLBI'S IMPACT

When the Institute was founded 50 years ago, our nation was in the throes of an epidemic of heart disease, as indicated by the vital statistics data shown in Chart 1. Beginning at the turn of the century, and particularly after the end of World War I, heart disease death rates increased steadily among women and quite precipitously among men. It seemed that there was no end in sight for this alarming trend, because we were quite ignorant about the causes of heart disease and extremely limited in our ability to treat or prevent it. Heart disease was an implacable and inexorable threat to the public health.

Who would have believed that this situation could be turned around in such a short period of time? But in fact, it has been, as can be seen in Chart 2, which extends the previous vital statistics data to the present time. Heart disease death rates among men are now about where they were 100 years ago, and among women they are 37 percent lower. Progress against coronary heart disease has been especially noteworthy. Not only do we have lifesaving treatments for heart attacks, but

we are able to prevent many of them from occurring—or at least postpone them until old age.

The same is the case with strokes, for which death rates have plummeted, due in great measure to improvements in detection and treatment of high blood pressure. The National Center for Health Statistics estimates that the average American can expect to live 5½ years longer today than was the case even 30 years ago and, as Chart 3 indicates, nearly 4 years of that gain in life expectancy can be attributed to our progress against cardiovascular diseases, including coronary heart disease and stroke.

Our assault on diseases that affect the very young has been equally vigorous and effective. For instance, the past 50 years have witnessed unprecedented improvements in the outlook for the 40,000 children born each year with congenital heart disease. In the 1940's, autopsies were virtually the sole means of identifying these congenital defects; now we can diagnose them in utero. Fetal diagnosis allows optimal medical management of children who may require life-saving surgery before they are a week old. The understanding of fetal and infant physiology, and the development of techniques to perform surgery safely on infants weighing as little as 3 pounds, allows many curative surgical procedures to be performed in infancy on children who, in the past, would have either died or lived very limited lives.

Neonatal respiratory distress syndrome, which as recently as 1970 claimed the lives of 10,000 newborns annually, is now responsible for fewer than 1,400 deaths each year, according to vital statistics. Children with inherited diseases of the lungs and blood, such as cystic fibrosis, sickle cell disease, and Cooley's anemia, which used to claim their victims in childhood, can now expect to live well into adulthood.

As you know, the Institute's mandate has encompassed blood safety issues for the past 25 years. Here again, our research programs have paid off richly, not only in terms of reducing human suffering but also in terms of reducing health care costs. For example, in 1970 the chance of contracting hepatitis through a blood transfusion was 23 percent, as shown in Chart 4. This risk decreased substantially in subsequent years as a result of various measures taken to exclude high-risk blood donors and test blood for infectious agents, and is now close to zero, according to data recently published in the journal Clinical Chemistry. The most recent innovation, a highly sensitive anti-hepatitis C test implemented in 1992, is estimated to have prevented 33,310 cases of hepatitis annually, resulting in savings of $323 million in health care costs.

PROMISING RESEARCH AREAS

As a result of the scientific discoveries and new research approaches developed during its first 50 years, the NHLBI is now poised to make a quantum leap in our understanding of many basic issues that govern health and disease. Let me describe several broad themes that are ripe for exploration in the near future.

One area of considerable interest, because it cuts across cardiovascular, lung, and blood diseases, is thrombosis—the formation of blood clots. As anyone with hemophilia can affirm, the blood's ability to clot in response to an injury that allows it to escape from the blood vessels is a critical, life-preserving function. However, blood clots that form inappropriately, within intact vessels or the chambers of the heart, are responsible for a host of life-threatening events, including heart attack, stroke, peripheral vascular disease, and pulmonary embolism, as depicted in Chart 5. We have already developed a number of practical interventions to combat the devastation caused by thrombosis—for example, thrombolytic drugs to restore blood flow in the case of an acute heart attack; anticoagulants to prevent the clots that tend to form in the upper heart chambers of patients with atrial fibrillation and subsequently travel to the brain, causing strokes. Many opportunities now exist to make further progress by understanding, at a more fundamental level, how blood interacts with its environment. For instance, our research on atherosclerosis has revealed that the size of the plaque that clogs arteries may be far less important than other characteristics that make it susceptible to erosion and rupture, thereby releasing substances into the bloodstream that promote thrombosis. Millions of heart attacks may ultimately prove preventable if we can unravel this mystery and develop effective interventions. Furthermore, advances in our understanding of the genetics of thrombosis, coupled with new, highly sensitive imaging techniques, may enable us to identify persons who are most susceptible to these events, so that we can target the interventions to those most likely to benefit.

Adaptive changes in tissue structure and composition, known collectively as "remodeling," are a vital element of normal growth and development. However, remodeling in the heart muscle, the airways, and the blood vessels in response to prolonged disturbances, such as hypertension or inflammation, is harmful. Just as pull-

ing too hard on a spring will stretch the coil out of shape and weaken it, years of uncontrolled hypertension can cause the cells of the heart muscle to lose their ability to contract, leading to heart failure. Similarly, remodeling of airway smooth muscle in response to chronic inflammation is a major feature of asthma. Exploration of the elements that regulate remodeling offers an unprecedented new opportunity to control or reverse many pathological processes.

Angiogenesis—growth of new blood vessels—is a form of remodeling that can have both harmful and beneficial effects and is, therefore, the object of intense investigation. Recent studies indicate that both anti- and pro-angiogenic agents have significant potential for therapeutic use. For instance, cancer research has revealed that suppressors of angiogenesis can significantly and safely inhibit the growth of tumors by starving off their blood supply. On the other hand, angiogenesis promoters have been used successfully to bypass blood flow obstructions in people's legs, an approach that could reduce the need for amputation. Just last month, scientists reported success in using an angiogenic growth factor to increase blood flow to the heart muscle in patients whose coronary arteries were obstructed. This approach could have tremendous potential for reducing the suffering and costs associated with coronary heart disease.

One additional example of remodeling involves the use of retinoic acid to stimulate growth of new air sacs, or alveoli, in the lungs of mice. Much work remains to be done before such an approach can be extended to humans, but it offers the first hope that emphysema—an invariably progressive and fatal disease—may be reversible.

One final area of opportunity that I would like to mention, which is a trans-National Institutes of Health priority, is research on diabetes. Considerable progress has already been made in developing effective therapies, and there is much hope that a cure may ultimately be achieved. However, in the meantime, thousands of affected patients die each year, not of diabetes itself, but of its cardiovascular complications, as the data in Chart 6, derived from vital statistics and several small cohort studies, reveal. We perceive an urgent need for basic research to understanding the way in which diabetes increases cardiovascular risk, and for clinical studies to establish optimal goals for control of blood sugar, hypertension, and cholesterol levels in diabetic patients and to determine the best approach to revascularization of such patients who have coronary heart disease.

I would be pleased to answer any questions that the Committee may have about the programs and plans of the NHLBI.

PREPARED STATEMENT OF HAROLD SLAVKIN

Mr. Chairman and Members of the Committee: The President in his fiscal year 1999 budget has proposed that the National Institute of Dental Research (NIDR) receive $214.6 million, an increase of $18.6 million over the non-AIDS portion of the fiscal year 1998 appropriation. Including the estimated allocation for AIDS in both years, total support proposed for NIDR is $229.5 million, an increase of $20 million over the fiscal year 1998 appropriation. Funds for NIDR efforts in AIDS research are included within the Office of AIDS Research budget request.

The activities of the NIDR are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

A GOLDEN ANNIVERSARY

The NIDR will celebrate its 50th anniversary on June 24th, 1998. From today's perspective, the oral health of Americans 50 years ago was not as bleak as "the undentisted ages" Henry James described a century ago, but fell far short of ideal. Most Americans expected to be—and were—toothless by age 45. Tooth decay was so rampant that Congress was moved to establish NIDR by "the appalling extent of dental disease and dental neglect." The new Institute would be responsible for "conducting and fostering research on the causes, prevention, methods of diagnosis, and treatment of dental diseases and conditions."

And so we have. In 50 years we have transformed the practice of dentistry and literally changed the faces of millions of Americans. Today's dental office reflects a generation and more of private sector, professional and research community innovation and collaboration that have produced the high-speed handpiece, Panorex X-rays and digitized radiography, broad-ranging infection control and prevention, aesthetic dental materials and protective sealants, and exquisite pre- and post-operative management of pain and inflammation. As a result of continuing declines in tooth decay and periodontal disease, only 10 percent of our population is toothless. From the initial discoveries that dental caries was an infectious disease that fluoride could help to prevent, NIDR scientists have built a research base that has opened the door to the study of all the tissues of the craniofacial complex. Importantly, the applications of dental science to improved diagnostic, treatment and prevention strategies are saving an estimated $4 billion a year in the cost of dental care in America.[1]

A STRATEGIC PLAN FOR THE 21ST CENTURY

Our mission to improve and promote craniofacial, oral and dental health through research remains. What has changed is how we hope to realize our goals. In the last year we published Shaping the Future, a strategic plan to carry us into the next century. We have streamlined our extramural and intramural research divisions to focus on six areas: Inherited Diseases and Disorders; Infection and Immunity; Oral and Pharyngeal Cancers; Chronic and Disabling Diseases; Biomaterials, Tissue Engineering and Biomimetics; and Behavior, Health Promotion and the Environment. These six areas reflect the penetration of oral science into all fields of biomedical and behavioral science and the imperative to address the riveting changes occurring throughout society worldwide: changes in demographics, in health care, in patterns of disease and in the very way we do science today. Ultimately, our goal is to meet the rising expectations of Americans to enjoy the best of health care and live to a ripe old age free of disease and disability.

AS THE TWIG IS BENT * * *

Ideally, that means ensuring babies a healthy start at the beginning of life. Much of the excitement in biomedical research today lies in the discovery of genes that are essential to development. Of these, certain genes can be described as master architects of the body: They determine the basic body plan for tissues, organs and systems. A misspelling or mutation in such a gene can give rise to a condition like Rieger syndrome in which children are born with defects in organs situated at the front of the body. They have eye defects that can lead to glaucoma, small undeveloped teeth and a protuberant umbilicus. They may also have heart, limb and pituitary defects. Such multiple defects occur early in development, as the cells that form the embryo migrate to create the front to back, side to side and top to bottom orientation of life forms that developed early in the course of evolution. Indeed, these master genes were first discovered in fruit flies, where they are called homeobox genes. The newly discovered Rieger gene, called RIEG in the human condition and Rieg in mice, is a new member of a family of bicoid homeobox genes—proteins expressed in anterior structures of the body. In the fruit fly a RIEG-type gene is responsible for the design of the head.

The finding that misspelling or mutations in a single gene can have so many ramifications is one of the more startling discoveries to come from molecular genetics research. In addition, two other syndromes we are studying underscore how often defects in teeth and bones occur along with other organ defects. For example, individuals born with cleidocranial dysplasia will be short, lack collar bones, suffer other craniofacial and skeletal abnormalities and yet may have more teeth than normal—all because they lack one copy of a gene that codes for a protein essential to bone formation. Mice lacking both copies of the gene are born with a complete lack of bone and die. A second multiple organ disorder is McCune Albright fibrodysplasia, a painful, crippling diseases in which there are bone lesions, changes in skin pigmentation and precocious puberty. Our investigators are working with scientists from the National Institute of Child Health and Human Development, the National Institute of Diabetes, Digestive and Kidney Diseases and the NIH Clinical Center to understand the disease process. As well, the need to help these patients is giving impetus to apply the principles of a revolutionary new science of Biomimetics.

---

[1] Brown, L.J., Beazoglu, T., and Heffley, D. (1994) Estimated savings in U.S. dental expenditures, 1979–1989. Public Health Reports, 109(2), 195–203. The updated figure was provided through personal communication from the authors.

This new science unites biomedical knowledge of the genes and molecules that orchestrate the normal growth of bones, teeth, cartilage and other tissues with engineering, materials and computer sciences to achieve the natural repair and regeneration of body tissues. NIDR scientists have been prime movers in the discovery of the genes that encode growth molecules, now organized into families, such as bone morphogenetic proteins (BMP's). In collaboration with industry, these and other growth-promoting molecules have been synthesized, combined with other compounds and scaffolding material and readied for clinical use. So promising is this field that NIDR, in collaboration with the National Heart, Lung, and Blood Institute and the National Institute of Arthritis, Musculoskeletal and Skin Diseases issued a Request for Applications (to be funded this year) to spur research. NIDR will issue a Program Announcement in fiscal year 1999 that specifically targets craniofacial-oral-dental tissues for biomimetic repair and regeneration.

ALL CANCER IS GENETIC

The path from the study of genes for development and repair to genes that figure in oral and pharyngeal cancer is short. Like all malignancies, these cancers develop because the genetic machinery that controls cell growth, differentiation and movement has gone awry, giving rise to a rogue clone of cells. With additional mutations the clone can become aggressive and invasive. This story has a tragic ending for the 9,000 Americans who die every year from oral and pharyngeal cancer. For those who do not die, radiation, chemotherapy and surgery leave a legacy of pain, disfigurement and dysfunction. After 5 years, the survival rate is only 50 percent.

Logic dictates that if we are to derail this pathologic process, we need to identify the multiple sets of genes involved in cell growth, understand their function, and learn what happens when they are mutated. We also need to understand what makes some people inherently more likely to develop these cancers than others—isolating so-called cancer susceptibility genes. The next step is to develop tests to detect the presence of such genes and other markers of risk—preferentially using easily obtained samples of saliva for diagnosis. Finally, we need to develop smarter treatments—ways to replace mutated genes with intact copies, for example, or ways to stop the formation of new blood vessels that feed a growing tumor. With the intense interest in advancing cancer research today, we have many opportunities for collaboration. We are already funding three of our four oral cancer research centers with the National Cancer Institute (NCI), and our plans call for further networking with NCI, NICHD, the Centers for Disease Control and Prevention, the American Dental Association, the National Dental Association, and other groups. These activities will highlight cancer prevention programs, especially efforts to eliminate tobacco use in young people.

PAIN AND HEAT: A GENETIC LINK

Not all gene discoveries relate to development or disease. One of the more striking findings in the past year solves a mystery that has long puzzled neuroscientists: How do we sense burning heat? It turns out it's by the same mechanism that makes a chili pepper taste fiery. When you touch a hot stove you excite a receptor on the surface of sensory nerve cells that will also react to the chemical in peppers that makes them hot—capsaicin. NIDR-sponsored scientists have now isolated and cloned the gene for the capsaicin receptor (technically known as vanilloid receptor 1—VR1) enabling them to study how the receptor works. Investigators now suspect that VR1-receptor-bearing nerve cells are involved in a number of chronic pain conditions, especially where inflammation plays a role, from viral and diabetic neuropathies and rheumatoid arthritis to oral mucositis pain caused by head and neck radiation or cancer chemotherapy. Interestingly, continued stimulation of capsaicin receptors can lead to cell death, which is the reason that capsaicin is being used as an ingredient in salves and chewing gum to relieve burning pain. With the new understanding of the pain-heat genetic link, still better approaches to relieve chronic pain may be on the horizon.

A second pain experiment in the past year does not resolve a mystery so much as underscore what investigators have long suspected: There are sex differences in response to pain. The experiment in question revealed that men and women reacted very differently to a particular kappa opioid analgesic used for post-operative pain control in patients undergoing wisdom teeth extraction. Women reported excellent pain relief, while men reported little or no relief. These provocative findings will be explored further as part of the agenda of the NIH Pain Research Consortium, which NIH Director Dr. Harold Varmus established in 1997 to enhance pain research and collaboration. The Consortium, co-chaired by the Director of NIDR and the Director of the National Institute of Neurological Disorders and Stroke, held a major sympo-

sium, New Directions in Pain Research, in November, 1997, bringing pain researchers and leaders in other fields of neuroscience together with patient groups for an exchange of ideas, findings and issues. Next month we will hold another NIH Conference on "Gender and Pain," and in May yet another NIH Conference on "Palliative Remedies for the Management of Pain." A major trans-NIH Program Announcement has just been issues to further catalyze pain research.

ORAL ROUTES FOR SYSTEMIC INFECTION

Periodontal disease, in which pockets of destructive bacteria in the gums attack the soft tissue and bone supporting the teeth, may lead to dangerous systemic complications throughout the body. Currently, periodontitis is being investigated as one of the culprits in the yearly birth of 250,000 premature, low birth weight (LBW) babies. Women with periodontal disease were found to be seven times more likely to deliver low birth-weight babies prematurely. Preliminary studies show that periodontal disease also may be a major contributor to cardiovascular disease. If this seems improbable, consider that a single tooth site of infection and bleeding in the mouth, if removed to the skin, would be equivalent to a one-inch-square open sore on the palm of your hand. The bacteria in such lesions may well release byproducts into the general circulation that can damage tissues directly or through the release of inflammatory mediators by the immune system. The constant production of such molecules in a chronic, inflammatory disease like periodontitis could then lead to tissue damage. In the case of pregnancy, these molecules can also induce pre-term labor. Further evidence of the potential damage to the body from oral bacteria comes from a recent study in which NIDR-supported investigators infused a common oral bacterium into the bloodstream of a rabbit. Within moments the bacteria secreted a unique protein with properties that stimulated the formation of a precocious blood clot, initiating a process that could lead to a heart attack or stroke.

NEXT 50 YEARS

Our Strategic Plan commits NIDR to three major initiatives: (1) to support world-class science across the six program areas described earlier; (2) to enhance research capacity by revitalizing infrastructure and training and career development programs; and (3) to intensify health promotion efforts so that research findings are readily adopted by providers and the public. A variety or organizational and administrative changes are in place to further these ends. As well, these changes will provide us with the flexibility and creativity that are needed to meet the challenges of a rapidly changing and complex society. In a year, we have seen unprecedented growth in the economy, exponential growth of information technology, and a rise in the standard of living. At the same time, we are witnessing a fundamental restructuring in health care delivery, we are faced with a steady stream of new or re-emerging diseases, and we must come to grips with the many bioethical issues occasioned by the progress of human genome and cloning research. These developments are fostering a climate of cooperation, collaboration, and communication that extends beyond NIH and the research community to the public at large. Communicating the facts of biomedical science is the best means we have to empower Americans to make decisions and life style choices to improve their health and prevent disease. That goal was intrinsic to the NIDR mission 50 years ago, and will continue to be a driving force in the century ahead.

My colleagues and I will be happy to respond to any questions you may have.

PREPARED STATEMENT OF PHILLIP GORDEN

Mr. Chairman and Members of the Committee: I am pleased to testify before the Committee on behalf of the National Institute of Diabetes and Digestive and Kidney Diseases. The President in his fiscal year 1999 budget has proposed that the NIDDK receive $927.5 million, an increase of $69 million over the comparable fiscal year 1998 appropriation. Including the estimated allocation for AIDS in both years, total support proposed for NIDDK is $944.3 million, an increase of $70.5 million over the fiscal year 1998 appropriation. Funds for NIDDK efforts in AIDS research are included within the Office of AIDS Research budget request.

A major goal of the NIDDK is to make investments in innovative technologies and discoveries that can be directly applied to patients in clinical trials. These advances then have immediate application to patient care and public health. This general process can be illustrated by examples in diabetes that clearly point to research advances and help chart our further progress. One of the most important objectives of our current research investment is to reduce the intensity and duration of an in-

dividual's exposure to high levels of blood glucose and to develop other risk-reducing therapies. Today, because of our earlier investments in basic science, we are able to pursue this objective through new research initiatives. It was our investment in basic research that produced the tools that enabled us to reach the point of applying clinical trial methodology. Through these trials, we could assess whether the complications of diabetes and onset of the disease itself can be prevented, thus laying the foundation for today's diabetes research agenda.

DIABETES AS AN ILLUSTRATION OF RESEARCH INVESTMENT

Diabetes is the most common cause of end stage renal disease. Thus, one of our major goals is to reduce the risk of this complication as well as other complications such as blindness, nerve degeneration and amputations. A class of drugs known as angiotensin converting enzyme inhibitors, originally designed to treat hypertension, were found in animal models to decrease the effect of diabetes on the development of kidney disease. When this approach was tried in diabetic patients who were developing kidney disease, we found a major effect of the drug in slowing the deterioration of kidney function. This is an excellent example of tertiary prevention, where the agent works independent of the effect on blood glucose concentrations. Now, if we add this effect to a major effect of lowering blood glucose concentration as shown in the Diabetes Control and Complications Trial, we see a dramatic effect of lowering risk by adding a form of secondary prevention to tertiary prevention. These major advances have already been introduced into clinical practice in both forms of diabetes.

These results also paved the way to development of primary prevention strategies for two ongoing clinical trials. In the first, the Diabetes Prevention Trial, we are testing whether the prophylactic administration of insulin can prevent or delay the onset of type 1 diabetes in at-risk individuals. In the second, the Diabetes Prevention Program, we are testing whether lifestyle and drug interventions can prevent or delay the onset of type 2 diabetes in at-risk individuals, including minority populations. These primary prevention trials are promising.

In a predictive model, the effects of these various interventions in type 1 diabetes can be added together and extrapolated to the future, as shown on Figure 1. This model shows that the risk of developing diabetic kidney disease in at-risk populations may be enormously decreased, and this relates to other complications as well. Thus, from our basic research investments, we have developed strategies to interdict the course of diabetes and its complications. Though successful, these therapeutic regimens are difficult to follow, especially for children and adolescents. Patients and their families want better technologies that will produce easier and more effective treatments.

To expand our therapeutic tools, we need innovative strategies for achieving the diabetes research advances of the future. Let me give you some examples of how we propose to achieve these goals. Specific mechanisms of interdicting the immune destruction in type 1 diabetes are now possible. For instance, we are using transgenic technology to create animal models to pinpoint mechanisms that will modulate the immune system, first in animals, and then in patients who are at-risk for the development of type 1 diabetes. Other key parts of our research agenda will be: (1) To discover the mechanism by which insulin-producing beta cells are destroyed, including exploitation of recently emerging concepts about the general mechanisms of cell death; (2) To identify possible viral or environmental factors that may cause type 1 diabetes, including retroviruses; (3) To find transcription factors that regulate the tissue-specific generation of insulin-producing cells, including the possibility of stimulating a progenitor cell to produce insulin after the mature insulin-producing cells have been destroyed; (4) To engineer insulin-producing cells using constructs that will confer a specific property on the cell, such as the properties of glucose recognition, glucose sensing, and other similar regulatory steps; and (5) To develop other cell-based therapeutic modalities.

In order to close the gap in the difficulty of administering insulin, we will foster research on a variety of glucose-sensing technologies. Recently, one of our investigators has presented an algorithm to relate interstitial or tissue glucose concentrations to blood glucose concentrations. A probe-sensing interstitial glucose concentration would avoid issues related to applying a probe to blood itself and would therefore be an important potential way to close the sensing loop. Thus, the concept of glucose sensing coupled to a delivery system is under vigorous pursuit and will clearly be a major effort in the next several years.

Further approaches to understanding the causes of diabetes will be pursued by genetic techniques. Six known genes are involved in several forms of type 2 diabetes, and several large scale studies using "high throughput" genomics are attempt-

ing to find new genes in more conventional forms of type 1 and type 2 diabetes. With NIDDK sponsorship, a consortium of scientists is pursuing the genetics of both forms of diabetes. We are enthusiastic about the application of genetic technology to our understanding of the complications of diabetes. For example, we now know that only about 40 percent of long-term diabetics ever develop renal disease and that diabetic renal disease has a familial association. We now have the opportunity to elucidate the specific genes involved and how they may be modified by other environmental factors. This will be the focus of intense research in the next several years.

Insulin resistance is a major feature of type 2 diabetes and a major investment in this area of research has led to our ability to conduct our prevention clinical trials. We now have four classes of orally administered drugs that are highly effective in the treatment of type 2 diabetes. These therapeutic advances are derivative of our basic research in insulin resistance and secretion. We now have state-of-the-art nuclear magnetic resonance technology to study glucose metabolism directly in the human body. This will provide important insights and new avenues of research into the role of circulating substrates and other factors that relate to insulin resistance. For instance, we are learning about the mechanisms by which exercise produces insulin sensitivity and are identifying new potential targets for drugs to modify insulin resistance. Further, the role of defective insulin secretion is becoming progressively well-defined in the onset of type 2 diabetes. These studies provide us with new potential therapeutic targets.

Our diabetes research agenda has advanced rapidly as new resources have become available. In this exciting endeavor we have been guided by the advice of leading scientific experts. To aid our short-term program development, we have the recommendations of a landmark trans-NIH symposium that the NIH Director and the NIDDK sponsored in September, 1997, along with eight other NIH components on: "Diabetes Mellitus: Challenges and Opportunities." We have also formed a trans-NIH advisory group of the leaders of those institutes to provide continuing advice. In addition, we have established the congressionally-directed Diabetes Research Working Group, which is developing a longer-range, comprehensive plan for the Congress. We are continuing to promote collaborations across the NIH and to seek partnerships with the biotechnology and pharmaceutical industries, and voluntary health organizations. Likewise, we will disseminate important research findings through the National Diabetes Education Program. This Education Program, which we support with the CDC and others parts of the diabetes community, is making a special effort to reach minority populations disproportionately affected by type 2 diabetes. For support of this program and all of our activities to improve the health of minorities through NIDDK research, I would like to extend our sincere appreciation to Congressman Louis Stokes, who has always been a strong advocate for minority health during his membership on this Committee.

OTHER EXAMPLES OF IMPORTANT RESEARCH NEEDS AND INVESTMENTS

Obesity is a major risk factor for type 2 diabetes, lipid disorders, hypertension, cardiovascular disease and cancer. As part of the Institute's Obesity Research Initiative, we provided leadership in establishing a Task Force on the Prevention and Treatment of Obesity to provide expert scientific advice to the NIH and the public; established Obesity/Nutrition Research Centers; and launched a Weight-Control Information Network. Through basic research, we have discovered multiple genetic loci for obesity in animals, with human parallels. The most dramatic discovery in the field of energy regulation was the identification of the first obesity gene and its protein product, leptin. In fiscal year 1999, we will continue to expand our programs to exploit the discovery of obesity genes and the complex neuroendocrine systems that regulate both food intake and energy utilization. Most importantly, we are making plans to initiate a major clinical trial, which we hope will show that the numerous health risks imposed by obesity can be reduced by voluntary weight loss.

Many diseases within the NIDDK research mission involve infectious and inflammatory processes. To combat chronic liver disease we will launch a major natural history study of hepatitis C, based on a Consensus Development Conference we sponsored with NIAID. We are also pursuing expanded research on the role of cytokines and other mediators of infection and inflammation in food-borne illnesses that affect the digestive system and the kidney, and are building on a trans-NIH initiative on hemolytic uremic syndrome. In addition, we will continue our efforts to find new therapeutic targets in the inflammatory bowel diseases. In urologic diseases, we are promoting enhanced basic research to understand the biology of the pelvic floor, and its susceptibility to infection and inflammation. We have reformulated the database on interstitial cystitis, and are collaborating with the NIA and

NICHD on urinary incontinence. We are also actively pursuing the possibility of developing a vaccine to protect against recurring urinary tract infections. Concomitantly, we are intensifying research on the biology of the prostate, which includes studies of benign prostatic hyperplasia, prostatitis, and prostate cancer, in collaboration with the NCI. In cystic fibrosis, we will be exploiting newly discovered concepts about how chronic infection is initiated and perpetuated.

In genetics, an example of recent research progress is the convergence of several discoveries with respect to iron, which is important in nutrition, growth, and the maintenance of red-blood cells. However, iron overload is involved in a variety of disease processes, such as hemochromatosis, one of the most common genetic diseases in the U.S. Recently, scientists discovered the major gene for this disease. Paralleling this discovery, is the elucidation of the protein responsible for iron transport in the digestive tract.

Our investment in basic research continues to be the wellspring of our innovative strategies for the future. We continue to make progress in understanding the role of a defective gene in the development of polycystic kidney diseases and are making plans to develop clinical milestones on which therapeutic strategies can be based. Similarly, endocrine research on hormones and growth factors is broadly applicable to breast, prostate and thyroid cancer, as well as to bone diseases such as osteoporosis. Other research with broad implications is a planned study of analgesic-associated kidney disease. A widely applicable model system is the zebrafish, which will provide a tool for visualizing pathways turned on in the development of insulin-producing cells in diabetes, as well as other developmental pathways. An example of basic research with unexpected therapeutic applications is work conducted by NIDDK intramural scientists on the properties of a toxin derived from a tropical frog, which shows promise of generating a new class of substances for effective pain management. Thus, progress in diabetes research and other disease-oriented research of the NIDDK depends on the continuing NIH investment in a strong foundation of fundamental and clinical research—along with research training and career development—as the underpinning of the entire biomedical research enterprise.

The activities of the NIDDK are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

This figure displays "model" projections of the potential benefits of past and ongoing NIDDK clinical trials on the rate of renal failure in people with type 1 diabetes. Similar benefits are projected for eye and nerve complications (data not shown). All patients enter the model before diabetes develops, according to the eligibility criteria for the NIDDK's ongoing primary prevention trial for type 1 (Diabetes Prevention Trial 1 or DPT–1). The treatment after entry into the model is described below:

Types of Prevention:

None.—No treatment before diabetes develops; the model assumes that the patient receives historical diabetes care. After diabetes develops, the model assumes that standard diabetes care is given, as defined in the Diabetes Control and Complications Trial, that is, metabolic control of blood glucose levels to maintain clinical well being, but without the use of intensive treatment techniques or use of drugs, called angiotensin converting enzyme inhibitors (ACE inhibitors), for reduction of excess levels of protein in the urine.

Tertiary Prevention.—1993—Clinical Trial with ACE Inhibitors: No treatment before diabetes develops. Standard DCCT care after diabetes develops. Use of ACE inhibitors in those developing gross proteinuria. This treatment regimen is assumed to reduce the rate (percent/year) of patients progressing from gross proteinuria to renal failure by 50 percent a year, according to the clinical trial funded by the NIDDK.

Secondary Prevention.—1993—Prevention of the Eye, Nerve and Kidney Complications of Diabetes in the NIDDK Clinical Trial of Glucose Control (the Diabetes Control and Complications Trial, commonly known as the DCCT). No treatment before diabetes develops. Intensive diabetes care after diabetes develops (that is close metabolic control of blood glucose levels), resulting in a measurement of blood glucose levels by a test called the called "hemoglobin A1C test" of 8 percent—levels which are approximately equal to the blood glucose levels maintained by the entire

DCCT cohort for the 5 years subsequent to the conclusion of the trial, and about 50 percent of the effect achieved during the trial. Use of ACE inhibitors is assumed if gross proteinuria develops, with the reduction in risk described above.

Primary Prevention.—Ongoing Trial—Prevention of the Onset of Type 1 Diabetes in At Risk Individuals Through Prophylactic Administration of Insulin in the NIDDK-Funded Diabetes Prevention Trial (commonly called the DPT–1). This clinical trial, which is currently in progress, assumes that the risk of developing diabetes is reduced by 75 percent by the interventions being tested—the prophylactic administration of oral or parenteral insulin. Care if diabetes develops is as described above, and includes intensive diabetes care and use of ACE inhibitors. Note that the figure shows the theoretical benefits of yet-unproven therapies, while benefits shown for ACE inhibitors and Glucose Control are proven benefits of these interventions—projected over the patient's lifetime—based on data obtained from completed clinical trials funded by the NIDDK.

PREPARED STATEMENT OF AUDREY S. PENN

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Institute of Neurological Disorders and Stroke for fiscal year 1999, a sum of $815.6 million, an increase of $61.3 million, or 8.1 percent. Including the estimated allocation for AIDS, total support proposed for NINDS is $844.3 million an increase of $63.6 million over the 1998 appropriation. Funds for NINDS efforts in AIDS research are included within the Office of AIDS research budget request.

Today, I appear before you as the Deputy and Acting Director of the National Institute of Neurological Disorders and Stroke (NINDS). As a neurologist and as a former grantee of NINDS and member of the Advisory Council, I welcome the opportunity to be able to personally report to you about the activities of the NINDS research programs. We have been part of some amazing success stories over the past several years and have great hope that even more may be achieved to improve the care and treatment of people with brain diseases.

PARKINSON'S DISEASE

Parkinson's disease (PD), is one of several neurodegenerative disorders in which progressively more and more neural cells in the motor control regions of the brain degenerate and stop working. In the case of Parkinson's disease, this process results in symptoms such as tremor and rigidity and eventually leads to disability and death. Other degenerative disorders such as Huntington's disease, amyotrophic lateral sclerosis, and Alzheimer's disease present with different sets of symptoms because different neural cells are affected.

NINDS has long maintained a strong research emphasis both in our intramural and extramural programs in Parkinson's disease. This commitment has been met with success, for example, in understanding more about the system of cells, affected in PD, which use dopamine as their functioning chemical unit. Over the past few years there has been an acceleration of new findings that mark a turn in the outlook for progress. Following a 1995 workshop on Parkinson's disease, NINDS initiated a collaboration with the National Human Genome Research Institute and extramural investigators which quickly showed that in a single large family PD was caused by an alteration in a gene on chromosome 4. Further study showed that the gene is the blueprint for a protein called synuclein. Fortunately, synuclein was not entirely unknown to scientists; it had been previously identified in synapses (the point of contact between nerve cells) of electric fish and had been studied in rats, birds, and humans. Synuclein has been found in amyloid plaques, or aggregates of protein, found within brain cells of people with Alzheimer's disease and now it has also been found in Lewy bodies, also aggregates of protein, which are found in brain cells from people with the more common, non-inherited form of Parkinson's disease. The first chart shows Lewy bodies stained with an antibody specific for synuclein. So, one research discovery has brought together investigative themes from two major neurodegenerative disorders and has also raised new questions. Scientists are working to find out the role of synuclein in PD and are looking actively for other defective genes that may contribute to PD in other cases. Research to study the role of genes is PD is a very exciting and important endeavor, but it is just one part of a spectrum of studies supported by NINDS. We are supporting efforts to design and improve therapies including surgical approaches (pallidotomy), deep brain stimulation, cellular implantation, and use of growth factors. As a major new effort, NINDS has issued a request for applications for Parkinson's Disease Research Cen-

ters of Excellence which will place emphasis on multidisciplinary and collaborative studies and will include both basic and clinical research projects.

I mentioned previously that brain cells of people with Alzheimer's disease and Parkinson's disease have abnormal aggregates of proteins that should not be there. The last few years have brought a remarkable convergence of evidence that several other neurological disorders result from abnormal folding and aggregation of proteins. Most notably, Dr. Stanley Prusiner, a grantee who has received funding from NINDS, the National Institute on Aging, and other NIH components, received the Nobel prize for his research to understand rare brain disorders known as transmissible spongiform encephalopathies (TSE's). In people who have inherited TSE's, a variation of a normally occurring protein called a prion is predisposed to become abnormally folded. The proteins clump together and eventually the nerve cells in which they are found die. Research also implicates abnormal protein aggregates in a group of diseases known as triplet repeat disorders; so named because one of the specific three-part coding units of the genetic code is repeated sequentially on the gene, an abnormal number of times. The second chart shows the difference between a normal gene sequence (and its product) and a triplet repeat (and its product). If protein aggregates play a role in causing nerve cells to die, then interventions to prevent them from forming may one day yield a new therapeutic strategy. Research to understand protein folding and protein-protein interactions in neurological diseases is an emerging and very active area of research which NINDS is pursuing and hopes to expand.

STROKE

Stroke is a major health problem in the United States; recent results from a study funded by NINDS at the University of Cincinnati Medical Center reveal that approximately 700,000 strokes occur each year in the U.S. Based on data from the National Center for Health Statistics approximately 150,000 Americans die from stroke each year. Those who survive are often left with major disability, at great emotional and financial cost to their families and to our society. Many people do not really understand what a stroke is, what the warning signs are, or what can be done for stroke. Strokes occur when a blood clot (thrombus or embolus) blocks the circulation of blood within the blood vessels of the brain or when a blood vessel ruptures. As a result, the brain experiences a loss of oxygen and energy (in the form of glucose) which can kill brain cells and cause various symptoms such as paralysis, loss of speech, or confusion.

NINDS supports and conducts research that encompasses the time before, during, and after stroke. For example, we have shown that surgery will prevent stroke in some patients. We also support an ongoing a clinical trial to test estrogen to prevent stroke in post-menopausal women who have had one stroke and are at risk for another, and we support epidemiological studies of risk factors for stroke in white, African-American, and Hispanic populations. The greatest contribution that NINDS has made to date for the acute strokes resulting from blood clots came from a 10 year research effort that demonstrated tissue plasminogen activator or tPA as the first proven treatment. The highly significant results showed that 11 more individuals out of every 100 patients were out of the hospital, free of major neurological impairments, not disabled, not in nursing homes, and back to their usual activity at the end of three months. This continues to be true at one year follow up. To be successful, however, the treatment must begin within three hours of the onset of stroke. The results with tPA have provided a whole new motivation to treat stroke as an emergency. The emergency aspects and the timing required for a successful result have required a change in attitude and behavior on the part of family, patients, and emergency and health care professionals. NINDS staff have been working closely with organizations involved with the care of stroke patients and the media to get the word out on "brain attacks." For example, I am sure that in your home states the paramedics, the emergency physicians at the community hospital, perhaps even the visitors at the local senior citizens center will be able to tell you that they have heard or read about advances in the treatment of stroke.

SPINAL CORD INJURY

The advance in the use of tPA to treat stroke is the second time in recent memory that NINDS had an impact on emergency care. In 1990, a multi-center clinical trial supported by NINDS confirmed the effectiveness of methylprednisolone for the treatment of acute spinal cord injury, and set a new international standard of treatment for these patients. NINDS grantees continue to strive to improve on success: The results from a second trial completed in 1997 have shown that giving the drug for a longer period of time can significantly improve recovery over the standard

treatment among patients who start treatment between three and eight hours of injury. NINDS supports many other efforts to understand the mechanisms by which trauma to the spinal cord produces injury and how the spinal cord might try to repair itself. We have shed some new light on these events. Recent results suggest that the regeneration of axons, the extensions from the nerve cell where signals are passed on and which are often severed during injury, may use a unique approach. Investigators have now shown that axons regenerate by extending blunt, growing tips which are filled by the proteins called neurofilaments. In contrast, during development, the axon is pulled along by long finger-like projections and then filled with the structural protein, actin. We need further investigations into these mechanisms so we may one day use the body's own capabilities to foster recovery.

CHILDREN AND NEUROLOGICAL DISORDERS

Cerebral palsy, autism, muscular dystrophy, epilepsy, the ataxias, neurofibromatosis, Batten disease—these are just some of the neurological disorders that can affect children. I am proud to say that NINDS has a long history of commitment to research to benefit the health of children. In fact, early in my career I participated on a study, funded by this Institute, that is one of the largest studies of the newborn period ever undertaken to investigate risk factors for cerebral palsy and retardation.

I would like to highlight just some activities in research on brain diseases in children. More than a third of all genetic disorders affect the nervous system, and hundreds affect infants and children. Recent progress includes gene discoveries for torsion dystonia, Batten disease, ataxia-telangiectasia, Niemann-Pick disease type C, and one type of childhood epilepsy. NINDS and the National Institute of Child Health and Human Development (NICHD) are co-sponsoring a clinical trial to follow up on evidence that the administration of magnesium sulfate to mothers at risk for premature delivery is associated with a reduced risk of cerebral palsy in their infants. We have funded new studies in autism and work with our colleagues in other Institutes to further advance research in autism.

NEW INITIATIVES

Finally, I will close with the mention of several major initiatives that NINDS will be involved with. In fiscal year 1999, NINDS with NIMH, will begin the brain molecular anatomy project (BMAP) to map gene expression in different parts of the brain during development, adulthood, and aging. A separate effort has been launched with NCI to characterize the genes associated with brain tumors which may be unique to the neoplastic state. Both efforts will result in a tremendous resource for investigators across the country. NINDS will also work with other interested institutes towards an expanded research program in pain. Another initiative will seek to accelerate the development of brain imaging techniques.

The activities of the NINDS are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

Mr. Chairman, I would be pleased to answer any questions you might have.

PREPARED STATEMENT OF ANTHONY S. FAUCI

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Institute of Allergy and Infectious Diseases (NIAID) for fiscal year 1999. The President proposes that the NIAID receive $702 million, an increase of 8 percent for NIAID non-AIDS research activities. Including the estimated allocation for AIDS research activities, total support proposed for the NIAID is $1.47 billion, an increase of 8.6 percent over the comparable fiscal year 1998 appropriation. Funds for NIAID AIDS research efforts are included in the Office of AIDS Research budget request.

The activities of the NIAID are covered by the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this perform-

ance plan and are linked to the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. The NIAID is anxious to meet the challenges set forth in this plan and we look forward to continued support from Congress that will facilitate our achieving these goals.

FIFTY YEARS: ADVANCING KNOWLEDGE, IMPROVING HEALTH

This year, the NIAID celebrates fifty years of progress in understanding, treating and preventing infectious and immunologic diseases. During the past five decades, NIAID-supported research in fields such as microbiology and immunology has led to new therapies, vaccines and diagnostic tools that have profoundly benefitted global health. Capping this remarkable half-century are recent advances and initiatives that promise to further reduce the burden of disease in this country and around the world. Meanwhile, new challenges to the public health continue to emerge, underscoring the need for continued progress in our fight against infectious microbes and diseases of the immune system.

IMMUNOLOGIC TOLERANCE

A long-standing goal of NIAID-supported immunology research is the development of new and better ways to prevent the rejection of transplanted organs and tissue "grafts" by the immune system. While current immunosuppressive drugs have greatly reduced graft rejection, these agents are highly toxic and increase a patient's risk of infection, cancer and other complications. In addition, despite major improvements in immunosuppressive therapy, 10 to 50 percent of transplanted organs and tissues are rejected by patients' immune systems within the first year.[1] Even with the latest immunosuppressive drugs, approximately 60 percent of transplanted kidneys, the organ most often transplanted, are rejected within 10 years.[2]

As we work to improve this record, we are encouraged by new findings, underpinned by years of basic immunology research, that show the feasibility of a totally new approach to preventing graft rejection. NIAID-supported researchers have demonstrated that it is possible to induce immunologic "tolerance" to a graft by turning off the specific immune responses that would otherwise attack it. Promising results in animal models have been achieved with transplanted kidneys and livers; early human studies suggest that long-term tolerance of transplanted bone marrow may be achieved with appropriate therapy.

One approach to inducing tolerance is to block the second of two signals needed by T cells to become activated and orchestrate an attack on a foreign tissue or organ. In this regard, several different blocking molecules have shown considerable promise. Other approaches to inducing tolerance involve manipulating immune system molecules called cytokines, or inducing the suicide of the immune cells that otherwise would attack a graft. The refinement of strategies for inducing tolerance could revolutionize the field of transplantation and benefit the tens of thousands of patients whose lives could be saved or improved by a donated organ. In addition, our growing knowledge of immune tolerance will help in understanding and treating other conditions such as cancer, autoimmune conditions, and allergic and infectious diseases.

BURDEN OF INFECTIOUS DISEASES

It is underappreciated that infectious diseases remain the leading killer of people globally and the third leading cause of death in the United States.[3] [4] Of the approximately 52 million deaths worldwide in 1996, more than 17 million were due to infectious diseases, including approximately 9 million among children.[5] In addition, a growing number of cancers and other chronic conditions have been attributed to infectious agents. For example, the bacterium Helicobacter pylori causes ulcers and stomach cancer, and Chlamydia pneumoniae has been implicated as a cause of artery-clogging plaques. Both hepatitis B virus and hepatitis C virus (HCV) can lead to liver cancer, and human papillomavirus is responsible for most cases of cervical

---

[1] United Network for Organ Sharing. "The 1997 Report of Center-Specific Graft and Patient Survival Rates." Richmond, VA.

[2] Cecka, J.M. 1996. The UNOS scientific renal transplant registry. Clinical Transplants. p. 1–14.

[3] World Health Organization. 1997. "The World Health Report 1997." Geneva: World Health Organization.

[4] Pinner, R.W. et. al. 1996. Trends in infectious diseases mortality in the United States. JAMA. 275:189–193.

[5] World Health Organization. 1997. "The World Health Report 1997." Geneva: World Health Organization.

cancer. In addition to their human toll, the financial burdens of infectious diseases are enormous. In the United States alone, costs associated with infectious diseases exceed an estimated $120 billion annually.[6]

In the face of the enormous challenges posed by infectious diseases, the sustained commitment of NIAID to basic and applied research has paid enormous dividends against newly recognized pathogens—such as human immunodeficiency virus (HIV) and HCV—and scourges which have long plagued humanity, including malaria, tuberculosis and life-threatening infant diarrhea.

PROGRESS AGAINST HIV/AIDS

HIV, the cause of the acquired immunodeficiency syndrome (AIDS), remains one of the greatest threats to global health. More than 30 million people worldwide are living with HIV/AIDS, a number expected to reach 40 million by the year 2000. In the 17 years since AIDS was recognized, an estimated 11.7 million people with HIV worldwide have died,[7] including approximately 380,000 in the United States.[8] Despite the mounting toll of HIV, recent developments have provided a measure of optimism. In the United States, AIDS deaths dropped 44 percent from the first six months of 1996 to the first six months of 1997; new AIDS diagnoses declined by 12 percent during the same period.[9] These encouraging trends are probably due to several factors, notably the increased use of potent combinations of anti-HIV drugs, and our growing ability to prevent and treat the many secondary infections associated with HIV disease.

Basic research into the structure of HIV and how it interacts with the immune system led to the development of the 12 antiretroviral drugs now licensed in this country. Various combinations of these drugs, as well as several investigational drugs now in clinical trials, have helped restore the health of many patients, dramatically reducing the amount of HIV in their bodies and lowering their risk of secondary infections, hospitalizations and death. In addition, new insights into the pathogens that prey on the weakened immune systems of HIV-infected individuals have led to improved prophylactic and curative therapies.

Unfortunately, many HIV-infected individuals have not benefitted from the currently available drugs, cannot tolerate their side effects, or have difficulty complying with complex treatment schedules that may require them to take 30 or more pills a day. In addition, the ability of HIV to mutate and become resistant to the current drugs is a persistent threat. Therefore, the development of the next generation of therapies—well-tolerated, effective drugs that can be administered with a minimum of doses for prolonged periods—remains a priority. Together with partners in academia and industry, NIAID-supported scientists are pursuing many new treatment strategies and exploring ways to boost an HIV-infected person's immune system.

HIV VACCINE RESEARCH

In many developing countries, where health care spending may be only a few dollars per person each year, such therapies will probably remain beyond the reach of all but the most privileged. Therefore, continued research into an HIV vaccine and other means of preventing HIV infection is crucial to slowing the epidemic in these settings, as well as in our own country. To speed the pace of discovery, NIAID has strengthened its efforts in HIV vaccine research. Among recent initiatives are 58 new grants to foster innovative research on HIV vaccines and the establishment of a Vaccine Research Center within the NIH intramural research program.

HEPATITIS C

Another recently recognized pathogen of great concern is hepatitis C virus (HCV), identified in 1989. HCV is a leading cause of cirrhosis, liver cancer, and a major reason for liver transplants. Worldwide, more than 170 million people are chronically infected with HCV, including 4 million individuals in the United States.[10] Annual HCV-related deaths number approximately 8,000 to 10,000 people in this coun-

---

[6] Institute of Medicine. 1997. "America's Vital Interest in Global Health." Washington, DC.: National Academy Press.

[7] UNAIDS: "Report on the Global HIV/AIDS Epidemic." Geneva, December, 1997.

[8] Centers for Disease Control. 1996. "HIV/AIDS Surveillance Report." 8(no. 2): 1–40.

[9] DeCock, Kevin. 1998. Presentation: Fifth Conference on Retroviruses and Opportunistic Infections, February 2, Chicago, IL.

[10] World Health Organization. 1997. "Weekly Epidemiological Record: March. 7, 1997." Geneva: World Health Organization.

try,[11] a figure projected to reach 24,000 deaths/year by 2017 if effective therapies are not found. To combat this epidemic, NIAID recently established a network of Hepatitis C Research Centers to study the virus and how it causes disease. In the past year, researchers at one of the new centers reported a major breakthrough: the construction of functional, infectious clones of HCV, using genetic engineering techniques. This advance has facilitated HCV studies in cell cultures and animal models.

RESPONSE TO THE THREAT OF H5N1 AVIAN INFLUENZA

We have come to understand that the emergence of previously unrecognized pathogens such as HIV and HCV is a continual process. As further evidence of this, the first known cases of human influenza caused by a virulent bird virus known as H5N1 avian influenza were identified in Hong Kong in 1997. Given the possibility that this avian virus might combine with a human influenza strain and become more readily transmissible, possibly resulting in a pandemic, NIAID moved quickly with our colleagues at the Centers for Disease Control and Prevention, World Health Organization and other agencies in addressing research questions and public health needs associated with the outbreak. Fortuitously, as part of our long-standing research into respiratory viruses, we had in our repository the specific antisera needed to quickly develop test kits for detecting the avian influenza virus. NIAID has also supported the production of a recombinant vaccine for use in at-risk laboratory and health care personnel, as well as a surveillance effort in Hong Kong to identify and characterize the source of the avian virus.

A COMMITMENT TO MALARIA RESEARCH

More than 40 percent of the world's population lives in areas at risk for malaria transmission.[12] Approximately 300 to 500 million cases of malaria occur worldwide each year; every 20 seconds, a child dies of the disease.[13] In the past year, the National Institutes of Health, together with research organizations and donor agencies from around the world, have worked to mobilize the scientific resources and political will needed to control this dread disease. The extraordinary interest among scientists, political leaders, the media and the general public in this new partnership, called the Multilateral Initiative on Malaria, is strong evidence that the global community has recognized the magnitude of the malaria problem.

At NIAID, we have strengthened our long-term commitment to malaria research. NIAID-supported malaria projects—many in collaboration with other government and international agencies—include a new repository of malaria research materials that are available to researchers worldwide; basic, field-based and clinical research on all phases of malaria research; and projects to determine the genetic sequences of important malaria species. In addition, new collaborations between intramural and extramural scientists on malaria vaccine research, production and evaluation are underway.

DIARRHEAL DISEASES

Like malaria, diarrheal diseases are leading killers of children, resulting in about 2.5 million childhood deaths each year.[14] At least a third of these deaths are probably due to rotavirus, a disease for which NIAID researchers have developed an effective, orally administered vaccine. As recently reported in The New England Journal of Medicine, this vaccine, the culmination of more than 20 years of research, reduced severe diarrheal illness by 88 percent in a study of infants in Venezuela, a country where rotavirus circulates year round.[15] The vaccine is nearing licensure in the United States and other countries, and promises to have a major impact on the health of children worldwide. In the United States alone, widespread use of the NIAID-developed rotavirus vaccine could greatly reduce the 500,000 doctor visits[16]

---

[11] National Institutes of Health. 1997. Consensus Statement: Management of Hepatitis C. Bethesda, MD.

[12] World Health Organization. 1997. "Weekly Epidemiological Record: September 5, 1997." Geneva: World Health Organization.

[13] World Health Organization. 1997. "The World Health Report 1997." Geneva: World Health Organization.

[14] World Health Organization. 1997. "The World Health Report 1997." Geneva: World Health Organization.

[15] Perez-Schael, I. et. al. 1997. Efficacy of the rhesus rotavirus-based quadrivalent vaccine in infants and young children in Venezuela. N Engl J Med. 337(17):1181–1187.

[16] Glass, R.I. et. al. 1996. The epidemiology of rotavirus diarrhea in the Untied States: surveillance and estimates of disease burden. J. Infect Dis. 174 (suppl 1): S5–S11.

and 100,000 hospitalizations related to rotavirus each year,[17] as well as the $1.4 billion in direct and indirect costs associated with the illness.[18]

THE PROMISE OF NEW TECHNOLOGIES

Many of the advances I have described have been facilitated by rapid advances in molecular biology, notably the development of fast and accurate methods for sequencing the genomes of disease-causing microbes. Sequence information can be used in many ways, such as finding targets for therapies, identifying antigens to incorporate into vaccines, detecting mutations that cause drug resistance, and determining the factors that influence the virulence of a microbe.

The success of the first microbe sequencing project—the delineation of the complete Haemophilus influenzae genome in 1995—encouraged the Institute's current efforts to sequence the full genomes of eight other medically important bacteria. NIAID also supports projects to provide complete or partial genome sequences of large parasitic protozoa.

MAINTAINING A RESEARCH BASE

The burden of infectious and immunologic diseases, in human and economic terms, is enormous. It is critical that we maintain a strong scientific infrastructure in core disciplines such as infectious diseases, immunology and microbiology to meet the challenges of these diseases. With skillful use of the increasingly powerful tools of molecular biology, by identifying research opportunities and priorities and vigorously pursuing them, and by sustaining a strong research base, we will be well-positioned to make further progress against current disease threats as well as the new diseases that will inevitably emerge.

PREPARED STATEMENT OF MARVIN CASSMAN

Mr. Chairman and Members of the Committee, good morning. I am pleased to present to you the programs of the National Institute of General Medical Sciences (NIGMS). The President in his fiscal year 1999 budget has proposed that NIGMS receive $1.115 billion, an increase of $77.6 million over the non-AIDS portion of the fiscal year 1998 appropriation. Including the estimated allocation for AIDS in both years, the total support proposed for NIGMS is $1.145 billion, an increase of $79.5 million over the fiscal year 1998 appropriation. Funds for NIGMS efforts in AIDS research are included within the Office of AIDS Research budget request.

The goal of NIGMS is to ensure the continuing productivity of basic biomedical research, which has provided the foundation for the astonishing developments we witness daily in the understanding and treatment of disease. In its 35-year existence, NIGMS has supported some of the most significant advances in biomedical science. One reflection of the success of NIGMS-funded research is the number of Nobel Prizes awarded to our grantees. Since 1962, we have supported almost 60 percent of all the American Nobel laureates in chemistry and physiology or medicine. Among these was the award in 1978 for understanding the way bacteria cope with foreign invaders, an esoteric study that would seem to have little practical value. Yet this work formed the basis for recombinant DNA technology, which underlies the biotechnology industry.

FROM BASIC RESEARCH TO DISEASE APPLICATIONS

But we do not have to go back 20 years to trace the contributions of basic research. A number of striking developments have emerged in the past year alone, of which I have time to describe only a few. The examples I have selected all have in common that they began with the examination of a fundamental biological process in an organism other than humans, but quickly revealed applications to human disease. Indeed, the studies were not even done in mammalian organisms, but in much simpler systems such as bacteria, yeast, and the common fruit fly. There are obvious reasons why many biological processes cannot be studied in humans, and the use of these models is based on the repeated observation that many fundamental processes are common to a variety of species. Examining these phenomena in model organisms provides a detailed understanding that can lead to general prin-

---

[17] Institute of Medicine. 1985. "New vaccine development: establishing priorities," p.410–423. In Diseases of importance in developing countries (Vol I). Washington, DC.: National Academy Press.

[18] Smith, J. et. al. 1995. Cost effectiveness analysis of a rotavirus immunization program for the United States. Pediatrics. 96:609–15.

ciples with broad applications. The examples I will give show how studies in bacteria, yeast, and the fruit fly have generated knowledge that can be applied to Lyme disease, neurodegenerative disorders, and cocaine addiction.

The first example is a study in an unusual bacterium that may lead to a therapy for Lyme disease. The bacterium is part of an esoteric class called archaebacteria, which are found in a variety of inhospitable locations such as ocean bottoms, hot acid springs, and high-salt environments. One of our investigators was interested in the very fundamental question of how this bacterium carries out protein synthesis, a universal requirement of all living organisms. It appeared that one essential component of protein synthesis was missing in the bacterium, and he was curious to see how the organism survived without it. It turns out that the component is present, but in a form unrelated to that found in all other bacteria and higher organisms. Or almost all. Careful examination of the genomic sequence of the organisms that cause Lyme disease and syphilis showed that in these pathogens there exist compounds with strong similarity to the material found in the archaebacterium, but these compounds are quite different from those with analogous functions in humans. Scientists could exploit this fundamental difference between a pathogen and its human host to develop new antibiotics to treat Lyme disease. Such antibiotics would attack the compound involved in protein synthesis in the bacterium without damaging this essential process in the human host. Parenthetically, this is but one illustration of the enormous value of having complete genomic sequences of organisms other than humans.

A second example is a discovery in yeast that sheds light on certain kinds of neurodegenerative diseases in humans. This sounds inherently unlikely, and certainly could not have been predicted. After all, even if a yeast cell did have a form of dementia, how would we know? But this relationship between humans and yeast is in the apparent existence of prion-like particles in both organisms. Prions are thought to be infectious protein particles that are implicated in the initiation of so-called "mad cow" disease and other disorders. The 1997 Nobel Prize in physiology or medicine was awarded to the scientist who championed the role of prions in disease. An NIGMS investigator has recently shown that there is a protein in yeast that has many of the same characteristics as the prions found in mammalian brains. For example, the yeast protein generates the same fibers formed by mammalian prions, which are comparable to those found in the autopsies of humans and animals that have died of diseases where prions were implicated. Furthermore, critical interactions with other materials in the cell are exactly the same for the yeast protein and mammalian prions. These studies now provide a model system to investigate an immensely complex problem in a comparatively simple organism, yeast. They even begin to suggest a new target for potential therapies.

Finally, we arrive at the common fruit fly, an organism that has provided us with the opportunity to study many fundamental biological phenomena, particularly in the areas of development and gene regulation. One of our investigators has spent many years studying fruit fly genes that are involved in the nervous system and in behavior. Comparable genes in humans are involved in depression and other mental disorders, as well as in Parkinson's disease and drug addiction. In the course of his work, the scientist used volatile—or "crack"—cocaine as a tool to stimulate neurological responses in the flies, which led him to observe that flies and mammals respond to cocaine in strikingly similar ways. This time-lapse image shows one such similarity—the circling movement of a single fly following exposure to cocaine. Rodents and primates display similar movement patterns in response to the drug. This, along with other behaviors, suggests that both the fundamental neural pathways involved in cocaine response and the linkage to behavior are retained across species. As a result of this work, the fruit fly now appears to be a very promising model system to examine the genetic and molecular pathways leading to cocaine sensitization, as well as to investigate the pathways involved in a variety of neurological disorders.

It is striking that in all of these examples, health-related applications emerged almost immediately from basic research studies. This is, of course, not the norm for most of the fundamental research studies that we support. And yet, it is not so far from the reality of modern biology. The mosaic of scientific research has expanded to the point at which basic research and its applications follow very closely. It is appropriate to remember a comment made by Louis Pasteur in 1871: "* * * there does not exist a category of science to which one can give the name applied science. There are science and the applications of science, bound together as the fruit to the tree which bears it." The examples I have given today describe a few such trees and their early fruits.

TACKLING BIOLOGICAL COMPLEXITY

If the past and the present provided such a bounty of important outcomes from basic research that can be applied to the problems of health and disease, the future promises even more. The incredible volume of detailed knowledge about fundamental biological processes suggests that we may soon be in a position to understand the design principles of living systems. NIGMS has recently held two workshops to identify how we can facilitate progress in this difficult research area. Participants in both workshops were unanimous in their opinion that progress will require interdisciplinary approaches. However, a major barrier is the shortage of biological scientists who also have the quantitative and computational expertise that is needed for progress to be made. We are pursuing several approaches to address this shortage. We have already created a program to support mathematicians, physicists, and engineers in collaborative research projects with NIGMS grantees that are intended to develop new approaches to the study of complex systems.

We are also planning two new training efforts in this area. One will provide individual postdoctoral fellowships to scientists with doctoral degrees in physics, mathematics, engineering, computer sciences, and related areas to allow them to be trained in basic biomedical research. The second will support courses and workshops designed to train biologists in computational and statistical methods.

Another important goal is understanding individual variability in drug responses, a field sometimes described as pharmacogenetics. NIGMS, in collaboration with several NIH institutes, will soon convene a working group of scientists to help us define new research directions in this area. In the meantime, we are collaborating in the initiation of training efforts in clinical pharmacology, a discipline that is critically linked to pharmacogenetics and that has significant shortages of trained personnel.

TRAINING FOR THE FUTURE

We continue our efforts to train tomorrow's scientists and to bring more underrepresented minorities into careers in biomedical research. A new initiative that we are planning for the coming year is to enhance traditional postdoctoral training by promoting the development of teaching skills through innovative programs that involve assignments at minority-serving institutions. We feel that this initiative will provide several benefits. It will be of particular value to the many scientists who during their graduate careers become interested in teaching, but have little or no opportunity to develop those skills. At the same time, it will provide minority-serving institutions with access to individuals who are on the cutting edge of their disciplines, while relieving scientists at those institutions from some of their teaching burden and allowing them time for research and collaborations.

The activities of the NIGMS are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

Thank you, Mr. Chairman. I would be pleased to answer any questions that you may have.

PREPARED STATEMENT OF DUANE ALEXANDER

BUDGET REQUEST

I am pleased to present the fiscal year 1999 President's budget request for the National Institute of Child Health and Human Development (NICHD) of $654.7 million, an increase of $47.4 million or 7.8 percent over the comparable fiscal year 1998 appropriation. Including the estimated allocation for AIDS in both years, total support proposed for NICHD is $727 million, an increase of $52.2 million over the fiscal year 1998 appropriation. Funds for NICHD efforts in AIDS research are included within the Office of AIDS Research budget request.

RESEARCH ACCOMPLISHMENTS

Congress established the National Institute of Child Health and Human Development 35 years ago to help the people of this Nation have healthy children at the

time they want them, and to help those children survive, learn, and develop in ways that allow them to reach adulthood free of disease and disability and able to contribute fully to society. As we have been celebrating our 35th anniversary, we have looked back at some of the accomplishments of our research that have made major progress toward achieving those goals for all American families. The list of our top achievements in those 35 years is impressive.

For example, NICHD-supported scientists developed and demonstrated the effectiveness of newborn screening tests for phenylketonuria (PKU) and hypothyroidism. Every newborn infant in the United States now receives these tests, and thanks to their use we prevent over 1,200 cases of mental retardation every year. Every parent whose child leads a normal life rather than being mentally retarded from these conditions can thank NICHD research.

Another example is the NICHD Diabetes in Early Pregnancy Study that showed clearly that rigid control of a diabetic mother's blood sugar before and during pregnancy markedly reduced her elevated risk of having a stillborn or malformed infant. This regimen has now become standard care. Every diabetic woman who has a healthy baby can thank NICHD research.

I have told this Committee before about the NICHD scientists who conceptualized and developed a conjugate vaccine to prevent Hemophilus influenzae type b meningitis. With this vaccine now standard care for infants, this disease has gone from the leading cause of acquired mental retardation in the United States, to near elimination. Every parent seeing their child immunized to protect it from this disease can thank NICHD research.

Through a combination of improvements from NICHD research in our ability to care for premature infants, such as better ventilation, surfactant to prevent respiratory distress syndrome, improved nutrition, and better control of infection, the birth weight at which half of premature infants survive has fallen from around 1,800 grams when NICHD was established to approximately 800 grams today. During this same time, the Nation's infant mortality rate has fallen by 70 percent. Every mother who takes a very low birth weight infant home from the hospital can thank NICHD research.

Leading the way in the Nation's decline in infant mortality rate in the last four years has been a marked reduction in Sudden Infant Death Syndrome (SIDS) deaths. As shown in the graph, for many years SIDS deaths were remarkably stable at 5,400 per year, or 1.4 deaths per 1,000 infant births. The research-based recommendation of the American Academy of Pediatrics in 1992 to place infants to sleep on their backs or sides rather than their tummies had only a small impact until the NICHD Back-to-Sleep campaign was launched in 1994. Since then, back or side sleeping has increased, and the rate of SIDS deaths has declined dramatically, with preliminary data for the first six months of 1997 indicating a rate of 0.5 deaths per 1,000 births. This represents a reduction of nearly two-thirds from the old steady state condition. The 3,000 fewer families each year who lose an infant to SIDS can thank NICHD research.

Our staff at NICHD and the scientists we support are justly proud of these 35 years of scientific accomplishments and their translation to practice to improve public health. There has been a good return on the investment of the American people through the Congress in the research supported by this Institute. But there is much more we can do, and with your support and encouragement, we are hard at work on hundreds of other conditions that still need to be addressed.

BIRTH DEFECTS

While strides have made in reducing several causes of infant mortality, less is known about its leading cause: birth defects. Our studies here range from basic investigations in genetics and developmental biology, using a variety of animal models including mice and zebrafish, to epidemiological studies of cause, and therapeutic and prevention research. Basic studies are particularly important because they allow us to elucidate the underlying processes of normal development and to identify what goes wrong to cause birth defects and genetic diseases. The fact that genes are conserved throughout the animal kingdom has enabled us to translate the leads from basic studies in animal models to understand human disorders, such as neural tube defects, skeletal anomalies, primary immune deficiencies, and disorders in the formative stages of the nervous system that lead to mental retardation or learning and behavior problems.

VACCINE RESEARCH

Progress in science is incremental, building on previous research. One example is the E. coli O157 vaccine. E. coli O157 is a bacterial food contaminant that causes

mild to fatal gastrointestinal and renal disease in about 20,000 people a year. This new vaccine was produced by our same intramural scientists who developed the Hib vaccine mentioned earlier, using the same conjugate vaccine concept and technology. We recently reported success in inducing high levels of protective antibody production against E. coli O157 in adult volunteers. One intriguing aspect of this vaccine is that we may be able to prevent the disease in humans by eliminating the organism at its source by vaccinating cattle. Studies testing this concept are currently under way, as are field trials of a conjugate vaccine to prevent typhoid fever, and studies of a Shigella conjugate vaccine to prevent dysentery in children.

PREMATURE LABOR

Applications of advances in genetics, especially from the Human Genome Project, continue to benefit NICHD as well as other Institutes. One case in point is microarray technology, which permits the study of thousands of genes at once to determine which are functioning ("turned on") at a given time. Our scientists are beginning to apply this technology to study gene expression in women in premature labor, and comparing that pattern with pregnant women not in preterm labor, with the goal of determining at a genetic level the heretofore elusive causes and mechanisms of premature labor. These studies also offer the potential to develop a much-needed diagnostic test to determine whether a woman is truly in premature labor, as well as identifying targets for therapeutic intervention. Research to reduce prematurity is an essential part of our effort to eliminate racial differences in infant mortality as part of the President's initiative on race.

READING DEVELOPMENT AND DISABILITY

Other new scientific technologies are allowing us to combine studies in biology and behavior to achieve a fundamental understanding of the origins of problems and follow the course of treatment to assess how the underlying problem is corrected. Nowhere is this more dramatic than in the studies linking fundamental neurosciences and reading behavior. One technique being used is called functional magnetic resonance imaging, and has generated the pictures you see displayed on the poster. These are images taken during attempts at a reading-related task by a person with normal reading ability, on the right, and a person with significant reading disability on the left. The disabled reader shows none of the activity in the region at the back of the brain used by the normal reader in the reading task, and increased activity in the front area of the brain reflecting intense effort to overcome the apparent block in function at the early stages of the task. We are now engaged in remedial interventions with a large number of children with reading disability and will be retesting them after they learn to read to determine whether the treatment results in use of the same parts of the brain that children with normal reading ability use, or whether they develop alternative pathways that allow them to read. Meanwhile, our basic studies and clinical trials of reading intervention in the classroom are continuing and are proceeding well.

CHILD DAY CARE

Results of research on the association between characteristics of child day care (quantity, quality, stability) and children's social, cognitive, and language development continue to come from the NICHD Study of Early Child Care. This longitudinal study of over 1,300 families is the most comprehensive and detailed study of child care ever undertaken. Adding to results described before, this year scientists continued to find that family income, quality of the home environment, maternal education or language ability, and mother's behavior toward the child are the best predictors of children's cognitive, language and social development. Scientists also reported that children in exclusive maternal care do not have a cognitive or language advantage over children in child care, and that those in center care actually tend to do better in those areas at age three than those in maternal care. For those children who are in child care, the researchers found that the more language stimulation children received, the better their cognitive and language abilities over the first three years of life. Children's self-control, compliance and problem behaviors were found to be only minimally predicted by child care: those in higher quality of care had somewhat more favorable outcomes in these areas than those in lower quality of care. The quality of care was also associated with better mother-child interaction over the first three years of life. While no relation emerged between the quantity of child care and children's psychological outcomes, more hours in care were associated with somewhat less optimal mother-child interactions over the first three years of life. In these interactions mothers were slightly less sensitive and responsive and the children were somewhat less engaged. Most recently, the investiga-

tors reported that characteristics of child care provision that can be regulated (adult:child ratio, group size, provider education and training) are related to cognitive and social outcomes of children at three years of age. All these findings taken together can help guide parents when they choose child care and policy makers when they make decisions about the support of families and child care programs.

WOMEN'S HEALTH RESEARCH

With the funds provided by the Congress in fiscal year 1998 and requested for fiscal year 1999, the NICHD will launch two major initiatives to improve women's health. First, to increase the number of obstetrician-gynecologists engaged in research, the NICHD, with support from the Office of Research on Women's Health, is establishing a group of Women's Reproductive Health Research Career Development Centers. At these sites newly trained ob/gyn clinicians will be linked with mentors and research facilities and equipment and given training to assist them in pursuing research careers focusing on addressing problems of women's reproductive health. Without this help, we are losing many individuals interested in and capable of pursuing clinical research, and this program is intended to remedy that situation. Second, we are working with the ob/gyn community and other Institutes to expand significantly research directed toward the long-term consequences women suffer related to child bearing—incontinence, uterine and rectal prolapse, chronic pain, and other harmful and disabling conditions. Our studies will range from basic neuroanatomical and connective tissue research, to epidemiologic studies relating management of pregnancy and delivery to long term adverse outcomes, to studies of the most effective management and rehabilitation for these disorders. We should do all that we can to help women avoid these consequences of childbearing, and the increased funding requested in the fiscal year 1999 budget will help launch an initiative to address this under-researched area.

PEDIATRIC PHARMACOLOGY

There is great hope that the proposed new FDA rules requiring drugs potentially useful in children to be tested in children, in combination with the NICHD Pediatric Pharmacology Research Unit Network, will finally end the decades-long era of children being "therapeutic orphans," forced to rely only on the results of drug tests in adults. To further facilitate the testing of drugs in children, the funds requested for fiscal year 1999 will allow NICHD to expand the Network to ten sites from the current seven, and to initiate a broad range of basic studies of child/adult and genetic differences in drug metabolism and response to different classes of drugs to help guide drug testing both in the Network and elsewhere.

Mr. Chairman, these are just a few examples of how NICHD research is attempting to improve the health and well-being of women, children, and families. I will be pleased to answer any questions.

PREPARED STATEMENT OF CARL KUPFER

Mr. Chairman and Members of the Committee: I am pleased to present the President's fiscal year 1999 budget request for the National Eye Institute (NEI) a sum of $374 million, an increase of $28 million (or 8.2 percent) above the comparable fiscal year 1998 appropriation. Including the estimated allocation for AIDS research within the Office of AIDS Research budget request, total support proposed for the NEI is $384 million, an increase of $28 million (or 8.1 percent).

In recent years the American people—through their representatives in Congress—have shown great confidence in the National Institutes of Health. Americans have placed tremendous faith in NIH's ability to conduct and support high quality research for a wide spectrum of diseases and disorders. The NIH research community—and in our case, the NEI—is grateful for this vote of confidence. Both the NIH and NEI have gratefully accepted the challenge to improve the health of the American people.

LABORATORY AND CLINICAL RESEARCH

It is important to point out that laboratory research serves as the foundation for clinical, or patient research. Clinical research improves diagnosis and treatment, which is the ultimate goal of the NEI. For scientists to get to the clinical research stage, a great deal of supporting laboratory research must first be conducted. That is why a significant amount of our funding goes for such research. The results of these studies may be stepping stones to discovery of an effective treatment or a means of prevention.

An excellent example of this bridge between laboratory and clinical research is the introduction of two new drugs used to treat glaucoma. Glaucoma, a major public health problem in the United States, is the leading cause of blindness in African-Americans. It is often associated with a rise in the normal fluid pressure inside the eye, leading to vision loss and even blindness. For many years, the NEI has supported laboratory research into the most effective drugs to control the flow of fluid into and out of the eye. This NEI-supported research led to clinical research, which resulted in the recent introduction by the pharmaceutical industry of two new FDA-approved glaucoma drugs—lantanaprost and dorzolamide. With their increased effectiveness and reduced side effects, these new drugs add important options for the treatment of glaucoma.

Other discoveries from laboratory research may provide significant insight into diseases seemingly unrelated to the original focus of the studies. An excellent case in point occurred at the NIH last Fall. Scientists searching for genes thought to be involved in resistance to cancer drugs discovered a gene that is expressed only in the retina. This led to collaboration between cancer and vision researchers and the discovery that this gene is linked to the most common juvenile form of macular degeneration, called Stargardt's disease. This disease affects about 25,000 Americans; develops primarily in people between the ages of six and 20; and leads inevitably to marked visual disability. This discovery may help researchers unravel the molecular mechanisms that lead to Stargardt's disease, which in turn may help unravel some of the mysteries surrounding the disease's adult form: age-related macular degeneration. The gene discovery also emphasizes in the strongest terms that the conduct of high quality research often leads to an unsuspected, but very valuable, addition to the medical literature. This knowledge can provide insight into related disease processes.

AGE-RELATED MACULAR DEGENERATION

Age-related macular degeneration, or AMD, is the leading cause of blindness in older Americans. AMD affects the macula, a tiny area in the retina that helps produce sharp, central vision required for "straight ahead" activities such as reading, sewing, and driving. AMD cannot be prevented, and treatment is effective in only a small number of cases. It is estimated that AMD already causes serious visual impairment in approximately 1.7 million of the 34 million Americans over age 65. As the "baby boom" generation ages, and in the absence of further prevention and treatment advances, the prevalence of AMD is estimated to reach epidemic proportions of 6.3 million Americans by the year 2030.

Although the fundamental cause of AMD remains elusive, we are making progress in our research. Several risk factors, including smoking, diet, cholesterol level, and genetic factors, appear to be associated with the disease. The NEI is conducting a large clinical trial, called the Age-Related Eye Disease Study, to assess whether antioxidants and/or zinc can slow down the development and progression of AMD. The NEI is also closely studying the possibility that deficiencies of two carotenoid antioxidants—lutein and zeaxanthin—may contribute to the development of AMD. The NEI convened a workshop of experts last month to develop a research approach that will best evaluate the effect of lutein and zeaxanthin on AMD.

NEOVASCULARIZATION

Neovascularization is the growth of new blood vessels in the retina and the major sight-threatening abnormality in diabetic retinopathy. During their lifetime, nearly half of all people with diabetes will develop some degree of diabetic retinopathy. The disease can blind as many as 25,000 people with diabetes each year. The NEI's continuing support for research on diabetic retinopathy has led to identification of several growth factors related to neovascularization. These growth factors may be stimulated by a lack of oxygen, causing new blood vessels to grow. The NEI is considering clinical trials on several pharmaceuticals that would inhibit the growth of these new blood vessels, and is working with the pharmaceutical industry in this effort.

BIOLOGY OF THE BRAIN

NEI research covers many other diseases and disorders of the visual system. For example, we are expanding research on the growth and development of neurons in the visual system to allow damaged nerve cells to survive and reestablish their normal connections. About 38 percent of all nerve fibers that enter or leave the brain pass through the two optic nerves which connect the eyes to the brain—and there are more than one million nerve fibers in each optic nerve. This is why research into preventing damage to these nerves and restoring their normal function is a

major neuroscience research priority. Such knowledge is also applicable to other parts of the brain.

Research into retinal degeneration will be expanded into understanding the mechanisms of cell death in the retina, which is the part of the eye that transmits visual information to the brain. Retinitis pigmentosa affects over 100,000 Americans and belongs to a group of inherited retinal degenerations that causes severe visual disability. We will expand our research into the therapeutic potential of growth factors that can either rescue damaged retinal cells or prevent degeneration from proceeding. A number of clinical trials will soon begin in this area. Other clinical trials are continuing to develop treatments that may prevent visual disability in very premature infants.

The molecular and cellular mechanisms regulating the growth of the eye are being pursued aggressively, since elongation of the eye is the major cause of myopia, or nearsightedness. About 25 percent of the adult population in the U.S. is nearsighted, and this condition appears to become more prevalent with each subsequent generation. The NEI is conducting clinical trials to develop strategies that may slow down the development of nearsightedness.

OTHER AVENUES OF STUDY

An integral part of the NEI's research portfolio is providing funding to clinician scientists who are committed to a career in research and have the potential to develop into independent investigators. The Mentored Clinical Scientist Development Award provides an intensive, supervised research experience. Depending on the candidate's previous research experience, a three, four, or five-year plan may be proposed. The plan integrates classroom studies with "hands-on" experience in the laboratory or in areas such as biostatistics and epidemiology.

One of the most critical components of translating research in the laboratory to our use in everyday life is the public/private partnership that is actively pursued by the NEI. In an effort to quantify the direct benefits of basic research to commercial enterprise, the NEI reviewed vision-related patents granted since 1975. We found that eye technology innovation has grown steadily, with almost a fourfold increase in the number of patents granted, from 224 in 1975 to 848 in 1996. The NEI is identified as the research sponsor for over 30 percent of the scientific articles referenced by these patents. An even greater number of non-eye care patents make reference to NEI-supported research, meaning that the commercial relevance of NEI research extends to technologies outside of the eye care arena.

QUALITY OF LIFE

The NEI is going beyond measuring patient health by the traditional standard of clinical outcome. We are also assessing a person's quality of life. We have developed a "Quality of Life" questionnaire that measures patients' perception of their own visual functioning. This questionnaire is intended to capture many aspects of visual disability that are identified by patients as being important for their daily activities. Patient outcome is not just what the doctor says it is—it's also what the patient says it is.

The NEI is supporting health services research as another way of improving patients' quality of life. Health services research is broadly defined to include topics such as increasing patient access to, and utilization of, vision care services. Health services research also includes improving the delivery of vision services by eye care professionals, and measuring the vision health of patients receiving eye care services. New health care technologies resulting from this research can allow physicians and patients to utilize the knowledge gained from clinical trial results. It can also help doctors and patients better understand quality of care and the cost effectiveness of care.

The NEI, through its National Eye Health Education Program, is developing a program aimed at raising awareness about the impact of low vision on daily living. We broadly define low vision as any visual condition, not correctable by glasses or contact lenses, that impairs everyday function. Among the target audiences of the low vision program will be people over age 65 and health care and social service providers. The low vision program will be instrumental in informing Americans about low vision and how the use of visual devices and rehabilitative services can maximize remaining vision to improve a person's quality of life.

The activities of the NEI are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan, which was transmitted to Congress on September 30, 1997. NIH's performance tar-

gets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

Finally, Mr. Chairman, I am proud to announce that the NEI has completed its sixth long-range plan for eye research. This five-year research plan outlines research strategies aimed at accomplishing our long range goals and objectives for each of our scientific programs.

Mr. Chairman, I look forward to answering your questions.

PREPARED STATEMENT OF KENNETH OLDEN

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Institute of Environmental Health Sciences (NIEHS) for fiscal year 1999, a sum of $348.1 million, an increase of $24.5 million over the comparable fiscal year 1998 appropriation. Including the estimated allocation for AIDS in both years, total support proposed for NIEHS is $354.8 million, an increase of $24.7 million over the fiscal year 1998 appropriation. Funds for NIEHS efforts in AIDS research are included within the Office of AIDS Research budget request.

ENVIRONMENTAL HEALTH SCIENCE AND PUBLIC POLICY

As shown in Chart No. 1, the focus of my presentation is "Bridging the Gap Between Environmental Health Science and Public Policy". In most instances the scientific and technical information available today is inadequate to develop scientifically sound and comprehensive solutions to complex environmental health problems. Without better information, how can we direct resources to areas of environmental health and safety that will have the most significant impact on human lives?

Might I ask, "How many times during your tenure in the U.S. Congress have you faced the quandary of being asked to intervene in environmental health policy issues without the benefit of sufficient information? To make decisions with enormous public health and economic consequences?

Just last summer I imagine that many of you were queried about the health effects of Pfiesteria following fish kills along our eastern shores. This is an important issue where the concerns of agribusiness, industry, tourism, and environmentalism are all potentially involved. As another example, many of your constituents have perhaps expressed concern about health effects of low level electric and magnetic fields. Your concern has certainly been voiced to me in the form of a directive in the 1992 National Energy Policy Act; as Director of the NIEHS, I am required to give to you this year a report on the possible risks of these exposures. Perhaps some of you have been involved in the recent discussions surrounding federal reference doses for mercury. This issue is particularly important because children are unusually sensitive to this neurotoxicant; thus, its presence in fish has special relevance to pregnant women and children. Also I suspect that many of you were involved in discussions surrounding new proposed ambient standards for ozone and particulate matter, which are being reassessed by the EPA as part of its requirements under the Clean Air Act Amendments of 1990. Finally, you will soon be asked to consider the Environmental Protection Agency (EPA) proposal to require detailed reporting about chemicals and potential health hazards in drinking water. While expansion of federal environmental "right to know" regulation for drinking water is in principle a good thing, can Americans make informed decisions given the magnitude of the data gaps in the toxicological profiles on the mixture of over 700 chemicals in the drinking water of the U.S.?

What these few examples have in common is that, all too often, important public health decisions have to be made in the absence of adequate information. It is this inadequate information base, coupled with the undeniable economic costs of remediation, that continually forces those of you in Congress to determine where the balance should be between suspected public health effects of environmental exposures and the economic costs of reducing these exposures.

The frequency of such quandaries indicate how important it is to invest in better science. By better, I not only mean more information, but I refer specifically to better data on how people differ in their susceptibility to environmental exposures, better data on the health effects of exposures to mixtures of chemicals rather than single compounds, better data on actual human exposures, better data on the mechanisms by which these exposures cause disease, and better methods to integrate all this information into regulatory standards. Although we have not reached this stage

yet, I am convinced that the new cutting-edge technologies in genetics and cell biology position us to attain this ideal.

Clearly we cannot fill gaps in data by flooding the void with brilliant assumptions about exposure, hazard potency, and characteristics of the population at risk. Instead we must make strategic investments that can lead us to the rational environmental health policies, as well as environmental protection policies, we will need for the 21st century and beyond. We at NIEHS have given great thought to what these investments should be, and I outlined some of them for you in last year's testimony. I would like to take this opportunity to provide a "report card" of where we now stand.

INDIVIDUAL SUSCEPTIBILITY

First, I discussed last year how a person's risk differs according to their genetic makeup and the need for this information to improve risk assessment decisions. An Environmental Genome Project was proposed that could address this knowledge gap. I am pleased to report that a trans-NIH effort, involving 15 Institutes, is underway to investigate the genetic basis of environmental disease susceptibility. The discovery of susceptibility genes is critical to a better understanding of numerous diseases, and the development of efficacious and cost-effective prevention and treatment strategies. Such studies will shed some light on the often asked question, "Why me, Doc?", and will help change the current one-size-fits-all approach to health care and environmental health and safety regulations.

EXPOSURE ASSESSMENT

Second, I noted that little is known about which compounds in our environment people are actually exposed to or how much of these exposures they absorb or store in their bodies. Recent advances in analytical techniques should permit detection of environmental and occupational chemicals in small samples of blood and urine. This past year the NIEHS has been developing an exposure assessment program, Body Burden 2000, that is evolving into a multiagency initiative involving the Centers for Disease Control and Prevention (CDC), Food and Drug Administration (FDA), EPA, Department of Defense (DOD), and others. Already we have experienced success in a pilot project with CDC designed to improve the exposure assessment of environmental endocrine disruptors. This information will be useful as regulatory agencies grapple with the issue of endocrine disruptors, particularly as they affect the health of children.

HIGH THROUGHPUT TECHNOLOGY

Third, I alerted you to the need for high throughput technologies for toxicologic testing. The last 50 years has witnessed the development of over 75,000 chemicals. Yet, according to a recently published Environmental Defense Fund report, "even the most basic toxicity testing cannot be found in the public record for nearly 75 percent of the top-volume chemicals in commercial use." (EDF, 1997). In a similar study, the National Academy of Sciences' National Research Council concluded that 78 percent of the highest-volume chemicals in commercial use "had not had even minimal toxicity testing" (NAS/NRC, 1984). We are clearly in a state of toxic ignorance and it is not likely to be resolved by our current reliance on 2-year rodent bioassays. The NIEHS has made considerable progress in developing technologies that can eliminate, or at least reduce, the testing backlog that leads to this state of toxic ignorance. As I have reported to you previously, the NIEHS, under the auspices of the National Toxicology Program (NTP), is evaluating the predictiveness of novel transgenic mouse models. As you can see in Chart No. 2, we have tested close to 30 chemicals in transgenic mice and the results compare favorably with results from our traditional bioassay. Also, since 1997, all 2-year studies reported by the NTP are accompanied by results from parallel studies in transgenic animals. This program will greatly increase our ability to evaluate the best uses for transgenic models in regulatory decision making. Chart No. 3 shows the potential benefit of using the transgenic models in testing, primarily the fact that we can do these assays faster and at less cost. One of the most exciting aspects of this program is that it is being done in partnership with the pharmaceutical and chemical manufacturing industries. Based on progress with these alternative systems, the FDA is now allowing some test data to be submitted using transgenic animals.

Relying on whole animal bioassays, even transgenic animals, will not completely solve our information deficit. The NIEHS is developing a new methodology, called computational biology, that allows regulators to use a variety of information—chemical structure relationships, tests in single cell systems, limited whole animal studies—to assess how environmental agents alter critical biological systems and cause

disease. The regulatory community has already used several examples of this approach as a basis for improving risk assessments. The NIEHS plans to provide even more tools for rapid assessments and is hoping to exploit advances in recombinant DNA technology, combinatorial chemistry, and microarray technology.

COMPLEX MIXTURES

The fourth strategic investment I discussed last year was the need to define health effects from exposures to complex mixtures, rather than the current system which only assesses effects of single compounds. The NIEHS will be funding university-based researchers throughout the country to address this critical research gap. I am confident that in the future I will have significant successes to share with you on the research outcomes of these studies.

CHILDREN'S HEALTH

I would like now to discuss our fifth strategic investment—children. As you know the developing child represents a particularly vulnerable target for adverse environmental effects. This Nation has been particularly vigilant in protecting its children at those times when solid, scientific information has been provided. The story of lead and its subsequent dramatic decline in children illustrates our determination to protect the child. This resolve, however, was only possible because of the firm scientific foundation provided by the research community, much of which was supported by NIEHS. The NIEHS continues to support research in the critical area of children's susceptibility to environmental agents.

According to a recent report of the National Resources Defense Council (NRDC, 1997), the worst environmental threats to children's health include: lead, air pollution, pesticides, environmental tobacco smoke, and drinking water contamination. Other important health concerns include children's greater vulnerability to radiation-induced thyroid cancer, their susceptibility to the neurotoxicity of polychlorinated biphenyls (PCB's) which are frequent contaminants in fish, and their potential interaction with environmental endocrine disruptors released into our environment that have the ability to alter hormone functions.

To address these problems the NIEHS is establishing Centers for Children's Environmental Health and Disease Prevention. Working jointly with the EPA and CDC, we have released an RFA to the research community that will establish Children's Environmental Health and Disease Prevention Centers to define the environmental influences on asthma and other respiratory diseases, childhood learning, and growth development.

The incidence of childhood asthma is rising at an alarming rate, particularly among the urban poor. Common household allergens in the air may be contributing to this devastating disease. It remains to be proven if removing the allergens from a household will provide an effective remedy in reducing asthma attacks or incidence. These propositions are under examination in multicenter, multiyear studies sponsored collaboratively by the NIEHS and the National Institute of Allergy and Infectious Diseases (NIAID). This Inner-City Asthma Study is a prevention trial to develop a comprehensive and cost-effective intervention strategy to reduce asthma morbidity in inner-city children and adolescents.

Given the NIEHS' interest in exposure assessment that I mentioned earlier, it is logical that we have added an exposure assessment study to complement this effort. This National Allergen Survey is being done in collaboration with the Department of Housing and Urban Development (HUD). It is a population-based, national survey of dust hazards in U.S. homes and will monitor for both allergens and lead. Our objective is to examine the relationship between allergen exposure and diseases such as asthma and allergies. This study will give us an estimate of allergen exposures in the general population, will estimate the magnitude of the allergen problem in the U.S., and will reveal how allergen exposures differ as a function of geographic region, socioeconomic status, housing type, and ethnicity.

SUMMARY

In summary, I have articulated a series of strategic investments worthy of public support. Chart No. 4 outlines the seven steps needed to resolve our current state of toxic ignorance. The NIEHS, by implementing these programs, is leading the way to modernize risk assessment and bridge the gap between environmental health science and the public policy it serves. I would be happy to respond to any questions you may have.

PREPARED STATEMENT OF RICHARD J. HODES

Mr. Chairman and Members of the Committee: The President in his fiscal year 1999 budget has proposed that the National Institute on Aging (NIA) receive $556 million, an increase of $38 million over the non-AIDS portion of the fiscal year 1998 appropriation. Including the estimated allocation for AIDS in both years, total support proposed for the NIA is $558 million, an increase of $39 million over the fiscal year 1998 appropriation. Funds for NIA efforts in AIDS research are included within the Office of AIDS Research budget request.

I am pleased to have the opportunity to highlight the efforts undertaken by the NIA to extend through research the healthy, active years of life for all Americans. For nearly a quarter of a century, the NIA has led the scientific effort to comprehend aging processes, producing many advances that enhance the quality of life and prevent costly disease and disability. Such discoveries have come at an opportune time. Facing a century in which 75 million babyboomers will turn 65, we all stand to gain from a healthy, fully engaged older population. Aging research is key to achieving this goal.

ALZHEIMER'S DISEASE RESEARCH

The NIA leads an intensive effort to conquer Alzheimer's disease (AD), a progressive brain disorder marked by an irreversible decline in intellectual abilities and by changes in behavior and personality. As the most common cause of dementia in older people, AD affects as many as four million Americans, with devastating effects to patients, their families, caregivers, and society. Fortunately, the pace of research findings is accelerating. For example, several studies point to the protein fragment beta-amyloid, a major component of the plaques that litter the spaces between nerve cells in the brains of AD patients, as having a key role in the neuronal destruction in AD. The process involved, however, has remained a mystery. This year, NIA grantees provided evidence that a newly-identified protein binds with the beta-amyloid, and that this process may contribute to neuronal dysfunction in AD. Grantees also recently identified a new pathological feature of AD brains, a plaque-like lesion that contains a previously unknown protein which could potentially provide a new diagnostic marker and improve understanding of the causes of AD. The recent generation of genetically engineered transgenic mice that express mutant human genes associated with AD and exhibit AD-like behavioral deficits and brain lesions may serve as a much needed animal model for the study of AD.

Based on research world-wide, people who inherit a particular type of apolipoprotein E (ApoE4) are recognized to be at special risk for the late onset form of AD. NIA grantees are therefore investigating the potential use of genetic testing for ApoE in the clinical diagnosis of AD. Results indicate that ApoE genotyping, although not sufficiently sensitive or specific alone as a diagnostic test for AD, may reduce the number of incorrect diagnoses by close to 30 percent when administered after a clinical evaluation. In a related study, scientists have found differences with respect to ApoE among African-Americans, Hispanics, and Whites. A 5-year, prospective, longitudinal study showed that, in the absence of ApoE4, the cumulative risks of AD to age 90 were four times higher for African-Americans and twice as high for Hispanics as for Whites. In the presence of ApoE4, the cumulative risk to age 90 was similar for individuals in all three ethnic groups. These results suggest that while the ApoE4 allele is a determinant of AD risk in Whites, the other two groups have an increased risk of AD regardless of their ApoE genotype, and that other genes or risk factors may contribute to the risk of AD in African-Americans and Hispanics.

In the critical effort to identify effective treatment for AD, studies reported in the past year have identified three new candidate interventions—antioxidants, non-steroidal anti-inflammatory drugs (NSAID's) such as ibuprofen, and estrogen replacement therapy. Two of these studies used 15 years' worth of data from NIA's Baltimore Longitudinal Study of Aging, now in its 40th year. The first study linked use of NSAID's with an approximately 50 percent reduced risk of AD. The second study associated a history of estrogen replacement therapy in postmenopausal women with approximately a 50 percent reduction in the risk of AD. Based on these and previous findings, the NIA plans to initiate clinical trials to test the effectiveness of ibuprofen and of estrogen vs. placebo in treatment or prevention of AD. In addition, NIA-supported researchers completed a placebo-controlled, randomized prospective clinical trial to assess the effect of the antioxidants vitamin E, selegiline, or the combination on progression of moderately impaired AD patients. The trial showed that selegiline and vitamin E may slow development of functional signs and symptoms of AD by several months, although they did not affect cognitive measures. This study provided the basis for a newly planned novel secondary prevention trial

to test whether high dose vitamin E slows the conversion to AD in people with mild cognitive impairment (that is, having a memory deficit but no dementia). This is the first trial designed to delay AD onset.

BIOLOGY OF AGING

Advances in basic biology have fueled a revolution in aging research. A notable example of this progress is the award of the Nobel Prize in Medicine to Stanley B. Prusiner, a long-time grantee of the NIA, the National Institute of Neurological Disorders and Stroke (NINDS), and other NIH components. Dr. Prusiner was cited for his once-controversial discovery of prions, "an entirely new genre of disease-causing agents," that cause "mad cow" disease and other lethal brain-wasting conditions. His laboratory's latest findings involve the mode of transmission of "mad cow" disease between species and the forms of prions associated with clinical disease.

Rapid progress has also been made on identifying genes that affect longevity in lower organisms. One of these genes (daf–2) regulates life-span in the worm Caenorhabditis elegans. A mutation in this gene can more than double the worm's life-span, if a second gene (daf–16) assists in the process. The daf–2 gene codes a protein equivalent in function to the human insulin receptor, part of a nutrient-sensing pathway the worm uses to monitor and alter its metabolism. These findings imply that the same biological system used by the worm for metabolic regulation could also be central to delaying the aging process and extending worm longevity. If this scenario is valid, the finding may help explain why rodents who eat a diet that is nutritionally balanced but 30 percent reduced in calories live 30–40 percent longer, stay active and healthy until late in life, and have fewer malignancies than do rodents not calorically restricted. In addition, these findings may advance understanding of how human insulin regulates metabolism and why this regulation fails in diabetes. To benefit from these discoveries, the NIA plans a new initiative to identify genes that modulate the rate of aging in humans. These findings are expected to yield insights into both aging and age-related diseases.

Major new advances have been made in understanding the role of telomeres and telomerase in aging and cancer. Telomeres, repetitive DNA segments found on the ends of chromosomes, help maintain chromosomal integrity and function. When cells divide, telomeres normally lose segments and shorten until, at a critical length, cell division ceases and cells become senescent. The enzyme telomerase compensates for telomere loss by adding DNA segments to the ends of chromosomes. This process rarely takes place in normal human cells, where telomerase response is absent or insufficient. In 80–90 percent of human tumor cells, however, telomerase activity is robust, and cells divide endlessly. How and why telomerase reactivates to contribute to cell immortalization is not known. But the correlation between telomerase activation and cancerous growth has stimulated many scientists to view telomerase inhibition as a potential new approach to cancer therapy. In recent months, scientists discovered and cloned the gene for the active subunit of human telomerase, making possible the critical study of how telomerase activity is regulated. Scientists have now inserted copies of the newly-cloned gene into normal, telomerase-negative cells in the laboratory, causing these cells to express telomerase. In contrast to the normal cells, which exhibit telomere shortening and cessation of cell division, the telomerase-expressing cells had elongated telomeres and have continued to replicate far beyond the limits observed for normal cells. These results confirm that telomere shortening causes cellular senescence under laboratory conditions. The ability to avoid senescence in normal human cells is expected to have important applications in research and medicine.

REDUCING DISEASE AND DISABILITY

As life expectancy increases, there is an urgent need to keep these additional years disease- and disability-free. Cardiovascular disease and cancer, as the two leading causes of mortality in the elderly, are important research targets. The only common cardiovascular disease now increasing in prevalence in the U.S. is heart failure, and a chief risk factor for this disease is isolated systolic hypertension. The NIA and the National Heart, Lung and Blood Institute supported a controlled clinical trial to test the effectiveness of low doses of the diuretic chlorthalidone to treat systolic hypertension in older people. Older people who were treated in the trial had 50 percent less heart failure than those not treated. The chance of developing heart failure dropped even more for persons who had previously had a heart attack, an improvement of 80 percent. Treatment of isolated systolic hypertension with this relatively inexpensive medication could make major differences in quality of life and save substantial medical costs. The NIA also collaborates with the National Cancer Institute on cancers in older people, including breast and prostate cancer. Using

data from the BLSA, NIA scientists and colleagues have produced several important advances about the role of prostate specific antigen (PSA), an enzyme useful for detecting and indicating the aggressiveness of prostate cancer. Some PSA binds proteins in the blood, and some PSA remains free, or unbound. At the time of cancer diagnosis, the ratio of free to total PSA in blood may predict whether the cancer will be fast or slow-growing. This can help the physician decide whether to treat or monitor the cancer. Avoiding unnecessary treatment, such as radiation or surgery, may reduce complications, including impotence and incontinence, as well as reduce health care costs.

NIA research also focuses on mobility and freedom from pain in older people. Loss of bone mass due to osteoporosis contributes to 1.5 million fractures each year in the U.S., according to a recent article in the publication Bone. An NIA controlled trial studied the effect of dietary calcium and vitamin D supplementation in maintaining bone density and preventing fractures in older men and women. This regimen prevented bone loss at all skeletal sites and was associated with a 50 percent reduction in the rate of symptomatic nonvertebral fractures. This underlines the importance of older persons' maintaining adequate levels of calcium and vitamin D to minimize bone loss. Osteoarthritis, a painful degenerative joint disease, also affects millions of older Americans. A controlled trial conducted at an NIA Older Americans Independence Center proved that walking and resistance exercises can safely improve function and reduce pain in patients with knee osteoarthritis, suggesting that exercise should be prescribed as part of the treatment for these individuals.

Supplements of hormones and hormone-like molecules, such as melatonin, DHEA, testosterone, and growth hormones, are of growing popular interest. Claims have appeared in the news that taking such supplements can make people feel young again or can prevent aging. Unfortunately, these claims have not been proved, and the wrong balance of hormones can be dangerous. The NIA is conducting research to define the biologic action of these hormones and to assess the clinical utility of replacement therapy of hormones that tend to decline, on average, with age. For example, research has focused on understanding observed age-related declines in testosterone, which could contribute to decreased muscle and bone capacity, and the biology of the menopause, which is associated with pathology such as increases in osteoporosis and cardiovascular disease. This initiative has great potential for developing effective strategies to promote strength and prevent disability in older men and women.

BEHAVIORAL AND SOCIAL RESEARCH

Behavioral and social research is instrumental in enabling older people to maintain or enhance physical and cognitive function and be fully engaged in life. The NIA also has consistently supported research to encourage long-term behavior changes that decrease risk of disease and disability. A new NIA centers initiative is increasing understanding of aging and improving health status in older minority populations, complementing the efforts of other centers that are developing strategies to keep people active and productive in late life. Significant progress is also being made on understanding and influencing changes with age in cognitive function. This year, a landmark study that compared identical and fraternal twins over age 80 found that the contribution of heredity to cognitive ability remains very strong, approximately 50 percent, even in old age. These results contradicted hypotheses that predicted an increased impact of environmental factors with age in determining intelligence.

The NIA also monitors the impact of population aging on disease and disability. Demographic research has shown that there are at least 1.4 million fewer disabled older persons in the U.S. than there would have been if the disability rates of the elderly had not improved since 1982. Further studies will identify and quantify the specific underlying causes contributing to the decline. Additional analysis will involve the dynamics of old-age life expectancy, projections of the support ratio, and health expenditures, as well as the implications of trends in health, disability, and life expectancy for national policies on retirement and programs for the elderly.

The NIA will continue to identify initiatives that maximize scientific and management efficiency and that have the potential for placing successful aging within everyone's reach. I would be happy to answer any questions.

PREPARED STATEMENT OF STEPHEN I. KATZ

Mr. Chairman and Members of the Subcommittee: I am pleased to present the President's budget request for the National Institute of Arthritis and Musculoskeletal and Skin Diseases. Including the estimated allocation for AIDS research in

both years, total support proposed for the NIAMS is $295.6 million, an increase of 7.6 percent over the fiscal year 1998 appropriation. Funds for NIAMS efforts in AIDS research are included within the Office of AIDS Research budget request.

BENEFITS OF MEDICAL RESEARCH IN BONES, JOINTS, MUSCLES, AND SKIN

Medical research has demonstrated time and again the genuine difference it can make in many dimensions of people's lives. While the Congressional Justification is full of such research advances, and I am very enthusiastic about and proud of those achievements, I want to focus today on my outlook for the future. What will life be like a decade from now if we invest in the bright scientific minds and in the unprecedented tools of medical research that are available to us today? What difference can it make in people's lives when we wisely invest the funds proposed in our fiscal year 1999 budget?

You have heard in my testimony in the past that virtually every household in America is affected by some disease or disorder of the bones, joints, muscles, and skin—and that these diseases take an enormous toll on one's quality of life. Because our research mandate is quite broad and diverse, progress realized from research that we support has the potential to benefit virtually every household in America. We hear a lot about the concerns of baby boomers and the aging of the American population. I would like to sketch out some dimensions of what life could look like if the research we are supporting, conducting, and planning realizes its full potential.

Imagine a future where quality of life is not compromised by old age or pain and suffering * * * where people are productive and independent well into their senior years. Bone fractures seriously compromise quality of life, and they are often a consequence of osteoporosis—a thinning of bones—that constitutes a major public health problem. We have learned an enormous amount about how bones become strong and that they are constantly being built up and broken down. This past year, in an important series of discoveries, researchers supported by NIAMS and the National Institute of Dental Research identified a gene essential for the buildup of bone—thereby opening up exciting opportunities for the development of potential new bone strengthening interventions to prevent bone fractures. This finding has clear implications for osteoporosis, Paget's disease, osteogenesis imperfecta, and other bone diseases. Move now to the schools. We are heartened to see children and adolescents benefitting from programs targeting their strong bones and reducing their sports injuries. We know that calcium is critical for maintaining integrity of bones and that people build up their bone "bank account" during the first three decades of life. During the past year, in studies in Mexican-American girls, we learned how the vitamin D receptor gene is related to bone mineral density, and why some girls may be more susceptible to low bone mineral density. We look forward to developments that will alter or reverse this susceptibility.

Move now to the beach and other recreational sites. Here we see people of all ages enjoying time outdoors while taking informed and proven precautions to avoid skin cancer caused by sunlight exposure. During the past year, we have learned more about how certain mutated genes cause skin cancer, the most common form of human cancer, and we are now trying to understand how these effects might be reversed or altered.

Move now to the doctor's office and other sites of health care. We see people clearly benefitting from better diagnostic tools, improved medical devices, and more effective treatments with fewer side effects—all derived from research. We are supporting studies of a number of technologies, such as MRI to identify early osteoarthritis and bone implant engineering to design bone and joint replacements with greater longevity. Move now to the world of information. People will continue to derive their information from many, diverse sources. My goal is that current, reliable information will be available to all of these people regardless of the venue they choose. When patients understand their disease, they can make sound decisions about their health care, and they can be empowered by the sense that they control their disease * * * their disease does not control their lives. We are working toward a world where pain and suffering are significantly reduced, where disabilities less frequently compromise daily life, where women and minorities are no longer disproportionately affected by so many diseases, and where quality of life and productivity are routinely experienced at high levels. Is this an ambitious vision? Absolutely. Is it really achievable? I think it is. Now I would like to share with you other examples of progress as well as our initiatives.

ADDITIONAL RESEARCH ADVANCES AND INITIATIVES

One of the most rewarding aspects of my job as Director of the NIAMS is the opportunity to report on the research advances we have supported over the last year. In arthritis, we know much more about changes that occur in cartilage cells lining the joints in people with osteoarthritis, and we are focusing increased emphasis on identifying appropriate markers to determine the diagnosis, prognosis, or severity of osteoarthritis. Recently, we have learned how certain genes are turned on and produce products that cause cartilage cells to die. Until recently, it was very difficult to propagate cartilage cells in a test tube, but certain growth factors have now been identified that enhance cartilage cell growth. These findings provide important scientific opportunities for increasing our understanding of osteoarthritis.

A major overarching category of diseases under study in our Institute is autoimmune diseases, those in which the body's own cells turn against the body and cause diseases such as rheumatoid arthritis, systemic lupus erythematosus, Sjogren's syndrome, alopecia areata, scleroderma, and others. We are making progress in all of these, and advances in understanding one of these diseases has implications for all of them. Studies in tumor suppressor genes—long an integral component of cancer research—have revealed new insights into rheumatoid arthritis. Investigators have reported this year that synovial tissue from the joints of severe chronic rheumatoid arthritis patients contain a mutated tumor suppressor gene that controls the growth of normal cells. This may, in part, account for the chronic overgrowth of joint-lining cells in rheumatoid arthritis.

Another important discovery was made by researchers in our NIAMS Intramural Research Program who identified the gene responsible for the disease called Familial Mediterranean Fever (FMF). Attacks of this disease are characterized by inflammation as manifested by arthritis, chest pain, abdominal pain, recurring bouts of fever, and skin rashes. This discovery will provide important insights into the causes of inflammation in FMF and many other inflammatory diseases, and provide for new and improved treatment for this and perhaps many other diseases characterized by inflammation. Funds provided in fiscal year 1999 will facilitate the development of animal models, diagnostic tests, and further identification of specific mutations in these patients. These brief highlights provide a glimpse of the hope that research offers for the many people suffering from the common, costly, crippling, and chronic diseases within the mandate of the NIAMS.

VALUE OF BEING A PART OF THE NATIONAL INSTITUTES OF HEALTH

One of the strongest assets we have as an Institute is being a part of the National Institutes of Health. We share a common goal and commitment—improving the health of the American people—and we work together toward that end. Very frequently you will hear about diseases that are supported by many different institutes. For example, research on osteoporosis is supported by some 14 different components of the NIH. Such an approach is not duplicative, but complementary. We all approach our studies from a different perspective, but the goal is improved understanding of and strategies to reduce osteoporosis. With complex diseases like fibromyalgia, we often take a multi-pronged approach. We support basic studies in understanding the disease process and the troubling symptoms that people with fibromyalgia experience. We support innovative scientific workshops (as we did in July 1996) to enable basic researchers who never heard of fibromyalgia, but are conducting the latest research on sleep disorders or pain, to talk to clinicians who see patients with fibromyalgia every day, but are stymied in how to improve their lives. We then consider the recommendations from such a workshop and develop and implement strategies based on these recommendations. Again, using the example of fibromyalgia, as a result of that scientific workshop, the Institute is issuing a request for applications for exploratory and developmental grants in this area, targeting the pressing research questions in this area. Similar approaches have been utilized for many other diseases, including rheumatoid arthritis, osteoarthritis, systemic lupus erythematosus, scleroderma, low back pain, repetitive motion disorders, and various skin diseases. We ask what is the best strategy for understanding each disease and how we can improve the lives of patients. Over and over again, we have seen how research in one area significantly informs our understanding of other diseases. That is why it is so essential to support studies across the research spectrum.

PARTNERSHIPS WITH VOLUNTARY AND PROFESSIONAL ORGANIZATIONS

In addition to our interactions with our colleagues across the NIH, we have also partnered with our colleagues in several voluntary and professional organizations. I am very pleased with the three new partnerships that have been developed this

past year. The first is a novel partnership with the Arthritis Foundation, the National Institute of Allergy and Infectious Diseases, and the Office of Research on Women's Health to support a national consortium of 12 research centers in the search for genes that determine susceptibility to rheumatoid arthritis. The Arthritis Foundation not only provides financial support, but plays an invaluable role in patient recruitment and in increasing awareness of this study, the largest such effort in the world. The NIAMS also has partnered with both the American Society for Bone and Mineral Research and the S.L.E. Foundation to co-fund grants. Such arrangements benefit both components—the voluntary and professional organizations benefit from the NIAMS' expertise in grant review, and the Institute is able to support more studies than would be possible without the co-funding. When we share common goals, as we do in the examples just cited, the partnerships are clearly beneficial—for the public, the voluntary groups, and the NIAMS.

The future: challenges and plans

What are the challenges to reaching the vision of the future that I described earlier and how do I plan to invest the budget to address those challenges? The increased budget will allow the NIAMS to support more research grants in key areas of opportunity and need, and we will expand our research portfolio in a number of priority areas. For example, we will explore specific opportunities to learn more about skeletal morphogenesis and growth, mechanisms of central nervous system damage and cardiovascular disease in systemic lupus erythematosus, hematopoietic (blood cell forming) and immune system effects on bone physiology, gene therapy for arthritis and skin disease, and structural biology of muscle membrane proteins. The NIAMS convened four working groups this year—in arthritis, bone, orthopaedics, and skin—to discuss clinical research needs and opportunities. There is a serious challenge in the field of clinical research, where problems include a shortage of people trained to do clinical research, and a shortage of people in the pipeline pursuing a career in clinical research. For example, our clinical panels expressed concern about the scarcity of individuals in NIAMS-related specialties, such as rheumatology, particularly pediatric rheumatology, as well as the dearth of physicians doing research in bone endocrinology, orthopaedic surgery, and dermatology. Our ability to derive maximum benefits from medical research will be seriously compromised if we do not address these shortfalls. Clinical researchers provide a vital bridge for translating bench research to bedside improvements, as well as translating bedside insights into bench opportunities. The new initiatives launched by the NIH in clinical research training and career development will help address important public health needs in NIAMS-mandated areas. I am confident that this aggressive and proactive approach will make a genuine difference in medical research in the future.

The activities of the NIAMS are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

In closing, I want to express my gratitude to the members of this subcommittee for their strong and unwavering support of medical research. I hope that ten years from now we will be able to speak about the benefits that medical research has enabled—that we will be able to enjoy progress in all aspects of the lives of the American people. I am focused on that goal—the research we are supporting, conducting, and planning is aimed at achieving that goal. I am optimistic that we are on the way to achieving that goal.

My colleagues and I will be happy to respond to any questions you may have.

PREPARED STATEMENT OF JAMES F. BATTEY, JR.

Mr. Chairman and Members of the Committee: I am honored to appear before you as the newly appointed Director of the National Institute on Deafness and Other Communication Disorders (NIDCD). Several members of Congress were actively involved in the creation of the NIDCD nearly ten years ago. As you envisioned, NIDCD has become the focal point of research in human communication supported and conducted by the Federal government in the fifty states. In the last several years, in my role as the NIDCD's Scientific Director, I was part of the Institute's growth and development, whose goal is to advance knowledge about the mechanisms

and processes of human communication, and revolutionizing prevention and treatment of disease and disorder. The President in his 1999 budget has proposed that the National Institute on Deafness and Other Communication Disorders receive $213.8 million, an increase of $14.9 million over the non-AIDS portion of the fiscal year 1998 appropriation. Including the estimated allocation for AIDS in both years, total support proposed for NIDCD is $215.7 million, an increase of $15 million over the fiscal year 1998 appropriation. Funds for NIDCD efforts in AIDS research are included within the Office of AIDS Research budget request.

COMMUNICATION SKILLS AT THE CENTER OF SUCCESSFUL LIFE IN THE NEW CENTURY

Communication skills will be central to a successful life in the new century for all Americans. For the 46 million Americans with communication disabilities, however, getting up and facing each day is a challenge. The simple acts of speaking, listening, of making their wants and their needs understood, are often impossible. For the individual who has vertigo, or the person who finds himself or herself suddenly unable to hear, the days are challenging. For those who cannot speak without stuttering or for those who are unable to express ideas clearly after suffering a stroke, for those who cannot use their voices to talk with a friend on the phone due to the devastation of throat cancer—each day is challenging. The days are challenging for the child who has autism. They are also a challenge for the individual who cannot participate in activities because his or her tinnitus has become overwhelming. For an older person a loss of balance can result in falls and fractured bones, and a loss of hearing results in isolation. For the young child who begins a struggle with language, that if not for intervention, will be a lifelong struggle—communication disabilities pose a constant challenge. NIDCD made important progress in the disorders of human communication this year and has identified new targets, new tools and new teams for accelerating discovery in fiscal year 1999.

NEW TOOLS: SENSORY IMAGING

In reviewing the progress of the past year, the advances made in human communication research are frequently based upon new tools, new targets and new teams of scientists looking at research in novel ways. For example, we now have the ability to see the brain at work during human communication through the use of powerful imaging tools. Much of the human brain is used for hearing, balance, voice, speech and the manipulation and production of language, as well as the ability to smell and to taste.

IMAGING PROVIDES FIRST OBJECTIVE VIEW OF TINNITUS

Having the ability to image brain activity patterns during various communication events involving stuttering, aphasia, tinnitus, and American Sign Language is revolutionizing our understanding of normal and disordered processes of human communication. In one of many remarkable advances this year, NIDCD scientists are able to visualize brain activity occurring with tinnitus, or ringing in the ears. Tinnitus has been extremely difficult to study without an objective model as it is associated with virtually every kind of hearing loss. These studies provide ground-breaking information about the nature of tinnitus, which will hopefully lead to improved strategies for diagnosis and treatment for the millions of Americans challenged with the incessant or intermittent audiotory sensation that is tinnitus.

SENSORY HAIR CELL REGENERATION PROGRESS

NIDCD-supported scientists are determining the properties of unique sensory cells of the inner ear called "hair cells." [Exhibit 1: Sensory Hair Cells] These cells are critical for converting mechanical energy from sound or motion into electrochemical signals sent to the brain. Loss of hair cells is frequently the cause of hearing impairment and balance disorders. NIDCD-supported scientists are studying the molecular mechanisms underlying hair cell regeneration in animal model systems with the ultimate goal of using this information to restore hair cells in individuals with hearing impairment and balance disorders.

COCHLEAR IMPLANTS RESTORE HEARING

In a different way, NIDCD scientists are trying to restore hearing through support of the development of the cochlear implant. The cochlear implant is a sensory neural auditory prosthesis that improves economic and social outcomes for post-lingual hearing impaired individuals. [Exhibit 2: Cochlear Implant and Figure A: Inner ear and cochlear implant] Here is a modern cochlear implant. Let me show you how it works. Part of it is surgically implanted within and behind the ear and the other

components are worn. The implant bypasses the nonfunctioning hair cells in the cochlea and stimulates the auditory neural pathway. The prosthesis also includes a voice processor that has been designed to sample and convert sound at high speed and through a brilliant speech processing strategy. As an indication of how well this implantable prosthesis works, many who become suddenly deaf in mid-career are now able to remain in their jobs. These individuals are able to use the telephone again after learning to use the implant through rehabilitation training.

EARLY IDENTIFICATION OF DEAF AND HARD OF HEARING INFANTS AND DEVELOPMENT OF LANGUAGE

NIDCD has continued to investigate the development of language, signed or spoken, in children who are deaf or hard of hearing. NIDCD-supported scientists have shown that the first six months of life represent a crucial period for subsequent development of language either spoken or signed. A number of states are implementing universal newborn hearing screening which begins with a test for auditory function very soon after birth. In 1998, NIDCD-supported scientists will complete a five-year study showing that two screening methods, measurement of otoacoustic emissions and auditory brainstem responses, can be used to accurately identify these deaf and hearing-impaired newborns. These research results will provide much needed guidance for implementing universal newborn hearing screening.

PROGRESS IN UNDERSTANDING OLFACTORY RECEPTION

The olfactory receptor gene family has about 1,000 members. More than five years ago, scientists discovered this large, multi-gene family, but had difficulty proving that these receptors responded to an odorant. An NIDCD-supported laboratory has shown that a member of the multi-gene family first identified as encoding a putative odorant receptor does indeed code for a protein that is capable of specific odor binding leading to a physiological response. Using a recombinant adenovirus, scientists were able to direct expression of a particular receptor gene in an increased number of rat olfactory neurons. Electrophysiological recording showed that increased expression of a single olfactory receptor gene increases odor and sensitivity to a small subset of odorants. These studies provide the basis for additional research that will correlate olfactory receptor structure with odorant responses.

NEW APPROACH FOR CHILDREN WITH SPECIFIC LANGUAGE IMPAIRMENT

NIDCD has also made progress in studying specific language impairment (SLI) in hearing children. Specific language impairment, or SLI, is a deficit in language acquisition found in the absence of other cognitive impairment, and is present in about 8 percent of American school age children. SLI is a common cause of poor academic performance and frustration with learning. For a long time the focus of research was upon language and language strategies. Within the last few years, however, NIDCD-supported scientists have determined that SLI is often caused by a specific inability to process rapidly changing auditory information, such as occurs in some normal human speech. These findings will allow a more precise diagnosis of SLI, and suggests new intervention strategies to help children with SLI.

MOLECULAR GENETICS COLLABORATION PROVIDES KEY TO FORM OF HEARING IMPAIRMENT

Molecular genetics is revealing genes involved in many disorders of human communication. The search for hearing impairment genes is greatly facilitated by the timely, collaborative information exchange among different NIH Institutes working with a common purpose. For example, when a gene for a syndrome consisting of hearing impairment coupled with thyroid abnormalities was identified by a National Human Genome Research Institute scientist, this information was shared with NIDCD intramural investigators. The NIDCD scientists used the information to show that different mutations in the same gene also causes recessive non-syndromic hereditary hearing impairment in some families.

IMPROVED UNDERSTANDING OF THE CAUSE OF RECURRENT OTITIS MEDIA

As every parent knows, otitis media or middle ear infection, is the most frequent reason that a sick child visits either emergency rooms or physicians' offices, and the estimated cost of treating otitis media is $5 billion a year. Otitis media appears to be increasingly resistant to conventional antibiotic therapy. One of the most difficult aspects of treating otitis media is that relapses often occur within several weeks of antibiotic treatment. This clinical problem was difficult to explain, since most middle ear effusions showed no evidence of bacterial infection when cultured. Using a

molecular biology technique (polymerase chain reaction assays), NIDCD scientists were able to detect the presence of bacterial mRNA in a significant number of culturally sterile middle ear effusions. This established the presence of viable organisms in some culture-negative Otitis Media with Effusion. Scientists believe that these elusive bacteria exist in biofilms, a kind of bacterial community that contains intact but indolent organisms deep within the film and away from antibiotics. Otitis media may serve as an ideal model for studying the role of biofilms in other recurrent infectious disease.

NEW TEAMS: VELOCARDIOFACIAL SYNDROME

In addition to new tools and new targets, new teams of scientists are providing collaborations for progress. NIDCD is convinced that multidisciplinary teams of scientists working together will be most effective in understanding the basis for human communication disorders. The NIDCD has already observed the benefit of this kind of collaboration. Velocardiofacial syndrome (VCFS) is a genetic disorder resulting in cardiac malformation and cleft palate, which has direct impact upon human communication skills. A team of NIDCD-supported scientists including molecular biologists, human geneticists, otolaryngologists, and cardiologists are searching for the gene or genes that cause VCFS. They are also developing better tools for diagnosis and treatment. This multi-disciplinary team is a model for future partnerships among clinicians and scientists. NIDCD sees an opportunity to support similar teams who will work together to understand the biology and genetics of voice, speech, and language disorders, and translate this understanding into improved diagnosis and better intervention strategies.

NEW NIH COLLABORATIVE TEAMS: NIDCD SUPPORTS AUTISM INITIATIVE

NIDCD was pleased to cooperate on an important autism initiative. Autism is a common developmental disorder found in children, affecting as many as one child in 1,000. One of the most striking problems these children face is the inability to communicate with other people. NIDCD has joined three other Institutes (National Institute of Child Health and Human Development, National Institute of Mental Health and National Institute of Neurological Disorders and Stroke) to support research to identify the genes that underlie autism, as well as to develop more effective intervention strategies. In another collaborative effort, NIDCD is working at defeating cancer of the head and neck. Each year, tens of thousands of Americans develop cancer of the head and neck. Conventional treatment using surgery and radiation therapy is often less than fully effective and results in destruction of organs critical for human speech. Clearly, better treatment modalities are needed. NIDCD has partnered with the National Cancer Institute and the National Institute of Dental Research to conduct and support research to determine the molecular mechanisms critical for the pathogenesis and progression of these malignancies. Cancer of the head and neck is unusual in that the scientist can watch the progression, remission or treatment effectiveness directly. In addition, these three institutes will work together to translate these basic scientific discoveries into more effective treatment options, sparing organs critical for human communication.

NIDCD COLLABORATES FOR HEARING AID IMPROVEMENT

NIDCD is collaborating with the Department of Veterans Affairs and the National Aeronautics and Space Administration to improve hearing aids and sponsored a workshop to showcase technologies existing in Federal laboratories to facilitate transfer of those technologies that could improve the function of hearing aids. NIDCD looks forward to funding applications from multidisciplinary collaborations designed to improve speech signal processing for hearing aids.

NEW PLAN

The pace of biomedical research advance is accelerating. To stay ahead, NIDCD is launching an accelerated planning process that will seek the collective ideas of the scientific community as to where the greatest need and opportunity lie in human communication research. New tools, new targets, and more importantly, new teams of investigators will be needed to rapidly and effectively seize the remarkable opportunities before us. We look forward to expanding our understanding of the biology and genetics of human communication disorders that affect 46 million Americans, and translating that knowledge into better strategies for diagnosis, early intervention and treatment. Thank you.

My colleagues and I will be happy to respond to any questions you may have.

PREPARED STATEMENT OF STEVEN E. HYMAN

Mr. Chairman and Members of the Committee: The President in his fiscal year 1999 budget has proposed that the NIMH receive $701.8 million, an increase of $52.4 million over the non-AIDS portion of the fiscal year 1998 appropriation. Including the estimated allocation for AIDS in both years, total support proposed for NIMH is $809.7 million, an increase of $59.5 million over the fiscal year 1998 appropriation. Funds for NIMH efforts in AIDS research are included within the Office of AIDS Research budget request.

EXCESSIVE DISABILITY STEMS FROM MENTAL ILLNESS

Mental illness is a serious burden for the American people and for the entire world. Data from the landmark Global Burden of Disease study sponsored by the World Health Organization, the World Bank, and the Harvard School of Public Health clearly establishes the enormous contribution of brain disorders to disability. Iin developed countries such as the United States, four of the leading ten causes of disability are mental disorders. As Figure 1 shows, these four are unipolar major depression, schizophrenia, manic depressive illness and obsessive compulsive disorder. Also on this list, however, are alcohol use, dementia, stroke, and drug use. When one adds these conditions to the four mental disorders that I mentioned, eight of the ten leading causes of disability are seen to be brain and behavioral disorders. In the United States, the leading cause of disability is unipolar major depression, a serious disorder that affects 5 percent of Americans at some point in their lives.

Serious depression often begins early in life, and reoccurrences throughout life are the rule. While the popular press recently has made much about the widespread use of antidepressants in the U.S., we should not be misled into thinking that the extent of use is evidence that all cases of major major depression are identified accurately and treated appropriately. Indeed, all available data tell us otherwise. Despite remarkable strides in developing treatments for depression, which compare favorably with treatments for almost any other chronic affliction of human kind, we are still unable to achieve full remissions or prevent recurrences in a disturbing fraction of sufferers. Also, the age of typical first onset of major depression vividly illustrates why mental disorders contribute so much to the burden of disability in the United States and worldwide. Mental disorders often begin early in life—if not in childhood, then most often in young adulthood, often at a time when a young person is just completing his or her education and society has a maximal investment in that young adult's future productivity.

With schizophrenia, too, and other severe disorders, again we have made remarkable recent progress in the palliation of symptoms. Still, it is the rare and exceptional individual with this illness who attains the level of independence and productivity that they would have achieved but for the onset of illness. These facts underscore a point that I make often but which, in the face of continuing widespread misunderstanding and stigma in our society, bears repetition. Mental disorders are real brain disorders, they are diagnosable, and we have treatments that make an extraordinary difference in the lives and productivity of many of the victims. Although research on mental disorders has much yet to accomplish, we have made encouraging progress in understanding and developing treatments, particularly for the most severe forms of illness. Unfortunately, this progress may be overlooked given the tendency of the popular media and even some mental health professionals to conflate the kind of mental stress and distress which we all suffer intermittently with serious mental illness.

Let me turn from this discussion of the burden of mental illness to two examples of progress that have been made during the last year, one in the area of basic science, and one in the clinical realm.

MECHANISMS OF CELLULAR MEMORY IN MENTAL ILLNESS

On prior occasions, I have had opportunity to speak to you about the importance of genetic vulnerability in the production, or origins, of mental illness. Today, I would like to describe to you how the brain records experience in a way that contributes not only to the formation of normal memories of many types but which can also contribute to the onset and maintenance of illness in genetically vulnerable individuals. Let me begin by noting that the hundred billion or so nerve cells in our brains each may make thousands of connections with other nerve cells. These connections, which are called synapses, are the fundamental units, or sites, of information transfer. Whenever we remember something, whenever we record an experience in our brains, the physical structure of our brains is altered. We are learning that memory is the result of the physical changes in these synaptic connections! When we learn,

the connection between some nerve cells is strengthened while connections between others are weakened. Research funded by several NIH Institutes, including NIMH, has revealed that structural changes that occur at the synapse when we learn are mediated by complex but highly orchestrated patterns of molecular change. Using a variety of animal models, including mice with experimentally altered genes, we have learned many details about the precise molecules that are involved in the recording of different kinds of memory, including explicit, conscious memories. What has remained elusive, however, has been the ability to correlate actual learning due to experience with its major physiologic signature of increased synaptic strength, a signature which goes by the name of long-term potentiation or LTP.

Several months ago, two separate research groups provided evidence for this long suspected correlation between increased synaptic strength and a behaviorally significant form of memory. This discovery was made not with the kind of memory associated with thinking or cognition, however, but with the memory associated with emotional experience. This important insight into mechanisms by which experience alters brain structure occurred during the course of investigations of learned fear—specifically, its neurobiologic correlates in a part of the brain, the amygdala, that processes emotion. Figure 2 illustrates the information available through the use of functional magnetic resonance imaging, or fMRI. This image vividly represents activation of the amygdala in response to pictures that are designed to elicit negative emotions, including fear. The data here show a composite increase in the magnetic resonance signal during the presentation of negative pictures, when compared with neutral pictures. Knowing how memories of fear are coded in the brain represents significant progress on the path toward a fuller understanding of normal brain function; for our purposes at NIMH, it also is a very important step on the path to understanding how panic attacks (which are experiences of spontaneous, overwhelming fear) lead to the disabling constriction of life which goes by the name of agoraphobia; similarly, the information already has shed light on the means by which overwhelming trauma often leads to long-term symptoms that may disable a person in many domains of life. Indeed, knowledge about the role of memory in emotional processing may be a valuable step toward understanding the severe anxiety symptoms that often occur in major depression. Most importantly, the discovery suggests specific strategies for developing novel treatments for each of the conditions I have listed. For one, the discoveries permit us to focus neuroimaging tools on the human brain with the aim of obtaining increasingly precise pictures of what goes wrong in the brain in mental illness. In addition, knowing precisely where in the brain information processing events occur and the mechanism by which they are recorded may permit us to develop highly targeted treatments.

RESEARCH FOCUS ON CLINICAL INTERVENTIONS

Even as we continue to make fundamental progress in understanding brain function and dysfunction, we are embarked on an ambitious program of clinical research with the goal of improving the lives of patients with mental disorders. As part of a reorganization of NIMH's extramural programs that we undertook last year to revitalize the Institute's attention to mental illness in the context of new science, I created a new funding division that will focus exclusively on our public health mission of improving treatment and prevention interventions. Given the pace of basic science, accompanied by new attention to "translational" research that seeks to apply fundamental knowledge of brain mechanisms to clinical uses, I believe that new treatments will become available at an increasing pace. We must ensure that such treatments find their appropriate place in clinical practice. Thus, an important challenge for NIMH, which we address principally through our new Division of Services and Intervention Research, is to find out what treatments work in children, in adults, in the elderly, and the circumstances or conditions under which they can be delivered most effectively. This Division also disseminates information to the public and to health care providers on proven treatments for mental illness.

ADVANCES AND CHALLENGES IN TREATING CHILDHOOD DEPRESSION

I would like to highlight a study that shows progress but at the same time points to the need for continued research. Last November, NIMH-funded investigators reported on a major clinical trial that documented the efficacy of the antidepressant, fluoxetine (Prozac), in children. This well-conducted trial demonstrated convincingly that pharmacologic treatments are indeed efficacious in children, as measured by stringent standards of clinical outcome, safety, and tolerability of the medication. The medication clearly worked but, at the same time, the response rate was not as high in children as it is in adults. This reduced efficacy is a matter of concern since older, so-called tricyclic antidepressants have not proven efficacious in children.

Thus, while we have one proven treatment, the development of novel, more effective treatments, including psychotherapies specifically designed for children, remains an urgent priority. We must also examine why we so often fail to identify children with depression and how children gain access to treatment. And, drawing on our capacities to look at very fine brain structures, we must study very carefully the impact of both depression and antidepressant treatments on the developing brain.

NIMH RESEARCH PRIORITIES

What are NIMH's priorities for the coming year? A wealth of scientific opportunities forces us to be very judicious in selecting areas for special focus and investment. In addition to modernizing and expanding the field of childhood mental disorder research—a task that entails attention to research training needs—and supporting clinical trials for children, an important priority is clinical trials of new treatments for schizophrenia. Several fundamentally new medications for schizophrenia that were designed on the basis of what we know about the neurobiology of the illness are coming onto the market and it is imperative that we address outstanding questions about their most appropriate use. Another priority is prevention research. Just last month, the Mental Disorders Prevention Research Workgroup, which under the aegis of the National Advisory Mental Health Council conducted an in-depth review of our portfolio, presented its final report. From the Workgroup's recommendations, the Institute will assign high priority to such under-researched areas as the prevention of suicide, with particular emphasis on suicide in older individuals.

We continue to emphasize the search for genes that produce vulnerability to schizophrenia, manic depressive illness, early onset depression, and other mental disorders. The Genetics and Mental Disorders Research Workgroup of our Advisory Council has issued a concise list of recommendations in areas that extend from creating and analyzing the necessary large samples of DNA and clinical data from families with high rates of certain mental disorders, to fostering collaborations across NIH, to sponsoring new NIMH initiatives in the genetics of mental disorders. We have implemented or are in the process of implementing, these recommendations—guidance that I find very helpful as we grapple with the enormous difficulties posed by the complexity of genetic vulnerability to mental disorders.

Research on brain development is a critically important priority for the Institute. While developmental neurobiology is a thriving field—and, indeed, I had occasion earlier this year to testify before the House subcommittee on issues of brain development and mental disorders—I am aware of important gaps in our knowledge base. Our progress in understanding emotional memory demands that we learn more about the development of those parts of the brain involved in processing emotion and integrating thought with emotion, brain regions that are critically involved in mental disorders. In partnership with the NINDS and several other NIH Institutes, we have initiated a project, called the Brain Molecular Anatomy Project, or B-MAP. The goal is to identify all genes that are expressed in the brain, using emerging gene discovery technologies. Knowing where genes are used in the brain is a first step in understanding what they do in cells and how they interact with other genes and environmental signals. This information will prove invaluable as we investigate the normal and abnormal changes that occur in the human nervous system at various stages of life.

In accordance with our National Mental Health Advisory Council report on Basic Behavioral Science, we have launched an effort that will bring to bear the benefits of behavioral science on critical public health issues including prevention of mental disorders. AIDS is an urgent area in which NIMH-sponsored behavioral science research already has had a salutary effect. Behavioral research has much to offer in efforts to enhance treatment adherence and compliance and in the development of new psychotherapies, which we need particularly to tailor to children and older people, which is especially important given the value of psychotherapy as a complement to pharmacotherapy in many serious mental illnesses.

Formidable gaps in our knowledge remain, but we have increasingly powerful tools to close them and make progress in the interest of Americans with mental illness.

My colleagues and I will be pleased to respond to any questions you may have.

PREPARED STATEMENT OF ALAN I. LESHNER

Mr. Chairman and Members of the Committee: The President in his fiscal year 1999 budget has proposed that the National Institute on Drug Abuse receive $395.1 million, an increase of $35.3 million over the comparable 1998 appropriation. Including the estimated allocation for AIDS, total support provided for NIDA is $576.3

million an increase of $49.1 million over the fiscal year 1998 appropriation. Funds for NIDA efforts in AIDS research are included within the Office of AIDS Research budget request.

NIDA ACCOMPLISHMENTS

I am pleased to report that during these historic times for science, the National Institute on Drug Abuse (NIDA) has had another year of exceptional accomplishment, as NIDA-supported researchers made enormous strides toward improved understanding, prevention and treatment of one of our Nation's most serious public health problems—drug abuse and addiction.

We now know more about abused drugs and the brain than is known about almost any other aspect of brain function. New technologies and new knowledge have revolutionized our insight into the brain. I mean this in the most literal sense. Using functional magnetic resonance imaging (fMRI), we have moved beyond a single snapshot of a brain high on drugs to being able to actually look at the dynamic changes of the brain that occur as an individual takes a drug. We can observe the different brain changes that occur as a person experiences the "rush," the "high," and finally the craving of a commonly abused drug like cocaine.

We are also using imaging technology to explore what neurochemical changes are occurring during addiction. As shown in Figure 1, using Positron Emission Tomography (PET) technology we can now see what tobacco smoking is doing to the human brain. Here you can see in the brain of the smoker a tremendous decrease in the levels of an important enzyme known to be responsible for breaking down dopamine, called monoamine-oxidase-A (MAO-A). This decrease in MAO-A actually results in an increase in dopamine levels. This may be a reason that smokers continue to smoke—to sustain the high dopamine levels, which result in the sensation of pleasure.

At an even more refined level, NIDA-supported scientists have identified one of the critical brain proteins that mediates nicotine addiction. Scientists pinpointed the beta 2 subunit of the nicotinic cholinergic receptor as being essential to the process of nicotine addiction. Using bioengineering tools, these researchers produced a new strain of knockout mice which lack this important protein. In contrast to normal mice, mice without this receptor did not self administer nicotine, though they did take cocaine. This clearly demonstrates that the brain reward pathway thought to be common to all addictions remains intact, even though nicotine itself loses its pleasurable effect.

These findings support a convergence of data which show that nicotine, just like cocaine, heroin and marijuana, all work to elevate levels of the neurotransmitter dopamine in the brain pathways that control reward and pleasure. It is this change in dopamine that we have come to believe is a fundamental characteristic of all addictions.

AVERTING A METHAMPHETAMINE CRISIS

Dopamine activity is central to one of the country's most alarming emerging drug problems, methamphetamine abuse. The use of this highly addictive drug, once dominant primarily in the Southwest, is spreading rapidly across the country. As shown in Figure 2, just a decade ago methamphetamine was confined to relatively limited pockets of use in the West. It is now spreading through the mid-West and becoming an emergent new problem in previously "untouched" cities.

This is of particular concern because of recent research demonstrating the neurotoxic effects of the drug. In non-human primates exposed to methamphetamine doses that are routinely used in human abusers, scientists have found profound effects on both the brain's dopamine and serotonin neurotransmitter systems. These long-lasting neurochemical effects are thought to be partly responsible for the severe behavioral abnormalities that accompany prolonged use of this drug. To avert a potential methamphetamine crisis, we need to develop effective medications to treat the addiction, as well as new tools such as anti-methamphetamine antibodies to be used by emergency room physicians to treat the growing number of overdoses.

We are confident that we will be able to develop effective treatments for methamphetamine, just as we have for other serious drug addictions such as heroin and nicotine. We have effective addiction treatments in our clinical toolbox and countless others that are being tested, although admittedly not enough. We do already have methadone and LAAM (levo-alpha-acetyl-methadol) for opiate or heroin addiction, and will be seeking approval for both buprenorphine and buprenorphine combined with naloxone in 1998. For tobacco addiction, there are several nicotine-replacement therapies, such as the patch and gum, and several non-nicotine ones as well, such as bupropion (Zyban) that are readily available.

TREATING ADDICTIONS

We do not, yet, have a medication to treat cocaine addiction, which remains both a national need and a NIDA priority. But we do have encouraging news. We are about to launch our first ever large scale multi-center clinical trial for a cocaine medication. In designing this trial we are capitalizing on a body of current findings that suggest that medications consistently work better when they are used in combination with behavioral therapies. When we initiate the trial in the Fall we will add a standardized behavioral component to one of our most promising compounds, selegeline.

NIDA hopes to expand upon this trial by launching a National Drug Treatment Clinical Trial Network to ensure that all potential addiction treatments are tested in real life settings. Our science has matured to the point where we can take a more systematic approach to rapidly and efficiently test the effectiveness of behavioral, psychosocial and pharmacological treatments in large-scale, multi-site clinical trials.

Although it can be done, addiction is not a simple disease to treat. Addiction is a chronic relapsing disease that results from the prolonged effects of drugs on the brain. It can affect every aspect of a person's life. This is why an individual's treatment program must address not only the individual's drug use, but also help restore their abilities to function successfully in society. The most effective treatment approaches must attend to all of addiction's biological and behavioral components.

It is these kinds of research-based concepts and approaches that are most needed by the frontline clinicians who are facing the day-to-day realities of treating their patient's drug addictions. We know that we cannot just disseminate research findings through journal articles in the hopes that a busy treatment provider will have time to read, analyze and implement a particular finding. That is why we translate these findings in a way that is both useful and used by treatment providers at every level. Toward this end, NIDA is sponsoring a National Conference on Drug Addiction Treatment next month. At this conference, NIDA will release the first two in a series of treatment manuals developed to help drug treatment practitioners provide the best possible care that science has to offer. The manuals take scientifically-supported therapies for addiction and offer detailed guidance on how to implement them in real-life practice settings.

REPLACING IDEOLOGY WITH SCIENCE

Undertakings like these exemplify our commitment to sharing research findings with the broadest community possible. An example of the positive impact that our research findings can have on society is seen in the recent efforts by many of our criminal justice colleagues to provide treatment to prison populations. NIDA-funded scientists have demonstrated that comprehensive treatment of drug-addicted prison inmates, when coupled with treatment after release from prison, reduces by 70 percent the probability of their being rearrested and the likelihood they will return to drug use.

Other important societal issues were addressed through a number of major conferences that NIDA supported such as our National Heroin Conference, and NIH's Consensus Development Conference on Effective Treatment of Heroin Addiction. Additionally, we are continuing to take our science to the true beneficiaries of our research endeavors—the American public. We joined with local partners across the country to sponsor a series of Town Meetings. Our April Town Meeting with the citizens of Boston will coincide with the March 29th premier of an outstanding five part series on addiction that Bill Moyers and his staff at National Public Television have produced. NIDA has provided substantial technical assistance in the development of this series and its accompanying educational materials.

We at NIDA want to replace ideology about drug abuse and addiction with science. We also want to provide the public with the necessary tools to play an active role in preventing drug use in their own local communities. Last year I showed you what has now become one of our most popular publications—"Preventing Drug Use Among Children and Adolescents". This user-friendly guide of principles summarizes knowledge gleaned from over 20 years of prevention research. Over 150,000 copies have been circulated to communities throughout the country as they evaluate existing prevention programs and develop new ones.

PREVENTING DRUG USE AMONG CHILDREN AND ADOLESCENTS

Understanding what makes a person more susceptible to a potential drug problem, and progression from first drug exposure to developing addiction, will enable us to much more effectively target our prevention efforts. Just as important, however, is the identification of protective factors, those behaviors, environments and

activities, that seem to enable many people to avoid drug use altogether, or get right back on track if they falter or relapse during treatment.

We are also supporting research that focuses on the special needs of older children and adolescents who have been placed in juvenile court detention programs, dropped out of school, or have become homeless. It is particularly important that we find effective prevention and treatment approaches for these special populations in light of a 1998 study which found that 13–19 year-olds who have both conduct and drug abuse problems, already are meeting standard adult criteria for marijuana dependence.

We are also continuing to study the effects of prenatal drug exposure. We are finding that some, though not all, of the cohorts of crack-exposed babies now entering elementary and middle school may be significantly, although perhaps subtly, affected. Because these effects can be subtle and expressed only as children develop, long-term follow-up is needed. Longitudinal studies will also enable us to examine whether prenatally drug-exposed children are more vulnerable, or at increased risk for drug abuse in childhood and adolescence.

GENETICS OF DRUG ADDICTION

Determining who is at most risk for addiction will be a critical research area addressed through NIDA's new Genetics of Addiction Initiative. A culmination of NIDA-supported family and twin studies, coupled with neurobiological and molecular breakthroughs, has provided us with the confidence to more aggressively explore the role of genetics in drug addiction. NIDA's multi-faceted approach in this endeavor will include the use of genome-wide scans, linkage and association studies in humans, and the continuation of animal studies to test and confirm the role of new candidate genes.

GOVERNMENT PERFORMANCE AND RESULTS ACT [GPRA]

NIDA's activities are covered within the NIH-wide Annual Performance Plan required under GPRA. The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congressional feedback on the usefulness of its Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

UNDERSTANDING THE COMPLEXITY OF ADDICTION

All of these exciting research efforts are moving us closer to truly understanding the complexity of addiction. It is only through a multi-disciplinary approach will we be able to unravel the remaining mysteries of addiction. NIDA will continue to use the most sophisticated research equipment and techniques, and seize all scientific opportunities that present themselves to ensure that no more lives are lost to what is ultimately both a preventable and, if not prevented, a treatable disease. I will be happy to answer any questions you may have.

PREPARED STATEMENT OF ENOCH GORDIS

Mr. Chairman and Members of the Committee: The fiscal year 1999 President's budget request for the NIAAA is $230,243,000, an increase of $17.5 million over the fiscal year 1998 appropriation. Including the estimated allocation for AIDS, total support proposed for NIAAA is $245,730,000, an increase of $18.6 million over the fiscal year 1998 appropriation. Funds for NIAAA AIDS research are included in the Office of AIDS research budget request.

PROBLEM OF ALCOHOLISM

Alcoholism is one of our country's most serious and persistent health problems. Approximately two-thirds of all American adults (ages 18 and older) drink an alcoholic beverage during the course of a year[1]. At least 13.8 million American adults

[1] Midanik LT, Room Robin. The Epidemiology of Alcohol Consumption. Alcohol Health & Research World 1992, 16:3:183–190.

develop problems from drinking.[2] Our young people, for whom alcohol remains the number one drug of abuse, also are at risk for developing alcohol-related problems. Recently published data from NIAAA's National Longitudinal Alcohol Epidemiologic Survey, which assesses lifetime risk for alcohol use disorders (alcohol abuse and alcohol dependence), provides convincing evidence that the younger the age of drinking onset, the greater the chance that an individual at some point in his or her life will develop a clinically diagnosable alcohol use disorder. As shown on Chart 1, young people who began drinking before age 15 are four times more likely to develop alcohol dependence during their lifetime than those who began drinking at age 21.

The health problems caused by alcohol use include damage to the brain, liver, gastrointestinal tract, and heart. The relative risk for many alcohol-related illnesses rises along with the quantity of alcohol consumed daily[3]. Other consequences of alcohol use include crashes and other injuries, domestic violence, neglect of work and family, and costs to society associated with police, courts, jails, and unemployment. Altogether, the consequences of alcohol abuse and dependence are estimated to cost the nation $100 billion[4] and 100,000 deaths a year[5].

PROMISE OF RESEARCH

NIAAA's research is guided by one fundamental purpose-to develop the necessary knowledge to effectively prevent and treat alcohol abuse and alcoholism and their related consequences. Through its nurturing of the Nation's alcohol research agenda, NIAAA makes an implicit promise-that science will yield practical applications that will help those who suffer as a result of alcohol abuse and alcoholism. In support of this mission, NIAAA conducts and supports a broad-based program of biomedical and behavioral research in areas such as the epidemiology of alcohol use, abuse, and dependence; alcohol's effects on the brain; the genetics of alcoholism, alcohol toxicology; the benefits to health of moderate drinking; the effects of public policies on preventing alcohol use disorders, and clinical trials to develop or evaluate alcoholism treatment therapies.

The activities of the NIAAA are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

PATHWAY FROM RESEARCH TO APPLICATION

While the promise of research is that science will yield practical applications, some areas of investigation will require a longer time to fulfill the promise than others. For example, the knowledge gained from clinical trials is almost immediately available for application to alcoholism treatment programs whereas complex basic studies investigating alcohol's effects on the brain and the relationship of these effects to behavior, will take longer to develop information that can be used to design new medications. Chart 2 shows the relative time frames in which various areas of research may be expected to yield practical applications and will serve as the basis for my further remarks.

Clinical Trials

NIAAA-supports clinical trials designed to develop new and evaluate existing treatments. Such trials led to the Food and Drug Administration's approval of the medication naltrexone as an adjunct to traditional treatment. A product of neuroscience research, naltrexone is the first medication since 1949 to be approved to help

---

[2] Grant BF, Harford TC, Dawson DA, Chou P, Dufour M, Pickering RS. Prevalence of DSM-IV Alcohol Abuse and Dependence—United States, 1992 Alcohol, Health & Research World 1991, 183:243–248.

[3] Boffeta P, Garfinkel L. Alcohol Drinking and Mortality among Men Enrolled in an American Cancer Society Prospective Study. Epidemiology 1990, 1:5:342–348.

[4] Rice DP. Ninth Special Report to the U.S. Congress on Alcohol and Health. DHHS, PHS, 1997 pg 388.

[5] National Institute on Alcohol Abuse and Alcoholism. Eighth Special Report to the U.S. Congress on Alcohol and Health. NIH Pub. No. 94–3699. Bethesda, MD: National Institutes of Health, 1993.

maintain sobriety after detoxification from alcohol. NIAAA currently is conducting clinical trials to determine which groups of patients are most responsive to naltrexone and the benefits and side effects of long-term use. Based on evidence that naltrexone, used in combination with verbal therapy, can prevent relapse more than standard verbal therapy alone, NIAAA is supporting clinical trials to evaluate the effectiveness of combined behavioral/naltrexone therapy to substantially reduce the current 50 percent relapse rate among those treated for alcoholism.

Two potential medications on the horizon are acamprosate and amperozide. Acamprosate has been clinically tested and used successfully for relapse prevention in Europe. After extensive consultations with the NIAAA, the pharmaceutical industry has launched clinical trials of acamprosate in the U.S. Because of its hypothesized mode of action, Amperozide, which has been shown to successfully reduce alcohol consumption by primates, is expected to be effective in treating human alcoholism. NIAAA also plans to test amperozide in collaboration with the Veterans Administration.

Two recent clinical studies demonstrate that it may be possible to intervene inexpensively with heavy drinkers before they progress to alcoholism. In the first randomized trial of this kind, investigators provided direct evidence that brief physician intervention with problem drinkers can decrease alcohol use and health resource utilization. These studies are important because detecting alcohol abuse at an early stage of development and prior to the onset of alcoholism has both practical and medical benefits.

Neuroscience

The complex mental processes that govern drinking behavior are carried out in the brain by many independent interactions among neural systems comprised of neurotransmitters and their receptors. Two main processes involved in drinking are being studied: positive reinforcement, or the pleasurable feedback an individual receives from alcohol use; and negative reinforcement, the discomfort associated with being deprived of alcohol. In positive reinforcement, alcohol appears to interact with the brain's "pleasure" or reward system to stimulate continued use. Negative reinforcement, which appears to involve separate neural systems, may result from the brain's chronic exposure to alcohol. Such exposure causes the brain's cells, or neurons, to adapt to the presence of alcohol and to "miss it when it is not present." Clarification of these processes will enable scientists to develop specifically designed medications tailored to individual physiology. The study of the mechanisms of action of the two medications currently used to prevent relapse—naltrexone and acamprosate—is informing this effort. These two drugs appear to work through different mechanisms to achieve the same effect; naltrexone by blocking positive reinforcement and acamprosate by acting on negative reinforcement.

Alcohol scientists are using advanced neuroscience techniques (e.g., patch clamping, imaging, electrophysiology, neurochemistry, and cognitive neuroscience) to understand the fundamental phenomena associated with alcoholism, i.e., physical dependence, tolerance, impaired control over drinking, and the craving for alcohol. However, investigating the specific effects of alcohol is challenging; alcohol interacts with and alters the activities of many different brain cell components and, consequently, may have diverse and profound effects on nerve cell function. For example, alcohol can affect various neuroreceptors causing the neuron to react by increasing or decreasing its usual functions. These receptors are divided into subunits. The different ways in which subunits combine affects the brain's sensitivity to alcohol, and quite possibly, the sensitivity to alcohol among different individuals. How an individual's pattern of subunits affects his or her initial sensitivity to alcohol and how alcohol influences the way in which subunits combine to affect sensitivity are both under study. Transgenic animals have been bred with different brain receptor compositions to determine which constitute those that are most vulnerable to alcohol. As we learn which subunit variations account for addiction, we will be able to develop new medications designed to interfere in the addictive process by acting on specific brain chemicals.

New Approaches to Medications Development

Medications have been traditionally developed either by lucky accident, or by finding new uses for established medicines. We are now moving into a new era in which our understanding of the shape and structure of important molecules in the body is dramatically improved with techniques such as crystallography and nuclear magnetic imaging. With the help of computers and powerful methods of combinatorial chemistry to create hundreds of new potential compounds rapidly, it will become increasingly possible to design new medications specifically to fit known biological structures and alter their function. The crystal structure of the alcohol metabolizing

enzyme, aldehyde dehydrogenase seen in Chart 3, was reported by NIAAA grantees this year. It is a fine example of how new insight into structure explains function, and is a prototype of what future medication development will exploit.

Genetics

There is ample evidence that a significant portion of the susceptibility to alcoholism is inherited. Genetics researchers are now actively engaged in identifying the genes that confer this vulnerability and developing ways to apply this information to clinical populations. The task is difficult because alcoholism is likely to be polygenic, with each gene contributing only a portion of the vulnerability. The search for the relevant genes is now actively pursued in several settings.

Through the Cooperative Study on the Genetics of Alcoholism (COGA), a multisite study at six centers, hundreds of probands and families have been interviewed, a complex computerized pedigree database has been incorporated, and statistical genetics and molecular biology techniques are being applied to "informative" families. Phenotypic markers shown previously to be relevant to alcohol are incorporated in the study, including biochemical markers, evoked potential responses, and tests of initial sensitivity to alcohol (the latter being a strong predictor of later alcoholism). COGA scientists have recently located chromosomal "hot spots," areas of potential linkage of alcohol dependence, on chromosomes 1, 7, 8, and 16. Also, the possibility of protective factors is suggested by possible linkage on chromosomes 4 for resilience to alcoholism. In addition, locations for the genes involved in the expression of evoked potential responses, a high-risk marker for alcoholism, have been tentatively identified. Because replication of genetic findings in independent populations is essential for their verification, NIAAA has funded two new genetic linkage studies. Although smaller in scale than COGA, the relative genetic, cultural, and phenotypic homogeneity of these studies' subject samples should enhance their likelihood of success.

Once we know which proteins are coded by the genes for alcoholism, alcohol researchers will be able to study the effect of various combinations of neurochemicals on these proteins and design medications that are targeted specifically to interrupt those processes which result in the development of alcoholism.

WHERE ARE WE GOING?

Research has diversified and consolidated our knowledge of alcohol problems. We will continue this progress into the new millennium by focusing on research to determine which aspects of the vulnerability to alcoholism are inherited; how genetic and non-genetic factors interact in the development of alcoholism; how biology and behavior interact in the development of alcohol use disorders; and by developing and testing new prevention and treatment and methods to reduce the risk for alcoholism, improve the chance for recovery and reduce the risk of relapse. NIAAA also will continue to pursue research aimed at preventing fetal alcohol syndrome, reducing drunk driving; understanding the effects of alcohol advertising on our nation's youth; improving adolescent alcohol treatment, and clarifying the health effects of moderate drinking.

My colleagues and I will be happy to respond to any questions you may have.

PREPARED STATEMENT OF PATRICIA A. GRADY

Mr. Chairman and Members of the Committee: The President in his fiscal year 1999 budget has proposed that the National Institute of Nursing Research (NINR) receive $62.4 million, an increase of $4.3 million over the non-AIDS portion of the fiscal year 1998 appropriation. Including the estimated allocation for AIDS in both years, total support proposed for NINR is $68.3 million an increase of $4.7 million over the fiscal year 1998 appropriation. Funds for NINR efforts in AIDS research are included within the Office of AIDS Research budget request.

Nursing researchers are at the frontiers of science, building the foundation of knowledge for the nation's 2.5 million registered nurses, the largest health profession in our Nation, and for other providers of health care. Our research is not disease specific, nor is it dedicated to a particular age group or population. What nursing research does is ask questions that probe the very core of patients' and families' personal encounters with illness or its avoidance, perhaps to a more immediate, intense extent than other disciplines of science. We ask, for example, whether men and women respond differently to drugs used for pain relief. What kinds of information will help people reach a decision about genetic testing? What can be done to ease the symptoms of terminal illness and to help patients maintain their quality of life, dignity, and sense of control at the end of life? We are the front-line integra-

tors of the science and insights that come from the multidisciplinary teams engaged in clinical and basic medical research. In recognition of this approach, we say nurses bring "Life to Research and Research to Life." In other words, nurses bring patient issues to nursing researchers for study, and nursing researchers return important information and answers that are directly applicable to people's lives and health care.

NURSING RESEARCH MAKES A DIFFERENCE

Let me give you some vivid examples of how nursing research makes a difference:

—NINR funded a Spanish Arthritis Self-Management Program that is now being used by the California chapter of the National Arthritis Foundation. The National Arthritis Foundation plans to expand this program nationwide, and they have provided funds to adapt the materials for Chinese patients with arthritis. The investigator is developing similar programs in Spanish for other disorders, such as heart and lung diseases, and is working with a major national HMO to implement these programs.

—Research funded by the Institute has shown, for the first time, that gender makes a difference in pain relief and that a painkiller that had little, or even no, effect on men provides women greater relief, with fewer side effects. This finding has launched a new awareness of the influence of gender on pain and its alleviation and has important implications for future drug development and therapy.

—Nurse researchers have developed an assessment scale that can actually predict within several days upon admission which nursing home patients are likely to develop pressure ulcers, a condition that is painful and dangerous. This important finding enables nursing home staff to take early preventive action. The assessment technique has been incorporated into the "Guidelines on Pressure Ulcers," published by the Agency for Health Care Policy and Research, which informs clinical practice.

—Nursing research has developed a model for early hospital discharge that is successful in reducing the costs of Cesarean deliveries, hysterectomies, and the complications of diabetes in pregnant women. Even more importantly, patient satisfaction with the quality of care has increased and rehospitalizations have been reduced. The investigator is consulting with several HMO's to facilitate adoption of this model into their operations.

Mr. Chairman, last October this subcommittee held a hearing on child health issues and asked a key question—What can be done to promote healthy lifestyles during childhood and the turbulent adolescent years that will continue throughout adulthood? Nursing investigators have found some important answers to this question as a result of their research. Let me cite an example that is particularly compelling—the Cardiovascular Health in Children (CHIC) project, first funded in 1990. Initial findings showed that an educational intervention conducted in 21 rural and urban elementary schools in North Carolina significantly reduced risk factors for cardiovascular disease in preadolescents. The issue then became how healthy habits learned through the intervention are sustained. To find out, the researchers are conducting a follow-up of these students for four additional years. The investigators are also testing the intervention in 6th through 8th graders to determine whether interventions at the elementary school or middle school levels are more effective. A key component of this study is the strong representation of minority students in the project—20 percent are African American. The investigators are now in discussion with the North Carolina school system to introduce the program more broadly. Since North Carolina lies in the middle of the Nation's heart disease and stroke belt, the impact of this program can be significant. The principal investigator is also working with her counterparts in Japan and France to compare cholesterol, obesity, and physical activity in children. Parts of her intervention will soon be replicated in elementary schools in the Kagamahari province of Japan, a rural area three hours from the city of Kyoto.

A FOCUS ON END-OF-LIFE RESEARCH

Let me highlight a particularly important area of research for the Institute that touches all of us—end of life. In 1997, NINR was designated by Dr. Varmus as the lead NIH Institute for palliative care research. NINR is the logical lead on this because of our broad span of research that encompasses people at all ages, from all populations, and who die from many different causes. The need for research in this area is clear. Advances in biomedical and behavioral research have greatly improved the length and quality of our lives. But what about the end phase of life? In this case, research and care issues associated with the inevitable experience of dying

have not kept pace. Everyone wants a "good death." Although our personal definitions of what this means may differ, the ultimate goal must be to make the transition from life to death as comfortable as possible, with reduced distress to the patient and families, leading to death with dignity.

Health care professionals are trained to cure disease and to save lives, but at life's final phase, the issue becomes one of managing symptoms effectively. This is a specialty area of nurses and of particular interest to nurse researchers. Last September we cosponsored a scientific workshop on treating the symptoms in terminal illness and issued a program announcement in collaboration with NCI, NIAID, NIMH and OAM to stimulate further research in palliative care to ease pain, difficulty with breathing, delirium, weakness, nausea, fatigue, and depression. We also seek studies of ethical concerns—for example, controversies connected with honoring the dying person's wishes—and how to help patients and their families make decisions. We look forward to this challenge and to working with our NIH colleagues. We also look forward to reporting back to you next year about progress on this important health and social concern.

RECENT ADVANCES IN NURSING RESEARCH

Let me now turn to three recent research advances that promise to affect the way health care is provided. Telehealth technology extends nursing resources to remote areas and right into individual homes. We can save lives by increasing early detection of disease or disease complications; and we can reduce costs by decreasing visits to the doctor's office. A case in point is a home monitoring project involving lung transplant patients. We already know that most rejection occurs in the first year after a transplant. Early detection therefore becomes key to survival, and patients can play an active role. By using an electronic diary and spirometer monitoring device, patients at home can record measurements of pulmonary function, vital signs, and symptoms, which are then transmitted once a week to a data center for review by health care professionals. The frequency and accuracy of these reports enable immediate intervention to prevent organ failure. Our findings indicate that patient adherence is at 82 percent. This project currently monitors more than 100 lung transplant patients. The potential of the spirometer-monitoring device for other pulmonary conditions appears promising.

Another advance is in the area of pain. Nurse researchers have long been active in this area. A new discovery challenges current practice and has important implications for surgical patients. Typically benzodiazepines, such as Valium, are used to sedate patients just prior to surgery. Our investigators have found, however, that Valium blocks the effectiveness of the morphine that patients receive later on to reduce pain during or after surgery. By combining a benzodiazepine antidote, in this case flumazenil, with morphine after surgery to counteract the effects of the earlier-administered Valium, patients experience greater pain relief without adverse side effects. This study adds important information to the increasing body of knowledge about the mix and timing of pain medications.

Another finding has implications for expanding the usefulness and accuracy of electrocardiograms (ECG's). Traditionally, a 10-electrode ECG attached to various points on the body is used to detect heart abnormalities, but the device is cumbersome, particularly if continuous monitoring is required. Investigators tested a device with only 5 electrodes to determine if it was as effective as the 10-electrode device. Results showed that in patients undergoing coronary angioplasty, both devices detected the presence or absence of ischemia—a deficiency of blood supply to the heart—in 150 of 151 patients. The 5-lead device also showed the location of the ischemia in the heart muscle in 148 out of 151 patients. The convenience and accuracy of the 5-electrode model has potential uses in a variety of settings, and it promises much improved flexibility of use. Examples are when the patient must be monitored continuously and needs mobility, or when an ambulance needs the capability to transmit ECG information continuously to the hospital before the patient arrives.

AREAS OF OPPORTUNITY FOR RESEARCH EMPHASES

A prominent characteristic of nursing research is its interdisciplinary perspective that is free of the boundaries of a particular disease, age group or technology. Collaborative efforts within NIH are an essential part of NINR activities, and our planned research directions for fiscal year 1999 reflect this emphasis. Let me describe briefly six of these areas that appear especially promising:

—Stroke is the number one cause of adult disability. Its symptoms can be discouraging for the patient and difficult to manage for health care providers and family caregivers. NINR will solicit research to identify and test nonpharmacological approaches to the management of stroke, including helping stroke pa-

tients learn to care for themselves and helping family members strengthen their own caregiving skills.

—We often take breathing for granted until disease, surgery, or other events interfere to make us uncomfortably, sometimes fearfully, aware of our need for the next breath. Mechanical ventilation provides relief, but the downside is the dangerous risk of inflammation, infection, and dependence on the machine. NINR plans a program announcement for multidisciplinary studies to address long-term ventilation issues, including quality of life, and ethical and cost considerations.

—As discussed in the subcommittee's hearings last November on the role of the mind in healing and health, the relationship between behavior and the immune system, known as neuroimmunomodulation, is an important but nebulous area in need of clarifying research. NINR will solicit proposals to examine the impact of behavioral interventions on physical status and how altered immune function affects people's psychological state and willingness to change behaviors.

—Although the U.S. infant mortality rate has decreased, the rate of low birthweight, typically premature births, has slowly increased. These babies are at risk for a multitude of physical and psychological problems, and account for a significant proportion of the annual health care expenditures for children. The National Center for Health Care Statistics reports that African Americans are over two times more likely to have poor pregnancy outcomes than whites, yet studies show economic and social conditions are not the cause. The challenge then becomes one of understanding the reasons for ethnic variations. An NINR initiative will focus on these and other issues that can inform prevention strategies for low birthweight in populations at risk. Since many health problems of adulthood have their roots in unhealthy behaviors in childhood and adolescence, the NINR plans to expand its prevention research in this area. Interventions at a younger age appear particularly critical. NINR will issue a program announcement to stimulate research that will reduce or prevent risky behaviors in young people, such as smoking, drug and alcohol abuse, and poor eating habits.

—Resurgence and emergence of infectious diseases and bacterial resistance to antibiotics is a worldwide issue. In addition to increased surveillance, new antibiotics and research into the immune system, NINR will encourage research to understand better the effects of behavioral influences on adherence to medical treatment, diet, personal hygiene, and sexual behavior.

In conclusion, I would like to stress that as we arrive at the 21st century, it is clear that health research, health care, and health choices are increasingly interdependent, and that nursing research will play a vital role in all three areas. A prominent private sector health care official, has said that the next decade will be the decade of the nurse. I agree. Scientifically validated methodologies, communication strategies, and effective interventions—coupled with a basic understanding of human nature and our Nation's diverse populations, will make a positive difference to the health and quality of life of the American people.

Mr. Chairman, I will be pleased to answer any questions you might have.

Prepared Statement of Francis S. Collins

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Human Genome Research Institute (NHGRI) for fiscal year 1999, a sum of $236,996,000, an increase of 10.4 percent over the fiscal year 1998 comparable appropriation. Including the estimated allocation for AIDS, total support proposed for NHGRI is $240,134,000. Funds for the NHGRI efforts in AIDS research are included in the Office of AIDS Research budget request.

GENE DISCOVERY

This is my fifth opportunity to appear before this Committee. As Director of NHGRI, I am proud of its leadership in the U.S. Human Genome Project and its cutting-edge research program on the genetic analysis of disease. Now at the halfway mark, progress in the 15-year Human Genome Project, its impact on health research and even public policy has surpassed the most ambitious expectations.

With Human Genome Project tools, it is possible to track down a disease-related gene even when nothing is known about the biochemical problems of the disease or how the gene works. This technique, based on identifying the position of a gene in the chromosome and then isolating it, was successfully used for the first time in 1986. Now, the increasing detail and quality of genome maps have reduced the time it takes to find a disease gene from years, to months, to weeks, to sometimes just

days, and scientists are using the tools to discover dozens of disease genes each year. Increasingly, gene hunters are combining positional cloning techniques with a new ''gene map'' to make gene finding even easier and quicker. Constructed largely by scientists at NHGRI-supported research centers and the National Library of Medicine, the map has doubled in its detail since the first version was released two years ago. It now contains 30,011 gene tags, which may represent nearly half of all human genes. Disease-gene hunters now have about a 50 percent chance they will find an already characterized gene waiting for them in the chromosomal neighborhood they know is involved in a disease.

The isolation of a gene for Parkinson's disease (PD) last year demonstrated the power of this new discovery method and showed conclusively that changes in DNA can cause PD in some families. Only two years ago, the National Institute of Neurological Disorders and Stroke held a workshop to explore using genetic approaches to understand PD. A team led by scientists in NHGRI's Division of Intramural Research (DIR) began large-scale genetic analysis of DNA from members of a large Italian family containing almost 600 people, more than 60 of whom have been diagnosed with Parkinson's. In nine days, NHGRI gene hunters mapped the gene to a region of chromosome 4, which contained approximately 100 genes. One of the genes in that interval had already been identified on the gene map and was known to encode a protein called alpha-synuclein. That gene was an excellent candidate for a Parkinson's disease gene because earlier research had already shown the protein builds up in brain cells of people with Alzheimer's disease, and people with PD have similar deposits. In just a few months, the researchers showed conclusively that an altered alpha-synuclein gene caused Parkinson's in the study families. Many have hailed this as the most significant advance in Parkinson's disease research in 30 years. Just ten days ago, a German research team used genome mapping tools to identify a new region on chromosome 2 that also appears to contain a gene that predisposes to Parkinson's. Some of the genes already known to exist in that region are providing excellent candidates for identification of the actual gene.

At NHGRI, intramural scientists and their colleagues have made tremendous progress this year in identifying the genetic components of some common cancers. These include identification of an altered gene that can cause multiple benign endocrine tumors and a type of pancreatic cancer—a syndrome called multiple endocrine neoplasia type 1 (MEN1), and a gene, called AIB1, linked to the growth and progression of breast cancer. DIR scientists and their collaborators this past year isolated a gene underlying the neurological disorder Niemann-Pick Type C (NPC), and other genes involved in rare diseases that shed light on normal cell function. A newly discovered gene called JAG1, for example, was shown to cause the rare childhood disease Alagille syndrome. JAG1 has already been studied in the fruit fly and may help explain how incorrect cell signals during development can result in a wide range of birth defects.

HUMAN GENOME PROJECT PROGRESS

The ultimate goal of the international Human Genome Project is to spell out, letter by letter, all 3 billion bases in the human genome by the year 2005. Since the start of the Human Genome Project, scientists have been experimenting with whole-genome sequencing methods on smaller, less complex micro-organisms. This past year, for example, NHGRI-supported scientists at the University of Wisconsin-Madison published the full DNA sequence of the bacterium E. coli—probably the most studied simple organism in all of science and the foundation of the biotechnology industry. Researchers now have access to the organism's genetics in their entirety—all 4,403 genes nestled among 4,639,221 base pairs of DNA, which gives them a powerful new tool to observe complete cellular systems, including metabolism, the regulation of gene activity, substance transport, and cell division.

NHGRI began pilot projects in 1996 to test strategies and technologies for full-scale sequencing of the human genome, which contains about 1,000 times more DNA than E. coli does. Already, investigators have deposited almost 40 million bases of high-quality human DNA sequence in GenBank. NHGRI grantees expect to produce 60 percent or more of the total human DNA sequence (1.8 billion base pairs), with the remainder to be contributed by other Human Genome Project partners in the United States and abroad. To complete its portion, NHGRI recently announced a $70 million initiative to establish a coordinated network of laboratories. Those laboratories are expected to produce an average of 300–500 million bases of finished, accurate human sequence per year by 2003. The sequence produced must have four characteristics—the ''4 A's'' of the Human Genome Project—(1) the sequence must be accurate, that is, the DNA spellings must be correct. The sequencing network will include quality assurance labs to ensure accuracy of 99.99 percent

or better. (2) Large-scale sequencing relies on the accurate assembly of smaller lengths of sequenced DNA into longer, genomic-scale pieces, so DNA coming from the NHGRI network will be assembled into long pieces that reflect the original genomic DNA. (3) Because human DNA sequence must also be affordable, a portion of the network will focus on technology development to reduce cost as must as possible. (4) Finally, high-quality, finished human DNA sequence should be available to the entire research community, so NHGRI has introduced policies to make sequence from the network accessible within 24 hours through public databases.

The Human Genome Project is unique among most biological research efforts in its establishment of specific, goal-oriented research plans. The current plan expires in October, 1998, so NHGRI is in the midst of establishing a research plan to cover the next five years. The new plan will include working toward completing the first full human DNA sequence, developing faster sequencing technologies for the future, studying sequence variation and its relationship to disease, identifying and analyzing the function of genes in the human genome, and continued studies of the ethical, legal, and social implications (ELSI) of new genetic technologies.

COMPLEX DISEASES

Straightforward rules of inheritance govern disease traits resulting from changes in a single gene, and it is now easier and faster than ever to track down and isolate such disease genes. But the inheritance of most common disorders—diabetes, heart disease, and most common cancers, which result from the interplay of environment, lifestyle, and small effects of many genes—is much more complex and requires even more powerful tools.

NHGRI has just launched a new initiative to help speed the breakthroughs in complex disease research—a major new goal for the Human Genome Project. Most complex diseases result from the combined effects of several relatively weak genetic contributions, and finding disease genes that have such weak effects has been painstakingly difficult. The search for such genes would be aided enormously by a thorough cataloging of the different versions of a whole list of genetic sites that occur in the human population. With such a catalog, scientists could begin to define which genetic differences are associated with a propensity for a specific disease and could help explain why, although we all carry the same genes, some individuals, families, and even ethnic groups appear to be more likely than others to develop certain diseases. To facilitate these studies, NHGRI is leading an NIH-wide effort along with 17 other Institutes to develop a very high-density map of slight-but-telling differences in the DNA code called "snips" (for single nucleotide polymorphisms or SNP's).

Another NHGRI initiative is contributing to the analysis of complex disease. The Center for Inherited Disease Research (CIDR), located on the Bayview campus of Johns Hopkins University, provides high-throughput genotyping services, study design advice, and sophisticated database assistance to research teams attempting to identify genetic locations and variations involved in complex diseases. A joint effort by eight NIH institutes, with the NHGRI serving as the lead, CIDR has just completed its first genotyping project for genomic changes associated with manic-depressive disorder. A second project, a study of deafness, has begun.

NHGRI is also involved in whole-genome studies to identify mutations that lead to adult onset diabetes mellitus and prostate cancer to understand and help remedy the disproportionately high rates of those diseases among African-Americans. These studies are supported by the NIH Office of Research on Minority Health and organized by an NHGRI-Howard University collaborative center for studying diseases that disproportionately affect minority individuals.

TECHNOLOGY DEVELOPMENT

Studies of genetic variation in large populations, complex diseases, and the simultaneous activity of multiple genes will rely on development of new technologies for large-scale genomic analysis. Such studies are already successfully using the marriage of semiconductors and DNA in so-called DNA chips. One version, which originated from an NHGRI grant to a scientist at a small California company, was recently featured on the cover of Fortune Magazine and in this year's State of Union address. That chip consists of a thin slice of silicon about the size of a postage stamp upon which threads of DNA, whose spellings are already known, are arrayed. Such DNA chips can be used for a broad range of studies, including identifying DNA changes that lead to disease. This would be particularly useful, along with family histories and data from large population studies, for establishing an individual's risk of developing common but hard-to-treat disorders like cancer, heart disease, diabetes, or psychiatric disorders, where multiple genetic alterations contribute, but

each on a small scale. A baseline genome scan could give patients and health care providers helpful information about an individual's disease risk profile and point to which prevention strategies—when available—should be put into place. Eventually, the chips may even be used to identify which patients are genetically most likely to respond to specific therapies. Diseases may be subclassified by their underlying genetic configuration rather than by physical symptoms. Administering drugs targeted only to that particular genetic subtype could maximize efficiency, minimize side effects, and reduce treatment time wasted on ineffective therapies. The pharmaceutical industry is eagerly awaiting advances in DNA chip technology, and a catalog of human DNA variations, to incorporate into their research and development programs for improved treatment strategies.

ETHICAL, LEGAL, AND SOCIAL IMPLICATIONS [ELSI]

These dramatic new abilities to read large amounts of genetic information have important implications for the privacy and fair use of that information. The Human Genome Project is unique among research programs in its commitment to address the ethical, legal, and social implications of its technologies side-by-side with the scientific agenda. NHGRI's ELSI research and policy development programs have spearheaded policy movement on a number of complex issues by supporting rigorous scholarly research and through development of options for state and federal policy makers.

One of the most active ELSI areas has been policy development related to the privacy and fair use of genetic information, particularly in health insurance, employment, and medical research. This past year, President Clinton announced his support for a comprehensive legislative solution to the problem of genetic discrimination in health insurance, based on recommendations the ELSI Working Group and the National Action Plan on Breast Cancer (NAPBC) developed in a workshop three years ago. Protection gaps in The Health Insurance Portability and Accountability Act, which took a significant step toward preventing genetic discrimination in health insurance, can now be closed by legislation that would expand those protections to the individual insurance market. In January, Vice President Gore announced Administration support for federal legislation to prohibit genetic discrimination in the workplace. Again, the Administration's recommendations are based on the recommendations of the NAPBC-ELSI Working Group, which held a workshop two years ago to address the use of genetic information in employer-provided insurance, in discrimination in hiring and promotions, and privacy of that information. NHGRI staff worked closely with staff from the Office of the Secretary of Health and Human Services, the Department of Labor, and the Department of Justice to present these options to the White House. NHGRI and NAPBC recently met for a third time to address problems related to protecting the privacy of genetic information in the medical record. Workshop participants identified areas where new or modified policies or practices might enhance privacy protections without discouraging crucial areas of research. The group is developing a set of principles for researchers, research institutions, state and federal agencies, and policy makers to consider in formulating privacy protections for research information.

Other significant steps have been taken to ensure the responsible integration of genetic tests into clinical practice. The Task Force on Genetic Testing recently concluded its two-year analysis of genetic testing in the United States and published a report that contains recommendations for federal agencies, testing laboratories, and health professionals. The Cancer Genetics Studies Consortium, supported by NHGRI and several other NIH Institutes, has published in medical journals their recommendations for follow-up care of individuals with specific cancer-causing gene mutations. Another product from the group describes informed consent for genetic testing for susceptibility to adult-onset cancer.

Recognizing the rapid pace of human genetics research and its impact on an increasing number of medical disciplines, the American Medical Association and the American Nurses Association, in collaboration with NHGRI staff, founded the National Coalition for Health Professional Education in Genetics. The Coalition's mission is to ensure that our nation's health care providers have the knowledge, skills and resources to integrate responsibly new genetic knowledge into health care. Approximately 100 organizations representing health care professionals, consumer groups, industry, genetics professional organizations, and government agencies participated in the Coalition's first meeting this past year. The new National Foundation for Biomedical Research, a government-created foundation "dedicated to creating public-private partnerships to promote the mission of the National Institutes of Health," is considering serving as the Coalition's administrative manager.

As the Human Genome Project approaches the half-way mark, the contributions it has made to understanding human diseases have been gratifying and remarkable. In the years ahead, the full DNA sequence of the human will give us unprecedented opportunities to observe and understand the literal thread of life. There is now no question that genome maps, sequence, and analytical tools will provide a robust technological infrastructure for biomedical research well into the next century.

The activities of the NHGRI are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan. My colleagues and I will be happy to respond to any questions you may have.

PREPARED STATEMENT OF JUDITH L. VAITUKAITIS

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget for the National Center for Research Resources (NCRR) for fiscal year 1999, a sum of $423 million, an increase of $51.5 million (or 13.9 percent) above the comparable fiscal year 1998 non-AIDS appropriation. Including the estimated allocation for AIDS in both years, total support proposed for NCRR is $514.8 million, an increase of $60.9 million over the fiscal year 1998 appropriation.

It is a pleasure once again to have the opportunity to discuss the accomplishments and future directions of the NCRR, which fills a unique and indispensable niche in the family of NIH institutes and centers. Unlike the other components of NIH, which focus on particular biomedical disciplines, diseases, or organ systems, NCRR provides the essential tools and infrastructure that facilitate all lines of NIH-supported research, ranging from basic to clinical investigations. NCRR can best be described as a catalyst for discovery, for without advanced instrumentation, up-to-date research facilities with access to specialized expertise, and animal models for human diseases, the scientific enterprise would be slowed and more costly. Each year more than 15,000 investigators, supported by more than $1.8 billion from the NIH categorical institutes, utilize NCRR-supported research resource facilities as integral parts of their research. Shared instrumentation grants and repositories for both biomaterials and animal models are also invaluable resources to thousands of additional extramural investigators. Our fundamental objectives are to direct NCRR's support to maximize sharing of research resources and technologies, enhancing multidisciplinary research by fostering collaborations among investigators, and leveraging federal funds.

ADVANCED INSTRUMENTATION AND COMPUTERS

Advanced instrumentation and computers have a fundamental role in most biomedical studies, yet they also account for some of the largest expenses. To help reduce costs while providing access to the most sophisticated research tools, NCRR supports shared instruments and resources, including a network of more than 60 biomedical technology resource centers that develop and provide access to critical technologies for health research, ranging from those for degenerative brain disorders, cancer, cardiovascular diseases to AIDS.

Shared resources are essential tools in efforts to unravel the complexities of the human genome as well as to define the genetic defects that lead to diseases such as sickle cell anemia, cystic fibrosis and a variety of cancers. This enormous undertaking requires an array of sophisticated and costly instruments such as sequencers, mass spectrometers, analytical ultracentrifuges, and nuclear magnetic resonance imagers. By awarding grants for these instruments as shared resources, their utilization is greatly increased. On average, more than 15 investigators share each instrument provided through NCRR's Shared Instrumentation Grant program. In fiscal year 1999, NCRR will significantly expand this unique program to assure that investigators have state-of-the-art research tools.

In recent years it has become increasingly clear that a complete picture of the genome can only be obtained if gene identification efforts are supplemented with studies to characterize the proteins produced by the genes. At an NCRR-supported microscopy and imaging resource at the University of California, San Diego, scientists are developing microscopic methods that permit mapping of both genes and their

products in situ for Alzheimer's Disease, for example. Resource facilities like this and others will accommodate investigator access and permit remote control of sophisticated instruments over the Internet and facilitate electronic communication with colleagues at other sites. Such arrangements will permit interactive tasks as if the collaborators are in the same laboratory. Continuing developments in computer technology and establishment of the ultrafast Internet-2 will allow extensive scientific collaboration and sharing of research resources and technologies. In fiscal year 1999, NCRR plans to expand these initial efforts, so in a few years cooperating university Internet sites will provide gateways to access sophisticated technologies, investigators and databases across the research community.

X-ray crystallography provides the ultimate details of molecular structures. The ultrabright synchrotron-generated X-rays have made it possible to increase resolution to levels that were not believed possible just a few years ago. For example, NCRR-supported scientists at Stanford University recently determined the detailed structure of the protein fibrinogen, which is essential to stop bleeding but also contributes to heart disease and stroke. As the human genome project identifies more genes, more proteins of unknown structure and function will require characterization in order to define the causes of disease and to develop novel therapies for them. In fiscal year 1999, NCRR plans to increase its support for investigator access to synchrotron beamlines.

As research problems become more complex, their solutions require more sophisticated technologies that demand an integrated approach. For example, the attached Figure summarizes the interaction of several costly, advanced technologies that contribute significantly to the development of novel drug therapies. This approach is commonly referred to as structure-based drug design. Either high energy x-rays, high field nuclear magnetic resonance or both technologies provide essential data about the structure of a purified protein. In the Figure before you, high energy x-rays, generated at the Advanced Photon Source at the Argonne National Laboratory, provide a key tool to analyze a crystallized protein. However, that crystallographic data may not be enough. That same protein may also need to be studied by high field nuclear magnetic resonance at an NCRR-supported research resource facility such as the Massachusetts Institute of Technology's Center for Magnetic Resonance to gain additional information to discern the protein's molecular structure. Data from synchrotrons or NMR's can be analyzed by a special software designed to run on a supercomputer, which may be located at the University of Pittsburgh. That processed information may then be moved over the Internet and analyzed by 3D Visualization tools, using the investigator's own workstation. The image in the center of the Figure was created with a molecular graphics system at the NCRR-supported University of California at San Francisco's Computer Graphics Laboratory. Visualization tools help identify the site on the molecule at which a drug may interact. Candidate drugs and proteins which may bind at the active site can be selected from databases over the Internet at sites somewhere in the U.S. or Europe. The molecule displayed is HIV–1 protease (shown in green and yellow) along with a drug candidate (depicted in magenta) bound within the enzyme's active site. The drug inhibits or blocks the biologic action of the protease and is a potential new treatment for HIV infection in man. The structure of HIV–1 protease was solved by members of the Crystallography Laboratory of the National Cancer Institute. Structure-based drug design is a faster and more cost effective approach to drug development than the empirical approaches used in the past.

Other recent developments in areas related to genomic research will generate major new multidisciplinary initiatives. Areas such as laser light source technology and design of extremely small-scale tools using nanofabrication and nanobioengineering techniques are now so advanced that engineers and scientists are constructing devices for detection of single molecules and miniaturizing instruments that will save expensive reagents and man hours. For example, the development of microchips for ultrasensitive DNA analysis is a revolutionary approach to miniaturization. Manufacture of these chips requires multidisciplinary expertise in production of computer chips, molecular biology, optics, and gene sequencing that will bring together physicists, engineers, and biologists. NCRR plans to extend its support to provide these powerful tools to identify genetic risk factors which may be modulated by diet, changes in lifestyles or other approaches to prevent, delay or treat disease.

BIOLOGY OF BRAIN DISORDERS

Thanks to powerful new technologies such as functional magnetic resonance imaging, or fMRI, and multiphoton laser scanning microscopy, scientists have gained increasingly detailed insight into the biology of the human brain. NCRR-supported re-

searchers at Carnegie Mellon University, University of Pittsburgh Medical Center, and Pittsburgh Supercomputing Center have combined the powers of fMRI, high-speed networks, and a supercomputer to produce high-quality 3-D images of the working brain within seconds of recording. To capitalize on these technological enhancements, NCRR will support development and acquisition of instruments that provide images of the brain, including images of tissue damaged by neurodegenerative diseases such as Parkinson's or Alzheimer's, in even more detail than currently possible. In addition, NCRR will support development of user-friendly database structures to facilitate investigator analysis and synthesis of vast data sets.

GENETIC MEDICINE

Nonhuman biological and disease models are indispensable to biomedical research. To understand gene function in cancer, diabetes and cardiovascular diseases, for example, scientists have developed thousands of genetically altered animal models in mice and rats. To assure preservation of these models, which are expensive to maintain, NCRR will create additional national and regional repositories to assure that novel genetically altered mice and rats can be distributed to investigators nationwide.

Certain studies with great implications for human health can best be carried out in nonhuman primates. Examples include development of a vaccine against AIDS and in-depth understanding of the immune system. Scientists at NCRR-supported Regional Primate Research Centers have developed procedures for producing genetically identical monkeys. Availability of these animals will facilitate development of an AIDS vaccine and provide a unique model to more effectively study tissue rejection associated with organ transplantation. NCRR plans to further develop this model.

Gene therapy is still at an early stage but holds great promise. NCRR, in collaboration with the National Cancer Institute, the National Heart, Lung, and Blood Institute and the National Institute of Diabetes, Digestive and Kidney Diseases, supported the establishment and maintenance of three National Gene Vector Laboratories that produce clinical-grade gene vectors, or carriers. These gene carriers are used in human gene therapy to transport therapeutic genes into cells where they are needed to alleviate or cure diseases such as cystic fibrosis, atherosclerosis, and an array of cancers. But the technique still needs refinement, and additional vectors need to be developed and studied. Because the safety of new vectors must be extensively examined, NCRR plans to support the development of additional vectors as well as their preclinical evaluations at NCRR-supported research resource facilities.

RESEARCH CAPACITY

NCRR administers an NIH-wide extramural construction grant program that requires matching institutional funding. The awards support renovation or new construction of research facilities at medical schools, hospitals, universities, and research institutions. According to a 1996 survey conducted by the National Science Foundation (The Status of Biomedical Facilities), academic institutions had deferred $3.6 billion worth of needed biomedical construction and repair or renovation projects. To help alleviate this need, NCRR plans to continue funding of construction projects to upgrade biomedical research facilities.

General Clinical Research Centers (GCRC's) play a key role in patient-oriented research and that research reflects that supported by the NIH categoric Institutes. The GCRC's host nearly 9,000 investigators who conduct nearly 6,000 research projects annually. The GCRC's provide infrastructure to academic institutions through the support of inpatient and outpatient research facilities and other resources vital for state-of-the-art, patient-oriented research. The GCRC's also provide an effective forum for training and junior career development for mentored, patient-oriented, clinical research. The GCRC's need to expand research activities into less traditional GCRC research areas, such as intensive care, emergency rooms, trauma units, and other specialized units. Seriously ill patients are increasingly studied at GCRC's, and the need for specialized testing and research nurse staffing to support those research studies has increased markedly. To address this need, NCRR in fiscal year 1999 will enhance support for the network of GCRC's which provide a critical interface to assure that scientific advances for rare diseases, cancers, diabetes mellitus, AIDS, cardiovascular and many other diseases are transferred from the laboratory to the patient.

To enhance research on diseases such as renal disease, diabetes mellitus, and cancer, that disproportionately affect minority populations, NCRR will support establishment of Centers of Clinical Research Excellence at NCRR-supported Research

Centers in Minority Institutions that are affiliated with medical schools. The centers will recruit new faculty, established investigators in clinical research, who will serve as mentors to junior investigators in an effort to build effective clinical research teams.

The activities of the NCRR are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

My colleagues and I will be happy to respond to any questions you may have.

PREPARED STATEMENT OF PHILIP E. SCHAMBRA

Mr. Chairman and Members of the Committee: I am pleased to present the President's non-AIDS budget request for the Fogarty International Center for fiscal year 1999, a sum of $19.1 million, which reflects an increase of $1.4 million over the fiscal year 1998 appropriation. Including the estimated allocation for AIDS, total support requested for the FIC is $30.4 million, an increase of $2.1 million over the fiscal year 1998 appropriation. Funds for the FIC efforts in AIDS research are included within the Office of AIDS Research budget request.

This year the FIC enters its 30th year as a focus of NIH international activities. Our mission is to assist this nation to deal with health problems that transcend national boundaries and that can be combated most effectively through international cooperation. Through training and research support, FIC enables American universities and research institutes to cooperate in regions of the world that, due to disease burdens, provide unique opportunities to advance international health.

WHY INTERNATIONAL HEALTH?

May I direct your attention to the chart which pictorially displays why international health is important. First, to protect Americans against global health threats. With frequent international travel, vast movements of populations of refugees, and potential changes in our climate affecting health, global trends are of increasing importance for us all. One has only to consider the emergence and spread of AIDS to recognize the necessity of confronting health needs in a global context. Moreover, international commerce presents new risks for the transfer of infectious agents for both humans and livestock, as well as toxic substances such as pesticides and pollutants, and even biologic and chemical agents.

Second, to fulfill a longstanding American humanitarian tradition. The Global Burden of Disease Study commissioned by the World Bank indicates that developing nations suffer over ninety percent of the burden of premature mortality as measured in lost years of life. These countries, constituting three-quarters of the world's population, now share a triple burden: the persistence of infectious diseases and malnutrition responsible for 16 million deaths per year, mainly children; a growing incidence of chronic disease and disability due to increased life spans and new risk exposures; and environmental and occupational health hazards which accompany industrialization.

Third, to advance America's global interests. The United States is at the vanguard of scientific progress and produces more knowledge, publications and medical interventions than any country in the world. Because of our leadership, we share an opportunity and an obligation to influence the international community, international organizations and developing and industrialized countries alike to address the health problems of those most in need. Further, international cooperation in biomedical science not only enables the United States to share skills and knowledge, but cultural and societal values intrinsic to scientific progress as well.

This nation's investment in research on global disease prevention produces significant economic returns. For example, the Institute of Medicine of the National Academy of Sciences reports that the United States saves $450 million every year by not having to vaccinate its citizens against smallpox. The World Health Organization predicts that our efforts to eradicate poliomyelitis will result in global savings of $500 million by the end of this decade. However, despite U.S. prominence in the creation of new drugs and medical devices as measured by percentage of world patents, our global share of exports to a market that exceeds $40 billion annually, namely

developing nations, is a mere 15 percent. International cooperation in health is one pathway to emerging markets enabling millions of citizens of these countries access to more modern drugs.

HOW DOES FIC MEET THESE CRITICAL CHALLENGES?

Please turn once again to our chart with the overlay which describes our major efforts. In the progress of biomedical science, one critical limiting factor is human talent. FIC's investment is in human capital, with a particular focus on developing nations. Scientific partnerships with these nations are of strategic importance. What follows describes our efforts to improve America's scientific capacity to conduct international research on global priorities identified in collaboration with our sister institutes at NIH and the scientific community.

With the support of this committee, the FIC International Training and Research Program in Emerging Infectious Diseases was initiated this past year to improve our capacity to understand the fundamental biology and epidemiology of new or resurgent infectious diseases. Launched in collaboration with the National Institute of Allergy and Infectious Diseases, the program explores the changing patterns of infectious diseases due to microbial evolution, human behavior, and economic development and land use.

The model for this new program is FIC's AIDS International Training and Research Program. Under this program, over 1,300 foreign scientists from over 80 countries in Africa, Asia, Latin America, and Central and Eastern Europe have received long-term HIV research training in the United States. Many former trainees are now co-investigators on NIH-supported research projects in developing countries where HIV/AIDS is epidemic. In addition, more than 41,000 physicians, nurses and laboratory technicians have gained new skills through in-country training courses. The emerging infectious diseases and AIDS programs, in tandem, represent investments in training and infrastructure that will assist the United States to develop vaccines and other interventions for diseases that require international trials. These include HIV, tuberculosis (TB), diarrheal and parasitic diseases, and acute respiratory infections.

HIV and other pandemics demonstrate that disease is not demarcated by national borders. In some cases, disadvantaged groups in the United States exhibit similar health risks with populations in resource-poor nations, risks due to micronutrient deficiencies and perinatal infections and other conditions. There are lessons to be learned domestically from research conducted abroad. For example, studies in Tanzania demonstrated that unless treatment regimens are supervised closely, TB rapidly becomes resistant to available drugs. That finding now has been applied to community health programs in New York City and other urban centers.

Another FIC global priority is to prevent adverse health effects of industrial and chemical pollutants. The FIC International Training and Research Program in Environmental and Occupational Health enables U.S. institutions to train scientists from regions of the world with high levels of contaminants in the environment and workplace, such as Eastern Europe, Russia and the new republics. The program is cofunded with the National Institute of Environmental Health Sciences and CDC's National Institute for Occupational Safety and Health, and National Center for Environmental Health. Current studies in Ukraine and Belarus undertaken after the accident at Chernobyl include the effects of radiation on growth and development, incidence of thyroid cancer, and reproductive health disorders.

One of the chief casualties of environmental decay is biologic diversity. There is a tendency to assume that our increasing technological sophistication moves us further from dependence on the natural world. However, it is likely that ecosystems maintained by diverse species are part of our protection against diseases. For example, deforestation has introduced new infectious agents into human populations; the depletion of ozone in the stratosphere erodes protection against the damaging effects of ultraviolet radiation.

The Earth's biota also is a continuing resource for new therapeutics. The FIC leads an interagency effort to discover new drugs from the earth's biological diversity. The International Cooperative Biodiversity Groups Program is funded in partnership with several NIH research institutes, the National Science Foundation, and U.S. industries. This program represents academic-industry consortia, examining genetic resources from terrestrial and marine environments worldwide. The program now is in its fifth year, and together these groups have examined over 3,000 species for activity in 13 therapeutic areas. At this early stage in the drug development process, there are approximately 25 high priority leads, including several to treat malaria, viral diseases, and cancer. Of equal importance, by demonstrating the economic and humanitarian potential of new drugs derived from biodiversity, this

program has influenced governmental efforts to sustain ecological balance in Argentina, Peru, Chile, Suriname and Mexico.

A root source of global health problems is demographic pressure. The world's population is now expanding at the unprecedented rate of nearly 1 billion per decade. Demographers at the United Nations estimate that virtually all of this growth will occur in the developing nations of Africa, Asia and Latin America. There is broad consensus that more stable population growth will enhance the prospects for improved living conditions for billions in the decades ahead. Yet this will require new medical technologies and social adaptations generated through research. Through our International Training and Research Program in Population and Health, FIC increases the capacity to conduct research on reproductive and neonatal health care and improves demographic capabilities in countries where population growth impedes economic development. The program is co-funded with the National Institute of Child Health and Human Development. Already, several collaborative projects have yielded discoveries. Scientists at the University of Virginia and the National Institute of Immunology in New Delhi, India have identified a specific antigen on spermatozoa in primates that will serve as the basis of a male contraceptive vaccine. If ultimately developed, this vaccine would be a major breakthrough in the field of contraceptive development.

Finally, in partnership with the National Library of Medicine, the FIC conceived an International Training Program in Medical Informatics to increase research capacity and health care through information technology. A pilot program with Africa will be initiated in fiscal year 1998. The fundamental goal is to develop collaborative teams of U.S. and African researchers and information specialists who apply state-of-the-art telecommunications and computer technologies to challenges in biomedical science and medical care.

As we come to the conclusion of this century, it is worth noting an important historical symmetry. NIH began as a small laboratory on Staten Island, tending to the needs of merchant marine sailors at the turn of the last century. The Laboratory of Hygiene proved its worth after diagnosing cases of cholera among immigrant passengers on the steamship "Alesia"—the first diagnosis of cholera in the western hemisphere. That landmark discovery was made possible through collaborations with the laboratory of Robert Koch in Berlin, who pioneered methods to isolate bacteria, and the laboratory of Louis Pasteur in Paris. This early discovery presaged the very practical benefits of public investments in basic research. It also signaled our reliance on international cooperation to accelerate the pace of discovery in medical science. This is our historic tradition, our public trust, and our mission at FIC.

Mr. Chairman, my colleagues and I will be happy to respond to any questions you may have.

PREPARED STATEMENT OF DONALD A.B. LINDBERG

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Library of Medicine (NLM) for fiscal year 1999. The President in his fiscal year 1999 budget has proposed that the NLM receive $171.3 million, an increase of $13.4 million over the comparable 1998 appropriation. Including the estimated allocation for AIDS, total support proposed for the NLM is $174.7 million, an increase of $13.5 million over the 1998 appropriation. Funds for the NLM efforts in AIDS research are included within the NIH Office of AIDS Research budget request.

FREE MEDLINE

I am proud to tell you the NLM has accomplished what I suggested to you last year when I said "it might actually be possible to offer MEDLINE without charge." This suggestion was echoed a week later in the testimony of world renowned heart surgeon Dr. Michael DeBakey, who chairs the NLM Board of Regents. It actually happened less than 3 months later, on June 26. Senators Arlen Specter and Tom Harkin provided a public forum for the announcement that the NLM would provide MEDLINE free to all users of the Internet and World Wide Web. Vice President Gore did the ceremonial "first free MEDLINE search." Successfully, I might add. A new feature introduced was the ability to link a MEDLINE user who wishes to get a full article directly to the home page of a number of medical publishers, where articles may be viewed or ordered. So far, about 100 journals are linked to MEDLINE and the number continues to increase.

Today, the world's largest database of peer-reviewed medical information is being queried more than 300,000 times each day—more than a tenfold increase in less than a year. Who is doing all this MEDLINE searching? The traditional users, of

course: doctors and other health professionals, librarians, scientists, and students. They are delighted with the new (and free) easy-to-use methods of access we have provided. But the more profound change is that the public—consumers, patients, parents, and other patient advocates—can now use MEDLINE to learn more about their own health and about how the results of medical research can affect it. This change has been fueled by widespread publicity of the announcement, including items in daily papers, weekly news magazines, consumer and other popular magazines, and televised reports; there were even episodes on NBC's "ER" and CBS's "Chicago Hope" that hinged on a MEDLINE search! Because of all this, MEDLINE is now being used by tens of thousands of people who a year ago had never even heard of it. Although many of the articles referenced in MEDLINE are too technical for the average person to understand, I believe that there is much in MEDLINE that is pertinent and useful for consumers. I am announcing here that we have begun to add references from carefully selected health newsletters for the public published by medical schools and other government agencies. We plan to enrich MEDLINE so that it will have even more information oriented toward the public.

OUTREACH

In expanding the potential audience for MEDLINE we will be relying more and more on the outreach mandate. You may recall that our legislation was amended directing us to publicize our services. The tremendous recent growth in MEDLINE searching notwithstanding, we still have a long way to go before every health professional knows about MEDLINE and how it can contribute to high-quality medical care. Our services are no longer even bound by national borders, since the Internet makes MEDLINE accessible around the globe. In fact, the NLM Board of Regents recently approved the report of a 2-year study of NLM's international programs; one recommendation was that the NLM should be a flexible partner and encourage the use of electronic information resources by health professionals in other countries. I should note that some 50 percent of MEDLINE records are from non-U.S. journals. Another international project, begun in 1997 at the request of the NIH Director, aims to enhance the ability of African malaria researchers to communicate electronically with colleagues in Africa and around the world and to access critical biomedical information from local libraries, remote databases, and the Internet. The project is part of the African Multilateral Initiative on Malaria.

The Library is targeting outreach efforts to several audiences that we believe can use our services to great advantage. We recently conducted a "train the trainer" program to teach older citizens how the Web can be used as a source of good health information. We want to set in motion a multiplier effect that will spread to senior centers, public libraries, and nursing homes across the country. AIDS is another special emphasis area. NLM's AIDS-related databases contain information that is useful to patients, families, and care providers, and we are working with community groups, including public libraries, to reach them. We are also reaching rural and other underserved health care professionals to show them how the Library's electronic information services can reduce professional isolation and put them in touch with the latest currents in biomedicine.

The NLM's Toxicology and Environmental Health Information Program has operated for many years and is only now getting the attention it deserves. A panel of distinguished scientists assembled by the Institute of Medicine has recommended that the toxicology and environmental health databases be made much more easily accessible and widely available (such as the NLM has done with MEDLINE). Those underutilized databases contain a wealth of information that could be used by scientists, educators, and the public in dealing with pollution, chemical spills, and other threats to the environment.

The NLM's outreach activities could not be successful without the assistance of the National Network of Libraries of Medicine (NN/LM). The mission of the Network is to make biomedical information readily accessible to U.S. health professionals irrespective of their geographic location. The eight Regional Medical Libraries that form the backbone of the Network are supported by contracts from the NLM. The 4,500 member institutions serve as the Nation's medical information infrastructure and provide a wide range of services, many of which are based on information resources provided by NLM. We have supplemented the contracts throughout the eight regions, to encourage innovative outreach projects, and plan to invest even more in the coming year. Closely connected to the NN/LM is NLM's Extramural Program for providing grant assistance. Several programs are outreach-related, including support to medical institutions to connect to the Internet. Other programs are for improving library resources of the NN/LM, health science communications, and research training in medical informatics.

NEXT GENERATION INTERNET

Usage of the Internet and World Wide Web has exploded. To ensure that the Internet will be up to handling future demand, a Next Generation Internet (NGI) initiative has been formed. This is a partnership between industry, academia, and several government science agencies, including the NLM. The NGI is a logical outgrowth of the High Performance Computing and Communications (HPCC) initiative and will provide affordable, secure information delivery at rates thousands of times faster than today and accelerate the introduction of new networking services for businesses, schools, hospitals, and homes. The NLM, which has in the past conducted a number of HPCC-related activities, plans to sponsor a variety of NGI health-care applications in such areas as advanced telemedicine, digital libraries, and distance learning. Such applications often require the nearly instantaneous transfer of many gigabits of data, for example in applications involving imaging. As important as the ability to transfer massive amounts of data—perhaps more important for health care—is the requirement for guaranteed quality of service and security of private information over the Next Generation Internet.

One of the most important aspects of the NGI in the health sciences is the use of computer and telecommunication technology for medical diagnosis and patient care—what has come to be called telemedicine. The concept encompasses everything from the use of standard telephone service to high-speed transmission of digitized signals in conjunction with computers, fiber optics, satellites, and other sophisticated peripheral equipment and software. The NLM has made a commitment to furthering telemedicine by sponsoring several dozen projects around the country, in a variety of rural and urban settings. Through these projects, now in their second year, we hope to evaluate the impact of telemedicine on cost, quality, and access to health care. Playing an important role in all these projects are two studies recently released by the National Academy of Sciences (and co-funded by NLM) on criteria for evaluating telemedicine and on best practices for ensuring the confidentiality of electronic health data. We expect the NLM-supported projects to serve as models for both evaluation and confidentiality. The NLM has just commissioned a third study by the Council that will take a hard look at the elements required if the NGI is to be of maximum service to health care and medical research. Capacity, quality, reliability, and security are some of the elements that will be evaluated; a strategy to achieve this infrastructure will be proposed.

Also intimately related to the NGI is Phase II of the Digital Libraries Initiative. The goals of the first phase were to advance fundamental research and build testbed networks for new technologies that capture, store, search, and retrieve knowledge from distributed electronic collections. Phase II, which is just under way, seeks to extend this technology to new application areas. NLM will contribute funds to this effort in order to assure that biomedical research institutions have an opportunity to compete for research grants and to develop imaginative and useful digital library applications of the NGI.

One of the most fascinating of the Library's high-tech enterprises is the Visible Human Project. This program has produced computer-generated images of two cadavers, one male and one female. NLM's relatively modest investment in the project has resulted in more than 1,000 licenses for use of the datasets by individuals and corporations in 27 countries. Thanks to the Visible Humans, doctors can practice procedures on "surgical simulators"; medical students can conduct dissection over and over using a CD–ROM called "The Recyclable Cadaver"; and non-invasive cancer screening techniques such as "virtual colonoscopy" are being developed.

MOLECULAR BIOLOGY INFORMATION SERVICES

Also closely connected to the NGI are the programs of NLM's National Center for Biotechnology Information (NCBI). The NCBI continues to advance the state of the art in analyzing the rapidly expanding wealth of information about our genetic makeup. NCBI has the most extensive and complete databases on DNA and protein sequence data in the world and logs over 2 million web hits a day. By all accounts it is the single most heavily used site in the world for molecular biology information. NCBI scientists collect and analyze molecular sequence information from laboratories at NIH around the world. The database, GenBank, recorded a milestone when the one billionth base was added just a few months ago—it took 18 years to collect the first one billion bases, but because of the explosive rate of growth, the second billion bases will probably be in the database just 18 months from now. NCBI has also been assembling all the data available on human genes resulting from the Human Genome Project. The NCBI's Human Gene Map now contains information on over 32,000 genes, nearly one-half of total estimated human genes. The Human Gene Map is on the web and allows everyone from a high school student to a Nobel

laureate to find genetic information at his or her level of expertise. Another scientific resource the NCBI recently created is the database on the genetics of Plasmodium falciparum sequences, the organism that produces the most severe form of malaria and is responsible for most of the 2 million malaria deaths each year.

NCBI has distinguished itself as an international focus for genomic information research and is in the forefront in applying this wealth of information to the detection and diagnosis of genetic disease. In collaboration with the National Cancer Institute, NCBI has embarked on a major project to produce the "molecular fingerprint" of cancer cells, to characterize what genetic steps occur as cells move from normal to cancerous states. The ultimate result of this research will be a powerful diagnostic tool that will provide a way to identify genes that directly cause cancer and identify cells in an early precancerous state, thereby enhancing the probability of early treatment.

BASIC LIBRARY SERVICES

Basic library services are the foundation on which is built the many advanced information products and services offered by the Library. The collection, begun in 1836, now numbers more than 5 million. Important as the collection itself are the Library's lending activities and cataloging and indexing services that make the information widely accessible through publications like the Index Medicus and databases such as MEDLINE. Several important workload indicators hit all-time highs in fiscal year 1997: a total of 519,000 journal articles were indexed for the databases (one-third more than the previous record). There were 630,000 requests from libraries around the world and on-site patrons for materials from the NLM collection (+8 percent). The trend is for steady growth in the collections, bibliographic and other databases that derive from the collections, and information services that depend on both. Basic library services must be protected if the Nation is to continue to benefit from its investment in biomedical research.

The activities of the NLM are covered within the NIH-wide Annual Performance Plan required under the Government Performance and Results Act (GPRA). The fiscal year 1999 performance goals and measures for NIH are detailed in this performance plan and are linked to both the budget and the HHS GPRA Strategic Plan which was transmitted to Congress on September 30, 1997. NIH's performance targets in the Plan are partially a function of resource levels requested in the President's Budget and could change based upon final Congressional Appropriations action. NIH looks forward to Congress' feedback on the usefulness of its Performance Plan, as well as to working with Congress on achieving the NIH goals laid out in this Plan.

My colleagues and I will be happy to respond to any questions you may have.

BUDGET SUBMISSION

Senator SPECTER. Dr. Varmus, I begin with a question which you and I discussed when we dedicated the building to our distinguished colleague, Senator Hatfield.

As I understand it, there are two budgets submitted, one which you give to OMB, which I believe you call an optimum budget—is that so?

Dr. VARMUS. Yes; that is our budget request.

As I explained to you in our letter, we had abandoned the time-honored tradition of making a very blue sky professional judgment budget and, instead, had provided to OMB our best estimate of what could be done given fiscal and political constraints to OMB as part of the negotiation with OMB over our budget.

We provided you yesterday with more of a traditional professional judgment budget, developed by each individual Institute and center—this is not a coordinated NIH final number but a set of numbers developed by each of the Institutes and centers.

Senator SPECTER. Would that be like the so-called optimum request?

Dr. VARMUS. No; it is more like the traditional professional judgment budget. The optimal request we put in to OMB this year was

10 percent above the fiscal year 1998 House mark, which was lower than our final fiscal year 1998 appropriation.

GRANT FUNDING

Senator SPECTER. Well, the question that I would like to have answered is if you had your druthers—or let me articulate it more precisely—if you had funds to make as many grants as you think are worthy, without the constraints of a budget and the limitations necessarily imposed by OMB, what would the figure be?

Dr. VARMUS. That is a number that has been put together by the individual Institutes and it is a number that comes out to be on average, about 23 percent above our appropriated level.

But I have two things to say, Mr. Chairman. First is that at NIH, we feel very strongly that we can accomplish a tremendous amount, be extremely happy, and have a very productive research environment with the President's request.

Second, I find it difficult to make a clear recommendation without taking into consideration the realities that exist—namely, that if NIH is awarded too much, it may be at the expense of other very worthwhile programs that the President has indicated an interest in, including programs that are supported by other Federal science agencies whose work is very important to our ultimate goals.

NCI BYPASS BUDGET

Senator SPECTER. Dr. Klausner of NCI, in the President's budget, it is $2.7 plus billion, but the professional judgment is $3.19 billion. Dr. Klausner, what is the difference in what you would accomplish with the $3.19 billion than the $2.77 billion?

Dr. KLAUSNER. Senator Specter, the $3.19 billion is the number from the NCI bypass budget, which I am requested to prepare by law and present to the Congress.

That bypass budget of $3.191 billion emerged from a pretty long process of prioritization and planning, and with that, compared to the President's budget, it is clear that we would be able to fund more like one-third of the grants, as opposed to about 28 percent. That is one of the differences.

CLINICAL TRIAL SYSTEM

Second, one of the major differences is that we are looking toward a major expansion in our clinical trial system, both an expansion and a redesign of our national clinical trial system. That is quite an expensive proposal and enterprise. The difference between those numbers very much depends upon the speed with which we can expand the clinical trials system so that the trials are faster, they accrue faster, they end faster, so that we can do more trials, and we can transform the clinical trial system from one that has been based, really, on a paper and pencil system for over 40 years to a new informatics-based electronic system and one that can more readily accommodate the more complex clinical trials that are associated with biologic markers, with genetic predisposition, with measures of the environment, et cetera.

So the difference would be the time it would take to rampup our clinical trial system, for example, to a size that we think would be optimal.

GRANT FUNDING POLICY

Senator SPECTER. Dr. Klausner, you say the difference in grant awards would be from 28 percent to 34 percent?

Dr. KLAUSNER. About that, yes.

Senator SPECTER. I am not challenging this, but what is the rationale for stopping at 34 percent? May there not be some great ideas behind those unopened doors in the remaining 66 percent?

Dr. KLAUSNER. Yes; there may well be.

Our feeling at this moment is that this is something we want to build to. We do feel that the peer review system, that does not necessarily simply reject grants but critiques them, provides feedback so that the grants that are submitted then could be improved and submitted again.

Senator SPECTER. Well, my question is what is the rationale for setting 34 percent and not having others?

As I look at the country's priorities and look at health care and the fact that we have a $1 trillion budget on health care. We look at $14 billion, which is a small fraction, would we not be better off as a country? Instead of granting 34 percent of the grants, to grant 68 percent of the grants.

I know that you don't have the whole budget before you, but the Congress does. What I am trying to find out is at what rational point do you stop and say that 34 percent is the line we ought to draw?

You are not even getting that, of course; you are at 28 percent.

Dr. KLAUSNER. Right.

Senator SPECTER. But I have a conviction—we went through this in some detail in 1995, after the House cut $900 million. We came to a hearing and we had the Hatfield-Specter-Kassebaum amendment—Senator Hatfield, because he was chairman of the full committee, and I of the subcommittee, and Senator Kassebaum because she was chairman of the authorizing committee. Unfortunately, we don't have Senators Hatfield and Kassebaum around anymore.

But why not more?

Dr. KLAUSNER. I think that is a very good question. Our view is that, ultimately, we would like all of the good ideas funded. But we do think that what this percentage means is this. A number of the grants that come in are reviewed by peer review, and, after the peer review, are sort of, in essence, in a range that are automatically funded. There are other grants beyond that which we actually hope to fund, but they go through a process of revision based upon the feedback, the input of peer review, which, actually, we think is quite healthy.

So there is, I think, for all of us this tension of wanting to make sure that all of the excellent grants are funded and wanting to maintain a robust and competitive peer review system. Is it exactly 34 percent or 35 percent? I think for all of us, we don't know where exactly that is.

We think quickly moving up toward about the 33, 34, 35 percent will both maintain the value of the responsiveness of the peer review system and will assure that more excellent grants are funded.

FUNDING FOR ALZHEIMER'S DISEASE

Senator SPECTER. I would like to move now to Alzheimer's, which has a tremendous amount of emphasis in the public mind. I understand Alzheimer's is divided among a number of categories.

Whom can I sensibly ask to respond on Alzheimer's?

Dr. VARMUS. There are four Institutes that have major roles in Alzheimer's research. I would recommend asking the National Institute on Aging which has taken the lead in coordinating the research among those four Institutes.

Senator SPECTER. And whom would I call on there?

Dr. VARMUS. Dr. Hodes.

Senator SPECTER. OK, Dr. Hodes. You are quite a way away from my dais, so it is tough to see you.

Dr. Hodes, why not more money for Alzheimer's?

Dr. HODES. I think as you have heard and seen in our written submissions, there certainly is a great deal of scientific opportunity for research on Alzheimer's disease.

Under the President's budget, the NIH overall budget and allocations to Institutes, there is potential for substantial commitment to Alzheimer's. The overall expenditures at NIH for 1999 estimated under the President's budget are about $374 million, about three-fourths of which is likely to be funded through NIA, the rest through other Institutes which also have substantial efforts in that area.

Senator SPECTER. How close are you, if you can quantify it or if it is a sensible question, to deferring Alzheimer's by 5 years? I keep hearing the statistic that if you defer Alzheimer's by 5 years, it saves $40 billion.

First, is that a sensible estimate?

Dr. HODES. It is a best estimate in an imperfect area of prediction.

DELAYING ALZHEIMER'S DISEASE

Senator SPECTER. OK. How close are we to deferring it for 5 years?

Dr. HODES. That is not easily answered. It's probably not right around the corner. The best of any accomplished results to date are quite modest and speak of delays in the progression of symptoms by a small number of months.

There is, however, a great deal of hope in the form of leads that have come, for example, from epidemiological studies, suggesting that women with a history of postmenopausal estrogen use, or men or women with a history of nonsteroidal anti-inflammatory use, have very striking reductions in their risk of Alzheimer's—in the range of 50 percent.

These kinds of exciting suggestions from correlations in epidemiology will lead to opportunities this year and next, and in years to come, for the initiation of clinical trials to directly test whether such agents, in fact, are capable of delaying the progression of symptoms or even the onset of disease.

Among the high priorities for use of the expanded funds awarded under the President's budget will certainly be an acceleration of the initiation and accrual of patients in these very important studies to see if, indeed, they do have the potential for substantial delays of Alzheimer's of the sort that you are asking about.

PARKINSON'S DISEASE

Senator SPECTER. Let me move to Parkinson's, another high visibility item. It is a little hard to judge those from my chair, but who, Dr. Varmus, should this next question be addressed to?

Dr. VARMUS. Dr. Penn.

Senator SPECTER. Dr. Penn.

Dr. PENN. Yes, sir; the opportunities in Parkinson's disease right now I think are very exciting. We are not at a brand new therapy. We are investigating therapies that are currently available and we are working with the gene that has been identified to find out more about what actually is going on with those cells that are dying.

Senator SPECTER. I hear talk about identification. Is it 16 genes? Have more genes been identified?

Dr. VARMUS. In the case of Parkinson's?

Dr. PENN. Yes; it's more like three or four mutations in one major gene.

We have multiple families where a gene defect will be identified, I would think, in the reasonably near future, and if those all coalesce to one story, we will be in great shape.

Senator SPECTER. Can you give any meaningful estimate as to how close you are on Parkinson's disease?

Dr. PENN. Again, I am going to quote Dr. Hodes. It is not a matter of months. It is more a matter of several years out. We have multiple therapies, multiple clinical trials in which we are trying to work this.

Senator SPECTER. So it is several years out. Within a decade?

Dr. PENN. A full decade? I hope not.

Senator SPECTER. Good.

Dr. PENN. I would say it would be a little bit sooner than that.

ALZHEIMER'S DISEASE

Senator SPECTER. How about Alzheimer's? Can you say that for Alzheimer's?

Dr. PENN. I would not want to speak to Alzheimer's.

Senator SPECTER. Oh, I am talking to Dr. Hodes on this. Can you say that for Alzheimer's, that it is not as much as a decade out?

Dr. HODES. I think the most that I think I can responsibly say is that within a period of 3 to 5 years, we should have extremely informative data about how successful the current best candidates are. The reason for doing the studies, unfortunately, of course, is precisely because we do not have any guarantees of what their outcome will be.

STATUS OF HEART DISEASE

Senator SPECTER. Let me turn now to Dr. Lenfant of the National Heart, Lung, and Blood Institute.

Take heart disease, how close are you? What are the parameters for an evaluation as to how close you are for significant improvements?

Dr. LENFANT. Mr. Chairman, first of all, I think that over the years we have made considerable progress, as evidenced by the decline in the death rate from the most prevalent heart disease, coronary disease/heart attack.

As I have reported to you over the years, the decline has been approximately 50 to 60 percent during the last 25 years or so.

Today, we have before you a number of alternatives which I believe very strongly will allow us to make considerable progress, not only in the treatment of this condition, coronary heart disease and heart attack, but also to address the complication of that condition, which, unfortunately, will continue to occur. Heart attacks often result in heart failure, which is an ever-increasing problem in this country. We see through the advent of molecular medicine, cell biology and the understanding of the most intimate component of heart tissue the prospect that some day, in the future, we will be able to replace current interventions, such as heart transplantation or artificial heart—which, as you know, during the last 20 or so years were commonly spoken about—by just restoring normal heart tissue and basically repairing the damage which is responsible for the heart failure.

So I think that before us we have enormous prospects and lots of work is going on at this time which is very, very successful.

Now if your question is when will all that occur, I would not venture to give estimates of the time that it will take. But I think that in the heart community—just during the weekend I was meeting with the American College of Cardiology during their early meeting—you can sense their optimism for making very significant progress and continuing what we have already accomplished during the last 20 or 30 years.

Senator SPECTER. Thank you.

ALTERNATIVE MEDICINE

The subject of alternative medicine has an enormous following from what I find on my open house town meetings. That office has not been very heavily funded.

Dr. Varmus, upon whom should I call here?

Dr. VARMUS. To talk about alternative medicine?

Senator SPECTER. Yes.

Dr. VARMUS. I think perhaps I would do that.

Senator SPECTER. Is the head of the Alternative Medicine Department here?

Dr. VARMUS. Well, we have two people who are below me in the hierarchy—Dr. William Harlan, who is the head of the Office of Disease Prevention, which has oversight of the Office of Alternative Medicine, which is handled by Dr. Wayne Jonas. But I think I can answer the question for you.

Senator SPECTER. Is Dr. Jonas here?

Dr. VARMUS. I don't know.

Is he?

[Pause.]

Dr. VARMUS. Dr. Harlan who is the immediate supervisor for that office is here, or I could answer the question for you, if you like.

Senator SPECTER. Does Dr. Jonas not rate high enough on the hierarchy to come?

Dr. VARMUS. His office is in a group of offices overseen by Dr. William Harlan.

FUNDING FOR OFFICE OF ALTERNATIVE MEDICINE

Senator SPECTER. OK.

Dr. Harlan, you have the floor. But you have to come forward to the microphone.

While he is coming forward, Dr. Varmus, I know, or at least I understand, that there has been some resistance to heavier funding for alternative medicine.

Dr. VARMUS. I have good news to report there, Senator Specter.

We have taken very good use, I believe, of the additional funds that were provided last year, and we have a number of——

Senator SPECTER. If Senator Harkin were here, the question would not have been so diplomatically stated. [Laughter.]

Dr. VARMUS. That may be. I appreciate the way in which it was stated. [Laughter.]

We have a number of new trials in progress with funds from that office. The office is working extremely well with the Institutes. We formed a transagency, Public Health Service-wide coordinating committee to look at alternative practices. I think the whole operation is on a much better footing.

Dr. Harlan.

Dr. HARLAN. I would agree with Dr. Varmus.

The progress, I think, has been very encouraging.

Senator SPECTER. Did you say that you do agree with Dr. Varmus?

Dr. HARLAN. Sorry?

Senator SPECTER. You say that you do agree with Dr. Varmus?

Dr. HARLAN. I do.

Senator SPECTER. I would have been surprised if you had not. [Laughter.]

Dr. VARMUS. I would have been extremely disappointed, Senator. [Laughter.]

Senator SPECTER. Go ahead, anyway.

Dr. HARLAN. Let me agree with the adjectives and adverbs that he has applied. I think the cooperation has really been outstanding with the Institutes in terms of developing new studies and new initiatives coming from the Office of Alternative Medicine.

The other thing that I think is quite striking is the ability of the office to combine the scientific expertise within the Institutes with the office and come together with a product that I think represents the best in science.

Senator SPECTER. Dr. Varmus, on assessing the priorities, why on a relative basis has alternative medicine been given so little, relatively?

Dr. VARMUS. The function of the office is to coordinate research in this area and to carry out research in cooperation with the Institutes.

The office has funds which are involved in setting up data bases, which has been done very effectively, especially with the cooperation of the Library of Medicine in the last year, to oversee the world's activities in this area—what people are actually doing—and providing guidance to the Institutes. The budget of the office went from roughly $12 million to about $20 million, a very substantial increase, in 1998. That new money was used to start a variety of clinical trials which will then be picked up by the Institutes.

Senator SPECTER. But not much of an increase from 1998 to 1999, just $1.5 million.

Dr. VARMUS. That is about an NIH average.

REQUEST FOR COMPREHENSIVE ACCOUNT OF FEDERAL ACTIVITIES IN ALTERNATIVE MEDICINE

Senator SPECTER. This subcommittee has requested a comprehensive accounting of current Federal activities in the field. The report which we received notes the only work done up to now has been a search of Internet sites of Federal agencies. Obviously, on its face, this is inadequate.

We are very interested to receive a complete report as to what is being done in the Federal Government and what is being done abroad. This way we can have a comprehensive compendium on this subject.

I want to emphasize, as I know Senator Harkin would if he were here, the tremendous interest that there is among the people on this subject. Just today, the front page of the New York Times has that remarkable story about the 11 year old. I will not ask you if you have retained her.

Dr. VARMUS. I'm sorry we didn't fund her, Senator.

Senator SPECTER. Well, I think we could handle that on a funding basis. [Laughter.]

I would ask you to make a high priority on reporting to this subcommittee what is going on in alternative medicine and to give us a projection as to what more could be done.

It is not inappropriate to respond to public interests and public concerns.

Dr. VARMUS. I agree.

Senator SPECTER. There is a tremendous amount in the literature. My colleagues and I are very frequently asked why not more and what is being done and isn't there something really here?

We talked about this in the past and I appreciate the jump from $11.9 million to $20 million between 1997 and 1998. However, I have a sense that more is in order, given the scope of your budget and given the scope of the public interest.

Did you want to make a comment?

Dr. VARMUS. Just very briefly, Senator.

I was hoping to be able to give you that report today. We still lack a few responses from other agencies that we are surveying. We know you want the report.

We will add to the report some responses to the questions you have raised today. I would like to give you a brief description of the transagency oversight we are providing and some indications of new directions the Institutes would like to take in cancer, arthritis, and several other areas that I think you would find interesting.

Senator SPECTER. There is another vote on, as I had said earlier there would be. I am going to have to excuse myself for just a few minutes. I shall return promptly and I will ask you all to wait.

We will recess for just a few minutes.

[A brief recess was taken.]

Senator SPECTER. We will turn on the 5-minute clock for rounds of questions by Senators.

ALTERNATIVE MEDICINE ABROAD

Dr. Varmus, when we recessed, we were talking about alternative medicine. What can be collated with respect to the medical information on alternative medicine beyond the confines of the United States?

Dr. VARMUS. What we have done recently is to make use of the National Library of Medicine to make all articles in all journals that describe activities in the alternative medicine research available to anyone who goes into the data base. That includes journals from all over the world.

Senator SPECTER. Including those which go beyond the United States?

Dr. VARMUS. Actually, the majority of those journals are not even in English. But we have translations and summaries.

PROGRESS OF HIV/AIDS RESEARCH

Senator SPECTER. To whom should I direct a question regarding AIDS funding, Dr. Varmus?

Dr. VARMUS. Either to Dr. Whitescarver, who is the Acting Director of the Office of AIDS Research, or Tony Fauci, the Director of NIAID, or to me.

Senator SPECTER. Let's go to Dr. Whitescarver, who was first mentioned.

Similar to the questions posed, could you summarize the progress on the research as to AIDS? Is it a realistic question to provide some approximate date when we might look for a cure?

Dr. WHITESCARVER. Thank you, Mr. Chairman.

AIDS has enjoyed some substantial support and many scientific opportunities, which I think have been addressed in a timely manner. As a result of that, we have therapies that have contributed to reduced hospitalization and people living longer.

The mortality rate has dropped considerably.

So I think there has been a great deal of progress in the last few years. We still have a long way to go because this epidemic is certainly not over. It is far from over and we don't know about the long-term efficacy of these new drugs, how long their benefits are going to last. There are already some problems coming up.

But the good news is there are second generations of these drugs in the pipeline. The molecular biologists have identified targets for drug development, new targets, therefore, new therapies are on the horizon.

To answer the second part of your question, I think that is very difficult, once again, as with most diseases to put a time on a cure or even a prevention. But I think we are moving rapidly in that direction, at least to put AIDS in the perspective of a chronic, manageable disease.

Senator SPECTER. Dr. Penn has estimated Parkinson's disease well within the decade. Could HIV be put in the same category?

Dr. WHITESCARVER. I think it would be safe to say, as a chronic manageable disease and maybe even a cure, within 10 years, yes.

CLINICAL TRIALS

Senator SPECTER. Thank you.

Dr. Varmus, on the issue of clinical trials. There has been a lot of concern about whether there are sufficient resources being developed. I know you have accentuated that issue. Are we doing enough on clinical trials with your current projection?

Let me rephrase that. Why do you think we are doing enough on clinical trials with your current projection?

Dr. VARMUS. I would say that we are doing more. I don't think the word "enough" is a word that I would use here.

There are several problems. One is the problem of having adequate number of trained personnel to carry out clinical research, clinical trials, in particular. The second issue is one of patient accrual into clinical trials. The third is simply supporting the clinical trials processes themselves which, as you know, are very expensive.

You have heard today from a number of investigators whose Institutes are markedly expanding their clinical trials activities.

In cancer, for example, there are many more, four or five times more drugs in the pipeline than there were 5 or 10 years ago. As a result, if we are going to test all those drugs that are being developed, we are going to need more patients in the pipeline.

You have heard about Alzheimer's disease, Parkinson's, and AIDS, where there are expanded opportunities for trying out new therapies.

NEW CLINICAL INVESTIGATORS

Senator SPECTER. Dr. Varmus, let me interrupt you to focus on another aspect here before my orange light goes on.

I am told the number of first time physician applicants for research project grants declined by 30 percent between 1994 and 1996. At that rate, we may have none by the year 2000.

Has this trend continued in 1997 and are you concerned about this market decline?

Dr. VARMUS. We are very concerned about it, Senator Specter. There are some nuances of interpretation here. For example, the data do not capture the number of physicians who are serving as co-principal investigators and who are, nevertheless, doing research.

In addition, we think that the number reflects changes that are occurring at academic health centers, where there is increased pressure for doctors to perform care to support the center rather than to do research.

One of the reasons we developed a new training and support mechanism for clinical investigation, the so-called K–23 and K–24 awards, is to ensure that a larger number of people enter clinical research and are able to sustain the activity, despite other demands on their time.

Senator SPECTER. In order of arrival, as is our protocol, Senator Kohl.

EPILEPSY

Senator KOHL. Thank you, Senator Specter.

Dr. Varmus, I would like to talk about epilepsy with you this afternoon. Is it Dr. Penn to whom I would address my question?

Dr. VARMUS. Yes; that would be appropriate.

Senator KOHL. Dr. Penn, I am interesting in focusing on diseases that affect children, particularly epilepsy.

Nearly 2.5 million Americans suffer from epilepsy and 30 percent are children. Currently, NINDS spends approximately $55 million on research for epilepsy while much larger amounts are spent on other diseases that affect far fewer people.

I do not want to pit one disease against another, but I am interested in knowing how you make decisions on funding neurological disorders within the NINDS. How do you decide on this smaller amount for epilepsy, given the large number of Americans who suffer from epilepsy?

Do you think that epilepsy should get more research dollars?

Dr. PENN. We, like other Institutes, Senator, work toward opportunity and really good clinical research. In epilepsy, we have several very nice studies going, both basic and clinical, and particularly in our own program in the Institute, we are working to actually develop more drugs for children with epilepsy.

The issue of priority setting and which disorders at any one time may get more money or less money is partly the science, partly the investigators out there. We don't particularly want to try to pit one disease against another, either. But there are times when there is great opportunity in one disorder and perhaps others are just going along.

We have major epilepsy centers. We have a major epilepsy center at Children's Hospital in Philadelphia, actually, for childhood epilepsy.

We are very concerned about the fact that a lot of childhood epilepsy is somewhat hard to treat. You need multiple drug therapy. We have an advisory committee to our drug development program looking at these very issues.

So it is not really a low priority with us. In fact, in the last several years it has taken on a very high priority, especially for children.

EPILEPSY FUNDING

Senator KOHL. I am not sure I understood the import of your answer. I was suggesting that since there are so many more Americans suffering from epilepsy, particularly children, than other diseases relative to the amount of money that is spent on research, I do not understand why we do not commit more money to epilepsy, given the number of Americans who are suffering from epilepsy. Perhaps you can elaborate on this.

Also, I understand that there is conceivably a cure for epilepsy that is out there, given enough research, that is out there within our grasp, given sufficient dollars for research, that developing a cure for epilepsy or a prevention in the first place is not beyond your conception, but that research dollars need to be committed.

Could you comment on that, please?

Dr. VARMUS. Perhaps I could make a comment, Senator.

First of all, there are many patients with epilepsy who are very successfully treated. There is a long history of research on epilepsy that has given us a number of medications that are extremely effective in controlling the disease.

Second, as Dr. Penn has pointed out, there are oversight committees that are looking at possible opportunities for research in epilepsy. These committees have been encouraging drug development for pediatric patients and those patients that have refractory epilepsy.

Third, what tends to happen in a field like epilepsy is that a new discovery encourages people to come into the field. That has happened in a very dramatic way in the last couple of years with the discovery of some genetic diseases whose mutant genes have actually been isolated in the last year or two. Those discoveries give us dramatic new insights into how structural abnormalities in nerve cells can contribute to the disordered electrical activity that leads to epileptic seizures.

We think those discoveries are going to draw many new people to this field and that we will be getting grant applications that will allow the portfolio to increase in the best possible way as a result of really outstanding applications.

Senator KOHL. In the event that we will provide significantly more funds to NIH over the next several years, which I support, do you anticipate spending a significant part of that on epilepsy research?

Dr. VARMUS. Yes, sir; we believe that virtually every disease we work on is going to benefit both directly and indirectly from increased expenditures for health research.

EPILEPSY—ACCESS TO TREATMENT

Senator KOHL. One of the complaints of many families who have children with epilepsy is that the research done at NIH does not always lead to treatments that families have access to and can afford.

What steps are you taking to make sure that the treatments you develop can actually be affordable and used by families?

Dr. PENN. We work directly with patient groups in our own programming with these drugs that we are working to develop. We are working really with very small businesses and with drugs which larger industries are not that interested in developing.

It is absolutely critical that we do that because some of our larger pharmaceutical industries have not really gone after the drugs that we need to treat epilepsy. Some of our best drugs are very old drugs. We need some new ones and we need them for children.

Therefore, we are trying to work and we are working directly also with the help of the FDA to develop these and, hopefully, to keep the costs down. I hear you, sir.

Senator KOHL. Thank you, Dr. Penn and Dr. Varmus.

Thank you, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Kohl.

Senator Cochran.

PREPARED STATEMENT OF SENATOR COCHRAN

Senator COCHRAN. Thank you, Mr. Chairman.

Mr. Chairman, I have a prepared statement which I hope can be printed in the record along with a question on the subject of clinical research, which you raised of Dr. Varmus.

Senator SPECTER. Without objection, it will be made a part of the record.

[The statement follows:]

PREPARED STATEMENT OF SENATOR THAD COCHRAN

Mr. Chairman, I believe as you do that there must be a strong federal commitment to medical research. Through the commitment of this Congress and the diligent efforts of the National Institutes of Health, an ever-expanding base of scientific knowledge about health and disease is being developed that has already begun to revolutionize both our approach to scientific inquiry and the practice of medicine.

Part of this medical research revolution is occurring in Mississippi. With NIH support, the University of Mississippi Medical Center, in conjunction with Jackson State University and Tougaloo College, is initiating a major study of cardiovascular disease in African Americans—the Jackson Heart Study. We are hopeful that the partnership between NIH and these Mississippi schools will yield important new findings on how to deal more successfully with this serious problem.

TRANSLATION OF RESEARCH

Senator COCHRAN. On another subject, we all are supporting increased funding for NIH. There is no question about the consensus here in the Congress that more money is needed for the programs that you administer. The President has requested an increase in funding.

It raises a question about whether we are doing enough to be sure that the findings of the research are being translated into programs of prevention, education, and the rest. I know the Centers for Disease Control is involved in some programs in our State, for example, and cancer screening is one example.

To what extent are you working with CDC and shouldn't there be a concomitant increase in CDC funding or program funding of that kind to keep pace with the new findings that you are going to come up with with the new money that is going into research?

Dr. VARMUS. Senator, all of the centers of the CDC work extremely closely with the Institutes of the NIH. As I mentioned to you during the recess, when I was down at the CDC a couple of years ago, I was very impressed with how much interaction goes on. I would be happy to provide you with the long list of collaborative enterprises we are engaged in with the CDC.

As you may also know, the Department of Health and Human Services developed a health research initiative that includes not only NIH but also the CDC and the AHCPR. We try to coordinate our research activities through that research fund, and we believe that we do perform complementary activities.

All that being said, the CDC is not the only instrument by which the findings that NIH generates are transmitted to the public. The NIH has a very deep investment in prevention research; we spend over $3 billion in prevention research activities. We have considerable outreach through public health communications and direct contact with professional groups and with patient groups. We have an elaborate computer outreach and telephone outreach. We pre-

pare instructive manuals on many topics. So we consider the CDC to be our partners in doing that phase of work, which we also agree is very important.

The National Library of Medicine has a special set of skills that are applied to telemedicine—to making medical information accessible to the public—and it might be useful to hear from Dr. Lindberg on that topic.

DIABETES RESEARCH WORKSHOP

Senator COCHRAN. I want to ask you about a couple of other things and if I have time in my 5 minutes, I will ask for additional information on that subject.

I would like for you to give us a status report or update, or one of your colleagues, on the last conference that you had on diabetes research.

I know there was a recent meeting of a diabetes research working group. I would like to know, if you could tell us, what the outcome of these meetings have been? Does the budget reflect a request for additional funding to implement any of the recommendations that might have been made?

Dr. VARMUS. We have had a number of important meetings, perhaps the most central of which was a workshop held early last September to look for unexplored opportunities in diabetes research. That was a propitious time for such a meeting because the Balanced Budget Act of 1997 also included a research initiative of $30 million per year for 5 years directed toward type I diabetes. The workshop provided a blueprint for that research.

In addition, there has been increasing interest in response to the high rates of diabetes, especially in some of our minority populations and as a consequence of the increasing role obesity plays in our society.

I think Dr. Gorden, from NIDDK, who has taken the lead role in coordinating research carried out by many Institutes of the NIH on diabetes related topics, might want to comment briefly.

Dr. GORDEN. Senator Cochran, good afternoon.

Senator COCHRAN. Good afternoon. It is good to see you, a fellow Mississippian. Let's all rejoice. [Laughter.]

Dr. GORDEN. We hope we are doing very well, Senator. I would just echo what Dr. Varmus has said. Really, the momentum that was generated at the September 4 meeting which Dr. Varmus participated in has carried through. We have a working group that has been congressionally authorized, that is starting to meet and will meet again at the end of this month, which will help us define a clearer blueprint for what we think we need to build in the future.

But we think we have put in place strategies that relate to both treatment and even new strategies that relate to prevention. We are really at the interface of trying to discover causes of diabetes, of which there are many.

So we think we have things in place that are going to address all of those important issues. As for the support we have gotten from the community in terms of planning and helping us, in terms of outreach, as you have mentioned before, we have also put into place an education program in collaboration with the CDC. This is a very active, very new program that was just inaugurated now in

order to translate some of the discoveries that we have already accomplished.

So there is really a very good mood in the community right now, a very positive movement, and I think we are all very excited about the prospects.

CHILDREN LEARNING TO READ

Senator COCHRAN. Thank you very much.

Let me ask my final question to Dr. Duane Alexander, who is Director of the National Institute of Child Health and Human Development.

Last year, during our hearing, we talked about research that had been done by this national institute and the fact that there were findings that really were not being used by other agencies of Government or by school districts. This is in the area of how to deal with the problem of children learning to read.

There were congenital and other factors that were discovered that were important in these situations. I would like for Dr. Alexander, if he could, to give us a status on the results of our efforts last year. We included language in our committee report about developing a national panel to translate the research into programs that could be used in the classroom for teacher education and for helping diagnose and screen children who had learning difficulties.

I do want to put in the record, if the chairman will permit, a copy of the statement by Dr. Alexander last year and our committee report to remind us of what we had done last year.

Senator SPECTER. Without objection, it will be made a part of the record.

Senator COCHRAN. Thank you.

[The information follows:]

READING DEVELOPMENT AND DISORDERS

As requested, the statement provided for the record last year by Dr. Alexander follows:

"I think that it is important to point out that our intensive research efforts in reading development and disorders is motivated to a great extent by our seeing difficulties learning to read as not only an educational problem, but also a major public health issue. Simply put, if a youngster does not learn to read, he or she simply is not likely to make it in life. Our longitudinal studies that look at children from age five through their high school years have shown us how tender these kids are with respect to their own response to reading failure. By the end of the first grade, we begin to notice substantial decreases in the children's self-esteem, self-concept, and motivation to learn to read if they have not been able to master reading skills and keep up with their age-mates. As we follow them through elementary and middle school these problems compound, and in many cases very bright youngsters are deprived of the wonders of literature, history, science, and mathematics because they cannot read the grade-level textbooks. By high school, these children's potential for entering college has decreased to almost nil, with few choices available to them with respect to occupational and vocational opportunities.

"In studying approximately 10,000 children over the past 15 years, we have learned the following:

—"At least 20 percent, and in some states 50 to 60 percent, of children in the elementary grades cannot read at basic levels. They cannot read fluently and they do not understand what they read.

—"However, the majority of these children—at least 90 to 95 percent—can be brought up to average reading skills if: (a) children at-risk for reading failure are identified during the kindergarten and first grade years; and, (b) early intervention programs that combine instruction in phonological awareness, phonics, and reading comprehension are provided by well trained teachers. If

we delay intervention until nine-years-of-age (the time that most children are currently identified), approximately 75 percent of the children will continue to have reading difficulties through high school. While older children and adults can be taught to read, the time and expense of doing so is enormous.

—"We have learned that phonological awareness—the understanding that words are made up of sound segments called phonemes—plays a causal role in reading acquisition, and that it is a good predictor because it is a foundational ability underlying basic reading skills.

—"We have learned how to measure phonological skills as early as the beginning of kindergarten with tasks that take only 15 minutes to administer—and over the past decade we have refined these tasks so that we can predict with 92 percent accuracy who will have difficulties learning to read.

—"The average cost of assessing each child during kindergarten or first grade with the predictive measures is between $15 to $20 depending upon the skill level of the person conducting the assessment. This includes the costs of the assessment materials. If applied on a larger scale, these costs may be further decreased.

—"We have learned that just as many girls as boys have difficulties learning to read. The conventional wisdom has been that many more boys than girls have such difficulties. Now females should have equal access to screening and intervention programs.

—"We have begun to understand how genetics are involved in learning to read, and this knowledge may ultimately contribute to our prevention efforts through assessment of family reading histories.

—"We are entering very exciting frontiers in understanding how early brain development can provide us a window on how reading develops. Likewise, we are conducting studies to help us understand how specific teaching methods change reading behavior and how the brain changes as reading develops.

—"Very importantly, we continue to find that teaching approaches that specifically target the development of a combination of phonological skills, phonics skills, and reading comprehension skills in an integrated format are the most effective ways to improve reading abilities.

"At the present time, we have held several meetings with officials from the USDOE and have discussed how these findings can be used across the two agencies. As an example of this collaboration, NICHD and USDOE have been developing a preliminary plan to determine which scientific findings are ready for immediate application in the classroom and how to best disseminate that information to the Nation's schools and teachers."

The excerpt from the Senate Committee report accompanying the fiscal year 1998 appropriations bill and addressing reading development and disorders is as follows.

"The Committee is impressed with the important accomplishments reported from the NICHD research program on reading development and disability, and is eager to have this information brought to the attention of educators, policymakers, and parents. Noting the fact that the NICHD is already collaborating with the Department of Education, the Committee urges the Director of the NICHD in consultation with the Secretary of Education, to convene a national panel to assess the status of research-based knowledge, including the effectiveness of various approaches to teaching children to read. The Committee recommends that the panel be comprised of 15 individuals, who are not officers or employees of the Federal Government and include leading scientists in reading research, representatives of colleges of education, reading teachers, educational administrators, and parents. Based on its findings, the panel should present a report to the Secretary of Health and Human Services, the Secretary of Education, and the appropriate congressional committees. The report should present the panel's conclusions, an indication of the readiness for application in the classroom of the results of this research, and, if appropriate, a strategy for rapidly disseminating this information to facilitate effective reading instruction in the schools. If found warranted, the panel should also recommend a plan for additional research regarding early reading development and instruction. The Committee looks forward to discussing the findings of the report during the hearing on the fiscal year 1999 budget." (Senate Report No. 105–58, p. 86).

RESEARCH ON READING DISABILITY

Senator COCHRAN. Then I would ask Dr. Alexander for his response on the status of that initiative.

Dr. ALEXANDER. Senator Cochran, the research on reading disability and how children most effectively can be taught to read has

continued to make excellent progress, both at the level of studying instructional methods as well as basic science studies of the brain processes involved in learning to read and blockages to that process.

I am very happy to report to you that the national reading panel has been appointed. We had excellent cooperation and collaboration with the Department of Education in soliciting nominees for this panel and selecting them.

We have put together a panel with outstanding expertise and diversity. The first meeting of that panel will be held on April 24 at the NIH, and we will be working very hard to try to complete the panelists' charge and get a report back to this committee by November.

Senator COCHRAN. Thank you very much, and I commend you for your leadership and your rapid response to the initiative that we started last year.

Thank you very much.

Dr. ALEXANDER. Thank you, Senator.

Senator COCHRAN. Thank you, Mr. Chairman.

Senator SPECTER. Thank you, Senator Cochran.

Senator Bumpers.

GRANT FUNDING

Senator BUMPERS. Thank you, Mr. Chairman.

Dr. Varmus, if you had all the money in the world and we were living in a perfect world, how many of those 24,221 applications would you have approved?

Dr. VARMUS. That's a tough question, Senator, because, as you know, they are not of equal quality. Some of them are of extremely high quality. People who have had tremendous experience in reviewing such applications would say that perhaps 30 to 40 percent are of real obvious merit and below that it is a gradient. Where you cut off is somewhat arbitrary.

It is important to distinguish, in my view, among three different kinds of applications. First are applications from first-time investigators, people who have never had a grant but have been trained, sometimes by NIH training programs. We would like to see them get at least one shot at showing what they can do as an independent investigator. Then there are applications which come from people who have already had support. They tend to do better than the newer applicants.

Then there are people who have had previous support and are applying for another grant, as opposed to continuing a previous grant. You could argue that there is, perhaps, less imperative to have those people receive a second, third, or sometimes even a fourth grant.

So I think it is important to disaggregate those numbers a little bit. But, overall, I would say that something in the range of between 30 and 40 percent of the total applications should be funded.

AVERAGE LENGTH OF GRANT AWARDS

Senator BUMPERS. Just quickly, what is the average length? Do you determine the length of the grant on the front end?

Dr. VARMUS. We do.

Senator BUMPERS. What is the average length?

Dr. VARMUS. The average length at present is roughly 4 years.

Senator BUMPERS. And, of course, you allow justification for extension of that if, at the end of the 4 years, there is a justification for extending it?

Dr. VARMUS. Well, it is not a question of justification. One has to reapply. That is what I mean by a competitive renewal.

Senator BUMPERS. Yes.

Dr. VARMUS. Those applications tend to do about twice as well as applications for a new grant.

DECLINING EFFICACY OF ANTIBIOTICS

Senator BUMPERS. Dr. Varmus, I don't know whether it was Newsweek or Time magazine that had a big story this week on a continuing story that is moderately alarming, and that is about the declining efficacy of antibiotics in certain diseases.

Do we tinker with what we have and try to strengthen it or do we look for new solutions in the case like that? What do we do?

First of all, I assume that is correct.

Dr. VARMUS. Yes; we are having increasing problems. There is no doubt about that.

Dr. Fauci, whose Institute addresses this problem every day, might want to comment. We do take this as a very serious problem. It is related to inappropriate use of antibiotics, to the fact that there are mechanisms of bacteria and viruses that allow for resistance to develop against antimicrobial agents like penicillin, that you are familiar with, and others.

CURE FOR EBOLA

Senator BUMPERS. Before we go to Dr. Fauci, as I am interested in his comments on that, do we do anything there? Are we doing any research in this country to speak of to find a cure for ebola?

Dr. VARMUS. We have some grant applications on ebola virus that are being funded by the NIAID. Whether there are any efforts being made to look for treatment or cure, I think it is important to point out, Senator, that traditionally we have had very few drugs for treatment of viral illnesses.

One of the remarkable things about the way in which we have advanced on the AIDS front is that we have developed several powerful drugs to treat HIV infection. Those have served as models for how we might go about attacking other viral infections.

Many other viruses make enzymes required for duplicating the viral genes, for making enzymes that chop up viral proteins, so-called proteases. HIV enzymes are now serving as models for how we go about approaching other viral infections, and those strategies are being considered in the context of many other viral infections, including ebola virus.

Tony, do you want to comment here?

Dr. FAUCI. Yes; we have a handful of grants. One very fine investigator that we are supporting is looking at a vaccine for ebola.

We have another grant or two looking at therapeutic approaches, which, as Dr. Varmus said, is very difficult. Viruses are one of the more problematic microbes to develop antimicrobial therapy for.

But it is not a dead issue with regard to attempts to develop appropriate antimicrobials.

ANTIBIOTIC RESISTANCE

I might mention in response to your previous question about how we are approaching antibiotic resistance, we consider that to be under an area of emphasis called emerging and reemerging microbes, which we placed a significant amount of effort on in the past couple of years, and particularly in the budget that we are defending here today. In emerging and reemerging microbes, one of the more important for our country is the development of microbes that are resistant to antibiotics. A particularly problematic area that we are facing now, where we actually moved some money in the middle of the fiscal year into the area is the recent occurrence, first in Japan and then in the United States, of vancomycin resistant staphylococcus aureus. This is a very substantial problem because vancomycin has been essentially the last firewall against staphylococcus aureus and we are seeing partial resistance now.

We have a new antibiotic, synercid, which we believe will be the next line of drugs against this. But that is just one microbe.

Approximately 70 percent of hospital acquired infections are, in fact, antibiotic resistant to at least one or more of the antibiotics. So it is a significant problem.

But as I mentioned, we are addressing it in our initiative in this and previous years on emerging and reemerging microbes.

Senator BUMPERS. Do you think you are doing all you can do? Do you have all the money to do everything you can do?

I see this as a really major, major health problem for the whole world.

Dr. FAUCI. As others have said, I don't think we could ever say that we are doing everything we could do. But I can assure you, Senator, that we have made this a major priority in the Institute.

Senator BUMPERS. Thank you, Dr. Fauci.

Thank you, Mr. Chairman.

Senator SPECTER. Thank you very much, Senator Bumpers.

INTERNATIONAL COLLABORATIONS ON INFECTIOUS DISEASE OUTBREAKS

Senator Faircloth.

Senator FAIRCLOTH. Thank you, Mr. Chairman.

Senator Bumpers, I could not help but think of that old joke that if Dr. Varmus had all the money in the world, he could farm for a couple of years. [Laughter.]

Senator BUMPERS. This is not the Agriculture Committee, Senator Faircloth. [Laughter.]

Senator FAIRCLOTH. Dr. Varmus, we welcome you. I attended last week's rally to add my support for increased funding for NIH. As I said then, I will say again. If we could find $18 billion for the IMF, we certainly can find the same amount of support to find a cure for the diseases that are ravaging this Nation and the world as a whole.

This morning, I stood on the steps of the Capitol under a 50-foot pink ribbon, and we spoke of the hope we have that we will find

a cure for breast cancer. You are certainly at the helm of that ship that we hope will be bringing a cure quickly.

Under your leadership and with the help of your Institute directors and many, many talented researchers, we are getting closer every day to the cure for cancer and many other dreaded diseases that have plagued generations and generations of people.

As you know, I introduced legislation last year asking that an institute for biomedical imagery be established at the NIH. As Senator Frist and I work together to see what we can do to get more research done in this area, we are certainly appreciative of your support.

Dr. Varmus, I have been deeply disturbed about your decision to discontinue the National Institutes of Health DNA Advisory Committee. Public objection has saved the committee, but you decided to relinquish their approval responsibilities to the FDA.

The FDA can only grant approvals based on safety and efficiency. FDA cannot address the ethical and moral implications of the new gene therapies which the National Institutes of Health committee did address.

I wish and would like for you to reconsider this decision as these new therapies deserve a more careful review than they are going to get from the FDA. I thank you.

Mr. Chairman, I have one brief question, which I will direct to whomever may wish to answer.

The Hong Kong flu outbreak last year demonstrated the need for global preparedness and the rapidity with which microbes and diseases can be spread around the world. We may and we will face future epidemics whose virulence could catch our existing public health networks unprepared.

What are we doing in research and what are the opportunities that NIH has pursued internationally to reduce the risk of future outbreaks?

I read something in a popular publication—I'm not sure what it was, though I believe it was Time—that the Asian flu, I believe it was, of World War I actually took several months to move from its beginning point somewhere in Kansas to the battlefields of Verdun. Of course, now it would go overnight.

Dr. VARMUS. This year's Hong Kong episode illustrates very nicely the way in which we try to respond to those threats and also illustrates very nicely an issue that Senator Cochran brought up about how we work with the CDC.

Dr. Fauci, whose Institute was involved in that response, might want to comment briefly.

Dr. FAUCI. Yes, Senator. There was a Public Health Service/DHHS flu pandemic plan that was put into effect immediately upon the identification of the first case in May 1997 and then the clusters in December. That was a plan that involved multiple agencies, both within and outside of HHS, and in HHS it was predominantly the Centers for Disease Control. You know from reading and seeing in the media the important role that they played there from a surveillance standpoint.

The NIH role is fundamentally that of research, and we played a role with the CDC because, initially, the H5N1 that was isolated a couple of decades ago, was put in our repository. We, in fact,

made antibodies to it, so that when the CDC needed antibodies immediately to make kits to do surveillance in Hong Kong, the surrounding areas, and in our own State and territorial health departments, the NIH made that available to them.

The surveillance was done in collaboration with the CDC and this was effective.

I might add that we were also able to supplement one of our grants. Dr. Varmus used his Director's reserve to move money over to immediately supplement one of our grantees who played a major role in the decision in Hong Kong to destroy the chickens which, as you know, essentially put an end to the epidemic there.

Again, this is part of our emerging microbes effort and is continuing. It is also a major priority in this year's budget for us.

Senator FAIRCLOTH. Thank you so much, Doctor.

Thank you, Mr. Chairman.

ERGONOMICS RESEARCH

Senator SPECTER. Thank you very much, Senator Faircloth.

We have kept you here a long time and we don't want to keep the progress of medical research in abeyance much longer. I do want to ask you one more question, Dr. Varmus, and that is with respect to the ergonomics issue. I know that you have already discussed this in detail with Bettilou Taylor, my clerk and very, very able staffer.

Dr. VARMUS. Yes; she is.

Senator SPECTER. She has the sharpest pencil on Capitol Hill.

Last year, Senator Harkin and I consolidated or eliminated 134 programs in our subcommittee to save $1.5 billion for the $907 million. These programs were added to NIH and others to guaranteed student loans, because that is where we consider the priorities to be.

Ms. Taylor had the conversation with you about the letter which was received from a number of Members of the House on this ergonomics issue. The letter had a line about "Thank you for agreeing to fund the National Academy of Sciences comprehensive peer review of all available scientific literature examining the cause and effect relationship between repetitive tasks in the workplace and musculoskeletal disorders." The letter further states, "Studies estimated the cost of $890,000 and it may take 24 months to complete."

I understand that you advised Ms. Taylor that you did not agree to that type of study and that you felt that the NIOSH report was quite good, but that maybe the solution would be simply to have a workshop to allow independent people to evaluate the quality of the NIOSH report and answer questions to see if there was any basis on how that study was carried out.

The concern I have is we have prohibited any regulations on ergonomics for 1 year and the understanding was that would be the end of it. This has been a very contentious issue and we want to be free at the end of this fiscal year, September 30, to move ahead on this very important subject. If there can be some modest study, if one is needed, that will not go beyond the fiscal year. What is your thinking on the subject as of this date?

Dr. VARMUS. Senator Specter, we are continuing to have conversations with the academy about how such a study could be done. But, of course, I took careful notice of the letter you sent to me on February 4, in which you stated that you were going to have conversations with the Members of the House who have been corresponding with me. I look forward to hearing about the results of your conversations with them.

I am open to suggestions. As Secretary Shalala said when she was here on March 10, I am basically in a holding pattern until I hear about how the two Appropriations Committees would like to try to reconcile their differences.

In the meantime, we are trying to work with the academy on a kind of arrangement that would be a reasonable one and would do something expeditiously.

Senator SPECTER. How long would that take?

Dr. VARMUS. We are not entirely clear yet. We have talked with them about bringing in some experts in this field who could give us some advice about how close we could come to providing either answers to Mr. Livingston's questions or their view about the extent to which we could answer the questions with existing knowledge.

The House is not asking for additional research to be done. They are asking for further review of the literature beyond the review that was done by NIOSH.

Senator SPECTER. That all can be accomplished before September 30?

Dr. VARMUS. I would think it could be, sir. I have made that view clear to the President of the academy Bruce Albert.

Senator SPECTER. So there has been no agreement by you to conduct a study that might take 24 months at $890,000?

Dr. VARMUS. No.

I have been very clear with my friends in the House that we are willing to entertain their request and we would like to do something, but we have not committed ourselves to a time or a cost.

Senator SPECTER. OK.

Dr. VARMUS. I look forward to hearing from you about how we should proceed in this issue.

Senator SPECTER. Well, we have not come to grips on that and my instinct is that we probably won't. I think the understanding we reached last year, which is that by September 30 we are going to move ahead, is really the one we are going to be moving on. If there can be some relatively brief study, hopefully at a low cost, as you see fit, but not to delay us.

We did not prohibit a study. We only prohibited regulations. We want to be free to act however the will of the Senate may be as of September 30. What you have just said is consistent with that.

Dr. VARMUS. As you know, I am in the middle here. But I would like to do things in good faith for both parties.

Senator SPECTER. That is not an unusual position for you given your pay grade as Director of NIH. That is a big position and there is a big middle. [Laughter.]

PREPARED STATEMENTS OF SENATOR TOM HARKIN AND SENATOR LARRY CRAIG

We have also received statements from Senators Harkin and Craig which will be inserted in the record at this point.

[The statements follow:]

PREPARED STATEMENT OF SENATOR TOM HARKIN

I want to welcome Dr. Varmus and his colleagues from NIH today and I look forward to working with all of you during the appropriations process this year. NIH is the premier medical research institution in the world. The research funded by NIH is key to maintaining the quality of our health care and key to finding preventive measures, cures and the most cost effective treatments for the major illnesses and conditions that strike Americans.

But I must say that I am concerned about how we're going to get the money to give NIH the increase that both Senator Specter and I would like to provide. Last year, the entire Senate went on record in support of doubling funding for biomedical research. But only a third of the Senate supported us when we tried to make good on that commitment by proposing an amendment to the budget resolution which increased funding in the health account to provide adequate funding for NIH and other health problems.

This year we have the same thing happening again. The budget resolution now being debated on the Senate floor, is—to put it kindly—extremely short sighted when it comes to support for finding cures, more cost effective treatment and preventions for the many diseases and disabilities that hit millions of Americans every year.

The sponsors of the budget resolution claim to have included $1.5 billion for an NIH increase. But that is just smoke and mirrors. The resolution partly funds the purported increase with cuts of $600 million in other public health programs—programs like community health centers and CDC prevention programs—cuts we cannot afford to make. The resolution also includes reductions in other functions affecting this subcommittee, including the pot of money for Head Start and Ryan White AIDS programs. Under the nondefense discretionary levels included in the budget resolution, we could not even do a continuing resolution at last year's level much less provide NIH with a significant increase.

The budget resolution before us makes crystal clear that the only way—the only way—we can devote the resources we need to health research—and to stop robbing Peter to pay Paul—is by going outside the regular discretionary spending process. The only way to adequately support medical research is through another mechanism. I believe the best other mechanism is that called for in S. 441, the National Fund for Health Research Act, that Senator Specter and I have introduced.

This year, we may have the opportunity to use proceeds from bipartisan, comprehensive tobacco legislation for medical research. In fact, increased funding for NIH is the one area about which tobacco bills introduced by Senators from both sides of the aisle agree. But the budget resolution does not allow us to do that. Senator Specter and I are working on an amendment to the budget resolution which will make those tobacco proceeds available for biomedical research. We ask your support for that amendment.

The budget resolution, as now drafted, shortchanges Americans' health and shortchanges efforts to control health care costs and keep Medicare solvent in the long run.

PREPARED STATEMENT OF SENATOR LARRY E. CRAIG

I would like to thank the Chairman for holding this hearing today regarding budget requests for the National Institutes of Health (NIH) for fiscal year 1999. I look forward to learning more about some of the scientific advances that have been made over the last year at the NIH, as well as the goals and long-term projects planned for the coming year. Past accomplishments, as well as future plans should be taken into account as we look at ways to appropriately allocate funds to the various programs within the NIH.

For the last several months, my staff and I have been hearing from various groups representing a broad range of diseases that get their research dollars through the NIH. The resounding message we hear from all of these groups is that their interests are not being adequately addressed in the way of funding. Each group has extremely valid reasons for wanting more funding and I find it difficult

to pick and choose which disease should get more research money. Each disease is important and each one has far-reaching impacts on our country. I think it is crucial that we decide on what level of funding is appropriate and then distribute those funds with a sense of fairness.

I applaud the NIH for the work they have done in developing new therapies and cures for diseases that will help resolve some of our country's greatest health problems. The long-term investments they have made in the areas of medical research and training will help to achieve many more new discoveries. Furthermore, sustained growth in funding for the NIH will help build upon past scientific achievement, address present medical needs and anticipate future health challenges.

I do believe the NIH should be given funding adequate to support research that moves us toward cutting-edge treatments and prevention efforts, while helping to reduce overall health care costs. However, as we all know, there are harsh budget realities that we must work within and that is why we are here today. We must find a way to provide the appropriate level of funding for these programs while being fiscally responsible.

I am strongly committed to fiscal responsibility. I also realize that the subcommittee is operating under significant budget constraints and will have to make difficult choices among competing programs. My hope is that the recommendations for NIH funding are made with the objective of searching for cost-effective solutions.

We can make significant strides in the field of medical research while still working toward a balanced budget. Balancing the budget is all about setting priorities. If we discipline ourselves and set priorities now, while moving toward and keeping a balanced budget, that will be the best way to preserve our ability to fund our priorities in the future.

I hope we will be able to shed some light on what these priorities must be as we continue to look for ways to adequately fund these very important programs, while working within our means. I look forward to hearing the testimony of all of our witnesses here today. Your expertise will be extremely valuable to me throughout this process.

ADDITIONAL COMMITTEE QUESTIONS

Senator SPECTER. This is a fascinating committee to chair because there are so many troubled people with ailments. We are almost at the 2 hour mark since we were convened here. So we are going to recess.

I want to say that there are many questions that we are going to submit for the record and ask you about. People have come to this subcommittee to meet with problems on osteoporosis, colon cancer, Batten's disease, juvenile diabetes, drug abuse, scleroderma, breast cancer, amyotrophic lateral sclerosis, spinal cord injury, sudden infant death syndrome, polycystic kidney disease, end stage renal disease, schizophrenia, cystic fibrosis, lymphoma, lupus—just to mention a few. We are very much concerned about all of them, as I know you are.

We will fight hard to get you additional funding because we think it is very much in the national interest to do so.

Dr. VARMUS. We are very grateful for your support, Senator. Thank you.

[The following questions were not asked at the hearing, but were submitted to the Department for response subsequent to the hearing:]

ADDITIONAL COMMITTEE QUESTIONS

BIPOLAR DISORDER

Question. Last year's Senate Labor-HHS-Education Appropriations report called for an NIMH research plan on bipolar disorder. This request is a clear indication that, as you have acknowledged publicly, there is too little bipolar illness research being funded by NIMH. This appears to be the case, particularly in the area of clinical research. As you know, bipolar disorder is among the most disabling of mental illnesses. The Subcommittee understands that NIMH has taken some steps to in-

crease bipolar disorder research funding. (a) Please describe what NIMH is doing as part of its current budget on manic-depressive illness research. How many new studies are being funded on this illness? What else, if anything, does NIMH intend to do to assure more research on bipolar disorder in fiscal year 1999 and beyond?

Answer. NIH in general and NIMH, in particular, are committed to moving forward in research on bipolar disorder. Let me describe two major initiatives currently in progress for fiscal year 1998. First, in the NIMH Genetics Initiative, and as part of its effort to identify genetic factors in bipolar disorder, the Institute will continue to build up its national resource of DNA sample from patients and their family members. Second, we have issued a solicitation for a five year contract ("Treatment of Bipolar Disorder") to launch a major public health study on ways to develop optimal treatment of bipolar disorder in adults and in geriatric populations. The study will assess the long-term impact of different treatments on a broad range of clinical and functional outcomes. Data from this study will inform treatment practice in community settings. Other studies are examining treatments for adolescents with bipolar disorder. Furthermore, we intend to increase research on the neurobiological underpinnings of bipolar disorder as well as clinical, behavioral, and epidemiological work that will be useful in finding ways to prevent this disorder.

At this time, it is not possible to predict how many studies on bipolar disorder will be funded in fiscal year 1999. This depends upon how many grant applications are submitted by independent investigators, and how scientifically sound and appropriate these applications are judged to be through the peer review process.

As outlined above, NIMH intends to explore all avenues to increase research on bipolar disorder as rapidly as the growing fundamental science base allows scientifically rigorous research studies to be undertaken.

TRANSLATIONAL RESEARCH

Question. NIMH has frequently noted the need to support "translational" research. However, for many policy-makers, patients and families, the definition of translational research remains unclear. Would you describe for the Subcommittee what you mean by translational research? How does NIMH intend to implement this kind of research and make relevant to the advance of severe mental illness treatment? What specific programs and policies does NIMH intend to put forward to advance translational research?

Answer. The term, translational research, is meant to describe a type of scientific inquiry that crosses usual conceptual and disciplinary boundaries. Historically NIH's support of biomedical research has focused on two major categories: basic biology and clinical research. Translational research seeks to translate "back and forth" between these two largely separate domains. It is anticipated that this will result in accelerated scientific progress that is directly applicable to clinical disorders. It is important to note that this is viewed as a bi-directional process, i.e., clinical research informing, as well as being informed by, basic research and vice-versa. A couple of examples may clarify the concept. Developmental neurobiology and genetics are both highly relevant to mental disorders. In both instances, hypotheses in clinical research are shaped by observations in basic research and vice-versa. The cognitive deficits observed in schizophrenia coupled with structural anomalies in the brains of schizophrenics have encouraged developmental neurobiologists to investigate the possible role of aberrant brain development in the etiology of schizophrenia. Conversely, the identification of a growing number of genes required for the precise specification of brain structure during development has given rise to clinical studies focused on the anatomic substrates of abnormal mental function. It is my belief that fostering translational research will enrich both basic and clinical research and will speed progress toward a complete understanding of mental disorders.

Implementation of this kind of research will require a continuing, close collaboration between basic and clinical mental health researchers. NIMH has begun to develop and strengthen such collaborations in research through specific research support mechanisms. For example, several recently published NIMH program announcements call for the development of four types of research centers focused on translational research. One type of center, the Silvio O. Conte Centers for the Neuroscience of Mental Disorders, will support the integration and translation of basic and clinical neuroscience research on severe mental illnesses, while other centers will focus on related research areas.

Translational research requires collaboration between scientists from multiple disciplines, an approach which, historically, has not been emphasized in research on mental illnesses. NIMH stimulates and sustains activity in translational research on severe mental illnesses through career-development mechanisms, which provide

support for young clinical investigators during the formative stages of their careers until they become fully independent researchers. In addition, small grant awards provide support for pilot projects and for first-time grants for young NIMH investigators. These awards can be used to explore translational and other research studies that would be difficult to fund under traditional support mechanisms. In addition, an NIH-wide RFA, Clinical Research Curriculum Award, is intended to stimulate the inclusion of high-quality, multidisciplinary didactic training as part of the career development of clinical investigators.

RESEARCH PRIORITIES

Question. There is concern among many that NIH in general, and the NIMH in particular, desire to invest less in disease-oriented and clinical research, and more in basic scientific research. Please describe for the Subcommittee what you think is the appropriate balance at NIMH between basic research funding and clinical and services research. Does NIMH intend to invest more in basic research? If so, how much more?

Answer. Research on the causes, treatment, and prevention of mental illnesses is integral to the mission of the National Institute of Mental Health (NIMH); indeed, this research is the primary focus of all NIMH programs. Mental illnesses are diverse and, even though science is rapidly making enormous strides, very little is known about the causes of any of these illnesses. We do know that the key to these illnesses lies in basic research on the molecular and cellular changes in the brain and on understanding how the brain is changed by these diseases to produce the behavioral manifestations of these illnesses. This is the only way that we will ever understand how to most effectively treat, or to prevent, mental illnesses. NIMH basic research is directed toward understanding the changes in the brain and behavior that determine mental disorders.

At the same time we must continue to apply what we already know to clinical studies and services for patients. Thus, support for clinical research and health services research by NIMH is also expanding. The NIMH assesses the balance between all these elements of its research endeavors and makes changes in emphasis as the scientific and clinical opportunities for studies warrant.

In shaping its research program, NIMH periodically establishes research priorities, then continues to evaluate these priorities in the light of accumulating research-based knowledge. The appropriate balance between basic research funding and clinical and services research varies somewhat over time as advances in science create new opportunities to address specific research questions and to explore new avenues to treatment or prevention, or as marked changes in the mental health-care landscape—such as the advent of managed care—create new public mental health questions. NIMH relies on the National Advisory Mental Health Council (NAMHC), composed of both expert scientists and representatives of the public, to continually monitor the Institute's program balance and to assist in setting and reviewing research priorities. The NAMHC reviews and approves all research grants awarded, and, in addition, through special workgroups and task forces, the Council undertakes comprehensive, in-depth reviews of major segments of the NIMH research program and these reviews produce quite specific recommendations for program directions and emphasis.

Based on recent recommendations by the National Advisory Mental Health Council and on emerging scientific opportunities, the NIMH intends to increase support for important areas of basic research as well as a broad spectrum of patient-oriented research—including clinical research, services research, and translational research that will accelerate the incorporation of basic research findings into clinical care. However, at this time, it is not possible to attach dollar amounts to these investments.

SCHIZOPHRENIA

Question. Schizophrenia is the most severely disabling mental disorder and is among the most severe illnesses that afflict mankind. The statistics bear this point out; (a) schizophrenia strikes in young adulthood usually resulting in a lifetime of severe disability, (b) consumers with schizophrenia account for nearly 25 percent of all those receiving disability payments from the federal government, (c) schizophrenia costs the nation $32 billion each year, (d) consumers with schizophrenia occupy 40 percent of all hospital beds in the United States, (e) 10 to 15 percent of its victims commit suicide. While there has been important treatment advances in the 1990's, much has to be learned about this disease. We still do not understand what causes this illness, we have no diagnostic markers for schizophrenia, and treatments are but palliatives and not cures. By NIMH's own accounting, investment in schizo-

phrenia research modestly declined in the first part of this decade—by approximately 10 percent. Given the severity of this illness and a record of decreasing research investment, what does NIMH plan to do to advance our understanding and treatment of schizophrenia? How much money is needed in this area of research? What are the most important barriers to research advances in schizophrenia, in your view? How can Congress assist you in conquering this terrible disease?

Answer. Schizophrenia research continues to have a prominent place in NIMH programs. The Institute is committed to studies of the neurobiological substrates of schizophrenia, its neurodevelopmental origins, and the inheritance of and expression of vulnerability genes in the brain, as well as other factors that may trigger or exacerbate schizophrenia. For example, the NIMH Genetics Initiative has provided new funding to augment the number of patient samples available for gene-finding efforts in schizophrenia. Efforts are also underway to characterize exactly which of the Gamma aminobutyric acid (GABA) brain regions and which neurons are affected. There are preliminary data to suggest that small GABA interneurons, in particular, may be abnormally "connected" in patients with schizophrenia, while there is a growing body of data pointing towards the involvement of specific emotional and higher cognitive centers of the brain. This localization is consistent with many of the behavioral manifestations of schizophrenia. Neurochemical theories of schizophrenia also continue to be studied, and there is growing evidence pointing toward the possible involvement of excitatory neurotransmission involving glutamate.

While we do not yet have a cure for this devastating illness, in the past few years, three new, "atypical" antipsychotics have become available. These represent major therapeutic advances, since they are better-tolerated, and preliminary evidence suggests that they may be more effective than traditional antipsychotics. NIMH has initiated clinical studies to determine if these new treatments are indeed more effective, and if so, in which patient groups they are best used.

Over the last 5 years NIMH has cofunded, with the Agency for Health Care Policy and Research (AHCPR), the Schizophrenia Patient Outcomes Research Team (PORT). The mission for this PORT was to identify and analyze the outcomes and costs of various treatments for schizophrenia; to determine the most cost-effective means to treat or manage the condition; and to develop and test methods for reducing inappropriate or unnecessary variations in treatment. The same investigative team was funded recently to conduct a field trial of a methodology for assessing the quality of care provided to patients with schizophrenia.

The fiscal year 1999 President's Budget request will permit NIMH to take advantage of the most important immediate research opportunities.

There are a number of reasons why progress in understanding schizophrenia and finding a cure has been slow. First and foremost, schizophrenia is a disease unique to humans. There is no animal or tissue model that accurately reflects the manifestations of the disease in man, and this necessarily limits the investigations that can be performed. Many of the powerful methods for studying molecular or cellular processes that have led to rapid advances in our understanding of other illnesses cannot be applied to schizophrenia, since they involve destruction or severe disruption of the tissues that are being studied.

There are other barriers as well. Schizophrenia is difficult to treat and few people with the diagnosis—even those who respond well to treatments—return to their preillness level of functioning. Because of this, we need to go beyond therapeutic studies and start thinking about prevention. Yet we know little about factors that influence the course of this illness. The NIMH is developing research to aid in identifying indicators of risk for onset of disease, relapse, poor functional outcomes, and suicide. The programs will also translate emerging findings from the basic sciences into new strategies for prevention and early intervention. We are hopeful of substantial progress in the next decade. There is also a lack of understanding of how the newer atypical antipsychotics work. Their mechanism of action is very complex, affecting multiple brain transmitter systems. This complexity may be a critical feature of their greater efficacy, and will remain a central focus of research efforts in the near future.

With the funds requested in the fiscal year 1999 President's Budget Request and the flexibility to use these funds in areas of greatest opportunity, NIMH will be able to accelerate research on schizophrenia.

SUPPLY OF RESEARCHERS

Question. As I am sure that you will agree, there is a great need to attract new researchers and clinicians into psychiatry—in the areas of genetics and severe mental illnesses in children and adolescents in particular. Could you please comment on the problems you see in terms of the human resources available to study and

treat these serious brain disorders? What do you intend to do to recruit new and talented individuals to these fields? How can Congress assist you in this activity?

Answer. Several high-priority research areas such as the genetics of mental illnesses and childhood and adolescent mental illnesses are drawing on a very small cadre of investigators, many of whom have pioneered these fields. However, as these areas of research develop and expand, progress depends on the availability of more well-trained investigators. The National Institute of Mental Health (NIMH) will develop strategies to attract more researchers into these critical areas. For example, in the area of pediatric mental illness, most researchers are drawn from the small groups of clinically trained child psychiatrists and child psychologists. Given the length of clinical training, many potential investigators are diverted (often for financial reasons) into non-research careers. However, while there are only 5,000 child psychiatrists nationwide, there are over 100,000 pediatricians, adult psychiatrists, and neurologists, from whose ranks new child mental health-focused investigators could be drawn.

NIMH anticipates two major activities in this area. (1) The Institute will issue a new career award to attract researchers such as neurologists, adult psychiatrists, and psychologists, who have not typically studied in this age group to encourage them to learn about how to do clinical studies of children and adolescents and to redirect their efforts. A similar strategy will be employed for other shortage, high priority research areas. (2) NIMH will develop supplements to existing research grants for young investigators who are interested in studying childhood psychopathology or other similar high priority areas.

The fiscal year 1999 President's Budget Request was developed after lengthy examination and discussion of scientific opportunities and research needs, and NIMH feels that this level of funding will provide good support for strengthening the recruitment of researchers into critical areas of study.

TUBERCULOSIS

Question. How does the morbidity and mortality due to tuberculosis compare with the disease burden for other infectious diseases? What is the impact of TB on economic development?

Answer. Tuberculosis (TB) kills approximately 3 million people each year, making it the leading cause of death due to a single infectious agent globally. In comparison, all acute lower respiratory infections combined were responsible for 3.9 million, malaria for 1.5–2.7 million, and HIV/AIDS for approximately 1.5 million deaths in 1996. TB accounts for more than one quarter of all preventable adult deaths in developing countries. One-third of the world's population is infected with the TB bacillus, and someone in the world is newly infected by TB every second. In the United States there were 19,855 cases of tuberculosis reported in 1997. The World Health Organization estimates that between now and the year 2020, nearly one billion more people will be newly infected with Mycobacterium tuberculosis, the bacterium that causes TB, 200 million will develop active disease, and 70 million will die. Causing even greater concern, is the estimate that up to 50 million people may already be infected with drug resistant strains of tuberculosis.

According to a recent study from the Battelle Centers for Public Health Research and Evaluation, published in the Archives of Internal Medicine, the United States spends an estimated $700 million per year on TB treatment and control. The impact of tuberculosis on economic development is particularly dramatic because most often affects individuals during their wage-earning years. A report recently issued by the WHO estimates that, if India, which has 2 million new cases of TB annually, spent the equivalent of $200 million per year on an effective TB control strategy, the tangible benefits to the Indian economy would be worth at least $750 million per year. In addition, if this epidemic is not adequately controlled, greater spread of multidrug resistant TB will result, potentially creating a far more serious impact on global health and economics. In the United States, it costs approximately $2,000 to treat a typical case of drug sensitive tuberculosis, while treating a case of multi-drug resistant TB costs up to $250,000.

Question. In the long-term, what is the best way to control and prevent tuberculosis and multi-drug resistant tuberculosis?

Answer. In the long run, the most effective tool for preventing tuberculosis would be a TB vaccine. Controlling TB will also depend on the development of new and improved diagnostic and therapeutic tools—including therapies that would shorten and simplify the course of treatment, drugs active against currently resistant bacteria, and more sensitive and specific diagnostic methods suitable to low income as well as industrialized countries. NIH is actively supporting research in all these areas.

The most effective current tool available for controlling tuberculosis is a strategy known as Directly Observed Treatment, Short-course or DOTS. Antibiotics can effectively cure drug-sensitive cases of tuberculosis and reduce development of additional drug resistant cases, but the treatment requires that patients take combinations of at least four antibiotics daily for a minimum of six months. DOTS ensures that patients comply with this difficult regimen by having health care workers observe patients swallowing every dose of their medications. Using a similar approach, the CDC along with state and local health authorities have made enormous headway since 1992 in controlling TB in the United States. In this same time period, the WHO Global Tuberculosis Programme has been focusing considerable resources to control the global epidemic by implementing DOTS as widely as possible. Despite these admirable efforts, only about 10 percent of patients worldwide with active TB disease currently have access to DOTS programs. The effectiveness of this resource-intensive control strategy is limited in many parts of the world by financial, logistical and political obstacles. Efforts to implement DOTS more widely are crucial to control this disease. However, it is estimated that even with a sustained global DOTS program, as many as 70 million people will die of TB in the next two to three decades.

Question. How big a priority is tuberculosis research at NIAID? How actively is NIAID trying to develop a TB vaccine? When can we hope to have an effective tuberculosis vaccine?

Answer. Tuberculosis research is a very high priority at NIAID. The TB research budget increased 1,311 percent from 1990–1999. NIAID supports a broad-based program of research on TB and its causative agent, Mycobacterium tuberculosis, consisting of basic and applied studies to better understand the biology, pathogenesis and immunology of TB, develop new tools for molecular epidemiologic studies, improve diagnostic and treatment strategies and advance more effective vaccines. Currently, NIAID supports more than 100 grants for basic and applied TB research. One grant is to the Institute for Genomic Research (Rockville, Maryland) to support the sequencing of the entire genome of a recent, clinical isolate of virulent M. tuberculosis. Progress has been rapid in the past year and sequencing is near completion. This will have significant implications for the development of future TB diagnostics, therapeutics and vaccines.

Development of a TB vaccine is a critical part of NIAID's overall TB research strategy, and it is our most important long-range goal. An effective TB vaccine is necessary to conquer the global epidemic, but to achieve this goal a number of years of testing will be needed. Recent technological advances such as sequencing the genome of the pathogen provide a solid foundation for the additional steps that must be taken. These include further basic research into the genetic make-up of the pathogen and the human protective immune response; development of vaccine candidates and animal models, and conduct of clinical trials with promising candidates. Once trials are completed, efforts will focus on vaccine production, licensure, and distribution. With a sustained effort and commitment, an effective TB vaccine can be achieved.

Question. How does funding for tuberculosis research at NIAID compare with funding for research on HIV and other infectious diseases?

Answer. Research on tuberculosis continues to be a high priority at NIAID. In fact, spending increases for TB research have outpaced both those for AIDS research and for the Institute's spending on all non-AIDS infectious diseases. Over the past decade, NIAID support for tuberculosis research increased 1,311 percent. In fiscal year 1990, NIAID provided $2.7 million in funding for tuberculosis research, and in fiscal year 1999, we estimate that support will be approximately $35.7 million. In comparison, support for AIDS research for the same period at NIAID increased 94 percent, from $394 million in fiscal year 1990 to $766.2 million in fiscal year 1999. Likewise, funding for all non-AIDS infectious diseases increased 70 percent, from $241.6 million in fiscal year 1990, to $411.9 million in fiscal year 1999.

Question. Dr. Barry Bloom is chairing a committee that will be reporting back to Secretary Shalala with recommendations on tuberculosis vaccine development. How do you intend to make use of these recommendations?

Answer. In March 1996, senior staff in the Office of the Secretary met with the Secretary's Advisory Council on the Elimination of Tuberculosis (ACET). During the meeting, the Council emphasized the importance of a national effort to develop an effective TB vaccine to meet the United State's goal of TB elimination. The Secretary's Office responded by requesting creation of a national strategy for TB vaccine development for her consideration. Subsequently, the ACET and the National Vaccine Program Office asked NIAID to convene a workshop to develop this strategy, since NIAID routinely assembles outside experts to provide recommendations and strategies for future efforts. At NIAID's request, Dr. Barry Bloom chaired the

resultant workshop, A "Blueprint for TB Vaccine Development," held March 5–6, 1998. A report from that meeting is currently being prepared for Secretary Shalala's consideration. NIAID believes TB vaccine development is an important area of current and future research and looks forward to receiving Secretary Shalala's response to its report.

Question. What tuberculosis research is being done outside of NIH, both in the U.S. and globally?

Answer. Both within the United States and globally, the majority of public sector and academic TB research is funded by the NIH; however, other significant efforts in U.S. TB research include those being pursued by the Centers for Disease Control and Prevention (CDC), focused largely on improving control and surveillance of tuberculosis, and by industry. Only a handful of large pharmaceutical companies appear to have major TB research programs focused on drug development or, in even fewer companies, vaccine development. Several biotechnology companies are also involved in R&D of improved TB diagnostics, therapies or vaccines. Unfortunately, many companies have decided not to pursue TB research because of financial and intellectual property issues that make identifying an "adequate" global market difficult.

In 1995, the WHO Global TB Programme attempted to ascertain the funding level of global TB research. The 13 institutions that responded to the survey (none of which were from private industry) spent a total of $92 million, approximately $62 million of which was NIH funding (approximately $34 million from NIAID). The remaining four highest funders were the U.S. CDC ($17 million), the Medical Research Council of South Africa ($3.6 million), the Medical Research Council of the United Kingdom ($2.4 million) and the Robert Wood Johnson Foundation in the U.S. ($1.65 million).

QUESTIONS SUBMITTED BY SENATOR THAD COCHRAN

IOM STUDY ON CLINICAL RESEARCH

Question. As you know, I am a cosponsor of the Clinical Research Enhancement Act based on the recommendations of a 1994 report of the Institute of Medicine. Over the past three years, this Subcommittee has raised serious concerns about the major obstacles confronting clinical research through which our investment in NJU's basic research efforts pays off with better patient care. Other than responding with modest intramural initiatives, you have asked that we await a report from your advisory panel on clinical research. Recently, that panel issued its report and, not surprisingly made recommendations almost identical to those of the IOM.

Dr. Varmus, why did the NIH not proceed with these initiatives three years ago when they were recommended by the IOM?

Answer. As you stated, the ground work examining the state of our nation's clinical research enterprise was conducted by the Institute of Medicine (IOM). This study, which was carried out from 1991–1994 and was partially funded by NIH, addressed a number of the important issues concerning clinical research, including its role of clinical research in the delivery of health care, the status of the clinical research infrastructure, and the need for well-trained clinical investigators. Although the 1994 IOM report was thorough and addressed a range of relevant issues its recommendations were very broad and were aimed at both the private and public sector entities that sponsor, conduct, or, in some way, play a role in clinical research. These include the accreditation and certification organizations, professional societies, universities, academic medical centers, industry, and the Federal Government.

Because NIH is but one of these entities and has a unique role, I responded to the 1995 Appropriations Committee report language that requested NIH to act on the recommendations of the IOM report by convening the NIH Clinical Research Panel (CRP). That panel was charged with examining specifically the role of NIH in ensuring the health of the Nation's clinical research infrastructure. To this end, the CRP was asked to examine several important areas of NIH-supported clinical research including, but not limited to, the General Clinical Research Centers (GCRC's), the NIH Clinical Center (CC), the recruitment and training of future clinical researchers by NIH, the conduct of NIH-sponsored clinical trials, and peer review of clinical research supported by NIH.

The CRP was also asked to deliberate on a number of issues that were not prominent concerns at the time of the IOM study, but reflect the rapidly changing clinical research environment today. These include the expansion of managed care, the emphasis on training primary care physicians, and the extensive transformation of the academic health care infrastructure.

By the time the CRP report was completed in December 1997, a number of the panel's recommendations were already being implemented. The complete report is available on-line at http://www.nih.gov/news/crp/97report/index.htm.

Question. And, what do you plan to do immediately to rectify this situation and make up for lost time?

Answer. NIH was implementing the recommendations of the Clinical Research Panel as they were brought forward. For example, the recommendation to track that part of the NIH budget devoted to clinical research was implemented by the creation of a prospective system to monitor the grants and other awarded funds which are devoted to clinical research. The recommendation to create a Clinical Research Training Program was implemented immediately. The creation of the new programs of career enhancing awards for clinical researchers continues this pattern.

Question. It is my understanding that the number of first-time physician applicants for research projects grants declined by 30 percent between 1994 and 1996? At that rate, we will have no new physician applicants by the year 2000.

Answer. We have noticed a reduction in the number of new physician applicants for NIH research grant support between 1994 and 1997. In 1997, the NIH received 1,769 applications from individuals with the M.D. degree who had never received NIH research project grant support. This number is approximately the same as observed in 1996 and is 22 percent below the peak observed in fiscal 1994.

To address this important issue, the NIH has recently announced new career award mechanisms designed to offer at least 80 young physicians new training opportunities in clinical research each year. This same initiative will also increase opportunities for mid-career clinical researchers who will serve as mentors. In addition, the initiative will support the development of high-quality instruction in clinical research methodology. We are hopeful that these new awards will ultimately increase the number of physicians submitting applications for clinical research grants. To provide some indication of the magnitude of this initiative, we estimate that, if all of the entry level awards supported by this program apply for research project grants after completing their career awards, there will be a greater than 10 percent increase in applications from physicians each year for several years into the future.

The NIH has also requested an increase in NRSA stipends designed to improve the attractiveness of NIH training opportunities. We hope this change will reverse recent reductions in the number of young clinicians engaged in postdoctoral research training. To attract bright young clinicians into NIH research careers, I believe that the NIH must modify its training and career award programs to accommodate changing revenue streams within the academic health center. We will continue to monitor application rates from clinicians in the future.

Question. First, can you tell us whether this trend continued in 1997, and are you not alarmed by this stunning decline?

Answer. As I have described, the number of new physician applicants has declined slightly and we are taking measures to encourage additional applications in the clinical area. However, our concern over this decline is mitigated by the fact that when we look at overall awards made to all those holding MD degrees, including both first-time applicants and those who have previously held NIH awards, there has actually been an increase. In fiscal year 1994 the NIH made more than 1,700 awards for new and competing projects to MD's, and this number has gradually but steadily increased to more than 2,000 in fiscal year 1997.

QUESTIONS SUBMITTED BY SENATOR CHRISTOPHER S. BOND

POLYCYSTIC KIDNEY DISEASE [PKD]

Question. I understand that there have been a number of recent breakthroughs in Polycystic Kidney Disease, leading many knowledgeable scientists to believe that effective therapies might be available for PKD patients in the near term. Is this true?

Answer. In the last two years, dramatic progress has been made in understanding the cause of PKD. The genes that are mutated in the two commonest forms of PKD (PKD1 and PKD2) have been cloned and sequenced and the protein structures deduced. We are beginning to understand the possible function of this protein, called polycystin, which is defective in patients with PKD1. This exciting finding may offer new insights into the mechanisms which cause renal cysts to form and grow, and is providing possible strategies by which to interfere with cyst growth. There is reason for optimism that this may lead to treatments which prevent progressive renal failure in patients with these diseases.

Question. If so, why has the PKD portfolio at NIDDK been reduced substantially in the last two years to a surprisingly small $5.2 million projected for this year?

Answer. While it is true that NIDDK funding for PKD research dipped in fiscal year 1997, overall the program has grown consistently and substantially over the past decade. This growth has occurred because of the scientific opportunities including the discovery referred to above.

From its start at about $1.5 million in fiscal year 1988, NIDDK funding for PKD research will reach an estimated $7.5 million in fiscal year 1998. About $5.2 million is for continuing noncompeting projects and the remaining $2.3 million is for new and competing renewal awards that have already been funded or that we anticipate funding. The fiscal year 1998 amount is a 19 percent increase over the fiscal year 1997 total of $6.3 million and represents a return to the peak funding for PKD research, which was $7.5 million in fiscal year 1996.

Question. The Appropriations Committees of both the House and Senate have recommended increased funding for PKD research for the past 6 years. How do you account for the very modest $5.2 million projected for this research in the present year?

Answer. As stated above, NIDDK funding for PKD research will reach an estimated $7.5 million in fiscal year 1998. The $5.2 million of the fiscal year 1998 is for continuing noncompeting projects and the remaining $2.3 million is for new and competing renewal awards that have already been funded or that we anticipate funding.

Question. Is the NIH ignoring the concerns of the Senate and House?

Answer. The NIH is, by no means, ignoring the concerns of the House and Senate. To capitalize on discoveries and encourage increased research on PKD, NIDDK has sponsored successful scientific meetings and solicitations for grant applications. Meetings held in 1995, 1996, and 1997 allowed researchers to benefit from the presentations and comments of peers, fostered collaborations and helped formulate subsequent NIH research solicitations. Since 1985 the NIDDK has issued six Requests for Applications and Program Announcements (PA) to increase interest in PKD research. The most recent was a PA with a $2.5 million targeted funding level.

Question. A number of the top administrators and scientists at the NIH have recently argued that PKD research is the hottest thing going on in kidney research. Some have characterized it as the most promising area in all of biomedical research. What kind of priority setting is going on at the NIH when the PKD research portfolio has been reduced by 30 percent in the past two years?

Answer. The statement that the PKD research portfolio has been reduced by 30 percent in the past two years is inaccurate. The estimated fiscal year 1998 funding amount for PKD research represents a 19 percent increase over fiscal year 1997. The NIH has a solid commitment to PKD research and we are optimistic about the future of NIH-funded research on PKD.

The NIH and the Polycystic Kidney Research Foundation have been involved in planning a new initiative for fiscal year 1999 to develop better methods to assess progression of PKD using state-of-the-art radiographic imaging techniques. This study should provide the needed tools to measure treatment outcomes in future trials. Also relevant to process in learning more about PKD is a new initiative to identify genetic loci and genes that either protect people from or predispose them to progressive kidney failure, the so-called nephropathy susceptibility gene initiative. As you know, many people at risk for renal disease, including some PKD-gene carriers, do not develop renal disease, while others progressively lose kidney function. It is expected that these studies will help to explain this phenomenon.

PRIORITY SETTING

Question. We have all witnessed a significant increase in the NIH's budget over the past few years. I am concerned about how the NIH sets priorities. What are the primary factors utilized at the NIH for setting these priorities for research?

Answer. The principles and mechanisms that guide the NIH in the continuous activity of managing its budget are comprehensively discussed in a recent NIH document, "Setting Research Priorities at the National Institutes of Health." The basic theme of the priority setting booklet is that the NIH builds its budget by evaluating current scientific opportunities and public health needs while maintaining strong support for investigator-initiated research. A copy of this document is attached for your information.

ATTACHMENT—SETTING RESEARCH PRIORITIES AT THE NATIONAL INSTITUTES OF HEALTH

OVERVIEW

Given the importance of medical research in fighting disease and improving the nation's health, the enormous range of possible subjects of research, and the thousands of talented investigators who seek funding, the National Institutes of Health (NIH) must make choices about where and how it spends its money, approximately $13 billion in fiscal year 1997.

The process of choosing is routinely called setting priorities, a phrase that is shorthand for an elaborate application of principles and mechanisms the NIH uses for evaluation and judgment. Making choices is complex and often difficult: the NIH's mission and its history demonstrate that no one thing—no single disease, no single investigator, no single Institute, no single method of funding research—comes first or claims permanent priority over others. The principles and mechanisms that guide the NIH in the continuous activity of managing its budget are the subject of this booklet. Some observations about the influences and facts that condition the process may add clarity. It is important, however, to keep in mind that this booklet describes the ways things work at the NIH now; it is neither a justification nor a defense of a system that has succeeded, but which also is imperfect.

Managing the NIH's budget requires many decisions

There are 21 Institutes and Centers (called Institutes for convenience) within the NIH. By law each must be funded and each is committed to certain domains of medical science (e.g., cancer, heart disease, aging, mental health). Their existence sets rough limits on both the current budget and future budgets.

The appropriations process, from the President's request through final passage of the bill by the Congress, obligates each Institute to determine how to allocate its own funds among many different activities of science—including investigator-initiated grants, the intramural research program, and research training, among others. These decisions are tailored to the Institute's research objectives.

Each Institute also decides which specific research grant applications to fund among those proposed by researchers working at universities or other research centers and whether to emphasize certain research topics within its domain.

The net effect of these decisions determines how much of the entire NIH budget is devoted to work in certain scientific disciplines (e.g., neurosciences, microbiology, genetics) or on certain diseases.

It is also important to note that past decisions—from the creation of an Institute to the establishment of research centers to the awarding of grants to individual investigators (averaging four years)—have longer lives than the annual appropriations. This leaves only a part of the entire budget available each year for new opportunities.

Assessing research according to money spent on specific diseases is imprecise

Public and congressional inquiries about how the NIH spends its money often focus on the amounts given to certain Institutes or devoted to research on a specific disease.

—Research on any disease is not confined to one Institute, and no Institute is dedicated to a single disease. An Institute's budget is an inadequate measure of support for research on specific diseases. Research into many diseases is often carried on in several Institutes simultaneously, e.g., several Institutes are supporting research on Alzheimer's disease.

—It is also extremely difficult to assign the large investments in basic research to any one disease. For example, the number of grants specifically devoted to heart attacks is smaller than the number of grants awarded for research on cardiac muscle biology and lipid metabolism, which have obvious and promising implications for understanding, preventing, and treating heart attacks.

—From long experience, we know that research aimed at one target often hits another, e.g., a gene causing breast cancer in mice plays a role in the development of brain tissue. It is impossible to attribute research and discoveries like this to one disease.

There is, consequently, no "right" amount of money, percentage of the budget, or number of projects for any disease.

There are limits to planning science

Science, dealing with the unknown, is inherently unpredictable (see "How Science Works" later in this booklet). Moreover, unforeseen crises and opportunities may re-

quire the NIH and individual scientists to abandon their plans or change the direction and focus of their research. Consider two examples:

—The emergence of new diseases (AIDS or Ebola), the rise of importance of others as our society changes (Alzheimer's disease), and the resurgence of old ones (tuberculosis) all require urgent attention. The expense of supporting new and unforeseen research, however, does not displace the need to continue investigations into heart disease, muscular dystrophy, arthritis, or diabetes.

—Unplanned and untargeted basic research on DNA in the 1960's and 1970's permanently changed the way medical research is done. These studies furnished the ground for the biotechnology industry that provides important therapeutic products, which we would otherwise not have, and set the stage for the Human Genome Project that has revolutionized our approach to virtually all disease.

Consequently, slightly over half, on average, of each Institute's budget supports the best research grant proposals regardless of specific applicability to prevention and treatment of a disease, but in expectation that their results will contribute to advances against diseases within their purview as well as diseases in other Institutes and to our knowledge generally.

It is also true, however, that a decision to increase support of one area of medical science—by design, according to a directive, or in response to a critical opportunity—now usually comes at the expense of something else and affects the planning of future research.

Decisions to create new Institutes or to expand research into specific diseases were historically accompanied by very large increases in the NIH budget. No programs had to be cut or attenuated. This is no longer the case. Consequently, directives to spend more on a specific disease or the need to respond to swiftly emerging threats (e.g., Ebola) constrain spending on other diseases or on fundamental research.

Various criteria shape the NIH's budget

Some general criteria, which condition the allocation of resources, are both influential and continuous.

—The NIH has an obligation to respond to public health needs, as judged by the incidence, severity, and cost of specific disorders. Calculating these needs is difficult, and there is not always a clear correlation between expense and results.

—The NIH applies stringent review for scientific quality on all research proposals in order to return the maximum possible on the public's investment in medical research.

—As an administrator of science, the NIH has learned that many significant advances occur when new findings, often unforeseen, expand experimental possibilities and open new pathways for the imagination. Not all problems are equally approachable, no matter their importance to public health. Pursuit of a rare disease may often have unexpected benefits for more common problems. By the same token, increased spending on a disease is wasteful when there are neither promising pathways to follow nor an adequate number of qualified investigators to fund.

—The NIH's portfolio must be large and diverse. Because we cannot predict discoveries or anticipate the opportunities fresh discoveries will produce, the NIH must support research along a broad—in fact, expanding—frontier.

—The NIH must continue to support the human capital and material assets of science. To this end, the NIH's budget supports research training, acquisition of equipment and instruments, some limited construction projects, and grantee institutions' costs of enabling the research programs.

To develop its research programs, the NIH seeks advice from many sources

The complexity of both planning budgets and spending money are apparent. With no claim to a monopoly on good ideas, the NIH seeks opinions and counsel from many quarters:

—The extramural scientific community, including both individual researchers and professional societies.

—Patient organizations and voluntary health associations which may deal directly with the NIH or indirectly through Congress and the public media.

—The Congress and the Administration.

—The NIH staff.

How the NIH solicits and acquires opinion and advice is detailed in "The Institutes" and "The Role of the NIH Director," the last two sections of this booklet. Some examples include:

—Review groups of accomplished investigators evaluate grant applications for merit.

—Each Institute convenes national advisory councils to review policy, with members from the public and from the medical and scientific communities.
—Every year, the NIH holds conferences and workshops to gather opinions and ideas on specific scientific, health, ethical, and administrative questions. For example, a Parkinson's workshop recently brought together clinicians and geneticists who together identified a chromosomal locus (and more recently the gene) that predisposes to the familial form of the disease. Their findings will also attract new investigators and could lay the groundwork for advances against the more common (non-familial) form of the disease.
—The NIH uses advisory groups of outside experts to assess trans-NIH activities (e.g., the reviews of the NIH intramural research program and AIDS research program) and to recommend budgetary and programmatic improvements.
—In addition to consultations with the Congress, patient organizations, and the Administration, Institute directors and staff seek opinions from other Federal agencies for both budgetary and programmatic insight, e.g., OMB and DHHS.

The final responsibilities for the complex and imperfect process of evaluating opinion, assembling the individual Institutes' portfolios, and determining expenditures remain with the NIH Director and the directors of the Institutes.

Evaluating opportunities and public health needs is complex

The NIH builds its budget by evaluating current opportunities and public health needs while maintaining strong support for investigator-initiated research. The NIH's requests for increases in funding for specific Institutes are based on proposals that: Exploit new discoveries, such as the isolation of new genes for human disease; encourage study of diseases that are only now able to be understood because of recent new discoveries; and strengthen technologies applicable to many disciplines and diseases, e.g., computer science, imaging, or gene mapping.

The emphasis the NIH places on funding unsolicited proposals from investigators from individual laboratories (investigator-initiated research) does not dismiss the efforts of advocates of disease-oriented research or propose they should not do more to advance their causes. Nor does the emphasis erect a wall between basic research and clinical research. The Parkinson's disease workshop mentioned above and others on autism, spinal cord injury, and diabetes mellitus have proved how profitable such collaboration can be.

It is also a responsibility of scientists to explain science and scientific progress to the public. Medical science is slow and difficult; its advances do not occur at equal rates on all fronts; the long-term relevance of basic science to treating human disease may be hard to see; scientists may be inexpert in explaining the connection between their work and the nation's health. The many criteria, standards, and influences that all operate simultaneously on the NIH are of themselves complex. There is, however, another component: science is not like other businesses. To explain this proposition, the next section expands on some ideas already here and presents some new ones.

HOW SCIENCE WORKS

Although the word "science" comes from the Latin scientia meaning "known things," scientists and the practice of science exist because of what we do not know. The aim of science is to move what we do not know into the realm of known things and then, with a greater store of knowledge, begin again, as if advancing a frontier. This basic truth about science makes it different from other enterprises. Many industries normally manage their resources, labor, and money to produce the same or similar products over and over. Science deploys its resources and talents to explore new areas and produce fresh results, which are not endlessly replicated, but which prepare the way for future and different explorations.

The many disciplines of medical research contribute to our store of knowledge and to one another, and all deserve exploration and funding. Discoveries that will increase our knowledge of the causes, progression, and treatment of asthma, for example, may stem from epidemiological, clinical, and molecular research, conducted by teams of investigators building on the discoveries of their predecessors, including those in other fields.

Since it is impossible to know with certainty which area will produce the next important discovery, the community of science, of which the NIH is a part, has to be open to all ideas. No one field has all the answers, but investigators in many different fields can ask the questions that will provide more knowledge about disease and health.

The uncertainty of where the most valuable discovery lies makes the setting of priorities tremendously difficult. But this uncertainty also fosters a creative and collaborative tension within the scientific community (and among the various Insti-

tutes at the NIH) which in turn imposes the discipline of evaluation, competition, and productivity on the choices we make about spending public money.

To approach it differently, science and the management of science are neither chaotic nor navigation by dead reckoning. Given the NIH's internal rigor and the legitimate interests of the public, including advocacy and patient groups, the Congress, and other scientists, expenditures for medical research are always in public view. Though different from other enterprises, science has businesslike aspects: Applications for grants are subject to peer review (which is discussed later in this booklet) and rated for merit, and investigators define and justify the goals and budgets of their research with precision.

It is a striking characteristic of science that it requires both creativity and precision to generate ideas and results. The precision with which investigators and administrators describe the targets and outcomes of research, however, cannot alter the inescapable truth that many of the results of research are unpredictable, given the pursuit of unknown things. The investigator examining patients with ataxia telangiectasia, a rare genetic disease, who discovers something new about the origins of cancer has not "stumbled" on a discovery, but rather has put himself or herself in a position to make the discovery and to bring it into the realm of known things which would not have happened otherwise.

This unpredictability has three important implications of its own.

First, science is by nature structured and self-correcting so that either a predicted or an unforeseen discovery has the advantage of adding to basic scientific knowledge and giving new direction to further inquiries. This self-correction, carried out under public scrutiny of the results, means that science operates in a dynamic marketplace in which an absolute or top-down control would be stifling. Control from the top or by directive grows inefficient as workers duplicate one another's labor or merely produce the same results; it tends to be slow to respond to new discoveries which can make the original grand design obsolete over night. Science's self-correction, on the contrary, demands more approaches and is quicker to adapt to change.

Second, scientific work is not a commodity that can simply be bought. Shifting priorities is more than the redistribution of dollars—more money alone does not solve problems. Recruiting new talent by advertising a new scientific opportunity, inviting scientists in allied fields to look across the fence, and training new investigators to work in a new area will produce more meritorious applications for funding and, most important, better results in the treatment of human disease.

Third, science and its administrators must constantly reevaluate and often change their priorities in light of new discoveries. Very simply, science itself sets its priorities as it refreshes and enlarges our knowledge: The more we know, the better the questions we can ask and the more wisely we can spend our money.

It is by asking as many questions as we can and by prudently spending what we have that the NIH can identify and pursue the most promising medical priorities. As priorities shift and acquire sharper focus, we are better able to look across the spectrum of scientific disciplines and of diseases. Our constantly renewed knowledge enables us to examine, for example, the effects of pesticides not on one kind of cancer but on all cancers, or to ask the next big question—what turns genes on or off?—with the confidence that we will soon begin to find answers which in turn will allow us to target diseases like Alzheimer's disease, cancer, and diabetes.

There are many reasons that America is blessed with a robust community of medical science and that the NIH is the world's greatest medical research organization. The freedom to explore, the training in our colleges and universities, an enthusiastic public, and an understanding Congress have all contributed to the nation's preeminence in medical research. And so, in part, has the community of science itself because of its abilities to refresh its priorities in order to seek opportunities that are ripe for pursuit and capture.

The rest of this booklet describes the principles and processes by which the NIH and its Institutes set their priorities and make their choices. It will also consider in greater detail the roles played by the Congress and the Administration, by professional societies, and by organizations focused on particular diseases in funding the research that brings what we do not know into the realm of known things.

NIH'S HISTORY

Decisions made in the NIH's early years still shape the agency's structure and activities. The NIH as we know it today is rooted in Constitutional language establishing the promotion of the general welfare as a goal of government. Throughout this country's history, citizens have looked to government to provide health care to specific populations, for collection of vital statistics on health, and for sanitation and control of infectious diseases. Although the NIH was born on Staten Island in 1887,

with another name and a mission to conduct research on infectious diseases, the modern NIH took shape shortly after World War II, when science came to be seen as a public good and supporting health research became a focus for public and congressional enthusiasm and funding.

In 1946, the NIH intramural research program (the research conducted by government scientists on the NIH campus in Bethesda, Maryland, since 1938) was joined by the NIH extramural research program. This occurred when wartime government medical research contracts at universities and medical schools around the country were transferred to the NIH and converted into grants. The transfer was an important event, for it firmly established the importance of enlisting scientists in the country's medical schools and universities in the national research effort against disease.

Just after the extramural research program began providing grants to scientists in universities and medical schools, the NIH recognized it needed a system to help select the highest quality research grant applications for funding. This rapidly evolved into the NIH peer review system, which relies chiefly on non-government scientists to review grant applications for scientific merit.

The NIH also recognized that supporting research demands a greater commitment than simply funding individual research projects. Since 1947, NIH grants have included compensation to the institutions where the research is to be conducted for the expenses of maintaining the research facilities and for administering the grants. Training future generations of laboratory and clinical researchers also became an established goal of federal funding of science.

The intramural research program on the Bethesda campus—which primarily focused on basic or laboratory science—was enhanced by the opening of its research hospital, the Clinical Center, in 1953. This addition acknowledged the importance of translating discoveries made in the laboratories to the bedside, and provided a way of taking questions raised through observation of patients back to the laboratory for exploration. The need to fund both laboratory research and clinical research thus became an established principle.

Encouraged by the availability of public funding, growing numbers of investigators around the country—many of them trained on the Bethesda campus—directed their efforts to basic and clinical research and applied to the NIH for research grants.

The NIH cultivated the cadre of talented, well-trained scientists eager to propose their ideas to the NIH for funding, thus creating the investigator-initiated research application as a way of tapping the best ideas to understand and combat disease.

The following two decades saw significant increases in funding for the NIH and the development of new programs. New Institutes continued to appear in response to legislative or executive decisions. The establishment of each new Institute represented a decision about the priority to be given to a disease or class of diseases (for example, the National Institute of Allergy and Infectious Diseases was established in 1948 and the National Institute of Neurological Diseases and Blindness in 1950), to aspects of the human life span (the National Institute of Child Health and Human Development was established in 1963 and the National Institute on Aging in 1974), and to broad areas of basic research and technology (the National Institute of General Medical Sciences was established in 1963 and the National Library of Medicine became a component of the NIH in 1968). Each of the NIH Institutes has been provided a separate, annual budget from the Congress, thus positioning each of them as a primary locus for setting priorities and making budget decisions within their domains. (See Appendix for list of Institutes)

HOW THE NIH FUNDS MEDICAL RESEARCH

Most of the NIH's budget supports the individual research projects conceived of and conducted by either government scientists working on the NIH campus or scientists based elsewhere, at universities, medical, dental, nursing, and pharmacy schools, schools of public health, non-profit research foundations, and private research laboratories. These scientists have been trained in one or more disciplines of science and are committed to enhancing knowledge related to human health and disease through research. NIH support of these research projects includes the salaries of scientists and technicians and the cost of equipment such as lasers or computers; of supplies such as chemicals and test tubes; and of procedures conducted with research patients.

Funding medical research also includes paying the costs associated with research, such as maintenance of buildings, electricity and library services, care of laboratory animals, and salaries of administrative staff who, for example, handle the financial aspects of the grants and set up review panels to ensure that patients participating

in research are adequately protected. This is true for all research, whether conducted in the intramural program by government scientists or through the extramural program by scientists in universities and medical schools or by scientists working in industry. These associated costs account for about 30 percent of the total cost of research projects.

In fiscal year 1996, approximately 11 percent of the NIH budget was spent in the intramural program and more than 83 percent of the NIH budget was used to fund research by scientists working elsewhere across the country (see FIGURE 1). In the extramural program, the NIH emphasizes funding investigator-initiated applications that originate with individual scientists. These Research Project Grants (or RPG's) can fall anywhere along the continuum of medical research, from molecular and cellular investigations to studies of new drugs to treat human illness. In fiscal year 1996, the NIH funded approximately 25,000 RPG's; the most common type, known as an R01 grant, supports a single project and a single principal scientist. Some Research Project Grants are program project grants, which support multi-disciplinary projects conducted by several investigators working on different aspects of a research problem. Yet another way the NIH supports research is through research centers. This type of grant is awarded to research institutions under the leadership of a center director and a group of collaborating investigators. Center grants fund multi-disciplinary programs of medical research and also support the development of research resources, aimed at integrating basic research with applied research and promoting research on clinical applications.

Another part of the NIH's budget is spent on research and development contracts, which are awarded to non-profit and commercial organizations for work requested and overseen by the NIH staff. For example, development of the drug taxol for treating breast and ovarian cancer resulted from NIH contracts aimed at developing better methods for isolating the anti-cancer agent from the Pacific yew tree and for clinical trials of its efficacy.

The NIH also supports training that enables young scientists to become skilled investigators who are available to apply their talents to future medical challenges. Trainees, who are at the predoctoral or postdoctoral level, are supported through grants either to individuals or to institutions such as medical schools and universities. Most of the cost is for stipends for the students. In recent years, the NIH has focused on enhancing the quality of training and improving the prospects for under-represented minorities rather than on increasing the total number of students in research training.

An imperative of supporting medical research is making a commitment to scientists to fund their work for a period of time sufficient for the projects to produce results. Research takes time. NIH grants are awarded for an average of four years; therefore, the bulk of each Institute's annual budget is already committed to funding the remaining years of research projects. The need to continue funding projects over multiple years is an important criterion when deciding to fund new projects. Accordingly, in any given year, only about 25 percent of the total funds allocated for research projects is available to fund new projects that may change the course of a line of research or move research into an entirely new area.

ASSESSING HEALTH NEEDS AND SCIENTIFIC OPPORTUNITIES

Deciding how and where to distribute the NIH's money—that is, determining the requirements of basic and clinical research, identifying whether a grant, contract, or center is the best means of funding a particular area of research, and responding to the emergence of new medical problems and new patient advocacies—is a challenge the NIH must face each year. It requires fresh assessment of the nation's health needs and renewed evaluation of scientific opportunity. Yet there are many ways of assessing health needs and many facets to identifying, and sometimes creating, scientific opportunities.

Assessing the health needs of the nation

The NIH is responsible for conducting research on the broad array of health problems affecting people in this country, but it cannot simply allocate funds to research on one disease or another according to a set formula. There are many possible ways of measuring the health needs of the nation and distributing research funds, each with advantages and drawbacks. If health needs alone were used to gauge priorities, research funds might be distributed based on: The number of people who have a particular disease; the number of deaths caused by a disease; the degree of disability produced by a disease; the degree to which a disease cuts short a normal, productive, comfortable lifetime; the economic and social costs of a disease; and the need to act rapidly to control the spread of a disease.

Using any one of these criteria to make funding decisions would produce a different result:

—Funding according to the number of individuals affected would emphasize common diseases, but might have a limited effect on overall health and survival (for example, much research would be done on the common cold and allergies and little on childhood cancers).

—Funding according to the number of deaths would neglect chronic diseases that produce long-term disability and high costs to society (diseases such as mental illness and arthritis would be neglected).

—Funding according to disability or economic cost raises questions about how well disability or economic costs can be quantified, and whether only the direct costs of medical care should be counted or whether indirect costs (e.g., lost productivity), which are difficult to measure, should also be included.

—Funding according to the economic cost of illness would under-fund diseases that result in a short illness and rapid death (this choice would provide a great deal of funding for Alzheimer's disease and muscular dystrophy and little, or none, for sudden infant death syndrome or certain types of cancer).

—Funding based solely on immediate dangers to public health may divert funds from areas of research of much broader long-term impact (this choice would mean that a great deal of research would be done on AIDS and tuberculosis and little on Parkinson's disease and asthma).

All of these criteria for weighing health needs are justifiable, yet applying any one of them exclusively would cause the neglect of some classes of diseases altogether. Moreover, any of these criteria used exclusively would, for example, under-fund research on rare diseases, research that has taught us much about the diseases themselves and a great deal about normal human biology, other diseases, and new approaches to treatment. For example, ataxia telangiectasia, xeroderma pigmentosum, and Bloom's syndrome are very rare inherited disorders that lead to an increased risk of cancer and hypersensitivity to ultraviolet radiation, X-rays, and some chemicals that cause mutations in DNA. Nonetheless, research into these diseases has not only helped people with those conditions, but has provided considerable knowledge about the causes of cancer in general.

Funding the continuum of research, from basic inquiries to clinical applications

Clearly, it is not easy to determine how to allocate funds according to the impact of various diseases. But the problem is actually much more complex than it appears, because while the NIH focuses much of its research on combating specific diseases and much of its funding supports research projects that are of obvious relevance to specific diseases, the NIH also places a high priority on funding basic research. These basic research projects may appear initially to be unrelated to any specific disease, but might prove to be a critical turning point in a long chain of discoveries leading to improved health. Each of the NIH Institutes supports basic research likely to advance particular areas of science that might prove relevant to clinical problems important to that Institute's mission. By supporting disease-related and basic research projects simultaneously, the NIH can achieve both near-term improvements in the diagnosis, treatment, and prevention of specific diseases as well as long term discoveries in basic science that in time will produce great advances in our ability to understand, treat, and prevent disease or delay its onset.

Consequently, the NIH uses no one measure exclusively, but all of these measures to assess the nation's health needs. The evidence of improved health in the past 50 years overwhelmingly demonstrates the importance of complementary accomplishments in basic and applied research. To continue improving the nation's health, the NIH also factors into its funding decisions current and evolving scientific opportunities.

Assessing scientific opportunities

Assessing scientific opportunities is no less complex than evaluating health needs. It requires expertise in various scientific fields, breadth of vision across many disciplines, and judgment to determine the likely yield from making investments in particular areas of research. It is never known with certainty which scientific areas will produce the greatest returns soonest. At any given time, moreover, some fields are judged to be progressing more rapidly than others and more likely to repay the investment in them by yielding great discoveries that advance knowledge. Scientific opportunities may arise from many sources, from a single technological development, or from a scientific "breakthrough." Often the breakthrough or even the knowledge accumulated is in an area that appears only remotely related to the area where it will have its greatest impact. Recognition of these scientific opportunities allow investigators to approach previously unanswered questions in new ways.

—*Basic Research Often Contributes to Specific Diseases*.—The unexpected contribution of basic research to specific diseases is evident in the case of recombinant DNA research, sometimes calledgenetic engineering. NIH support of basic research on enzymes and genes over many decades, exciting and challenging to scientists but initially with no apparent relevance to practical applications or human disease, has led to a host of new drugs and diagnostics. For example, in the mid-1980's human growth hormone produced by recombinant DNA methods was approved for treating certain growth problems in children. This synthetic human growth hormone proved to be safer than using pituitary-derived human growth hormone extracted from cadavers, which had been found to transmit the virus causing Jakob-Creutzfeldt disease, a deadly neurological disorder. In addition, recombinant DNA techniques revolutionized how biological research is done and gave rise to a new industry—biotechnology. This technology, in just over a decade, has had a profound impact upon medicine, agriculture, and the chemical industry.

Work in blood lipid research and heart disease illustrates how health needs and scientific opportunities coincide. Nearly 50 years ago, the NIH identified research on coronary heart disease as an important health priority. This disease is caused by atherosclerosis, the build up of lipids (fatty substances) in the heart's main arteries, which can block blood flow and thereby cause the death of heart tissue—that is to say, a heart attack. Progress in this area was slow at first, but then scientists began to associate lipids (such as cholesterol, carried in the blood) with the development of atherosclerosis in humans. In the early 1960's, research on the NIH Bethesda campus led to a way of classifying various types of lipid abnormalities in families. This work led to meaningful associations between variations in lipid metabolism and atherosclerotic heart disease. In addition, through carefully planned, long-term epidemiologic studies (studies of the occurrence and distribution of disease in large groups of people), the understanding emerged that risk factors such as blood cholesterol levels and cigarette smoking, as well as high blood pressure (which was recognized much earlier as a predictor of premature death) can make people susceptible to disease. Identifying scientific opportunities in basic, clinical, and epidemiological research on lipid metabolism has resulted in phenomenal progress in understanding the underlying processes that lead to atherosclerosis, as well as its prevention and treatment.

Benefits from this research include the development of cholesterol lowering drugs and changes in behavior (less dietary fat, no smoking, more exercise), with a dramatic decrease in age-adjusted mortality from heart disease as a consequence. Still, many challenges in coronary heart disease remain. Future targeted areas of research include an analysis of why cholesterol accumulates in artery walls and ways to facilitate its removal, and prevention of the accelerated form of atherosclerosis which causes between 30 and 40 percent of grafts to become narrowed again after bypass surgery.

Capitalizing on scientific opportunity depends, in part, on individual scientists designing specific research projects they believe have the greatest significance and offer the best chance of producing important knowledge. Therefore, the NIH places great reliance on investigator initiated research—projects conceived by individual scientists and submitted to the NIH to undergo review by other scientists and be considered for funding. Sometimes, the NIH solicits research applications through Program Announcements (PA's) and Requests for Applications (RFA's), as described in more detail later in the booklet. Review for scientific merit is conducted by groups of predominantly non-government scientists (with knowledge in a relevant area) convened as panels called study sections. Currently, there are about 100 study sections, which normally meet three times a year to review grant applications.

The merit of a research proposal is assessed by several criteria, including: the importance of the problem or question; the innovation employed in approaching the problem; the adequacy of the methodology proposed; the qualifications and experience of the investigator; and the scientific environment in which the work will be done. Currently, slightly more than one in four grant applications received by the NIH is ultimately funded. (See FIGURE 2)

In addition to judging the scientific merit of individual research grant applications, the study sections, in aggregate, have another important effect on the science supported by the NIH. After each study section reviews and rates the grant applications assigned to it by NIH staff, the relative ratings of applications from all study sections are then integrated. Because, for the most part, grants are funded in order of their rating relative to other applications in the same field, the fact that a study section has been constituted in a particular area usually guarantees that at least some applications in that area of science will be funded. Because of this effect, the NIH must monitor changes occurring in science to ensure that study sections, as

a group, are appropriately constituted so that they can assess the research applications in all areas of scientific endeavor. The creation of new study sections, the restructuring of established study sections, and the use of special panels has such an important effect upon the areas of science funded by the NIH that any proposed changes of the study sections are carefully evaluated.

—*Breakthroughs Bring New Opportunities*.—As an example of a breakthrough offering new opportunities, consider recent discoveries in the causes of obesity, which have stimulated the NIH to invest more money in this particular area of research. Obesity affects nearly one-third of the U.S. population. It is associated with an increased risk of high blood pressure, high blood cholesterol, and Type II diabetes (or non-insulin dependent diabetes) and is an independent risk factor for coronary heart disease and osteoarthritis. Obesity has been studied for many years from many perspectives, and is of interest to at least 10 NIH Institutes. But the problem has remained intractable. Recently, scientists have found that mice and rats with certain inherited mutations that predispose to obesity lack a hormonal mechanism for maintaining healthy patterns of eating and activity. Through this mechanism, the animals—and, presumably, humans—regulate diet and exercise through the brain's response to a hormone, called leptin, that is produced by fat cells. Although it appears likely that this hormone is itself deficient in a significant number of obese people, the isolation of the genes for leptin and the leptin receptor has already deepened our understanding of metabolism and stimulated additional fundamental research. Encouraged by the new findings, more and more scientists are moving into this field of investigation. This is likely to expand knowledge of the causes of obesity, hasten the development of more effective medical therapies for weight problems, and ultimately help to reduce the prevalence of many chronic, obesity-related diseases.

THE INSTITUTES

The NIH is made up of 21 Institutes and Centers, each with a separate, annual budget from the Congress and, most critical to the question of priorities, each with a mission established by the Congress. To decide which grants to fund and which programs to support in terms of its mission, the director of each Institute confers with the Institute's program leaders. Like the director, they are scientists knowledgeable in research relevant to the Institute's mission and responsible for administering that area of research. The director also confers with members of the Institute's national advisory council (as mandated by the Congress), which meets three or four times a year to review all grant applications eligible for funding (after peer review) and to make recommendations on matters of policy and research emphasis. The council, which is composed of both scientific and public members with expertise relevant to the Institute's mission, may also make recommendations to the Institute director about funding particular, meritorious grants that are seen as very important but which may not have received the best scores from scientific reviewers. The council may also review and comment on special initiatives proposed by the Institute or, for example, on research training policies.

The director engages in discussions with scientists in the extramural program and intramural investigators, with groups of patients and their families interested in research on particular diseases, with professional and scientific groups, with representatives of the Administration and members of Congress, and with the public. (See FIGURE 3)

Advice is sought on many issues, including: The potential impact of particular research areas on human health; the critical scientific opportunities; gaps in knowledge that merit special effort; the cost of specific research projects and their benefits; economic issues, including the potential effects of the research on quality of life; the balance between intramural and extramural research; the balance among laboratory research, clinical research, and epidemiological research; and the specific type of funding to use for various research areas, for example, selecting among grants, contracts, and support of centers (see definitions of the types of funding).

Funding the highest quality science

The advice an Institute director receives from many sources on the factors enumerated above provides much of the information needed to decide which grants and programs to support and which programs to initiate or eliminate.

As described earlier, research projects emerge from the creativity, skill, and knowledge of extramural scientists who submit grant applications to the NIH. These are reviewed by panels of scientists who are expert in the proposed field of research. Intramural scientists are also peer reviewed by special groups called Boards of Scientific Counselors, consisting of scientific experts chosen mainly from outside the

government. Thus, it is the highest rated projects that form the backbone of the science funded by the Institutes and by the NIH. The outstanding ideas of scientists objectively rated for their own merit and against publicly stated criteria, like those listed in the previous section, guide the funding decisions of the NIH.

Creating research opportunities

While over half of the Institutes' funds support grant applications submitted by scientists working in universities, medical schools, other professional schools, and independent research centers on subjects they deem important, there is also a complementary process within the Institutes to look at broad areas of science and identify areas of research where special emphasis is warranted. The scientific program leaders in the Institutes help identify scientific opportunities or techniques ripe for application by staying abreast of the scientific literature and attending conferences and meetings of professional societies where new basic and clinical findings are presented and debated. If, for example, an Institute is convinced that a particular area of science offers opportunity, but extramural scientists are not generating research proposals in that area, the Institute may decide to organize a workshop or conference to identify specific scientific needs and opportunities, stimulate research applications, and attract scientists into the field. Or if an Institute wants to encourage extramural scientists to apply their particular skills to a new challenge, Institute program leaders may generate a concept that will become a Program Announcement (PA), an ongoing request for applications in a broad area of interest, or a Request for Applications (RFA), a one-time request for applications addressing a specific scientific area. While only a small percentage of an Institute's funds is spent on research generated in response to RFA's and PA's, this modest investment has been a catalyst for scientific progress.

Although funding is usually determined by the scientific merit of research applications, an Institute may determine that an area of research is of such great promise that funding is provided even if the grant application does not have as high a relative rating as other applications. Only the Institute director has the authority to make this decision and it requires his or her awareness of the whole picture of the Institute's mission. The Institute director may determine that some laboratory research areas are in need of greater attention and require more funding or that some areas are ripe for translating laboratory or animal studies to patients in clinical research studies. The Institute director would discuss these decisions with council members (and others) before funding this research.

The Institutes may also collaborate on common research interests or to advance certain topics of research. For example, both the National Institute of Neurological Disorders and Stroke and the National Heart, Lung, and Blood Institute are interested in stroke, and five Institutes—the National Institute of Arthritis, and Musculoskeletal and Skin Diseases, the National Institute on Aging, the National Institute of Dental Research, the National Institute of Diabetes, Digestive and Kidney Diseases, and the National Institute of Child Health and Human Development—are interested in osteoporosis. Each Institute brings a different perspective and interest to an issue, so their collaborations encourage a multi disciplinary approach to research problems. Sometimes, Institutes cofund research projects that are important to the mission of each.

—*Collaborative Success Story*.—An example of a cross-Institute collaboration that has produced a distinct benefit is the collaboration between the National Institute of Neurological Disorders and Stroke (NINDS) and the National Human Genome Research Institute (NHGRI) in Parkinson's disease. Parkinson's disease is one of the most devastating and prevalent neurodegenerative disorders. The advent of dopamine replacement therapy in the 1960's provided significant improvement for many patients, but the effectiveness of the treatment declines over time and there are troublesome side effects. There has been great interest among both patients and researchers to develop a more effective treatment or even to prevent the disease, but the mechanism of Parkinson's disease is not sufficiently understood.

In 1995, a group of scientists called together by NINDS and other Institutes concerned with Parkinson's disease reached the unexpected conclusion that Parkinson's disease is likely to have a stronger genetic component than was previously thought. NINDS subsequently issued a program announcement inviting research grant applications in the genetics of Parkinson's. In addition, a collaboration involving NHGRI intramural scientists and NINDS grantees was established to study the genetics of families affected by Parkinson's. In November 1996, scientists from the NHGRI and NINDS and their collaborators at Robert Wood Johnson Medical School and in Italy announced they had pinpointed the location of a gene responsible for some cases of Parkinson's disease, showing

that a single gene alteration can cause the disease. In June 1997, the specific responsible gene was identified. Learning where the protein product of the gene is located in nerve cells and how it works may help scientists design treatments for all forms of Parkinson's disease—not only inherited cases, but also those with no familial risk.

The Intramural Research Program

The Institutes sometimes also co-fund research programs with agencies outside the NIH when a scientific opportunity is ripe for both agencies. For example, the National Cancer Institute has collaborated with the Department of Defense on breast cancer studies, and the National Heart, Lung, and Blood Institute has worked with the Health Care Financing Administration on clinical trials of lung reduction surgery in the late stages of emphysema.

Most of the Institutes have intramural research programs. Amounting to approximately 11 percent of the total NIH budget in fiscal year 1996, they focus on specific health problems of special concern to a particular Institute and conduct basic research that may not target a specific disease, but relates to the overall mission of the Institute. As with extramural research, program adjustments, driven by scientific opportunity, are constantly being made to the intramural research programs. The Institute intramural research programs are led by scientific directors, outstanding scientists who, with the Institute director, are responsible for organizing and administering both laboratory and clinical research. They undergo peer review by a Board of Scientific Counselors, which advises the director of the Institute on the importance and quality of the programs, thus providing yet further scrutiny of the distribution of resources to particular research areas and scientists. The intramural programs of the Institutes are also reviewed by the national advisory councils and, sometimes, by additional panels of outside experts convened to address specific issues.

Ideas from outside the NIH also influence research choices. For example, in 1971 President Nixon signed the National Cancer Act, making cancer research a national priority. The Congress, responding to constituents, has also influenced NIH priorities by occasionally identifying research areas that the Institutes should consider more intensely. The Institute directors meet with congressional members and staff throughout the year, and formally during the annual budget hearings, to discuss the research advances of each Institute during the past year and describe their plans for the next. Through both the Administration and Congress, as well as through patient advocacy groups, the public influences the Institutes' decisions. In addition, the national advisory councils set up by each Institute and other NIH advisory committees include members specifically designated as "public" representatives. Proposals and opinions from scientists, the Congress, the Administration, and the public assure that the Institutes establish their priorities in the light of many views. Ultimate responsibility for the allocation of financial and other resources of an Institute rests with the Institute director. After careful evaluation of all of the factors described above, the Institute director determines how and where the Institute's resources will be distributed.

—*IRP Flexibility and Concentrated Expertise*.—Two particular characteristics of the NIH intramural research program proved advantageous at the start of the AIDS epidemic, even before the disease was named. First, the intramural program has the flexibility to redirect resources and expertise quickly when an urgent research problem or public health threat is recognized. In addition, the intramural program has a concentrated expertise focused exclusively on research, and an atmosphere that encourages discussions and collaborations across disciplines.

Intramural scientists studying the immune system and virologists studying the cause of AIDS were able to draw on colleagues in, for example, the dental, neurological, and eye Institutes for consultations on particular clinical manifestations of AIDS. An informal series of patient conferences was set up at the very beginning of the epidemic, in the early 1980's. This concentrated effort led to major accomplishments in AIDS research by the NIH intramural program, for example: a detailed description of the effects of HIV on the immune system; development of a treatment for a viral infection, cytomegalovirus, causing blindness in AIDS patients; early development of policies to screen blood donors (and hence to prevent the further spread of AIDS through the blood supply); understanding of the unusual proteins encoded by HIV genes; development of a blood test for HIV; formulation of hospital guidelines for working safely with AIDS patients; and early studies of the first treatment for AIDS, the drug AZT.

THE ROLE OF THE NIH DIRECTOR

Though each Institute within the NIH determines how it will deploy its talent and funds, the NIH Director plays an active role in shaping the agency's activities and outlook. With a unique and critical perspective on the whole of the NIH, the Director is responsible for providing leadership to the Institutes and for constantly identifying needs and opportunities, especially for efforts that involve multiple Institutes. The Director stays in touch with each Institute's priorities and accomplishments through regular senior staff meetings, discussions with scientific interest groups (scientists who have interests in a specific area and can provide guidance in solving scientific questions), and briefing sessions with Institute directors. The Director also seeks advice from special panels of experts convened to address issues that are of interest to more than one Institute, e.g., reviews of NIH support of research relevant to human gene therapy, the NIH investment in clinical research, the operation of the NIH intramural research program, and the effectiveness of the NIH peer review procedures. In addition to this flow of information from scientists, the Director is advised through discussions with the Administration, usually through the Department of Health and Human Services (DHHS), and with the Congress.

Within the NIH, the NIH Director is primarily responsible for advising the President on his annual budget request to Congress on the basis of extensive discussions with the Institute directors. The formulation and presentation of the NIH budget provides an established framework within which priorities are identified, reviewed, and justified. A key strategy of the NIH Director in the past few years is the identification of Areas of Research Emphasis, broad categories of NIH-sponsored research that show extraordinary promise and productivity. Each year, the NIH Director requests proposals from the Institutes for areas of research that would benefit from special emphasis. Six broad areas of emphasis have been identified for fiscal year 1998; five of these, including "Biology of Brain Disorders," "New Approaches to Pathogenesis," "New Preventive Strategies Against Disease," "Genetic Medicine," and "Advanced Instrumentation and Computers," were also identified in fiscal year 1997. A new Area of Research Emphasis, "New Avenues for Development of Therapeutics," emerged from consideration of Institute proposals for new initiatives for fiscal year 1998. The Institutes are encouraged to develop new initiatives within these Areas of Research Emphasis and to respond to emerging health needs through both inter- and intra-Institute efforts. The NIH Director uses these proposals to build the President's budget in order to ensure that new initiatives are meritorious and timely and that budget increases are used to capitalize on recent scientific developments. The Director has two additional tools to identify and fund NIH research efforts. First, the Director may, following a clearly defined process, transfer up to one percent of the total NIH budget among Institutes. Second, the Director has a Discretionary Fund. Both are used to jump start particularly exciting or urgent areas of research:

—Transfer funding from the Director typically follows extensive discussions between and among the NIH Director and the Institute directors, and advice from outside experts to identify particular research initiatives that reflect NIH-wide priorities, show real promise, or reflect an emerging need that requires a timely infusion of funds. DHHS, the Administration, and congressional appropriations subcommittees are then notified of the NIH intent to transfer the money. No single Institute can lose more than one percent of its appropriated funds in this process.

—The NIH Director uses the Discretionary Fund, as appropriated for this purpose by the Congress, to support specific research opportunities that arise during the course of a year that would otherwise have to wait until the following year for funding. The NIH Director can, in this way, provide early support to research by giving additional funds to a single Institute or to several Institutes. The NIH Director can also use these funds to respond to specific requests from the Congress or to a public health emergency. One way the Director's Discretionary Fund has been used in recent years is to fund the Shannon Awards (named after an illustrious former NIH Director), which provide some funding for deserving projects that could not be paid for within the available budget. This is a means of keeping investigators, especially new investigators, active scientifically until funding becomes available for supporting their research applications.

Program offices in the Office of the Director are also responsible for enhancing some of the cross-Institute coordination of, for example, minority health, women's health, disease prevention, rare diseases, behavioral and social science research, and complementary and alternative medicine. Another program office is the Office of AIDS Research, which has been given broad legislative authority to plan, coordinate, evaluate and budget all NIH AIDS research. Like the other offices within the

Office of the Director, it funds research through the various Institutes. The NIH is strongly committed to identifying, developing, and pursuing research that reflects broad approaches to understanding human illness and health.

Many diseases under study at the NIH require the input of more than one Institute. While the Institutes themselves enjoy close collegial relationships and employ a number of mechanisms to foster their collaborations, the NIH Director has a unique overview of the range of endeavors across the entire NIH. The Director thus can influence all the Institutes to focus on matters of importance to them all.

CONCLUSION

All of the activities described here have the common purpose of informing the NIH of scientific opportunities and of important needs in public health. Recognizing needs—and establishing priorities among them—stimulates the most promising medical research and advances our knowledge. The continuing dialogue between the public and scientists ensures a system that is both stable and responsive—a system that effectively and efficiently meets its goal to improve the nation's health through medical research.

APPENDIX—NIH INSTITUTES AND CENTERS [1]—DATE ESTABLISHED

National Cancer Institute (NCI)—1937
National Eye Institute (NEI)—1968
National Heart, Lung, and Blood Institute (NHLBI)—1948
National Human Genome Research Institute (NHGRI)—1989
National Institute on Aging (NIA)—1974
National Institute on Alcohol Abuse and Alcoholism (NIAAA)—1970
National Institute of Allergy and Infectious Diseases (NIAID)—1948
National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)—1986
National Institute of Child Health and Human Development (NICHD)—1963
National Institute on Deafness and Other Communication Disorders (NIDCD)—1988
National Institute of Dental Research (NIDR)—1948
National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)—1950
National Institute on Drug Abuse (NIDA)—1974
National Institute of Environmental Health Sciences (NIEHS)—1966
National Institute of General Medical Sciences (NIGMS)—1963
National Institute of Mental Health (NIMH)—1946
National Institute of Neurological Disorders and Stroke (NINDS)—1950
National Institute of Nursing Research (NINR)—1986
National Library of Medicine (NLM)—1968, became a part of the NIH
National Center for Research Resources (NCRR)—1956
John E. Fogarty International Center (FIC)—1968

NIH WORKING GROUP ON PRIORITY SETTING

Stephen I. Katz, Chair, Director, National Institute of Arthritis and Musculoskeletal and Skin Diseases
Anne Thomas, Co-Chair, Associate Director for Communications, National Institutes of Health
Marvin Cassman, Director, National Institute of General Medical Sciences
Rex Cowdry, Acting Deputy Director, National Institute of Mental Health
Patricia Grady, Director, National Institute of Nursing Research
Suzanne Hurd, Director, Division of Lung Diseases, National Heart, Lung, and Blood Institute
John McGowan, Deputy Director, National Institute of Allergy and Infectious Diseases
Ken Olden, Director, National Institute of Environmental Health Sciences
Mary Miers, Chief, Science Policy and Analysis Branch, National Institute of Neurological Disorders and Stroke
Al Rabson, Deputy Director, National Cancer Institute
Helen Simon, Chief, Office of Program Planning and Evaluation, National Institute of Arthritis and Musculoskeletal and Skin Diseases
Lana Skirboll, Associate Director for Science Policy, National Institutes of Health
Harold Slavkin, Director, National Institute of Dental Research
Harold Varmus, Ex-Officio, Director, National Institutes of Health

[1] Each with a separate annual budget from the Congress.

Judith Whalen, Associate Director for Science Policy, Analysis, and Communication, National Institute of Child Health and Human Development

SARCOIDOSIS

Question. Have there been any recent breakthroughs which have provided insight into the cause or causes of sarcoidosis?

Answer. The cause(s) of sarcoidosis is a question that has recently received increased attention. The National Heart, Lung, and Blood Institute (NHLBI) supports two major clinical studies which are investigating the cause of or contribute to development of sarcoidosis.

In one, "A Case-Control Etiologic Study of Sarcoidosis" (ACCESS), investigators will use information obtained from study participants to identify environmental exposures, family characteristics, and co-existing diseases that contribute to sarcoidosis. In addition, blood samples will be analyzed to pinpoint exposure to infectious agents or genetic variations that may occur more frequently in sarcoidosis patients than in a control population. Information about relatives with sarcoidosis will be used to determine the frequency of familial disease and to provide preliminary information about the inheritance pattern of the disease.

In another study, "Genetic Epidemiology of Sarcoidosis," the investigators will conduct analyses in a large population of African-Americans, which may explain the pattern of inheritance of sarcoidosis and the role of major and minor genes in the development of the disease. Moreover, the investigators will look for an association of 50 specific candidate genes with the development of sarcoidosis. In addition, the NHLBI supports a study on the role of the immunologic and inflammatory processes mediating the granulomatous inflammation seen in pulmonary sarcoidosis.

Although these studies are not yet far enough along to provide answers to the question of the cause of sarcoidosis, final results of the investigations should improve our understanding of sarcoidosis and identify avenues of more specific investigation.

PEDIATRIC RESEARCH

Question. Are efforts underway to focus more resources on the diseases and illnesses that affect our nation's infants and children?

Answer. The NIH supports a large and varied pediatric research portfolio, which is more than $1.6 billion in fiscal year 1997. This includes studies ranging from those to better understand normal developmental processes, from the prenatal period through adolescence, to studies concerning specific children's diseases and health problems. These studies and activities include basic biological and behavioral research, clinical trials, health services research, and efforts in public health education.

Most recently, the NIH made a formal commitment to increase the participation of children in NIH-supported clinical research. Medical treatments applied to children are often based on testing done in adults. Problems can arise from this situation because children have different reactions and physiologic responses than do adults. Additionally, scientifically-evaluated treatments are less available to children due to previous barriers to their inclusion in research studies. To address these concerns, the National Institute of Child Health and Human Development (NICHD), in conjunction with the Office of Extramural Research, established a trans-NIH working group to develop a policy and an implementation plan for requiring applicants proposing research involving human participants to describe their plans for including, or justification for excluding, children in the project. Based on these efforts, the NIH published guidelines on the inclusion of children in research in the NIH Guide for Grants and Contracts, and the formal policy will be implemented starting October 1, 1998.

The fiscal year 1997 NIH Appropriation also included $5 million to fund a Pediatric Research Initiative. The funding level for this initiative was increased to $38.5 million in fiscal year 1998. These funds have been allocated to various Institutes and Centers to encourage innovative pediatric research and collaborative efforts in three designated areas: pediatric therapeutics, developmental abnormalities, and pediatric asthma. These areas were selected because of their significant impact upon child health. For example, drugs are a critical component of pediatric care. However, the majority of drugs administered to children have not been tested in pediatric populations. New drugs for treating childhood illnesses need to be developed, and appropriate testing of available drugs must be done so that they can be used safely and effectively in children. Developmental abnormalities are another important aspect of child health. While they stem from diverse causes, many have an underlying genetic component. Most developmental abnormalities are relatively rare, but collec-

tively, they have a profound effect on the health and quality of life of the Nation's children. Finally, asthma is a major chronic disease involving obstruction of the bronchial airways. Its prevalence and severity in children is increasing in the U.S., particularly in minority populations.

The health and well being of our Nation's children is paramount. Medical research conducted and supported by the NIH is an indispensable element for ensuring continued and steady improvement in the health and quality of life of children. The NIH continues its strong commitment to research that addresses both the disorders that affect infants, children, and adolescents and the factors that enhance and promote normal, healthy development. NIH-supported pediatric research will continue to yield and expand important advances in understanding, diagnosing, treating and preventing illnesses that affect children throughout all stages of development.

CLONED HUMAN EMBRYOS

Question. Does the NIH support legislation which bans the creation of cloned human embryos?

Answer. The NIH does not support legislation that would ban the use of somatic cell nuclear transfer using human cells in order to investigate, and hopefully, someday, produce cells and tissues that may be used to prevent and treat serious and life-threatening diseases and other medical conditions. I do, however, believe that the use of somatic cell nuclear transfer cloning to create a human being is untested, unsafe, and morally unacceptable. However, we agree with the National Bioethics Advisory Commission that this issue must continue to be debated. Therefore, I support the President's bill that would include a ban on the use of somatic cell nuclear transfer cloning techniques to create a human being, with a five-year sunset provision to provide for further review of the ethical and scientific issues associated with the use of somatic cell nuclear transfer and that would protect important biomedical research.

QUESTIONS SUBMITTED BY SENATOR LAUCH FAIRCLOTH

RESEARCH PRIORITIES

Question. There is concern among many that NIH in general, and the NIMH in particular, desire to invest less in disease-oriented and clinical research, and more in basic scientific research. Please describe for the Subcommittee what you think is the appropriate balance at NIMH between basic research funding and clinical and services research. Does NIMH intend to invest more in basic research? If so, how much more?

Answer. Research on the causes, treatment, and prevention of mental illnesses is integral to the mission of the National Institute of Mental Health (NIMH); indeed, this research is the primary focus of all NIMH programs. Mental illnesses are diverse and, even though science is rapidly making enormous strides, very little is known about the causes of any of these illnesses. We do know that the key to these illnesses lies in basic research on the molecular and cellular changes in the brain and on understanding how the brain is changed by these diseases to produce the behavioral manifestations of these illnesses. This is the only way that we will ever understand how to most effectively treat, or to prevent, mental illnesses. NIMH basic research is directed toward understanding the changes in the brain and behavior that determine mental disorders.

At the same time we must continue to apply what we already know to clinical studies and services for patients. Thus, support for clinical research and health services research by NIMH is also expanding. The NIMH assesses the balance between all these elements of its research endeavors and makes changes in emphasis as the scientific and clinical opportunities for studies warrant.

In shaping its research program, NIMH periodically establishes research priorities, then continues to evaluate these priorities in the light of accumulating research-based knowledge. The appropriate balance between basic research funding and clinical and services research varies somewhat over time as advances in science create new opportunities to address specific research questions and to explore new avenues to treatment or prevention, or as marked changes in the mental health-care landscape—such as the advent of managed care—create new public mental health questions. NIMH relies on the National Advisory Mental Health Council (NAMHC), composed of both expert scientists and representatives of the public, to continually monitor the Institute's program balance and to assist in setting and reviewing research priorities. The NAMHC reviews and approves all research grants awarded, and, in addition, through special workgroups and task forces, the Council under-

takes comprehensive, in-depth reviews of major segments of the NIMH research program and these reviews produce quite specific recommendations for program directions and emphasis.

Based on recent recommendations by the National Advisory Mental Health Council and on emerging scientific opportunities, the NIMH intends to increase support for important areas of basic research as well as a broad spectrum of patient-oriented research—including clinical research, services research, and translational research that will accelerate the incorporation of basic research findings into clinical care. However, at this time, it is not possible to attach dollar amounts to these investments.

SCHIZOPHRENIA

Question. Schizophrenia is the most severely disabling mental disorder and is among the most severe illnesses that afflict mankind. The statistics bear this point out; (a) schizophrenia strikes in young adulthood usually resulting in a lifetime of severe disability, (b) consumers with schizophrenia account for nearly 25 percent of all those receiving disability payments from the federal government, (c) schizophrenia costs the nation $32 billion each year, (d) consumers with schizophrenia occupy 40 percent of all hospital beds in the United States, (e) 10 to 15 percent of its victims commit suicide. While there has been important treatment advances in the 1990's, much has to be learned about this disease. We still do not understand what causes this illness, we have no diagnostic markers for schizophrenia, and treatments are but palliatives and not cures. By NIMH's own accounting, investment in schizophrenia research modestly declined in the first part of this decade—by approximately 10 percent. Given the severity of this illness and a record of decreasing research investment, what does NIMH plan to do to advance our understanding and treatment of schizophrenia? How much money is needed in this area of research? What are the most important barriers to research advances in schizophrenia, in your view? How can Congress assist you in conquering this terrible disease?

Answer. Schizophrenia research continues to have a prominent place in NIMH programs. The Institute is committed to studies of the neurobiological substrates of schizophrenia, its neurodevelopmental origins, and the inheritance of and expression of vulnerability genes in the brain, as well as other factors that may trigger or exacerbate schizophrenia. For example, the NIMH Genetics Initiative has provided new funding to augment the number of patient samples available for gene-finding efforts in schizophrenia. Efforts are also underway to characterize exactly which of the Gamma aminobutyric acid (GABA) brain regions and which neurons are affected. There are preliminary data to suggest that small GABA interneurons, in particular, may be abnormally "connected" in patients with schizophrenia, while there is a growing body of data pointing towards the involvement of specific emotional and higher cognitive centers of the brain. This localization is consistent with many of the behavioral manifestations of schizophrenia. Neurochemical theories of schizophrenia also continue to be studied, and there is growing evidence pointing toward the possible involvement of excitatory neurotransmission involving glutamate.

While we do not yet have a cure for this devastating illness, in the past few years, three new, "atypical" antipsychotics have become available. These represent major therapeutic advances, since they are better-tolerated, and preliminary evidence suggests that they may be more effective than traditional antipsychotics. NIMH has initiated clinical studies to determine if these new treatments are indeed more effective, and if so, in which patient groups they are best used.

Over the last 5 years NIMH has cofunded, with the Agency for Health Care Policy and Research (AHCPR), the Schizophrenia Patient Outcomes Research Team (PORT). The mission for this PORT was to identify and analyze the outcomes and costs of various treatments for schizophrenia; to determine the most cost-effective means to treat or manage the condition; and to develop and test methods for reducing inappropriate or unnecessary variations in treatment. The same investigative team was funded recently to conduct a field trial of a methodology for assessing the quality of care provided to patients with schizophrenia.

The fiscal year 1999 President's Budget request will permit NIMH to take advantage of the most important immediate research opportunities.

There are a number of reasons why progress in understanding schizophrenia and finding a cure has been slow. First and foremost, schizophrenia is a disease unique to humans. There is no animal or tissue model that accurately reflects the manifestations of the disease in man, and this necessarily limits the investigations that can be performed. Many of the powerful methods for studying molecular or cellular processes that have led to rapid advances in our understanding of other illnesses

cannot be applied to schizophrenia, since they involve destruction or severe disruption of the tissues that are being studied.

There are other barriers as well. Schizophrenia is difficult to treat and few people with the diagnosis—even those who respond well to treatments—return to their pre-illness level of functioning. Because of this, we need to go beyond therapeutic studies and start thinking about prevention. Yet we know little about factors that influence the course of this illness. The NIMH is developing research to aid in identifying indicators of risk for onset of disease, relapse, poor functional outcomes, and suicide. The programs will also translate emerging findings from the basic sciences into new strategies for prevention and early intervention. We are hopeful of substantial progress in the next decade. There is also a lack of understanding of how the newer atypical antipsychotics work. Their mechanism of action is very complex, affecting multiple brain transmitter systems. This complexity may be a critical feature of their greater efficacy, and will remain a central focus of research efforts in the near future.

With the funds requested in the fiscal year 1999 President's Budget Request and the flexibility to use these funds in areas of greatest opportunity, NIMH will be able to accelerate research on schizophrenia.

SUPPLY OF RESEARCHERS

Question. As I am sure that you will agree, there is a great need to attract new researchers and clinicians into psychiatry—in the areas of genetics and severe mental illnesses in children and adolescents in particular. Could you please comment on the problems you see in terms of the human resources available to study and treat these serious brain disorders? What do you intend to do to recruit new and talented individuals to these fields? How can Congress assist you in this activity?

Answer. Several high-priority research areas such as the genetics of mental illnesses and childhood and adolescent mental illnesses are drawing on a very small cadre of investigators, many of whom have pioneered these fields. However, as these areas of research develop and expand, progress depends on the availability of more well-trained investigators. The National Institute of Mental Health (NIMH) will develop strategies to attract more researchers into these critical areas. For example, in the area of pediatric mental illness, most researchers are drawn from the small groups of clinically trained child psychiatrists and child psychologists. Given the length of clinical training, many potential investigators are diverted (often for financial reasons) into non-research careers. However, while there are only 5,000 child psychiatrists nationwide, there are over 100,000 pediatricians, adult psychiatrists, and neurologists, from whose ranks new child mental health-focused investigators could be drawn.

NIMH anticipates two major activities in this area. (1) The Institute will issue a new career award to attract researchers such as neurologists, adult psychiatrists, and psychologists, who have not typically studied in this age group to encourage them to learn about how to do clinical studies of children and adolescents and to redirect their efforts. A similar strategy will be employed for other shortage, high priority research areas. (2) NIMH will develop supplements to existing research grants for young investigators who are interested in studying childhood psychopathology or other similar high priority areas.

The fiscal year 1999 President's Budget Request was developed after lengthy examination and discussion of scientific opportunities and research needs, and NIMH feels that this level of funding will provide good support for strengthening the recruitment of researchers into critical areas of study.

STROKE

Question. As a member of the Congressional Heart and Stroke Coalition, I am particularly concerned about NIH resources devoted to stroke. Stroke will cost this nation an estimated $43.3 billion in medical expenses and lost productivity in 1998, including more than $7 billion in direct Medicare and Medicaid expenditures. Yet, the President's fiscal year 1999 budget would allow only $88.5 million for the National Institute of Neurological Disorders and Stroke-supported stroke research. Actual fiscal year 1997 funding for NINDS stroke research was a mere $76.8 million. Actual fiscal year 1997 overall NIH stroke research funding was only $143.1 million.

How do you account for this inequitable allocation for resources to stroke? What are you doing to rectify this situation?

Answer. Stroke is a serious health problem as shown by its rank as the third leading cause of death in the U.S. Stroke is one of 600 disorders which lie within the mission of the National Institute of Neurological Disorders and Stroke (NINDS). As with other disorders, allocation of resources is the culmination of a number of

factors including scientific opportunities and public health burden. NINDS and other Institutes at NIH have long been committed to stroke research. I would like to highlight just some of the advances and major contributions that have been made by NIH in the prevention and treatment of stroke. For example, tremendous progress has been made in preventing stroke by controlling high blood pressure. But there are other risk factors and the more we understand and control these, the more we can prevent stroke. NINDS clinical studies have demonstrated that many strokes can be prevented by either medical or surgical means. Beginning in 1987, NINDS funded clinical trials to evaluate the use of a surgical procedure, known as carotid endarterectomy, in which a blockage in the carotid artery is removed. The studies were designed to look at the severity of the blockage and whether the patients in the study already had a stroke or warning signs of a stroke. Now that the results that describe which patients can benefit from the surgery have been published, patients and their physicians have important information that they need to make health care decisions. There is now no question that surgery benefits patients who have 70 percent or greater stenosis or narrowing of the carotid arteries. The most recent result, announced in 1998, shows that, for symptomatic patients with stenosis of 50–69 percent, surgery may be worthwhile. For people with symptoms, but less than 50 percent stenosis, surgery is not as beneficial. Another prevention strategy, for which NINDS initiated clinical trials is to evaluate the relative benefits of aspirin and warfarin to prevent stroke in patients who have irregular heart beats or atrial fibrillation. Results from the study, announced in 1990, 1994, and 1996 demonstrated that both aspirin and warfarin can be beneficial and provided information as to whether the use of aspirin or warfarin may be preferable, depending on other factors about the patient. NINDS also has ongoing a number of clinical trials that will further benefit people at risk for stroke. These include a study of vitamin intervention for stroke, stroke prevention in African Americans, and the use of estrogen to decrease the risk of a repeat stroke in postmenopausal women who have already had at least one stroke.

In 1996, the FDA approved the first emergency treatment for stroke based on data from an NINDS-supported clinical trial. Research in animal models, followed by clinical observations, had led the NINDS to design and initiate a clinical trial to evaluate tissue plasminogen activator (t-PA) as an emergency treatment to be used within three hours of the onset of the most common type of stroke—that due to a blockage of a major vessel. In the clinical trial, the drug, t-PA, was administered within three hours of a stroke so as to dissolve the offending clot and restore blood flow. The results show that t-PA increases a person's chances for a recovery with minimal or no disability by 30 percent when given within three hours.

What all of these findings have done, has been to change the way physicians, scientists, and the public think about stroke. Stroke can be prevented in many cases, but when it occurs, like a heart attack, it is a medical emergency that requires quick action so as to begin treatment as soon as possible while the effects of the injury can still be reversed. This is just the beginning, however. As with many of the other brain disorders, such as epilepsy, Parkinson's disease, multiple sclerosis, and neurodevelopmental disorders in children, progress in stroke research is benefitting from advances in molecular biology, brain imaging, and other scientific fields. For example, by understanding how the brain reacts to stroke, scientists are trying to find ways that can protect the brain until t-PA or a similar treatment can restore the blood flow. These neuroprotective modalities still will have to be administered very rapidly, hopefully in the ambulance or first thing upon arrival in an emergency room so that as many brain cells can be protected as possible before there is irreversible damage. Several activities are under way to further progress in stroke research. NINDS has joined with several other institutes to encourage new research on "Symptom Management for Chronic Neurological Conditions" which may benefit survivors of stroke. NINDS also expects to fund additional clinical studies in stroke and has taken steps to encourage new clinical trials by making available planning grants for support for the design of a clinical trial and the organization of an effective research group. Also, in the development of the fiscal year 1999 budget, I have included stroke research as an area of emphasis.

Research on stroke is an excellent example of how opportunity and need have together produced a high level of return on our research investment. We are proud of the progress that has been made against stroke and pledge continued support to strengthening and advancing efforts in stroke research.

CHRONIC OBSTRUCTIVE LUNG DISEASE [COPD]

Question. Recent information collected by NIH shows that only two diseases over the past 30 years have shortened average life expectancy, HIV and COPD. Can you

tell me what is being done at the National Heart, Lung, and Blood Institute (NHLBI) to address the public health implications of COPD, and what should Congress be doing to address the disease?

Answer. Chronic Obstructive Pulmonary Disease (COPD), is a major public health burden in the United States; the major risk factor is cigarette smoking. The National Heart, Lung, and Blood Institute (NHLBI) considers research on COPD to be a high program priority and has devoted considerable resources to it. In addition to a significant research effort to study the basic mechanisms that lead to the lung damage that occurs in COPD patients, the Institute supports several clinical trials. Most noteworthy is the Lung Health Study, a project that is underway in ten clinical centers, which will follow individuals with early signs of COPD to learn more about the natural history of the disease process once it begins. The Institute also supports a study on the efficacy of lung volume reduction surgery in patients with advanced disease.

Given the knowledge base that has been developed by NHLBI, coupled with new molecular technologies that have revolutionized biomedical research, the future holds great promise to learn even more about COPD and to translate these findings into programs that will have an impact on public health. For example, we believe that it is now possible to identify the genetic risk factors that predispose an individual to COPD and to lung cancer caused by smoking. The NHLBI will conduct a workshop this fall that will include epidemiologists, experts in pulmonary medicine, and those with experience in using molecular techniques to study large populations, as a first step in developing a long range program plan in this area. The NHLBI and the National Cancer Institute have also initiated discussions to develop programs to explore the relationship of COPD and lung cancer. These efforts will require significant input from the scientific community.

Two public health initiatives from the NHLBI were initiated in 1997. One, the National Lung Health Education Program, designed to develop strategies for early detection of lung damage through measurements of pulmonary function, represents a partnership with several major medical organizations. The other, global Strategy for Detection and Management of COPD, represents a cooperation with the World Health Organization to develop a comprehensive program of early detection (especially using lung function measurements), appropriate disease management strategies (for those with a diagnosis of COPD) and use of aggressive smoking cessation (and smoking avoidance) programs.

Through this comprehensive program of research to examine mechanisms of lung damage, clinical research and outreach initiatives, with major new directions targeted to programs of primary prevention, the NIH is confident that more progress can be reported in the future to address the public health implications of COPD.

BIPOLAR DISORDER

Question. Last year's Senate Labor-HHS-Education Appropriations report called for a National Institute of Mental Health (NIMH) research plan on bipolar disorder. This request clearly indicates that, as you indicate publicly, there is too little bipolar illness research being funded by NIMH. This appears to be the case, particularly in the area of clinical research. As you know, bipolar disorder is among the most disabling of mental illnesses. The Subcommittee understands that NIMH has taken some steps to increase bipolar disorder research funding. Please describe what NIMH is doing as part of its current budget on manic-depressive illness research. How many new studies are being funded on this illness? What else, if anything, does NIMH intend to do to assure more research on bipolar disorder in fiscal year 1999 and beyond?

Answer. NIH in general and NIMH, in particular, are committed to moving forward in research on bipolar disorder. Let me describe two major initiatives currently in progress for fiscal year 1998. First, in the NIMH Genetics Initiative, and as part of its effort to identify genetic factors in bipolar disorder, the Institute will continue to build up its national resource of DNA sample from patients and their family members. Second, we have issued a solicitation for a five year contract ("Treatment of Bipolar Disorder") to launch a major public health study on ways to develop optimal treatment of bipolar disorder in adults and in geriatric populations. The study will assess the long-term impact of different treatments on a broad range of clinical and functional outcomes. Data from this study will inform treatment practice in community settings. Other studies are examining treatments for adolescents with bipolar disorder. Furthermore, we intend to increase research on the neurobiological underpinnings of bipolar disorder as well as clinical, behavioral, and epidemiological work that will be useful in finding ways to prevent this disorder.

At this time, it is not possible to predict how many studies on bipolar disorder will be funded in fiscal year 1999. This depends upon how many grant applications are submitted by independent investigators, and how scientifically sound and appropriate these applications are judged to be through the peer review process.

As outlined above, NIMH intends to explore all avenues to increase research on bipolar disorder as rapidly as the growing fundamental science base allows scientifically rigorous research studies to be undertaken.

TRANSLATIONAL RESEARCH

Question. NIMH has frequently noted the need to support "translational" research. However, for many policy-makers, patients, and families, the definition of translational research remains unclear. Would you describe for the Subcommittee what you mean by translational research? How does NIMH intend to implement this kind of research and make relevant to the advance of severe mental illness treatment? What specific programs and policies does NIMH intend to put forward to advance translational research?

Answer. The term, translational research, is meant to describe a type of scientific inquiry that crosses usual conceptual and disciplinary boundaries. Historically NIH's support of biomedical research has focused on two major categories: basic biology and clinical research. Translational research seeks to translate "back and forth" between these two largely separate domains. It is anticipated that this will result in accelerated scientific progress that is directly applicable to clinical disorders. It is important to note that this is viewed as a bi-directional process, i.e., clinical research informing, as well as being informed by, basic research and vice-versa. A couple of examples may clarify the concept. Developmental neurobiology and genetics are both highly relevant to mental disorders. In both instances, hypotheses in clinical research are shaped by observations in basic research and vice-versa. The cognitive deficits observed in schizophrenia coupled with structural anomalies in the brains of schizophrenics have encouraged developmental neurobiologists to investigate the possible role of aberrant brain development in the etiology of schizophrenia. Conversely, the identification of a growing number of genes required for the precise specification of brain structure during development has given rise to clinical studies focused on the anatomic substrates of abnormal mental function. It is my belief that fostering translational research will enrich both basic and clinical research and will speed progress toward a complete understanding of mental disorders.

Implementation of this kind of research will require a continuing, close collaboration between basic and clinical mental health researchers. NIMH has begun to develop and strengthen such collaborations in research through specific research support mechanisms. For example, several recently published NIMH program announcements call for the development of four types of research centers focused on translational research. One type of center, the Silvio O. Conte Centers for the Neuroscience of Mental Disorders, will support the integration and translation of basic and clinical neuroscience research on severe mental illnesses, while other centers will focus on related research areas.

Translational research requires collaboration between scientists from multiple disciplines, an approach which, historically, has not been emphasized in research on mental illnesses. NIMH stimulates and sustains activity in translational research on severe mental illnesses through career-development mechanisms, which provide support for young clinical investigators during the formative stages of their careers until they become fully independent researchers. In addition, small grant awards provide support for pilot projects and for first-time grants for young NIMH investigators. These awards can be used to explore translational and other research studies that would be difficult to fund under traditional support mechanisms. In addition, an NIH-wide RFA, Clinical Research Curriculum Award, is intended to stimulate the inclusion of high-quality, multidisciplinary didactic training as part of the career development of clinical investigators.

CLINICAL RESEARCH

Question. Failure of NIH to Respond: As you know, several members of the Labor/HHS/Education Appropriations Subcommittee are co-sponsors of the "Clinical Research Enhancement Act" based on the recommendations of a 1994 report of the Institute of Medicine (IOM). Over the past three years, the Subcommittee has raised serious concerns about the major obstacles confronting clinical research through which our investment in NIH's basic research efforts pay off with better patient care. Other than responding with modest intramural initiatives, the NIH has asked that the Subcommittee await a report from the Director's Panel on Clinical Re-

search. Recently, that panel issued its report and made recommendations almost identical to those of the Institute of Medicine. Why didn't NIH just proceed with these initiatives three years ago when they were recommended by the IOM? And what does NIH plan to do immediately to rectify this situation and make up for lost time?

Answer. As you stated, the ground work examining the state of our nation's clinical research enterprise was conducted by the Institute of Medicine (IOM). This study, which was carried out from 1991–1994 and was partially funded by NIH, addressed a number of the important issues concerning clinical research, including its role in the delivery of health care, the status of the clinical research infrastructure, and the need for well-trained clinical investigators. Although the 1994 IOM report was thorough and addressed a range of relevant issues, its recommendations were very broad and were aimed at both the private and public sector entities that sponsor, conduct, or, in some way, play a role in clinical research. These include accreditation and certification organizations, professional societies, universities, academic medical centers, industry, and the Federal Government.

Because NIH is but one of these entities and has a unique role, I responded to the 1995 Appropriations Committee report language that requested NIH to act on the recommendations of the IOM report by convening the NIH Clinical Research Panel (CRP). That panel was charged with examining specifically the role of NIH in ensuring the health of the Nation's clinical research infrastructure. To this end, the CRP was asked to examine several important areas of NIH-supported clinical research including, but not limited to, the General Clinical Research Centers (GCRC's), the NIH Clinical Center (CC), the recruitment and training of future clinical researchers by NIH, the conduct of NIH-sponsored clinical trials, and peer review of clinical research supported by the NIH.

The CRP was also asked to deliberate on a number of issues that were not prominent concerns at the time of the IOM study, but reflect the rapidly changing clinical research environment today. These include the expansion of managed care, the emphasis on training primary care physicians, and the extensive transformation of the academic health care infrastructure.

By the time the CRP report was completed in December 1997, a number of the panel's recommendations were already being implemented. The complete report is available on line at (http://www.nih.gov/news/crp/97report/index.htm).

NIH was implementing the recommendations of the Clinical Research Panel as they were brought forward. For example, the recommendation to track that part of the NIH budget devoted to clinical research was implemented by the creation of a prospective system to monitor the grants and other funds awarded which are devoted to clinical research. The recommendation to create a Clinical Research Training Program was implemented immediately. The creation of the new programs of career enhancing awards for clinical researchers continues this pattern.

Question. Decline in Physician-Scientists: The number of first-time physician applicants for research project grants declined by 30 percent between 1994 and 1996. At that rate, we will have no new physician applicants by the year 2000. First, does this trend continue in 1997, and is the NIH alarmed by this stunning decline?

Answer. We have noticed a reduction in the number of new physician applicants for NIH research grant support between 1994 and 1997. In 1997, the NIH received 1,769 applications from individuals with the M.D. degree who had never received NIH research project grant support previously. This number is approximately the same as that observed in 1996 and is 22 percent below the peak observed in fiscal 1994.

To address this important issue, the NIH has recently announced new career award mechanisms designed to offer at least 80 young physicians new training opportunities in clinical research each year. This same initiative will also increase opportunities for mid-career clinical researchers who will serve as mentors. In addition, the initiative will support the development of high-quality instruction in clinical research methodology. We are hopeful that these new awards will ultimately increase the number of physicians submitting applications for clinical research grants. To provide some indication of the magnitude of this initiative, we estimate that, if all of the entry level awardees supported by the program apply for research projects grants after completing their career awards, there will be a greater than 10 percent increase in applications from physicians each year for several years into the future.

FUNDING FOR THE GENERAL CLINICAL RESEARCH CENTERS

Question. The IOM and the Director's Panel on Clinical Research identified the General Clinical Research Centers (GCRC's) as a critical resource for patient-oriented research. Both reports recommended that these be funded more generously.

The GCRC budget has declined as a proportion of the NIH budget from 3 percent in 1968 to 1 percent for the current year. Given all the obstacles and challenges confronting clinical investigation, shouldn't the lion's share of the funding increase for the National Center for Research Resources should be allocated to the GCRC's? Has the NIH considered using the NIH Director's discretionary fund or transfer authority for this purpose?

Answer. There is no question that the General Clinical Research Centers (GCRC) are a critical resource for clinical research for NIH. We agree that it is important to support the GCRC's at a level required to permit appropriate patient oriented clinical research as supported by the NIH categoric institutes. The NIH commitment to do so is indicated by recent statistics. Between fiscal year 1993 and the fiscal year 1999 President's budget request, resources for GCRC's have grown about 43 percent, the same percentage increase as NIH as a whole, and the proportional relationship between the two has remained constant over that period. This reflects the condition of research as a whole, and the necessary balance between basic studies and the translation of research results to patients.

I have no plans currently to use the Discretionary Fund or the transfer authority to increase funding for the General Clinical Research Centers. I believe that the level of funding requested for the GCRC's in the President's Budget is appropriate.

QUESTIONS SUBMITTED BY SENATOR LARRY CRAIG

NUTRITION RESEARCH

Question. I anticipate that NIH is involved in a great deal of research exploring the relationship between nutrition and various health conditions and diseases. Would you tell the committee about this research, which Institutes are involved, and any future plans for this important area of study?

Answer. You are correct. Nutrition is one of the most widely cross-cutting research areas at the National Institutes of Health (NIH). All of the Institutes, as well as the Clinical Center, the National Center for Research Resources, and several offices in the Office of the Director provide funding for nutrition research. This encompasses basic and clinical studies on the role of nutrients in health and disease. Nutrition research is coordinated across the NIH by the NIH Nutrition Coordinating Committee (NCC), which also has served to facilitate interactions relating to physical activity and health. The NCC includes liaison members from a number of other agencies of the Department of Health and Human Services, as well as from the Departments of Agriculture and Defense.

By definition, nutrition research funded by the NIH includes studies to assess the consequences of food or nutrient intake and utilization in the intact organism, and the metabolic and behavioral mechanisms involved, including investigation of variables in nutrient intake at the cellular and subcellular level. The 17th Report of the NIH Program in Biomedical and Behavioral Nutrition Research and Training, published in January 1997, contains an extensive overview of recent nutrition research funded by the NIH. Numerous examples are cited, ranging from studies of the molecular genetics in the control of energy balance to research on the role of diet in lowering blood pressure to the effectiveness of nutrient support in cancer treatment to studies of nutritional factors in cognitive development and behavior. This report is available from the NIH Division of Nutrition Research Coordination, located in the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

As far as future plans are concerned, each Institute at the NIH has plans that reflect the role of nutrition research in its overall programs. In addition, trans-NIH nutrition research efforts are led by the NCC. Currently, such initiatives include consideration of studies of the neuroendocrine basis of obesity, the prevention of obesity, and the role of physical activity and nutrition in health. These reflect the interest of many NIH Institutes in obesity as an underlying cause of disease, and the recognition that progress in obesity research has tremendous potential to improve public health.

Question. Within NIH, is there a single "advisory committee," or some other coordinating entity responsible for overseeing nutrition-related research? If not, do you think the Institutes could benefit from the establishment of such an entity?

Answer. Yes, the NIH Nutrition Coordinating Committee (NCC) facilitates communications regarding nutrition research, both among the NIH institutes and with liaison agencies in the Departments of Health and Human Services, Agriculture, and Defense. This body has been responsible for the development of several trans-NIH nutrition research initiatives. The NCC is administered within the National Institute of Diabetes and Digestive and Kidney Diseases' Division of Nutrition Re-

search Coordination, which represents the NIH on numerous other interagency committees concerning nutritional issues.

I think the NCC is doing a good job. It has been quite active in fostering nutrition research at the NIH and in involving other Federal agencies in this area. Currently a number of the NIH Institutes, as well as the Centers for Disease Control and Prevention (CDC) and the Department of Defense, are working through the NCC to develop trans-NIH initiatives in obesity research.

Question. To what extent do health professionals with nutrition expertise advise NIH on its research activities and funding priorities? How many registered dietitians and other nutrition professionals serve on NIH advisory committees and review panels? Could you tell us on which panels they serve?

Answer. Nutrition research is widely dispersed throughout all of the NIH Institutes, reflecting the interdisciplinary nature of this field. Nutrition researchers are essential in advising NIH by serving on Institute advisory councils, participating in workshops, and on peer review groups and through dialog between professional societies and the NIH. I cannot provide you with an exact number of nutrition advisors to the NIH, because most nutrition researchers are not organizationally located in nutrition departments. In addition, most registered dieticians (RD) involved in research cite higher degrees and do not necessarily inform us that they have RD degrees.

Some examples of representation of nutritionists in NIH activities are: The NIDDK-sponsored National Task Force on Prevention and Treatment of Obesity comprises primarily nutrition researchers. The NIDDK always includes a member of the nutrition research community on its advisory council and also has an exofficio representative from the Beltsville Human Nutrition Research Center of the Department of Agriculture. The National Heart Lung and Blood Institute (NHLBI) Expert Panel to Develop Clinical Guidelines on the Identification, Evaluation, and Treatment of Overweight and Obesity in Adults comprises people of different expertise, however most have been involved in some aspect of nutrition related research. The NHLBI advisory council currently includes a nutrition researcher who also is an epidemiologist and has a Ph.D., M.P.H., and R.D. degrees. Nutritionists and registered dietitians are represented as advisors on NHLBI's national education programs including the Coordinating Committees of the National Cholesterol Education Program and the National High Blood Pressure Education Program. They play important roles in advising these programs on a variety of educational programs on nutrition-related strategies and materials, including those targeting special populations.

Regarding the peer review of nutrition, a considerable body of nutrition research is reviewed in the Nutrition Study Section, whose members are primarily nutrition researchers. However, nutrition research also is widely reviewed in a large number of other study sections, due to its interdisciplinary nature. This dispersal ensures the best review for each particular application.

DIABETES

Question. Dr. Varmus, diabetes impacts the very young as well as older Americans. I know that NIDDK leads diabetes research. What roles do other institutes, such as the National Institute of Child Health and Human Development (NICHD) and the National Institute on Aging (NIA), have for diabetes given the impact the disease has on their key constituencies? What is the role of other institutes which oversee areas where diabetes causes devastating complications, such as blindness, heart disease, stroke, and amputations?

Answer. The NICHD has a broad program of research in diabetes. Diabetes is the most common endocrine disorder that occurs during human gestation. With the introduction of insulin therapy and the implementation of rigorous glucose control, the incidence of maternal and fetal mortality has been reduced to that observed in the general obstetric population whose members have normal glucose tolerance. However, subtle morbidities persist. A longitudinal study aims at clarifying changes in maternal carbohydrate metabolism in women with gestational diabetes (GDM) in early and late gestation. These women are at risk of developing type 2 diabetes over the two to three decades after their pregnancies. This explains the importance of pursuing a longitudinal study. In addition, the knowledge acquired will lead to improvements in the diagnosis and treatment of GDM, based on the understanding of the pathophysiology of the disorder.

Other research supported by the NICHD is aimed at understanding the genetic and environmental causes of disease in order to develop strategies to prevent both type 1 and type 2 diabetes. By supporting immunogenetic research in multiply-affected families, the NICHD played a key role in discovering that type 1 diabetes is an autoimmune disease. The NICHD built on this discovery by providing partial

support for the world's largest, most comprehensive study of the natural history of type 1 diabetes, the NIDDK's Diabetes Control and Complications Study. A major accomplishment of this ongoing study has been to enable doctors to predict the rate of conversion from having no disease to clinical diabetes in close relatives of type 1 diabetics. This important advance paved the way for the Diabetes Prevention Trial-1, supported by the NIDDK, NICHD, and NIAID, which is designed to delay or prevent the onset of type 1 diabetes by attenuating the body's autoimmune attack on the beta cells of the pancreatic islets.

The NIA is collaborating with the NIDDK on new research initiatives on the prevention and treatment of diabetic complications. Specific areas of interest to the NIA include: (1) age-related changes in pancreatic cell function (e.g., altered insulin production or response), and (2) implications of age-related physiologic changes on the rates of progression of complications in older people with type 1 diabetes.

Type 2 diabetes and its cardiovascular complications (e.g., atherosclerosis, hypertension) pose a significant health problem to older adults, yet the processes involved in the development of diabetic complications are not clearly understood. Ongoing NIA-supported research has been examining the role of impaired glucose metabolism and insulin resistance in the development of vascular problems associated with diabetes. Moreover, NIA scientists are studying 2,000 of the participants in the Baltimore Longitudinal Study of Aging to address the question of whether complications of diabetes occur at comparable plasma glucose levels in younger and older individuals and to determine the incidence rates for overt clinical diabetes, coronary heart disease, stroke, and mortality among these aging persons.

The majority of diabetic patients suffer from, and ultimately succumb to, some form of cardiovascular disease (CVD) such as heart attack, stroke, congestive heart failure, and peripheral vascular disease, but why diabetes causes excess CVD and how such complications can best be prevented is not well understood. The NHLBI supports a range of studies to understand the basic mechanisms underlying this propensity of diabetes to develop CVD and the reasons why other CVD risk factors (e.g., high blood pressure, dyslipidemia) tend to co-occur with diabetes. The Institute also conducts trials of CVD treatments, such as revascularization procedures, to identify the best approaches to be used in diabetics. On the horizon are new approaches to therapy that may facilitate glucose control and lead to a lower risk of CVD complications. These new avenues are being pursued vigorously.

The National Eye Institute (NEI) has an extensive portfolio of diabetes-related research, and is an active participant in the NIH diabetes initiative. One area of particular priority is the study of diabetic retinopathy, which is often associated with the growth of abnormal new blood vessels (neovascularization). Recent work has identified several agents involved with retinal neovascularization. Vascular endothelial growth factor (VEGF) and pituitary gland factors, such as growth hormone and insulin-like growth factor-1, are possible causative agents. Systemic inhibition of these substances may have therapeutic potential.

Other diabetes research that the NEI is pursuing is related to the role of protein kinase C (PKC) in retinal neovascularization. VEGF functions by binding to receptors on the surface of cells lining the retinal blood vessels. This can result in activation of an intracellular signaling pathway involving PKC. An orally-administered inhibitor of PKC has been developed and has been shown to be effective in improving retinal blood circulation and in preventing the growth of blood vessel cells under laboratory conditions. The NEI is working with the pharmaceutical industry to set up human clinical trials of this inhibitor.

Diabetes is the most common cause of peripheral neuropathy (nerve damage) in the United States, a complication that affect about 60 percent of people with the disease. The National Institute of Neurological Disorders and Stroke (NINDS) supports studies of the neurological complications of diabetes. This work includes research into the possible causes of neuropathy, including the role of deficiencies in neurotrophic factors. Other studies focus on the mechanisms underlying the pain that characterizes diabetic neuropathy.

PRIMARY PULMONARY HYPERTENSION [PPH]

Question. Primary pulmonary hypertension (PPH) is a rare, progressive, and fatal heart/lung disease that strikes mostly females. Following report language in the fiscal year 1996 NIH Appropriations bill, a program announcement was issued encouraging researchers in primary pulmonary hypertension to submit proposals. How many have you received and how many are being funded? If few have been received and/or funded, how can this be rectified?

Answer. The study of primary pulmonary hypertension is a high priority for the NHLBI, and it supports several projects related to this disease. The program an-

nouncement "Cellular and Molecular Mechanisms of Primary Pulmonary Hypertension" resulted in 12 applications to date. One new project has been funded and three additional projects which are highly meritorious scientifically will be reviewed at the May 1998 meeting of the National Heart, Lung, and Blood Advisory Council. Three applications will be reviewed at study section meetings in June. The new projects in response to this announcement will address innovative and creative approaches to this devastating disease.

We will evaluate the success of the program announcement after we have had a chance to see how many additional applications are submitted during the remainder of this calendar year. The pulmonary research community has shown an increased level of interest in this disease. If only a small number of applications are available, we will consider other mechanisms to stimulate high quality research in this important area of lung research.

Question. Although progress has been made in this area, there are no animal models of PPH. This is typically a necessity for research proposals to be deemed worthy. How are allowances made for this problem and how well versed in this rare disease are the scientists who read and rate the PPH proposals?

Answer. Although there is no single animal model that mimics primary pulmonary hypertension in its entirety, there are a number of animal models that have been used for many years to study pulmonary hypertension in general. Information gained from these studies is providing new understanding of how the pulmonary circulation is controlled and what might go wrong in PPH. In addition, genetically altered animals are now being used to study pulmonary hypertension. One of the objectives of the program announcement discussed previously is the development of an animal model that mimics PPH.

We feel there is adequate expertise on the study sections to review the applications. In fact, the current chairman of the study section that reviews most of the PPH applications has spent his entire research career working on pulmonary hypertension. In addition, when it is felt that there is not appropriate expertise to review a particular application among the regular study section members, special ad hoc members are invited to do the review.

Question. One of the drugs, prostacyclin, used to treat PPH is extremely expensive. One estimate places the cost of the drug alone at an average of $5,000 monthly for each of the 1,000 patients nation-wide on this drug—a bill of $5,000 monthly and $60,000,000 yearly for these patients. How is NIH supporting or planning to support research to find an effective treatment that is manageable cost-wise for the PPH victims and the American public?

Answer. The focus at NIH is aimed at supporting basic research projects to determine the fundamental cellular and molecular factors underlying the disease. It was through such projects, leading to an understanding of the basic mechanisms that regulate the pulmonary circulation, that the drug, prostacyclin, was discovered to be useful in PPH. We believe that further investigations into pulmonary vascular biology, including the role of nitric oxide in regulating pulmonary vessels, and the role that genetic factors may play in the familial form of PPH, will eventually lead to new approaches and strategies for treating PPH.

QUESTIONS SUBMITTED BY SENATOR TOM HARKIN

BEHAVIORAL SCIENCE RESEARCH

Question. Dr. Varmus, this Committee remains very interested in behavioral science research at NIH. Over many years, we have encouraged NIH to pay significant attention to health problems that involve behavior, either as a cause or as a symptom.

For example, smoking is a behavior that leads to cancer, emphysema and other diseases. Illegal drug use is a behavior that leads to AIDS and other diseases. Of course we need research on cancer, emphysema and AIDS, but we also need research on the behaviors themselves. What leads young people to take up smoking or to start abusing drugs? What can we do to discourage these behaviors? Or, to take other examples, are there effective interventions to discourage unhealthy behaviors like violence, child abuse, and teen pregnancy?

Answer. Tobacco use usually begins in early adolescence, typically by age 16. Almost all first time tobacco use occurs before young people graduate from high school. If adolescents can be kept tobacco-free, most will remain tobacco-free for the rest of their lives.

Almost all adolescents will, at some time, feel pressured to try tobacco. Peers, siblings, and friends are powerful influences. The most common situation in which a

cigarette is tried is when a young person is with a friend who already smokes. Particularly susceptible to peer influences are adolescents who lack parental support and involvement in their lives.

Young people are sensitive to perceived signals that smoking is the norm. These include visible public smoking, the availability of cigarettes to minors, and the widespread promotion and advertising of tobacco products. Cigarette advertising appears to increase young peoples' risk of smoking by conveying the message that smoking has social benefits and that it is far more common than it really is.

Young people may be repeatedly exposed to outdoor billboards portraying apparent benefits of tobacco use, especially in inner-city neighborhoods. Increasingly, tobacco companies market their products through promotional activities that reach youth. Cigarette ads visually associate smoking with independence, adventure-seeking, and physical attractiveness—themes that appeal to young people. Young people with low self-esteem are particularly receptive to this message.

Young people who come from a low-income family and have fewer than two adults living in their household are especially at risk for becoming smokers. Female and male adolescents are now equally likely to smoke, but male adolescents are substantially more likely than females to use smokeless tobacco products. White adolescents are more likely to smoke and to use smokeless tobacco than are black and Hispanic adolescents. Insufficient knowledge of the health consequences of smokeless tobacco use is also a factor.

Behavioral risk factors for tobacco use include low levels of academic achievement and of involvement in school activities, and lack of skills required to resist influences to use tobacco.

The National Institute on Drug Abuse (NIDA) recently issued a research-based guide to preventing drug use among children and adolescents. Researchers have identified many risk factors, each of which represents a challenge to the psychological and social development of an individual. While many people mistakenly believe that "the drug problem" emerges during adolescence, research conducted over several decades has made it clear that drug use in adolescence has much earlier roots. Factors that affect early development of children in the family are probably the most crucial, such as: chaotic home environments, particularly those in which parents abuse substances or suffer from mental illnesses; ineffective parenting, especially of children with difficult temperaments and conduct disorders; and lack of mutual attachments and nurturing. Other risk factors include inappropriately shy and aggressive behavior in the classroom; failure in school performance; poor social coping skills; affiliations with deviant peers; and perceptions regarding approval of drug-using behaviors in the school, peer, and community environments.

The development of prevention programs provides knowledge of which protective factors make it less likely that young people will use drugs. The most salient protective factors include strong bonds within the family; parental monitoring with clear rules of conduct within the family unit and involvement of parents in the lives of their children; success in school performance; strong bonds with prosocial institutions such as the family, school, and religious organizations; and adoption of conventional norms about drug use.

In addition, the availability of drugs, trafficking patterns, and beliefs that drug use is generally tolerated also influence the number of young people who start to use drugs.

Studies have shown that educational efforts can effectively reduce the onset of tobacco use among adolescents. Promising results have been seen in school-based programs that teach young people how to resist social influences to smoke. School-based smoking-prevention programs that identify social influences to smoke and teach skills to resist those influences have demonstrated consistent and significant reductions in adolescent smoking prevalence, and effects have lasted one to three years. Programs to prevent smokeless tobacco use that are based on the same model have also demonstrated modest reductions in the initiation of tobacco use.

Such programs are even more successful when they are supported in both the adolescent's home and community. The effectiveness of school-based smoking-prevention programs appears to be enhanced and sustained by comprehensive school health education and by community-wide programs that involve parents, the mass media, community organizations, or other elements of an adolescent's social environment.

Though school-based anti-smoking programs can be effective, more aggressive measures also appear to be needed. Raising the price of cigarettes appears to discourage youth from trying tobacco. Econometric studies indicate that increases in the real price of cigarettes significantly reduce cigarette smoking among both young people and adults.

Also effective are strongly enforced laws that prohibit the sale of tobacco to young people, and policies in the school, workplace, and community that restrict smoking. A crucial element of prevention is access: adolescents should not be able to purchase tobacco products in their communities. Active enforcement of age-at-sale policies by public officials and community members appears necessary to prevent minors' access to tobacco. Communities that have adopted tighter restrictions have achieved reductions in purchases by minors.

A 1994 report from a committee of the Institute of Medicine, Growing Up Tobacco Free: Preventing Nicotine Addiction in Children and Youths, recommends tougher regulation of tobacco ads so that all features of advertisements and promotions that appeal to youths and influence them to use tobacco are eliminated. In addition, the report indicates that governments and private organizations should reinforce the emerging view of smoking as an unaccepted behavior. Other programs, such as paid anti-smoking advertisements, and smoke-free zones in schools and workplaces, can help generate a "tobacco-free norm." The IOM report also recommends that support for research on tobacco use by children and adolescents be increased, including studies of smoking trends among different ethnic groups.

Concerning drug use, effective prevention programs have been carried out which make use of family relationships, peer relationships, the school environment, and the community environment. The most effective programs involve all of these for sustained periods of time.

Since the most vulnerable periods for drug use among youth are transitions, between one developmental stage to another, or when there are difficult life changes, prevention programs often are designed for particular transition periods.

While none of the prevention programs tested so far have eliminated drug use among young people, a variety of programs have demonstrated substantial reductions in use or delayed onset of use, both of which are important outcomes in terms of the long-term burdens of drug use.

The NIH has had a longstanding program of research on aggressive and violent behavior in children and youth so I will focus the major part of my comments on this topic.

It has been shown that the best hope for high-risk children is to interrupt the development of the pattern of violence early on. Researchers funded by the NIMH are studying interventions for young children designed to prevent serious behavior problems from developing. While preventive interventions aimed at single risk factors, have had only modest and short-lived effects, more promising are programs that are coordinated and long-term. NIMH studies suggest that these programs should span the first several years of school, with particularly intensive interventions during the transitions, such as school entry and from elementary to middle school. NIMH is now testing models of early prevention that are aimed at improving the lives of high-risk children in multiple domains, by not only teaching the children better coping skills, but by also training their teachers and parents in the skills and knowledge that will improve the environments in which these children live. Communities also have participated in the intervention planning and delivery.

Other NIMH research focuses on interventions targeted toward older youth who display chronic serious aggressive behavior. Once a chronic pattern of aggressive behavior is established, it is highly resistant to change. In contrast to the generally ineffective, punitive interventions for youth delinquency, several NIMH funded interventions have had success in preventing delinquent behavior to become chronic in at-risk and seriously troubled youth. One of the most promising approaches is the Specialized Foster Care (SFC) Program. The SFC model provides the opportunity for intensive, individualized treatment in a nonrestrictive family setting. This type of foster care is an enhanced by providing the foster parents with substantial training in intensive monitoring, consistent discipline, and positive reinforcement.

The SFC program was based on NIH research findings which showed that at-risk and delinquent youths should not be grouped together during treatment. Instead, these youth should be isolated as much as possible from each other, while maximizing their interaction with pro-social youth and with adults who have received special training. In comparison to the usual group care arrangements, therapeutic foster care has resulted in half as many self-reported offenses, fewer runaways, and half the number of arrests, in the 18 month period following placement. While other programs targeting this population have failed to produce lasting results, this type of foster care was able to sustain its positive effects, with reductions in serious delinquency persisting for at least one year after the intervention ended. During the past decade an increasing number of Specialized Foster Care programs have been setup. In addition to successful intervention, therapeutic foster care has demonstrated a significant cost savings, approximately $2,000 less per month than the cost of group care.

While much progress has been made in the area of research on youth violence research, a 1998 National Research Council report "Violence in Families: Assessing Prevention and Treatment Programs," noted that very little intervention research has been conducted on family violence. A recent NIH initiative is designed to help address this gap. Entitled "Violence against Women and Violence within the Family, this Request for Applications (RFA) encouraged research on the abuse of children and the elderly, partner violence, sexual violence, and multiple episodes of family violence. This trans-NIH funding program to focus on violence was coordinated by the Office of Behavioral and Social Science Research (OBSSR) and co-sponsored by five NIH institutes and two other NIH Offices, in collaboration with the National Institute of Justice (NIJ), the National Center on Child Abuse and Neglect, and the Centers for Disease Control and Prevention (CDC).

Ten research grants were awarded and include studies of interventions for treating domestic abuse in Latino families, protecting battered women, healing the children of battered women, preventing abuse of the elderly by care givers, and treating violent adolescent males from abusive homes.

Effective programs to prevent teenage pregnancy have been shown to share several common characteristics. First, they clearly focus on reducing one or more sexual behaviors that lead to unintended pregnancy. They propose a small number of specific behavioral goals, such as delaying the initiation of sexual activity, use of contraception, and providing a clear message by continually reinforcing a strong stance on these behaviors. Next, the behavioral goals, teaching methods and materials must be appropriate to the age, sexual experience, and culture of the students. Third, effective programs must be based on solid theoretical approaches previously shown to be effective in influencing other health-related risky behaviors. Fourth, effective programs should continue long enough to complete their planned activities. Fifth, teaching methods should provide personalized messages while giving accurate information about the risks of unprotected intercourse and the ways of avoiding it. They must address the social pressures that adolescents experience and teach and practice of communications, negotiation, and refusal skills. Finally, effective programs must have teachers or peers who believe in the programs and then provide appropriate training for them.

Question. In addition to understanding behavior as a cause of disease, we need to better understand behavior as a symptom. For example, NIH should look into the behavioral consequences of dementia and other neurological or mental disorders.

In light of the clear connection between behavior and health, what recent steps have you taken to encourage basic and applied behavioral research at NIH? In your view how well is the Office of Behavioral and Social Science Research integrated into the work of NIH?

Answer. Many such efforts are underway at NIH. For example, the NIH Office of Behavioral and Social Science Research (OBSSR) recently announced a special trans-NIH, interagency Request for Applications (RFA) focusing on "Innovative Approaches to Disease Prevention through Behavior Change." The RFA invites applications to test interventions designed to achieve long-term health behavior change. The health behaviors of interest—tobacco use, physical inactivity, improper diet, and alcohol abuse—are among the top ten causes for premature mortality and morbidity. The initiative is being co sponsored by four other NIH Offices and 11 NIH Institutes, with additional funding from the American Heart Association.

Another recent OBSSR RFA was designed to help build the research capacity of the behavioral and social sciences. In collaboration with the National Center for Research Resources (NCRR), National Institute of Nursing Research (NINR), National Institute on Drug Abuse (NIDA), and National Institute of Dental Research (NIDR), the OBSSR sponsored a request for applications for "Educational Workshops in Interdisciplinary Research." This RFA invited grant applications to develop and conduct short-term educational workshops in interdisciplinary research. Designed to foster cross-disciplinary communication and research collaborations, the RFA emphasized facilitating the integration of different fields of social and behavioral sciences research and/or the integration of these areas with the more biological fields. Ten projects were supported under this initiative. Because it was so successful, the OBSSR expects to reissue the RFA in fiscal year 1999, with participation from several additional NIH Institutes.

Another trans-NIH initiative, cosponsored by eight institutes and three offices of the NIH, is a program announcement (PA) entitled "Methodology and Measurement in the Behavioral and Social Sciences." This just-issued PA encourages research on methodology and measurement, in order to improve the quality and scientific power of data collected in the behavioral and social sciences.

The National Cancer Institute (NCI), in conjunction with the National Institute of Child Health and Development (NICHD), NIDA, NIDR, the National Institute of

Mental Health (NIMH), and NINR, has issued an Request for Applications (RFA) for grants applications to study interventions for "Prevention and Cessation of Tobacco Use by Children and Youth in the U.S."

In addition to these trans-NIH activities, projects are also underway at the individual NIH Institutes to encourage basic and applied behavioral research.

—NIA's program announcement "Social Cognition and Aging" invites basic research and training grant applications to study how representations of social events, societal and cultural norms and personal characteristics influence behavior, reasoning, emotion and motivation.

—NHLBI's "Nutrition Academic Award" encourages the enhancement of medical school curricula to increase opportunities for students, house staff, faculty, and practicing physicians to learn nutrition principles and clinical practice skills with an emphasis on preventing cardiovascular diseases.

—One of NIAAA's recent RFA's, seeks to stimulate assessments of alcohol-related HIV preventive interventions that have the potential for reducing the risk of transmission of HIV in alcohol using, abusing, and dependent populations. Other NIAAA RFA's encourage research to examine the "Effects of Alcohol Advertising on Underage Drinking," as well as studies of the efficacy of "Treatment for Adolescent Alcohol Abuse and Alcoholism."

—NICHD recently offered an RFA to continue the "Family and Child Well-being Research Network" cooperative agreements investigating the relationship of family factors to child welfare.

—Under its new RFA, "Mental Health Research for Survivors of Torture and Related Trauma," the NIMH is inviting grant applications for research on the extent and nature of mental health problems related to torture within the U.S., and on the effectiveness of interventions for survivors of torture.

—Because benefits from combination medication regimens for HIV can be sustained only if rigorous adherence to precise dosing requirements is maintained, NINR's program announcement, " Understanding and Improving Antiretroviral Regimen Adherence," encourages research on factors influencing adherence and nonadherence, and on methods to improve and assure adherence and compliance to drug therapy regimens for HIV.

—A recent NIMH program announcement invites applications for "Centers for Behavioral Science Research in Mental Health." The purpose of these Centers is to provide integrated multi disciplinary research environments in which to pursue questions focused on basic behavioral science related to mental health and mental disorders. NIMH also has a program announcement, "Specialized Mental Health Intervention Research Centers," designed to provide the scientific infrastructure to facilitate assessment of treatments for major mental disorders, and of the preventive and rehabilitative interventions related to those treatments.

—In partnership with NINDS and the National Down Syndrome Society, NICHD is inviting research grant applications that address various aspects of cognition and behavior in individuals with Down Syndrome (DS). Areas of interest include the developmental and neurological mechanisms underlying characteristic loss of function, approaches toward preserving or improving level of function, and methods to assess the effects of various interventions.

—NIDCD has a new program announcement for studies on the assessment of the efficacy of behavioral treatments, as well as the use of computational neuroscience models and other new approaches to investigate higher cognitive functions in communication, such as perception, discrimination, plasticity, multisensory integration, learning, language and memory.

As you know, Congress established the Office of Behavioral and Social Sciences Research (OBSSR) to facilitate the growth and development of health-related behavioral and social sciences research at the NIH. Although the office is relatively new, I believe the OBSSR, under the direction of Dr. Norman Anderson, has made significant progress in fulfilling its trans-institute mission.

The OBSSR has initiated several activities that integrate behavioral and social science into the overall work and mission of the NIH. One of the first tasks it undertook was to establish a definition of behavioral and social science research that could be used consistently across the institutes so as to assess and monitor progress in this area. This definition is now used across all of the institutes to report funding in behavioral and social sciences.

Developing initiatives designed to stimulate research in the behavioral and social sciences at NIH has been a major activity of the OBSSR. The office works very closely with the institutes to encourage them to enhance their behavioral and social sciences research portfolios. To date, the OBSSR has facilitated four trans-NIH collaborations including RFA's on Family Violence; Interdisciplinary Training Work-

shops; Strategies for Health Behavior Change; and a Program Announcement that encourages proposals for methodological research. Because this is such an important role for the OBSSR, and to ensure that the NIH is addressing the most critical behavioral and social science questions, I have asked Dr. Anderson, the Director of OBSSR, to begin a formal process to establish priorities for research in behavioral and social sciences. These priorities will be established with input from a wide constituency of scientists, advocacy organizations, and the public. This assessment will then be used to assist the OBSSR as it works with the institutes to increase their funding of behavioral and social science.

The OBSSR has also sponsored conferences and established working groups that have the wide participation of NIH institutes and centers. For example, the Science of Self-Report Conference addressed an issue of immense interest to all of the institutes. Because of the demand for information on this topic, the conference proceedings will be published this year. Currently, the OBSSR, in collaboration with the Office of Disease Prevention, is organizing a conference on prevention to be held this fall. Entitled, ''The Science of Prevention: Contributions from Behavioral and Social Research'' the conference will report on NIH research that demonstrates how behavioral and social programs can prevent health problems, can make it less likely that such problems will develop among high-risk individuals, and can assist in the management of chronic health problems so that relapse is less likely.

NIH Working Groups are integral to cross-institute collaboration, and the OBSSR has organized and/or participated in several, including the Child Abuse and Neglect Working Group and the Working Group on Psychoneuroimmunological Research. Most recently, the OBSSR has organized a Working Group on the Behavioral Assessment of Transgenic Animals to devise a comprehensive, standardized battery of behavioral tests for examining such animals. Currently, no comprehensive battery of tests exists which severely limits their use in the study of diseases such as Alzheimer's disease, schizophrenia, and depression.

I know you are aware of the efforts NIH has been making to refine our peer review system, and to integrate the review of grant applications from the former ADAMHA institutes into the reviews done by the Center for Scientific Review (CSR). The OBSSR is playing an integral role in this endeavor, organizing and chairing a special working group, the NIH Behavioral and Social Sciences Review Integration Working Group. The goals of this group are: to assure that the study sections in the fields of behavioral and social science reflect the current state-of-the-science; to create a structure that can adapt to future developments in science: and, to ensure high quality peer review that identifies the most meritorious applications.

Another measure of how well the OBSSR is integrated into the work of NIH has to do with my appointment of Dr. Anderson to critical NIH committees. For example, because of the importance of the perspective of OBSSR, I have appointed Dr. Anderson to the search committees for the Directors of NIMH, the National Institute of Neurological Disorders and Stroke, and National Institute of Deafness and Other Communication Disorders. In addition, Dr. Anderson serves on the Peer Review Oversight Committee (PROG), which is charged with evaluating the peer review process across NIH.

Finally, in order for me to be better informed about this important field, I have asked Dr. Anderson to organize periodic briefings for me on new developments in research on behavioral and social sciences.

RESEARCH TRAINING

Question. As you know, the National Academy of Sciences has proposed detailed recommendations regarding training of researchers under the National Research Service Awards program. Among its suggestions, the Academy urged NIH to increase training awards in the fields of behavioral science, health services research, nursing, and oral health.

What steps, if any, has NIH taken to implement the recommendations of the National Academy of Sciences?

Answer. In its 1994 report Meeting the Nation's Needs for Biomedical and Behavioral Scientists, the National Academy of Sciences (NAS) recommended an increase in the number of National Research Service Award (NRSA) training positions in the areas of behavioral science, nursing research, oral health research, and health services research. In the same report, the NAS also recommended a substantial increase in NRSA stipends, which was considered to have priority over increases in numbers of training positions. Within the fiscal year 1997 and 1998 budgets NIH was able to provide small stipend increases for predoctoral trainees and postdoctoral fellows having up to one year of previous experience. Once stipend levels are increased, the NIH focus on the need for increased training positions in the fields of behavioral

science, health service research, nursing and oral health. The NIH has also asked the NAS, in its new study to help identify scientific fields which will benefit from increased training support. In the course of this study, the eleventh in the series of Congressionally mandated studies of the NIH training program, the NAS will be reviewing human resource needs in all biomedical and behavioral fields and will report its findings and recommendations shortly after the end of this calendar year. The fiscal year 1999 President's Budget requests an increase of 25 percent in stipends over fiscal year 1998 levels.

CLINICAL RESEARCH

Question. Failure of NIH to Respond: As you know, in 1994, the Institute of Medicine published a report expressing concern about the decline of clinical research in this country. Over the past three years, this Subcommittee has raised serious concerns about the major obstacles confronting clinical research through which our investment in NIH's basic research efforts pays off with better patient care. Other than responding with modest intramural initiatives, you have asked that we await a report from your advisory panel on clinical research. Recently, that panel issued its report and, made recommendations almost identical to those of the IOM. Dr. Varmus, what do you plan to do to rectify this situation and make up for lost time?

Answer. Although many of the final recommendations overlapped with those directed in the IOM report, the recommendations from the Clinical Research Panel, which I appointed, extended the recommendations of the IOM report.

NIH did not wait to implement the recommendations of the Clinical Research Panel until it completed its work in 1997. Recommendations were addressed as they were brought forward by the Panel. For example, the recommendation to track that part of the NIH budget devoted to clinical research was implemented by the creation of a prospective system to monitor the grants and other awarded funds devoted to clinical research. The recommendation to create a Clinical Research Training Program was implemented immediately. The creation of the new program of career enhancing awards for clinical researchers continues this pattern.

Question. Decline of Physicians: It is my understanding that the number of first-time physician applicants for research projects grants declined by 30 percent between 1994 and 1996? First, can you tell us whether this trend continued in 1997, and your reaction to this decline?

Answer. The reduction in the number of first-time applicants with the M.D. degree seems to have leveled off in fiscal 1997 to about 22 percent below the peak observed in fiscal 1994. Nevertheless, the participation of physicians in NIH research training programs is considered essential and any erosion in the number of applications from physicians is viewed with considerable concern. To address this important issue, the NIH has recently announced a new set of career award mechanisms: one is designed to offer new training opportunities in clinical research to at least 80 young physicians each year. Another will increase opportunities for mid-career clinical researchers who will serve as mentors to beginning investigators. The third will support the development of high-quality didactic instruction in clinical research methodology. We are hopeful that these new awards will ultimately increase the number of physicians submitting applications for clinical research grants. To provide some indication of the magnitude of this initiative, we estimate that, if all of the entry level awardees supported by this program apply for research project grants after completing their career awards, there will be a greater than 10 percent increase in applications from physicians each year for several years into the future.

Question. Related to this issue, I am concerned that you have eliminated the R29 grant, which has been useful in helping get young investigators established. Certainly, with the steep decline we are already seeing in first-time physician applicants, it is important that steps be taken to assure that the elimination of the R29 does not exacerbate the problem. It is my understanding that you believe that steps can be taken to assure special consideration of new applicants within the peer review process, but that many in the research community do not share your optimism. Please tell us how you plan to assure special status for new applicants, how you plan to monitor any trends in the success of new applicants, and what you plan to do to immediately correct any negative effects of the elimination of the R29.

Answer. Our new policy, to use the regular R01 research project grant application and designate specifically which come from new investigators, was adopted after careful analysis. It was found that the R29 mechanism often was not actually advantageous for new investigators, as it involved limitations on funds and required a five-year time commitment as well as a minimum of 50 percent effort. Under the new approach, these restrictions do not exist.

To ensure a fair review for new investigators, NIH staff are carefully explaining the new policy to scientific peer review panels and advisory boards and councils, the application form has been revised to allow new investigators to indicate their status and to ensure that reviewers can clearly identify those applications. To stabilize the number of new investigators entering the research system, the NIH has committed to supporting at least the same number of new investigators as in fiscal year 1998; The goal is to ensure that new investigators receive sufficient resources to sustain their research programs and to maintain the same influx of investigators in order to promote a healthy medical research system in the future.

Question. Funding for General Clinical Research Centers: The IOM and your panel identified the General Clinical Research Centers as a critical resource for patient-oriented research and both reports recommended that these be funded more generously. It is my understanding that the GCRC budget has declined as a proportion of the NIH budget from 3 percent in 1968 to 1 percent for the current year. Given all the obstacles and challenges confronting clinical investigation, how much of the funding increase for the National Center for Research Resources should be allocated to the GCRC's? In addition, have you considered using your discretionary fund or transfer authority for this purpose?

Answer. There is no question that the General Clinical Research Centers (GCRC) are a critical resource for clinical research for NIH. We agree that it is important to support the GCRC's at a level required to permit appropriate patient oriented clinical research as supported by the NIH categoric institutes. The NIH commitment to do so is indicated by recent statistics. Since fiscal year 1993, the increase for the GCRC's has matched that of the NIH as a whole, and that relationship has remained the constant over that time. This reflects the condition of research as a whole, and the necessary balance between basic studies and the translation of research results to patients.

I have no plans currently to use the Discretionary Fund or the transfer authority to increase funding for the General Clinical Research Centers. I believe that the level of funding requested for the GCRC's in the President's Budget is appropriate.

Question. Peer Review: An outside advisory committee concluded that clinical research is on "an even playing field" when reviewed by study sections that have a grant load for review that is at least 50 percent patient-oriented. Last July, a report published in the Journal of the American Medical Association suggested that two-thirds of patient-oriented research grants are being reviewed by the wrong study sections. At a minimum, patient-oriented research should be triaged away from study sections that review 60 percent or more basic research grants. What action has the NIH taken to reform the peer review process to give clinical research an appropriate review?

Answer. The Director of the Center for Scientific Review, Dr. Ellie Ehrenfeld, has made this a high priority issue. Soon after her arrival at NIH in January 1997, she retained Dr. Michael Simmons, a pediatrician at the University of North Carolina, Chapel Hill, to work with NIH staff and members of the clinical research community to find solutions to the clustering problem outlined in previous reports. As a result, she expects to establish, within this calendar year, two Special Emphasis Panels (SEP) for review of patient-oriented, translational research and small clinical trials in the areas of cardiovascular science and clinical oncology. These applications account for approximately half of the applications now reviewed by the type of "low density" study sections to which you refer. Subsequently, she is considering creating a third SEP related to "Human Investigations" for review of applications related to patient oriented, to translational research and for small clinical trials that will be collected in a group from among proposals usually reviewed in several "low-density" study sections. In all cases, the principal investigators will be informed of this option for review by the new SEP and asked if they wish to have their applications so reviewed. Thus, they may choose to cluster their clinically-oriented applications in the SEP or distribute them to one of the many study sections that can accommodate the diversity of diseases, biology, organ system, and technology being studied.

Question. Defining Clinical Research: When the Institute of Medicine issued its report, it defined clinical research in such a manner that only 10–15 percent of NIH research project grants qualified as "patient-oriented." Many of the researchers who have contacted me take issue with the definition used by your panel, which concluded that 30 percent of grants are "patient-oriented". What underlies this difference in grant classification?

Answer. Clinical research, defined by the Clinical Research Panel that I appointed, refers to research conducted using human subjects (or material of human origin, such as tissues or specimens and human cognitive phenomena) for which an investigator directly interacts with human beings. It includes research on mechanisms of human disease, therapeutic interventions, clinical trials, development of

new technologies, epidemiologic and behavioral studies, and outcomes and health services research. The IOM addressed only a part of the clinical research spectrum defined above and also limited its analysis to that subset of grant applications reviewed by the Center for Scientific Review (formerly the Division of Research Grants); the Clinical Research Panel noted that over 50 percent of clinical research grant applications are reviewed by units within the other NIH Institutes and Centers.

Question. Should the NIH use the more conservative IOM definition to assure that new initiatives are properly focused on clinical research?

Answer. Clinical research is a broad field. As defined by NIH, clinical research has changed the face of modern medicine. A generation ago, most of the treatment and prevention strategies that are so successful today were unknown. Transplantation of the kidney, heart, lung, and liver extends the lives of those who, just a decade or two ago, would have had no hope. New surgical techniques and medical devices, including pacemakers and artificial joints, save lives and restore the quality of life for many people. High blood pressure and its deadly consequences, such as stroke and heart attack, are treatable. Modern pharmacotherapies allow those suffering from mental illnesses like depression and schizophrenia to lead productive lives. Today, because of the pace of science and the breadth of discovery, the time frame between a new laboratory finding and an innovative treatment for human disease is greatly foreshortened. Clinical research is, more than ever, a vital link in the research continuum by which the public ultimately benefits in the form of new treatments and prevention strategies. Many of these examples would not have been captured by the IOM definition of clinical research.

Dr. Ehrenfeld also has established the Panel on Scientific Boundaries for Review as an ad hoc working group of the CSR Advisory Committee to undertake a comprehensive examination of the principles governing organization of all CSR study sections. Among the issues they will consider is the dilemma, which extends beyond clinical research, of meeting needs for in-depth expertise on the one hand and the requirement for scientific breadth on the other.

PARTICIPATION OF MULTICULTURAL SCIENTISTS

Question. What is the NIDCD doing to promote existing opportunities for participation by scientists from multicultural populations in communication disorders research? Are there any plans to make additional research opportunities available?

Answer. The National Institute on Deafness and Other Communications Disorders (NIDCD) uses a number of training mechanisms for scientists from multicultural populations to participate in communication disorders research. In particular, the NIDCD Partnership Program was launched with the support of the Office of Research on Minority Health (ORMH) in 1994. It is a pilot program designed to maximize opportunities for underrepresented individuals to become involved in research in human communication. Undergraduate and graduate students, medical students, faculty, and administrators at the Morehouse School of Medicine/Atlanta University Complex (MSM), the University of Puerto Rico (UPR), the University of Alaska System (UAS), and Gallaudet University have participated in the Program. Collaborations have included experiences in the laboratory, in program management, grants management, planning and public affairs, as well as curriculum development and workshops.

In addition, the NIDCD uses a number of research and development mechanisms to attract multicultural scientists, including Postdoctoral Training Programs, Opportunities for Foreign Scientists, College and Postbaccalaureate Student Programs, High School and Undergraduate Student Programs, and Summer Programs.

The NIDCD is an active participant in the NIH-wide NRSA program for Predoctoral Fellowship Awards for Minority Students and for Students with Disabilities. In fiscal year 1998, the NIDCD, in collaboration with the ORMH reissued a request for applications for a small grants program to support the dissertation research of minority students in the sciences of human communication. To date, this program has resulted in ten grant awards. In fiscal year 1996 and 1997, the Institute and the ORMH issued a program to foster the research career development of faculty in minority academic institutions in the sciences of human communication, resulting in five awards.

An important vehicle for the research training is the Research Supplements Program for Underrepresented Minority Individuals and the Research Supplements Program for Individuals with Disabilities. This program provides funds to supplement regular research grants for studies performed by persons in such groups.

The anticipated growth of the Institute's research grant portfolio in fiscal year 1999 will provide us with the opportunity to increase the size of our research train-

ing and career development enterprise. The NIDCD expects to continue previously implemented programs and to consider the implementation of new targeted programs to increase the flow of the investigator pipeline into the sciences of human communication.

The NIDCD will participate in the following new NIH-wide research career development award initiatives for fiscal year 1999: (1) the Mentored Patient-Oriented Career Development Award, (2) the MidCareer Investigator Award in Patient Oriented Research, and (3) the Clinical Research Curriculum Award. The current NIDCD portfolio of career development awards already includes a large proportion of clinician-scientists developing patient-oriented (clinical) research programs (approximately 75 percent) as well as basic research programs (approximately 25 percent).

This past September the NIDCD called an expert panel together to provide recommendations for the future of the Partnership Program. Among the key recommendations were: (1) to continue the Partnership Program and maintain pilot status so that tracking of participants can be continued; (2) to expand the program to extramural grantee institutions that serve large numbers of the disadvantaged groups in order to increase research training opportunities for additional basic and clinical scientists; and (3) to enable larger numbers of researchers to be trained, NIDCD-funded grant holders should be systematically incorporated into the program. Responding to the ad hoc expert panel recommendations, NIDCD is planning to expand this program into the extramural community. The Institute proposed the EXTRA! Partnership program to support this expansion and it will be supported in part by ORMH funding.

COMMUNICATION DISORDERS IN MULTICULTURAL POPULATIONS

Question. We are aware that attention is being given to stroke and Sickle Cell Anemia in Minority populations. Are there any plans to expand research relative to the variety of communication disorders that occur as a result of other conditions that may be prevalent in multicultural populations?

Answer. In May 1997, NIDCD cosponsored, with Howard University, and with funding from ORMH, a national conference entitled "Communication Disorders and Stroke in African American and Other Cultural Groups: Multidisciplinary Perspectives and Research Needs". A number of research needs were identified by the speakers, by audience participants and by a post-conference committee which formulated a series of research recommendations. It recommended that research goals might be best accomplished through the establishment of centers focused on communication disorders and stroke in African-American and other cultural groups.

In anticipation of the establishment of such centers, a program of exploratory grants (P20) is being developed in conjunction with ORMH. These grants would allow potential applicants the necessary start-up and preparation funds and time, thereby allowing those institutions which do not have a long history of NIH funding to develop critical components and enhance the likelihood of successful competition during peer review. Historically Black Colleges and Universities and universities/medical centers with access to significant numbers of minority individuals will be encouraged to apply.

ETHNIC BALANCE AMONG RESEARCH SUBJECTS

Question. We also understand that the Institute is to ensure that there is a racial and ethnic balance among research subjects. What is the NIDCD doing to ensure that research being conducted incorporates this kind of balance?

Answer. The NIH Peer Review System ensures that, for clinical studies, there is an appropriate racial and ethnic balance among research subjects. NIH policy requires that minorities be included in all research involving human subjects, and the NIH Revitalization Act of 1993 requires that there be monitoring of such inclusion. In response to the Revitalization Act, a centralized database was developed by the Center for Scientific Review (CSR) to assist in tracking demographic information. In January of 1995, such information was required for all NIH supported Phase III clinical trials. An NIH-wide committee was established to coordinate these activities. Each month, the committee meets to discuss further implementation of the gender/minority tracking system. NIDCD is represented in each of these meetings. To provide additional follow-up, NIDCD health science administrators contact individual principal investigators if problems are noted.

THYROID DISEASE

Question. An estimated 13 million Americans have thyroid disorders, more than half of which remain undiagnosed. The symptoms of the disease may often be ignored or misdiagnosed, with women and the elderly being most at risk. If left un-

treated, thyroid disease can cause long-term complications, elevating cholesterol levels which may lead to heart disease and cause menstrual irregularities which may lead to infertility. Given the large numbers of Americans impacted by various thyroid disorders, what research is underway at the NIDDK and other Institutes to further the accurate diagnosis and treatment of thyroid disease?

Answer. NIH supports a great deal of research on thyroid diseases and conditions. More than 200 research projects, NIH-wide, received support in fiscal year 1997 (some 62 of these by NIDDK). In the area of diagnosis, there are 55 research efforts underway, and in the treatment area, 107. New developments in both the diagnosis and treatment of thyroid diseases depend on an understanding of the interactions of thyroid hormone (TH) with an amazing variety of other hormones, of the metabolic effects of TH, and of the regulation of metabolism by enzymes throughout the body as well as in the nucleus of each individual cell. Thyroid hormone is a member of the "steroid/retinoid/thyroid" family of hormones that directly interact with the genetic material in the nucleus of the cell. Some of the specific conditions under study include autoimmune disorders (thyroiditis, Graves' (hyperthyroid) disease, the role of the TH receptor in autoimmunity and in the development of hearing disorders, and disorders of growth and development of body organs, as well as cancer); endocrine dysregulation in HIV/AIDS; polyendocrine interrelationships, including the effect of TH on pituitary hormone function; the mechanisms and effects of TH actions on carbohydrate metabolism and diabetes, on obesity and atherosclerosis, and on heart and brain function; the genes linked to thyroid disease; hypothyroidism, including screening of the population; resistance to TH; and environmental effects on the thyroid. To sum up, the interactions of TH that must be dealt with in designing approaches to diagnosis and therapy are extremely complex, but are under intensive research at NIH.

TAX CREDITS FOR RESEARCH

Question. I read Monday that House Republicans are proposing using revenues raised from higher cigarette taxes to pay for a "medical innovation tax credit" intended to stimulate medical research. Drug and biotech companies could take the credit for amounts they spend on clinical trials to test new drugs and medical devices at academic medical centers.

Dr. Varmus, are you familiar with the House proposal? If so, what is your reaction to the proposal?

Answer. I am not familiar with the House proposal that you mention. I am aware of similar legislation recently introduced in the Senate (S. 1885) by Senator D'Amato (R-NY), "The Medical Innovation Tax Credit," which would enable pharmaceutical companies to deduct an amount, equal to 20 percent of certain medical innovation expenses, for clinical research testing activities conducted at specified academic institutions such as medical schools, teaching hospitals, and not-for-profit hospitals.

Question. Is this type of tax credit a smart way to fund biomedical research? How would you weigh the benefits of enacting this type of tax credit versus increasing funding for NIH?

Answer. Tax credits are one way to encourage medical research, and the Administration has been supportive of innovations such as the Research and Experimental Tax Credit. But tax credits serve to energize the research that is primarily of interest to private industry, i.e., applied research for product development.

NIH funding supports undirected or fundamental research; in fact, the cornerstone of NIH's success is support for individual research projects that are designed and conducted by scientists at universities, and other private and public research institutions by the award of grants and within the NIH intramural program. These study protocols capitalize on the most promising science rather than the development of a specific product. This fundamental or "undirected" research not only advances our understanding of human biology and of the mechanisms of disease, but also identifies opportunities for the development of new ways to diagnose, treat, and possibly cure or prevent disease. This basic research that NIH supports provides the foundation upon which the private sector builds the applied research that it funds.

Federally-sponsored and private sector research have different yet complementary roles in the biomedical research enterprise. While a tax credit will encourage applied research as specifically related to work in the private sector, it is not a substitute for increasing the funding for NIH. If tax benefits are provided in lieu of increasing the NIH budget, then there will be a net loss for the NIH as well as for our national biomedical research enterprise.

OFFICE OF ALTERNATIVE MEDICINE

Question. Dr. Varmus, last year's conference report provided that at least $7 million of the $20 million made available for the Office of Alternative Medicine would be for peer reviewed research grants that respond to program announcements by the Office of Alternative Medicine. We had urged you to use these funds to support quality clinical trials that can validate promising alternative therapies.

Dr. Varmus, what progress has been made this year to respond to our report language and to increase the number of clinical trials studying alternative therapies.

Answer. On December 19, 1997, I convened a meeting of NIH Institute and Center directors and representatives from other federal agencies including the Center for Disease Control and Prevention, the Agency for Health Care Policy and Research, and the Food and Drug Administration to address the development of clinical trials in complementary and alternative medicine (CAM). This group met with the Director of the Office of Disease Prevention and the Director of the Office of Alternative Medicine (OAM) to discuss promising initiatives. This meeting and subsequent work with the OAM resulted in the following new initiatives being developed for fiscal year 1998. Also, OAM's commitment of $1.9 million to the National Institute of Mental Health for funding the St. John's Wort clinical trial is ongoing.

	In millions
Research Centers. A request for applications to fund up to four new research center programs in alternative medicine was released and applications were reviewed on April 2–3. These grants will fund centers for alternative medicine focusing on cardiovascular disease, AIDS, addiction and pediatrics at approximately $1 million each	$4.0
Acupuncture and Osteoarthritis. A request for applications to study the effect of acupuncture in the treatment of osteoarthritis in the knee was issued and the applications reviewed on April 13. Based upon this peer review an estimated cost of the projected budget has been increased from $0.5 to $0.75 million. This study will be a large clinical trial to evaluate the effect of acupuncture on this widespread disease	.75
Cancer. The OAM and the NCI are planning to begin the testing of two CAM cancer interventions beginning this year, one of which is shark cartilage. Estimated cost is $0.50 each	1.0
Acupuncture Clinical Trials. A program announcement developed by OAM and seven other Institutes was released in March to solicit applications for pilot trials of acupuncture for a number of conditions. These applications will be reviewed on July 15	.75
Field Investigations. CDC—A physician has been assigned by the CDC, and supported by the OAM, to do several field investigations, in concordance with OAM's original Congressional mandate. Up to four such field investigations will be finished by August 1998	.065
Intramural Projects. The OAM intends to fund two intramural research projects at $0.125 million each in CAM related research. Six applications from NIH intramural scientists have been received and funding is anticipated in July. An intramural panel of scientists have been convened to review the applications	.250
Intramural Clinical Fellow. In collaboration with the NIAAA, an intramural clinical fellow has been identified to work on the use of acupuncture in alcohol abuse. In addition to testing abstinence, neurochemical and neurophysiological parameters will be studied using Magnetic Resonance Imaging (MRI), functional MRI and SPECT (SPECT)	.285
Total fiscal year 1998 OAM Initiatives	7.100

CONCLUSION OF HEARINGS

Senator SPECTER. Thank you for being here and that concludes our hearings. The subcommittee will stand in recess subject to the call of the Chair.

[Whereupon, at 3:50 p.m., Wednesday, April 1, the hearings were concluded, and the subcommittee was recessed, to reconvene subject to the call of the Chair.]

DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 1999

U.S. SENATE,
SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS,
Washington, DC.

NONDEPARTMENTAL WITNESSES

[CLERK'S NOTE.—The subcommittee was unable to hold hearings on nondepartmental witnesses, the statements and letters of those submitting written testimony are as follows:]

DEPARTMENT OF LABOR

PREPARED STATEMENT OF W. RON ALLEN, PRESIDENT, NATIONAL CONGRESS OF AMERICAN INDIANS

INTRODUCTION

Good morning Chairman Spector, Vice-Chairman Harkin and distinguished members of the Appropriations Subcommittee on Labor, Health and Human Services, and Education. Thank you for the opportunity to present testimony regarding the President's budget request for fiscal year 1999 Indian programs and services. My name is W. Ron Allen. I am President of the National Congress of American Indians ("NCAI"), the oldest, largest and most representative Indian advocacy organization in the nation, and Chairman of the Jamestown S'Klallam Tribe located in Washington State. The National Congress of American Indians was organized in 1944 in response to termination and assimilation policies and legislation promulgated by the federal government which proved to be devastating to Indian Nations and Indian people throughout the country. NCAI remains dedicated to advocating aggressively on behalf of the interests of our 230 member tribes on a myriad of issues including the critical issue of adequate funding for Indian programs.

THE PRESIDENT'S FISCAL YEAR 1999 BUDGET REQUEST

Department of Labor

The Native American programs authorized under Section 401 of the Job Training Partnership Act (JTPA) (Public Law 102–477) is the primary source of Indian program funding under the Division of Indian and Native American Programs (DINAP) in the Department of Labor (DOL). The secondary funding source, which surrounds the Welfare-to-Work (WtW) program, was authorized by Congress as part of last year's balanced budget act. Together, these two programs represent DOL's main source of support for employment and training services provided to American Indian and Alaska Native workers—the most seriously disadvantaged segment of the American workforce.

Native American workers benefit from two special provisions in JTPA. First, the Native American program under Section 401 of Title IV provides comprehensive employment and training services for youth and adults on a year-round basis in all portions of Indian country—on and off-reservation. Second, JTPA contains a special set-aside of funds to cover services to Native youth in reservation areas, including Oklahoma and Alaska, under the JTPA Summer Youth program.

In analyzing the current need for job training opportunities for Native Americans, NCAI recommends that not less than $65 million be provided for the Section 401 program in fiscal year 1999, an increase of nearly $12 million over the President's request of $53.8 million. It should be noted that while the President's budget reflect a general increase in JTPA programs, tribal JTPA programs where the only programs that did not receive additional funding. Mr. Chairman, this is unacceptable. Tribal JTPA program funding must be increased to ensure better job opportunities for tribal members. In addition, NCAI recommends that no less than the full amount of the President's fiscal year 1999 budget request of $15.8 million be provided for the tribal set-aside in the Title II–B Summer Youth program in the summer of 1999. In this way, Congress will help assure that tribal youth are better prepared to enter the workforce.

With $30 million authorized over the next two fiscal years for the tribal component of the WtW program, $15 million is expected to be released by DINAP in fiscal year 1998, with the remainder being made available in fiscal year 1999. This program will provide employment services for long-term welfare recipients. Under the current law, federally-recognized tribal governments along with 13 named Alaska Native organizations are eligible for the special 1 percent set-aside of WtW money. So far, over 65 WtW plans for Indian and Native American (INA) have been submitted to the DINAP, with a little over 100 tribes, intertribal consortia and Alaska Native groups covered under these plans.

However, since the inception of the WtW program, the Office of Management and Budget (OMB) has held up release of funds for tribal plans, insisting that the money be made available only in quarterly installments. Such limitations are complicating the administration of these programs at both DINAP and the tribal level. Furthermore, there are no provision in the law that limit such release of funds to INA-WtW plans. NCAI asks this Committee to ensure that the authorized funding levels for tribal WtW is made available to tribes in a timely manner, without excessive regulatory requirements being developed by the Administration beyond those required under current law.

Department of Health and Human Services

Administration for Native Americans

The Native American Programs Act (NAPA), which is administered by the Administration for Native Americans (ANA), is the only federal program serving all Native Americans regardless of where they live or their tribal affiliation. The NAPA promotes self-sufficiency of American Indians and Alaska Natives by encouraging local strategies in economic and social development. This promotion is critical in overcoming the paramount obstacles of social and economic underdevelopment in many Native American communities.

NCAI supports the President's fiscal year 1999 budget request of $34.9 million for the ANA, an amount equal to the current enacted funding level. The ANA projects that in fiscal year 1999, grant applicants will total 725. Of these, 225 grants are projected to be awarded under the fiscal year 1999 budget request. A total of 175 will be "new starts" grants, and 50 will be continuation grants. ANA also anticipates awarding 21 contracts in fiscal year 1999. These grant and contract awards will include financial assistance for social and economic development and governance, training and technical assistance, research, and demonstration and evaluation projects.

Financial support of these projects are expected to result in sustained improvements in the social and economic conditions of Native Americans within their communities, while increasing the effectiveness of Indian tribes and Native American organizations to achieve their own social and economic goals. Such goals include the expansion and creation of businesses and jobs in many areas including tourism, specialty agriculture, arts and crafts, cultural centers, light manufacturing, health care systems, housing, day care, fishing, and other natural resource development. Other benefits include increased capacity-building and infrastructure development for tribes and organizations, particularly through the development of codes, court systems, and the revision of existing tribal constitutions.

Native American Program assistance through the ANA has moved many tribal and Native programs from dependency on federal services, or operating federally-mandated programs, to developing and implementing their own discrete projects. ANA continues to serve a large and diverse base of Native American communities and organizations, many of which have little in the way of resources and lack sustainable economic development opportunities. Congress is urged to support the tribal self-sufficiency goals promoted by the ANA through supporting the President's fiscal year 1999 budget request for this agency.

Administration for Children and Families

The enactment of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (welfare reform) (Pub. L. 104–193), generated a myriad of issues that impact tribal governments. The most critical of these issues is the ability of tribes to enjoy equal treatment under the welfare reform law as sovereign governments, similar to that afforded to the states. As tribes have previously stated "welfare reform is one of the greatest changes to occur to Indian country since the enactment of the Indian Reorganization Act". What many tribes perceive welfare reform as being, is the devolution of the federal trust responsibility to the states as well as an encroachment upon the government-to-government relationship that exists between Indian tribes and the federal government.

As an initial response to this law, tribal governments directed NCAI to develop and submit to Congress a set of tribally specific amendments to the welfare reform law. If adopted, these amendments would have resolved many of the tribal leaders initial concerns. However, only those tribal amendments that the DHHS included in their welfare reform technical corrections package were considered by Congress and included in last year's balanced-budget act. As I have stated previously, empowerment of tribal governments only works if federal funding levels are there to ensure such transition of powers. Unfortunately, the President's fiscal year 1999 budget does not provide any new discretionary funding sources that allow for such transitions in the area of tribal welfare reform initiatives.

Most tribal communities continue to suffer from a lack of adequate infrastructure, economic development and other community improvement factors necessary to properly administer their own welfare reform programs. In order to achieve these community development goals, tribes must have adequate funding for economic development, technical assistance, data collection, construction, job training, children and family support services, housing, transportation, alcohol and substance abuse programs and tribal enforcement plans. If federal support is not offered to help tribes create jobs, sustainable economies and community well being, welfare reform may lead to forced relocation, or even starvation, for many Native American families.

The President's fiscal year 1999 budget request again fails to provide the Division of Tribal Services (DTS) its own discretionary program authorization and budgetary line-item. Because of this, the DTS continues to be forced to borrow scarce resources from other agency programs in order to provide services to tribal governments in the areas of Temporary Services for Needy Families (TANF) and Native Employment Works (NEW) laws. The ACF has tried to provide necessary funding to carryout these duties, but it has become more and more obvious that without line-item funding authorization for the DTS, the ever-increasing needs of Indian tribes surrounding these welfare reform programs will not be met.

NCAI urges Congress to immediately authorize $10 million in initial line-item funding for the DTS. As part of this authorization, NCAI asks Congress to also expand the DTS role beyond just TANF and NEW, to include welfare reform related tribal services under the ACF including child care, child support and enforcement, and child protection services. Creating a more streamlined approach to serving tribal governments welfare reform program needs will benefit all parties involved in providing, obtaining and accounting for these services. NCAI also calls upon Congress to hold oversight hearing on welfare reform's impacts on Indian country. In this way, tribal leaders can report directly to Congress on their needs, goals and objectives surrounding the conversion of tribal cash assistance populations into tribal workforce populations.

Administration on Aging

Within the Older Americans Act (Public Law 89–73), there are four provisions that are of special importance and interest to Native American elders. The first is Title VI: Grants for Native Americans. The purpose of this title to promote the delivery of supportive services, including nutrition services to older American Indians, Alaska Natives, and Native Hawaiians. NCAI requests that the full $30 million authorized for Title VI be appropriated in fiscal year 1999. Funding under Title VI provides key "front-line" services for 229 programs serving reservation elders, including congregate and home-delivered meals, transportation and a wide variety of other elder related services.

The second provision is Title V: Community Service Employment for Older Americans. This program provides funds to ten national sponsors, including the National Indian Council on Aging (NICOA), to train low income elders through community service agencies. NCAI requests an appropriation of $463 million for Title V programs in fiscal year 1999, with at least $5.4 million earmarked for Indian elder programs. The Title V program is especially important for Indian country due to the

significant need for our Indian elders to acquire job skills and supplement their very limited incomes.

The third provision is Title IV: Training, Research, and Discretionary Projects and Programs. Activities supported under Title IV have helped organizations such as NICOA gather knowledge about the problems and needs of Indian elders, and design and test innovative services to meet the needs of this rapidly-increasing population. Additionally, Title IV provides the only source of training funds for Title VI program directors. For fiscal year 1999, NCAI requests $630,000 in appropriated funding under Title IV, with at least $130,0000 earmarked for a continuing grant to NICOA to gather information on Indian elders and to quantify their needs. The remainder should be directed to grants for training and development of Title VI services providers to better serve Indian elders.

The forth and final provision is Title VII: Allotments for Vulnerable Elder Rights Protection Activities, Subtitle B: Native American Organization Provisions. Subtitle B was intended to assist in prioritizing elder rights issues and carrying out elder rights protection activities in Indian country. With deteriorating economic and social conditions in much of Indian country, elder abuse is on the rise. Prevention programs for tribes throughout its elder communities are desperately needed, and yet, no funds have ever been provided for Subtitle B, despite an authorization level of $5 million. State programs currently received $4.5 million for ombudsman services and $4.7 million for prevention of elder abuse programs, however, these programs seldom, if ever, reach Indian country. Mr. Chairman, we request that the full $5 million be appropriated in fiscal year 1999 for these tribal programs under Part B of Title VII.

Within the next sixty days Congress is expected to undertake reauthorization of the Older Americans Act (OAA), which includes many tribally-specific programs highlighted above, that serve our Native American elders. Our tribal cultures teach us to humbly respect our Indian elders as the teachers of our traditions to us and our children. We urge Congress to honor this respectfulness by reauthorizing the OAA and fully fund all Indian elder programs under this Act.

Health Resources and Services Administration

Given the size and distribution of the American Indian and Alaska Native population—less that 2 million—it comes as no surprise that most communities are typically not well informed, nor skilled, when interacting with formal government programs or answering to their requirements. This limitation is felt in most program and policy arenas, and especially so in the context of the evolving U.S. health care domain. HIV/AIDS programs—as microcosms of this health care transformation—manifest the entire breadth of these complications and problems.

Federal support of HIV/AIDS work in Native communities falls into four principal categories. The first of these, the National Institutes of Health, is a highly competitive venue, requiring very sophisticated scientific skill and considerable resources. Work through the Institutes in Native communities is based in university settings, and if a local Native population is involved in research design preparation, it is typically on a minor level. The second entity, the Centers for Disease Control and Prevention (CDC), is more active in providing education and prevention to Native populations, but these are subject to state and local controls. CDC procedures require local Community Planning Councils that set priorities and require competitive grant proposals to obtain funding. These procedures circumvent the trust responsibilities between the Federal and AI/AN governments, and they create near-impossible situations for Native funding possibilities. Even if a community has the resources and capacity to assemble a quality proposal, actual population numbers are often too small to satisfy council priorities for higher levels of efficacy for each dollar spent.

The third means of support is through the Health Resources and Services Administration (HRSA), specifically the Ryan White CARE Act (Public Law 104–146). This support is the most available source for Native American HIV/AIDS care, but it is not without its own complications. Ryan White monies are distributed through it various titles, only one—Title V—addresses the federal government's responsibility to the AI/AN population. Part F of Title V, authorizes the Special Projects of National Significance (SPNS) program and is funded at 3 percent of the total amounts appropriated for Titles I–IV. Part F also identifies a priority to support the development of innovative care programs in Native communities. However, no continuing Title V monies are available for Native programs while Ryan White continues to receive increased funding. NCAI is concerned that the Native American provision has not been funded to the extent that the increase in the overall titles would lead us to expect. We ask this Committee to insure that there is a set-aside under Ryan White Title V for Native Americans that equals no less than $3 million to provide AIDS care.

The fourth category, the Indian Health Service (IHS), seems a reasonable locus to handle these allocations, but IHS has failed to identify HIV/AIDS as a priority, leading to the dissolution of its national HIV/AIDS pharmaceutical support program and its national AIDS office. This trend will continue to escalate as the IHS increasingly decentralizes and turns over its responsibilities to tribal programs. Clearly, IHS does not have a history—nor, more importantly, a future—in providing care to AI/AN peoples living with HIV/AIDS, especially those located in urban areas. Of all the federal programs with monies available for HIV/AIDS programs in Native communities, Ryan White has the most potential in the near future.

Department of Education

For Indian children and adults attending public schools on or near reservations, the fiscal year 1999 budget request will not be afforded them programs that improve their educational opportunities. For fiscal year 1999, the Department of Education's Office of Indian Education (OIE) request is $66 million, a modest increase of $6.3 million over fiscal year 1998. Of this amount, approximately 1,250 local education agencies will receive an additional $2.2 million increase over fiscal year 1998 to provide supplemental programs—tutoring, counseling, and curriculum development—to over 448,000 Indian students attending public schools. Also included in this request is $3.3 million to reinstate OIE's discretionary grant program for Indian children.

In fiscal year 1996, funding for the discretionary grants programs (Indian children and adult education) and the National Advisory Council on Indian Education (NACIE) were zeroed out. This unfortunate trend is proposed to continue in fiscal year 1999. Although we support the $66 million request for the formula grant program, which will help met the special educational and culturally related academic needs of Indian students, and are pleased that the discretionary funding for Indian children has been restored, we continue to urge the reinstatement of OIE's discretionary grant program for Indian adults and funding for NACIE. These programs not only improve the educational opportunities for Indian adults, but provide funding for educational personnel development, demonstration projects, and fellowships which are all necessary for the future of all Indian students.

Also, under the Improving America's Schools Act (Public Law 103–382), OIE is authorized to make grants to Indian tribes to plan and develop a centralized tribal entity that would: coordinate all education programs operated by the tribe; develop education codes for schools; provide support services and technical assistance to schools serving children of the tribe; and perform child-fund screening services for pre-school age children to ensure proper placement and to coordinate the provision of any needed special services. Under the law, $3 million is authorized for these grants; however, no funding has ever been appropriated. Per Resolution No. SFE–97–041, we request that $3 million be allocated in fiscal year 1999.

In the Office of Special Education and Rehabilitative Services, Indian tribes receive up to 1.5 percent of the funds appropriated for the Vocational Rehabilitation State grants which $2.3 billion has been requested for fiscal year 1999. Of this amount, tribes will receive $17.3 million, an $1.9 million increase from fiscal year 1998. Per Resolution No. SFE–97–033C, there is a need for an additional $4.5 million above last years level. This additional funding would allow tribes the opportunity to provide 11 more culturally appropriate Vocational Rehabilitation (VR) services to their members with disabilities. Furthermore, Per Resolution No. SFE–97–034SC, new funding is needed to provide technical assistance and training to existing and proposed American Indian VR programs.

CONCLUSION

Mr. Chairman, we urge the Congress to fulfill its fiduciary duty to American Indians and Alaska Native people and to uphold the trust responsibility as well as preserve the Government-to-Government relationship, which includes the fulfillment of health, education and welfare needs of all Indian tribes in the United States. This responsibility should never be compromised or diminished because of any Congressional agenda or party platform promises. Tribes throughout the nation relinquished their lands as well as their rights to liberty and property in exchange for these ongoing services as well as this trust responsibility. The President's fiscal year 1999 budget is a positive step towards acknowledging the fiduciary duty owed to tribes.

We ask that the Congress consider the funding levels in the President's budget as the minimum funding levels required by Congress to maintain these services and the federal trust responsibility. The consensus of Indian country is that the federal government's budgetary process has failed to provide for effective services and minimum to raise the living standards of Indian communities consistent with non-Indian communities. In order for federal government to reasonably expect tribal government to truly achieve the self-determination, self-governance and self-sufficiency

goals mutually identified by the federal government and the tribal governments will not be achieved unless meaningful increases are provided for Indian programs and services.

Mr. Chairman, this concludes my statement. Thank you for allowing me to present for the record, on behalf of our member tribes, the National Congress of American Indians' initial comments regarding the President's fiscal year 1999 budget.

PREPARED STATEMENT OF PATRICIA E. MARKEY, LEGISLATIVE CONSULTANT, UNITED DISTRIBUTION COMPANIES

Mr. Chairman and members of the Subcommittee: United Distribution Companies (UDC) is a group of companies providing natural gas distribution service to customers chiefly in the Midwest and Northeast. Nearly half of all LIHEAP-recipient households heat with natural gas. UDC companies are deeply committed to meeting the energy needs of all our customers, in particular, those of low and fixed-income. Our member companies are a vital part of the communities we serve.

Mr. Chairman, earlier this year, frigid weather struck the Northeast, as well as other parts of our country. Many people had a very difficult time dealing with the severity of the storms. It only takes one day of frigid weather to lead to disaster. Last winter, certain regions of the country experienced record cold weather coupled with record levels of snowfall. In particular, some Midwestern areas suffered through brutal weather well below zero for extended periods of time that forced some states to virtually shut-down. To compound the severity of the problem, as the weather began to turn bitter, prices for fuel oil, propane gas, and in some states natural gas rose dramatically over previous levels. Oil prices skyrocketed and propane prices doubled and tripled in some areas of the country.

These conditions challenged and stressed the "average" American household, but to millions of low-income elderly, disabled and working poor families this confluence of factors became overwhelming. The choices many were forced to make were untenable; however, the situation that many low-income families face in trying to meet their home energy needs is difficult even under "normal" circumstances. Most of us can take the comfort of a warm home during the winter, or some means of cooling in the heat of summer for granted. Try to imagine what it would be like if you did not have the resources to secure these basic necessities. For millions of seniors, disabled, working-poor families, and others across this country, LIHEAP is more than economic assistance, it is a lifeline for health and safety. No one can go without heat in the winter. Mr. Chairman, in the coming months you and your colleagues will work to craft necessary spending measures for fiscal year 1999 that will set the fiscal spending priorities for the next year, as well as maintain the course towards a balanced budget. As you chart the course to continue to protect our nation's fundamental health, education and social services priorities, we ask you to provide critical funding for home energy assistance for low-income Americans.

LIHEAP FUNDING RECOMMENDATION

Mr. Chairman, we applaud you, Senator Harkin and the other members of this subcommittee for your tireless efforts last year to fashion a broad bipartisan Labor-HHS-Education spending bill. We also commend you for your leadership to move towards restoring necessary funding for energy assistance. This year, on behalf of all of our residential customers—especially the low-income customers who live in our communities—we urge you to continue on this course and to restore critical funding for LIHEAP. We ask for your support for the Low Income Home Energy Assistance Program, and urge that this Subcommittee and the Congress adopt the following in the fiscal year 1999 Labor, HHS and Education Appropriations Bill: Provide an appropriation of at least $1.319 billion for the fiscal year 1999 LIHEAP; provide an "advance appropriation" of at least $1.319 billion for the fiscal year 2000 LIHEAP; and eliminate the set-aside for the Leveraging Incentive Program.

In addition to the funding above, UDC also endorses the continuation of the "Emergency Contingency Fund," consistent with LIHEAP's authorization statute, which authorized $600 million. However, in our view, the emergency funds should not be used in lieu of regularly appropriated funds for LIHEAP. It is essential that the states have the necessary monies to assist needy households and not be subject to the vagaries of the release of emergency monies.

After a careful review of the facts, UDC is urging a restoration of LIHEAP core funding to at least the $1.319 billion level. In recent years, funding for the program has dropped precipitously. The National Energy Assistance Directors' Association (NEADA) estimated that between fiscal year 1995 and fiscal year 1997, 1.3 million

needy households—many of them elderly or disabled—lost necessary aid due to insufficient funds. We believe that the $1.319 billion in regular appropriations is the bare minimum amount necessary to enable the restoration of crucial aid to those households that lost LIHEAP assistance over the past two years.

The U.S. Department of Health and Human Services reports that between fiscal year 1981 and fiscal year 1995, the number of federally-eligible households has risen 45 percent; during this same time, however, LIHEAP funding was cut from $1.85 billion to $1.419 billion. The fiscal year 1998 funding for the program is even lower—$1 billion. In turn, the number of households assisted dropped dramatically. In 1981, over 7 million eligible households received LIHEAP aid; however, last year only 4.5 million needy households were assisted with LIHEAP benefits. Reduced federal funding has also resulted in smaller assistance grants for those in need of LIHEAP.

We applaud the Congress for recognizing the pivotal role that advance appropriations plays in the implementation of LIHEAP by the states, and we urge you to continue to give the states the necessary tools to plan the next year's program prior to the next heating season. In the past, piecemeal funding had a disruptive effect on the states' abilities to plan and implement their LIHEAP Programs. An advance appropriation of at least $1.319 billion for fiscal year 2000 is central to the effective administration of the program.

UDC shares the views expressed last April on LIHEAP before the House Subcommittee on Early Childhood, Youth and Families. Witnesses questioned the value of the Leveraging Incentive Program given the inadequacy of funding. UDC would like to go a step further than that, and recommend the elimination of the Leveraging Incentive Program. Unfortunately, LIHEAP has not been funded at the levels the Congress intended when the Leveraging Program was designed. The legislative history makes clear that the Congress intended that leveraging monies only be appropriated as supplemental funding to the full authorized amount—more than $2 billion.

Congress ought not to penalize low-income seniors and families living in states that do not mandate programs for low-income households, or do not have casino revenues for lifeline programs dedicated to vulnerable citizens. There is no "level playing field" in the states when it comes to leveraging. Also, recent changes in the federal rules on leveraging marginalize the benefit of states' leveraging efforts. The paperwork burden on the states for qualifying for leveraging is disproportionate to the size of the program. We question the value of continuing the effort at LIHEAP's current funding. Such constraints also make the Residential Energy Assistance Challenge (R.E.A.Ch.) Program unrealistic. In addition, R.E.A.Ch. is duplicative of other ongoing efforts.

BROAD SUPPORT FOR LIHEAP

During the first session of the 105th Congress, you and Senator Harkin, as well as, several other key members of the Senate led the effort to restore critical funding for LIHEAP. Mr. Chairman, we are sure that you are also aware of the congressional letters—with broad bi-partisan support—urging the restoration of LIHEAP in the fiscal year 1999 Budget.

In addition, the National Governors' Association (NGA) supports maintaining adequate federal funding for LIHEAP. The NGA has endorsed LIHEAP as a targeted block grant that provides the states with the necessary flexibility to best assist the elderly, disabled, and working-poor households in meeting their home energy needs. The Governors have also urged the Congress to continue to provide advance appropriations for LIHEAP to avoid unnecessary disruption in the program.

Another long-standing supporter of LIHEAP, the National Association of Regulatory Utility Commissioners (NARUC)—representing the state regulatory bodies responsible for regulating the rates and services of electric and gas utilities throughout the United States—has also had a longstanding policy urging the Congress to reject any further cuts or rescissions to LIHEAP. In its most recent action, NARUC has urged the Congress to provide at least $1.3 billion for fiscal year 1999 and fiscal year 2000, and to continue to provide advance appropriations. LIHEAP is recognized as the foundation for many low-income programs authorized/mandated by the state public utility commissions.

THE NEED: LIHEAP HELPS SENIORS AND THE DISABLED

Let us examine the households that actually receive LIHEAP. Of the 5.5 million households which received LIHEAP assistance in fiscal year 1995, approximately 70 percent of these families had annual incomes of less than $8,000. In fact, in Pennsylvania and Iowa, 61 percent and 87 percent respectively, of LIHEAP recipients

earned less than $8,000. Yet despite this low income, the majority of recipient households are not receiving public assistance. As an example, in Illinois, 70 percent of LIHEAP-recipient households are not on welfare.

On average, one-third of LIHEAP households are elderly. States, such as Maine, South Dakota, Georgia, Tennessee, South Carolina, Nevada, and Louisiana, and Arkansas find more than 40 percent of their LIHEAP recipient households include an elderly person. Four states represented on your subcommittee, Mississippi, Texas, South Carolina and Nevada had approximately 60 percent of recipient households which included an elderly person(s). Due to federal cuts, many of these households may have lost assistance. For example, in Pennsylvania, 25 percent of seniors that received LIHEAP in fiscal year 1995 lost all benefits in fiscal year 1997 due to cuts. Finally, nationwide, nearly one-quarter of the households served include a disabled member. The following 17 states had in excess of 30 percent of LIHEAP-recipient households with a disabled member: New Hampshire, Mississippi, North Carolina, Idaho, Texas, South Carolina, Arkansas, Nevada, Wisconsin, Arizona, Georgia, Oregon, Tennessee, Kentucky, Louisiana, California, and Illinois.

According to a 1994 report by Oak Ridge National Laboratory, many low-income households' expenditure for residential energy (their energy burden) exceeds 30 percent of income. The report also states that all the low-income households which are federally eligible for LIHEAP spend over $1,000 per year or 10 percent of income on energy. Typically, low-income households pay four times the percentage of monthly income for energy costs than an average household in America pays. In Illinois, the average family pays 5.9 percent of its income on home energy in winter, while the average low-income family pays between 20–37 percent of income for these energy bills.

ASSISTANCE CRITICAL TO POOR MAKING TRANSITION OUT OF WELFARE/WORKING POOR

One of the primary goals of the 104th Congress was to secure a comprehensive reform of our nation's welfare system. A key underlying principle of the legislation is to assist low-income families and individuals become/remain self-sufficient. LIHEAP is such a program; LIHEAP is the antithesis of welfare. LIHEAP is designed to address the needs of low-income families in meeting their annual energy expenses. LIHEAP promotes self-sufficiency; it protects these families on the edge of poverty from falling deeper into debt, and allows them to have more control over their lives and their resources. LIHEAP will become all the more important as more welfare recipients make the transition to employment.

Working-poor households account for approximately one-third of the LIHEAP-recipient population. Changing dynamics in the work place, including inadequate and stagnating wages, part-time employment, and fewer benefits are swelling the ranks of the working poor. Some of these households have learned that a job does not necessarily get you out of poverty. To illustrate, on December 10, 1997, Catholic Charities USA released the results of its 1996 survey—the most comprehensive report available of private social services and activities. It reported that increasingly, working people are coming to them in crisis. This organization provided emergency food and shelter to almost 7.9 million people in 1996. Over half of those assisted were not on welfare. They need help with grocery or utility bills to make it to the next paycheck. For many, the choices are between heat and food, rent, medicine for a child, or bus fare to work. Catholic Charities has cited that there are not enough "decent" jobs; therefore, many people will not have "the safety net of minimum benefits, and our agencies simply do not have the resources to handle the increased demand." Thus, everyone has not benefited from the economic expansion.

Low-income families struggle to stay together. With resources stretched thin, a meaningful LIHEAP benefit helps families face daily challenges to pay for basic necessities. If you take away or reduce their energy assistance, that is one more push toward dependence. These families are worth the investment of a LIHEAP benefit to keep them independent. LIHEAP fosters independence rather than dependence. It helps low-income people stay off welfare.

HEALTH AND SAFETY CONCERNS

In attempting to argue that LIHEAP is no longer needed, program critics have misrepresented "shut-off" moratoria as a "safety-net" in protecting low-income families. In those states in which moratoria exist, the moratoria may provide some protection for low-income consumers, but no long-term protection. Moreover, moratoria do not exist in all states (including cold weather states). In fact, the NARUC survey on "uncollectibles" catalogues the states policies on "shut-offs," and illustrates that the states' policies vary greatly. In addition, moratoria do not govern unregulated fuels—such as propane, fuel oil, or wood; often do not govern emergency situations;

and do not relieve low-income families of the ultimate obligation to pay for their home energy costs when the moratoria end. In addition, HHS reports that nearly one-third of LIHEAP-recipient households use bulk fuels; thus, are unprotected. In states such as Wisconsin, Minnesota and New Hampshire between 30 to 40 percent of their low-income households use unregulated fuels.

With higher payments for home heating fuel, low-income families face tough choices: heat-or-eat; go further into debt which will jeopardize their ability in the future to become self-sufficient; or use potentially unsafe alternative methods to heat which could result in tragedies. Elderly households might use single room space heaters and turn their thermostats down; these actions will increase the risk of hypothermia for these customers. Yet other low-income customers will move households together to make ends meet. Tragically, overcrowded substandard housing, and the improper use of space heaters have proven to have disastrous consequences in our communities.

TARGETED LIHEAP BLOCK GRANT WORKS

Mr. Chairman, LIHEAP works! As designed by the Congress, LIHEAP is a block grant that is targeted to assist low-income households with the costs of home energy. While there are broad federal guidelines for LIHEAP, the states are encouraged to tailor their programs to best meet their individual needs. The Governors determined what agencies should administer the program, what eligibility standards will be used, how benefits will be structured, the guidelines for the crisis program, and the range of assistance to be rendered.

In addition to program flexibility, the administrative costs of the program are minimal—in the range of seven to eight percent. This ensures that the majority of LIHEAP dollars (generally 92 to 93 percent) are directed to energy assistance benefits for the low-income families that it was intended to help. Carry-over funds are minimal and typically run about 3 percent in most years. Late funding decisions by the Congress have unfortunately forced some states to further restrict eligibility and to reserve additional start-up funding for September.

LIHEAP IS THE CENTERPIECE OF PRIVATE AND UTILITY EFFORTS

The burden of low-income household needs does not rest solely on the Federal Government. Our member companies are involved in and concerned about the well-being of our communities—both in economic and human terms. The states and the private sector recognize their responsibility to contribute to the needs of these consumers.

UDC member companies have developed a host of innovative and effective programs to assist their low-income consumers; these include: operating and/or contributing to fuel funds; providing discounts and credits to low-income customers; providing partial or full waivers of home energy connection and reconnection fees, and late payment charges; partial or full waiver of home energy security deposits; and partial forgiveness of home energy arrears. Moreover, many of our companies are involved in various energy conservation/management activities. Overall, millions of dollars each year are dedicated to assisting the low income with their fuel bills. However, these efforts and most other private efforts are built around LIHEAP as their cornerstone.

Private charitable efforts alone cannot "take up the slack" for reduced federal funding. Two months ago, Caroline Myers, Executive Director of the Crisis Assistance Ministry in Charlotte, North Carolina, testified on this subject before the House Labor, HHS, and Education Appropriations Subcommittee on behalf of an organization which she chairs, the National Fuel Funds Network (NFFN). NFFN's member fuel funds are organizations that raise private contributions in their local communities to help low-income households pay their home energy bills. Fuel funds range from small church groups which distribute hundreds of dollars in a single neighborhood to large independent organizations which distribute millions of dollars across a state. Fuel funds may be a division of a large, social service agency or they may be operated by a local utility or energy company. NFFN's testimony went into further detail about some of the other private sector programs that exist to help bridge the gap between federal LIHEAP funding and the need that exists throughout the nation. Her testimony illustrated that private efforts cannot make up for adequate LIHEAP funding.

CHANGING ENERGY POLICIES AND UTILITY RESTRUCTURING CREATE UNCERTAINTY

More than 50 percent of low-income households in this country heat their homes with natural gas. Federal and state policies favoring greater competition in both the electric and natural gas industries have shifted significant costs away from indus-

trial customers, and other users with energy alternatives, to residential customers. These households are now paying a higher share of the costs of purchasing and transporting natural gas today than they did in 1980, when LIHEAP was first created. Thus, low-income households continue to face increasing energy burdens.

Last year, in testimony before the House Subcommittee on Early Childhood, Youth and Families, Joel Eisenberg, Senior Analyst for Public Policy at Oak Ridge testified on the potential impact of the restructuring of the electric industry on low-income households. He stated that there is "substantial uncertainty as to whether residential consumers in general, and low-income consumers in particular, will benefit from these changes to a significant degree. In some places there is concern that residential rates may actually increase." Eisenberg noted that momentous change in the electric and gas industry is in process. He cited recent data for the natural gas industry from the Energy Information Agency (EIA) which indicate that between 1985 and 1995, savings for residential consumers have been relatively small so far—in the range of 1 percent.

Deregulation and increasing competition create intense financial pressures on gas and electric utilities. As a result, these companies cannot afford to shoulder the responsibility associated with serving low-income households without government support in the form of continued LIHEAP funding. Since its inception, LIHEAP has been a strong and successful public-private partnership that has worked to address the problem. If government pulls out of this partnership, a serious financial hardship will be created for our low-income citizens.

CONCLUSION

Mr. Chairman, last April's House hearing examined the LIHEAP Program. Witnesses included Members of Congress, as well as representatives from the states, and the private and public sectors. The panel included a representative from a local agency and a former LIHEAP-recipient.

Mr. Specter, the witnesses gave a strong endorsement of LIHEAP and the need for more adequate funding. They told compelling stories about low-income households who have benefited from the program. The Maryland LIHEAP-recipient described her situation as the primary wage earner for a family of five. Behind in her utility payments, this divorced mother was scheduled to be disconnected. Qualifying for LIHEAP was the linchpin to securing continued utility service and working out a long-term repayment schedule.

The witness representing a local agency recounted information about numerous beneficiaries of the program, including a divorced mother in her thirties with three young children. Recently diagnosed with cancer, this mother had to quit her job in January when she developed side effects to the chemotherapy. This forced her to go onto AFDC and file for disability. Her income dropped from $1,600 to $406 per month; consequently, she fell behind in her utility bills. LIHEAP helped bridge the gap during this crisis. As the House witness cited, "This is an example of the kind of situation that can plunge a self-sufficient working family into poverty."

Mr. Chairman, the changes in the welfare system adopted in the last Congress will have profound implications. As families move from dependence towards independence, they will need targeted supplemental assistance. Families in transition normally start at, or near, minimum wage levels. In order for them to continue working and gaining employment experience, so that they can be eligible for better jobs in the future, they need help to maintain a basic standard of living from programs such as LIHEAP.

As the winter ends, problems for the poor do not! The spring brings collections pressures on unpaid heating bills. Without the safety-net afforded through LIHEAP low-income households could lose gas and electric service. The truth is simple. LIHEAP is a public-private partnership program that works for low-income households and helps to make energy service available and more affordable to them.

PREPARED STATEMENT OF ROY O. PRIEST, PRESIDENT, NATIONAL CONGRESS FOR COMMUNITY AND ECONOMIC DEVELOPMENT

The National Congress for Community Economic Development (NCCED) is pleased to submit this testimony on the fiscal year 1999 Labor, Health And Human Services, Education, and Related Agencies Appropriations legislation before the Subcommittee. NCCED is the national trade association for over 2200 non-profit community based organizations known as "CDC's" who are committed to community-based economic development. NCCED's members are actively involved in housing renovation and construction, real estate development, industrial and small business

development, employment generating activities and other programs to revitalize their communities.

NCCED is able to provide the Subcommittee with concrete and invaluable insight into how the Jobs Opportunities for Low Income Individuals Program, the Community Economic Development Grants Program (OCS) and other so-called Welfare-to-Work programs are, and can be used to revitalize communities throughout the country. CDC's are actively using these programs to strategically redevelop economically depressed urban and rural areas. CDC's have more than 25 years of experience in evaluating community needs for housing, economic development and social services.

Our successful use of funding from both the private and public sectors, including corporations, banks, foundations, individuals, and local, State and Federal government sources stands as proof positive of our ability to support the well-meaning objectives of the Administration and Congress.

JOBS OPPORTUNITIES FOR LOW INCOME INDIVIDUALS PROGRAM (JOLI)

The Job Opportunities for Low Income Individuals (JOLI) Program was originally authorized as a demonstration under Section 505 of the Family Support Act of 1988 and was recently expanded in the Personal Responsibility and Work Opportunity Reconciliation Act of 1996. The success of the JOLI program was recognized when Congress dropped its demonstration status and increased the authorization from $6.5 million to $25 million. JOLI's mandate is to create job and business opportunities for welfare recipients and other low income individuals. The program is administered by the Office of Community Services (OCS) within the Department of Health and Human Service (HHS) and is designed to evaluate what strategies are effective in transitioning individuals from welfare to work. Under the program, grants are provided to private, nonprofit corporations to make investments in local business enterprises that will result in the creation of new private sector jobs for low-income individuals. Fifty-six nonprofit organizations have been funded through the JOLI program since 1990 and are using their funds to implement a range of job creation strategies including self-employment, business expansion and business creation. HHS estimates that these JOLI investments will lead to 3,875 new jobs and the establishment of 1,708 new micro-businesses.

In fiscal year 1998, only $5.5 million was made available to CDC's and other organizations. Unfortunately, the President's budget request for fiscal year 1999, as in the past three years does not include a request for the JOLI Program. This is a highly competitive program that if funded at the fiscal year 1998 level still will not meet the capacity of CDC's and other organizations to implement key job creation strategies. In 1997, 188 applications were submitted nationwide requesting a total of $76.4 million. Only ten programs were funded.

In some of your States, examples of the number of grant requests is very illustrative:

—Seven applications requesting $3,168,499 came from Pennsylvania. Only one was funded at $499,216.

—Three applications came from South Carolina requesting $534,909. None were awarded funding.

—Six applications requesting $2,623,589 came from Washington. None were funded.

—Six applications requesting $2,843,003 came from Missouri. Only one was funded.

NCCED supports and would urge funding of the JOLI program at its authorized level of $25 million in your fiscal year 1999 bill. JOLI is the only permanent federal program whose principal mission is to create job and business opportunities for welfare recipients and other low income individuals. These funds will be critical to CDC's struggling to create new employment and business opportunities for welfare recipients' transitioning off welfare.

COMMUNITY ECONOMIC DEVELOPMENT GRANTS (CED)

Section 681 of the Community Services Block Grant Act authorizes the Discretionary Authority of the Secretary of Health and Human Services. Under this authority, the Secretary can make grants to private, nonprofit organizations through the Office of Community Services (OCS) for a variety of activities. Under the Community Economic Development (CED) grant program, OCS has the authority to make grants to Community Development Corporations (CDC's) to promote business and employment opportunities in urban and rural low-income communities.

CED is a competitive, discretionary grant program whose funds go to support business and economic development projects launched by CDC's. Most CED grants are used to finance commercial real estate development, including manufacturing

and industrial facilities, business incubators, and public facilities—investments with the potential to generate new jobs and lead to a more stable employment and business environment in economically depressed areas.

Because of the unique nature of this program, there is great demand for CED discretionary funding. In 1996 alone, 335 applications for CED were submitted, but only 71 grants were awarded due to limited funding. CED grants average $500,000 and competitive CDC applications must demonstrate their ability to leverage private sector investment and create new jobs at a competitive cost.

The most recent data compiled on CED funds found that some $26 million in CED funds has been invested in low-income communities. This investment leveraged an additional $51 million in other financing and created some 4,500 jobs. Since its inception, the CED program fund has been responsible for the creation of more than 20,000 permanent jobs in poor communities. By regulation, 75 percent of the jobs created under CED go to low income individuals.

Again, examples of the number of grant requests from some of your States is very illustrative:

—Seven applications came from North Carolina requesting $2,425,000, but only one award of $550,000 was made.

—Five applications came from Alabama requesting $1,273,178, but none received funding.

—14 applications came from Pennsylvania requesting $3,652,323, but only three won awards totaling $798,000 [This program helped the Mon Valley Initiative create a small business incubator.]

—Two applications came from Washington requesting $1,049,312, but only one was awarded $500,000.

—Four applications came from Missouri requesting $1,097,993 but only one was awarded $500,000.

—Three applications came from South Carolina requesting $534,909, but none were awarded funding.

The CED program is unique among federal economic development programs. No other federal program exclusively targets investment capital to low-income communities, using community organizations as a vehicle to invest in job-generating businesses. In many poor urban communities and rural areas, there is a constant shortage of investment capital. Private financial institutions are often unwilling to provide the most important element in a community development project—equity capital. CED funds fill this critical capital gap.

NCCED supports the continuation of CED funding at a minimum at its current level of $23.7 million for fiscal year 1999. CED is a major source of support for the efforts of community based organizations to generate jobs and business development opportunities for low-income persons. Recently complied data on the benefits of previous grants found that grantees leveraged or raised almost twice the amount of money that they had received in CED grant funds—almost $55 million—from other sources.

Between 1991–95, the CED program created over 4,200 jobs of which 94 percent were filled by low-income and unemployed people or people receiving public assistance. At a time when we are seeing real progress in moving people from welfare to work, NCCED is confident that the investment of $23.7 million in fiscal year 1999—the same as in fiscal year 1998—for the CED program will continue to serve as a catalyst for the levels of private and public sector investment that will assure that we reach our national goal of creating 20,000 permanent jobs for low-income people.

CONCLUSION

NCCED is pleased to submit this testimony on the fiscal year 1999 Labor, Health and Human Services, Education, And Related Agencies Appropriations. We urge your support and inclusion of funding in your fiscal year 1999 bill for the Jobs Opportunities for Low Income Individuals Program and the Community Economic Development Grants Programs at their current fiscal year 1998 levels.

PREPARED STATEMENT OF THE NATIONAL JOB CORPS COALITION

Mr. Chairman and members of the Subcommittee, it is an honor to submit to you the National Job Corps Coalition's (NJCC) testimony and request for full funding of Job Corps in fiscal year 1999. Thanks to your support, more than 69,000 of America's most at-risk youth have had the resources necessary to become productive, taxpaying citizens each year. Your support for full funding of Job Corps is testimony to your commitment to serve this difficult population—economically disadvantaged

youth with multiple barriers to employment. Through Job Corps, they have a second chance.

You and the members of the Subcommittee have a responsibility to invest in programs that work and yield returns for America's tax dollars. Job Corps is a cost-effective program that continues to produce tangible results.

For more than 30 years Job Corps has consistently and competently demonstrated its ability to address our country's need to educate and train economically disadvantaged youth. In Program Year 1996 (July 1996-June 1997), 80 percent of all Job Corps student left the program to join the workforce, enlist in the military, or enroll in higher education. However, the true value of Job Corps can best be appreciated by considering the immense costs to our country from the alternative paths these at-risk youths may have taken such as chronic unemployment or dead-end jobs, criminal activity or welfare assistance. There is no doubt that Job Corps is a sound investment that merits continued support.

Center Operations

The NJCC's request for fiscal year 1999 Job Corps funding totals $1.317 billion. This includes $1.144 billion for base level operations at 118 Job Corps centers nationwide. These funds will ensure that Job Corps provides full-time comprehensive residential education and support services to Job Corps' approximately 69,700 students in 46 states. Funding at this level will also ensure that all new Job Corps centers initiated in 1993–94 are fully operational by the end of 1999.

Facility Construction and Rehabilitation

Historically, Job Corps centers have been located in previously used facilities such as former hotels, military bases, orphanages, and seminaries. More than 50 percent of Job Corps' facilities nationwide are over 30 years old. The renovation and rehabilitation of these structures was seriously underfunded in the 1980's and 1990's. The failure to sufficiently fund Job Corps facility needs led to a substantial backlog of repairs. Structures that were old when Job Corps acquired them, often remain in service beyond their useful lives. At some centers, this has affected program performance, threatened safety and health codes, or violated building codes. The NJCC's request of $89.4 million for facility construction and rehabilitation will help to prevent continued deterioration of structures and mechanical systems and make further inroads into this backlog of unmet repair needs. To expedite the review and construction process, Job Corps is investigating options such as design-build.

Center Relocations

Centers located in cramped, inadequate, or unsafe structures where needed modifications are not cost-effective or are unrealistic due to site size, need to be relocated to suitable facilities. Relocating these centers will enhance their results by removing barriers that impede performance. It will also decrease maintenance costs. Thanks to your support for funding in fiscal year 1998, the Cleveland Job Corps center will be relocated this year. The fiscal year 1999 NJCC request asks for $20.5 million to relocate one of four such remaining Job Corps centers—Jacksonville, Atlanta, Cincinnati and Little Rock. These centers have been on the Department of Labor's relocation list for more than 10 years. By funding these relocations, Job Corps will be able to fulfill congressional intent which encouraged the Department to relocate centers that are in poor physical condition, particularly where it is a deterrent to center performance.

Modernization of Equipment and Facilities

Emerging new technologies and a constantly changing job market are challenges that Job Corps faces when trying to ensure student training meets the needs of today's employers, and students in turn are placed into high growth occupations that yield higher placements into stable, full-time jobs. Outdated or obsolete tools, equipment, and materials hamper Job Corps' ability to adequately train students in modern occupations and meet the needs of employers. By upgrading Job Corps vocational offerings and modernizing equipment and facilities, Job Corps will be able to prepare students for jobs of the 21st century and beyond.

The NJCC requests $15.4 million as the second installment of a five year plan to continue to invest in the modernization of Job Corps' vocational training and facilities. Job Corps, working closely with workforce development entities and employers, will be able to intensify its existing efforts to review and update curricula and to modernize its vocational offerings, equipment and programs. This will also enable Job Corps to convert or substantially modernize an estimated 50 percent of its 1,500 vocational classes, facilities and equipment into new or substantially updated trades.

Upgrade of Classroom and Dormitory Furnishings

In addition, the replacement of equipment and furnishings used throughout Job Corps campuses has received low budgetary priority over the years. Many centers are in need of funds to replace torn and tattered equipment and furnishings. Improving the campus environment will help Job Corps enhance student retention rates through better daily experiences. In turn, this will encourage students to stay in the program, complete training and achieve higher outcomes such as learning gains, GED's and quality placements.

Job Corps is successful in training students because it simulates the workplace environment in its classrooms and shops. The NJCC's request includes $5.1 million for this purpose. This will help ensure Job Corps students have access to up-to-date workstations, tools, computers and furnishings. For many disadvantaged youth, a Job Corps campus is the only home they know. Replacement of worn furniture in dormitories will help Job Corps maintain a living environment that is a comfortable and safe haven for learning.

Incremental Expansion

Since 1990, Congress has supported the goals of the Job Corps 50–50 Plan, a long-term initiative to strengthen and enhance existing Job Corps services and programs while incrementally opening 50 new centers to serve 50 percent more youth each year. Currently, Job Corps has the capacity to enroll 67,000 new students each year—14 percent more after a decade of incremental expansion. However, this represents only a fraction of Job Corps' at-risk youth target population. Census reports indicate that five million young people aged 16–24 live in families with poverty level incomes. The jobless rate of teenagers and young adults is higher than that of adults due to less education and training.

Disadvantaged youth will continue to need help in acquiring academic, vocational and social skills provided by Job Corps to become self-sufficient members of the nation's workforce. In addition, our country will need to fill jobs to remain competitive in the world economy. This can only be done if employers have access to a national network of skilled entry-level workers. During the last decade, Congress has twice called upon Job Corps to expand services to disadvantaged young people by opening new Job Corps centers in communities not being served. Job Corps responded quickly.

An investment of $33 million in targeted funds will ensure continued incremental expansion of five new facilities to more adequately serve this population. It will also help to fulfill congressional intent, as stated in the fiscal year 1998 Conference Report for Labor, Health and Human Services, Education, and Related Agencies, "to examine low-cost options for serving more at-risk youth through Job Corps, such as expanding slots at existing high-performing centers, constructing satellite centers in proximity to existing high performing centers, particularly in States without Job Corps campuses, and developing new centers where suitable facilities can be provided to Job Corps at no cost." The Committee will be making a wise, cost-effective investment in Job Corps expansion.

Job Corps/Head Start Partnerships

Historically, Job Corps has had difficulty increasing the number of women served through Job Corps due to a shortage of child care services. An estimated 10 percent of students entering Job Corps each year have dependents. More and more Job Corps students are single parents who cannot enroll in the program unless provisions for their children can be made. With a shortage of child care services on Job Corps campuses, Job Corps' single parents are put on waiting lists for enrollment. In addition, new legislation has left a void in child care services for disadvantaged youth seeking job training skills. Under Welfare Reform, the Child Care and Development Block Grant was established as the primary child care subsidy program for low-income families. This block grant provides vouchers to single parents to help pay for child care, but does not cover costs to build or retrofit existing facilities for use as child care facilities. Job Corps' students who are parents are considered the "working poor" and are not a priority for child care vouchers.

The NJCC's request is $10 million above the Administration's request to provide additional child care services on Job Corps campuses. This one-time infusion of $10 million will build or retrofit up to 10 child care facilities on up to 10 Job Corps campuses nationwide. These funds will also help to fulfill congressional intent in fiscal year 1998 Appropriations language which encouraged Job Corps to develop linkages with the Head Start program.

A collaborative partnership between Job Corps and Head Start will allow both programs to maximize the use of limited resources to serve their targeted populations—low-income youth and children. It will also serve geographic and demo-

graphic areas not being served by established programs. Finding suitable child care facilities is often a prohibitive factor to Head Start in serving its targeted population. Job Corps can help fill this need. Job Corps will provide quality child care facilities and Head Start will operate 10 child care programs. Building additional child care facilities on Job Corps campuses will allow Head Start and Job Corps to jointly serve up to 350–400 additional children and their parents annually. This will help facilitate program enrollment of and/or completion by Job Corps' single parents who will be able to receive the education, training and parenting skills needed to become productive members of society; and their children will receive Head Start's comprehensive, quality child care services. The community surrounding the Job Corps center will also benefit from enrollment at these quality child care facilities and from partnerships developed through this collaboration.

Job Corps/Community Partnerships

Job Corps centers are emerging as an integral part of America's changing and growing workforce development system. Through strong partnerships with One-Stop career centers, close relationships with local employers, increasingly visible community projects, innovative school-to-work training, and on-line communication between Job Corps and workforce development entities, Job Corps operates on the premise that state and local involvement is a prerequisite for success. Through these linkages, Job Corps will enhance their services to ensure an optimal experience for Job Corps students.

Conclusion

By funding the NJCC's request for fiscal year 1999 at $1.317 billion, the Subcommittee will help to reduce the number of young Americans who depend on public assistance by breaking the cycle of poverty and welfare dependence. As more and more Americans strive to make the transition from welfare to work, cost-effective education and training programs will be vital to their success.

Job Corps is a national, residential education and vocational training program with a proven history of results that justify its costs. In addition, Job Corps is a trusted program that capitalizes on public-private partnerships, quality programs and fiscal integrity to offer the disadvantaged youth of our nation a brighter future. Moreover, Job Corps helps to keep America competitive in the global economy by providing a pool of qualified entry-level workers who comprise a significant and growing portion of the nation's workforce.

Mr. Chairman and members of the Subcommittee, it is with great pleasure that we submit to you testimony on behalf of the National Job Corps Coalition. We thank you for your continued leadership and dedication to America's disadvantaged youth. Through your continued support, more than 69,000 young people who participate in Job Corps each year will have the opportunity for a better, more self-sufficient future. Thank you.

PREPARED STATEMENT OF KAY GUINANE, CONSULTING ATTORNEY, NATIONAL CONSUMER LAW CENTER

Introduction

Mr. Chairman and Members of the Committee, the National Consumer Law Center appreciates the opportunity to submit written testimony regarding appropriation of funds for the Low Income Home Energy Assistance Program (LIHEAP) for fiscal year 1999. This testimony is submitted on behalf of our low income clients, who live with an increasing threat of loss of utility service due inability to pay.

The National Consumer Law Center (NCLC) is a nonprofit corporation dedicated to the interests of low income consumers. Founded in 1969, NCLC provides specialized legal support and consulting services to low income customers, their advocates, government agencies and private attorneys in all aspects of consumer and utility law. NCLC has helped utilities, regulatory commissions and advocates design low income affordability programs in dozens of states over the past several years. NCLC has published leading reports on the impacts of energy costs on the poor as well as manuals on related law.[1]

NCLC is a strong supporter of the Low Income Home Energy Assistance Program, as it is the primary safety net between low income consumers and disconnection of utility service. It is efficiently designed to target benefits to households most in dan-

[1] Manuals relating to utility service include "Access to Utility Service", "Tenants Rights to Utility Service", The Regulation of Rural Electric Cooperatives", and "A Guide to Low-Income Energy Efficiency".

ger of losing that vital service. However, without adequate funding, LIHEAP cannot get the job done. In fiscal year 1999 Congress has the opportunity to restore this program to a level of funding sufficient to provide the protection and assistance that low income households desperately need. On behalf of our low income clients we urge Congress to appropriate no less than $1.437 billion, the fiscal year 1994 level, for fiscal year 1999 and an advance appropriation for fiscal year 2000 of at least $1.6 billion. Emergency funding is also necessary.

The Need for LIHEAP

In fiscal year 1998 the overall funding level for LIHEAP reached an all time low. This was primarily because no emergency funds were released, due to relatively mild winter weather. However, the ongoing crisis low income households face in maintaining utility service did not change significantly as a result of weather patterns. Instead, the impact of reduced funding has meant lower levels of assistance for fewer households.

The human impact of these lower funding levels were confirmed in a telephone survey of some of our clients. In Illinois the LIHEAP program opened and closed again in October, when funds ran out. Throughout the winter things were "going crazy with shut offs", according to Lillian Drummond of the South Austin Coalition Community Council in Chicago.[2] In many cases, LIHEAP assistance payments were not large enough to induce the utilities to reconnect. In East St. Louis, Illinois the story is much the same. Joe Hubbard, who has been with the Catholic Urban Program for thirty six years, says "This is the roughest I've ever seen." He explains that since the cold weather never got severe enough to invoke state winter protection rules (below 32 degrees Fahrenheit for a 24 hour period), disconnections were allowed. Then when the weather did turn colder, households could not get reconnected. "Those people are out there lost," he stated.[3] Both Drummond and Hubbard cite increasing use of disconnection by utilities as a collection mechanism, which most impacts the elderly and working poor.

In Wichita, Kansas diminished LIHEAP funds have also resulted in increasing difficulties for low income households. Sunflower Community Action reports that the LIHEAP program ran out of money early, with many households being shut off. Food pantries, United Way, the Salvation Army and other community based organizations are scrambling to help, but lack resources needed to get households reconnected.[4]

The most chilling report on the impact of utility disconnection comes from Timothea Howard, Lead Organizer of the Columbia Heights/Shaw Family Support Collaborative in Washington, D.C. She states that "for a significant number of households loss of utility service is a contributing factor to children going into foster care." When families cannot stretch their incomes to pay for food, rent and utilities, they tend to pay for rent and food first, not realizing that landlords will report utility disconnections. Living without utility service is considered neglect, which results in removal of children from the home by protective services.[5] Surely it would be more humane and cost effective to keep the family together by providing energy assistance.

Census statistics also show a widespread need for the LIHEAP program. Between 13.4–26 percent of U.S. households are eligible, according to statutory standards. (See Table I)

---

[2] Telephone Survey, NCLC, March 27, 1998, Interview Lillian Drummond, Staff, South Austin Coalition Community Council, Chicago, Ill.

[3] Telephone Survey, NCLC, March 27, 1998, Interview with Joe Hubbard, Staff, Catholic Urban Program, East St. Louis, Ill.

[4] Telephone Survey, NCLC, March 27, 1998, Interview with Laura Dungan, Staff, Sunflower Community Action, Wichita, Kansas.

[5] Telephone Survey, NCLC, March 27, 1998, Interview with Timothea Howard, Lead Organizer, Columbia Heights/Shaw Family Support Collaborative, Washington, D.C.

TABLE I.—HOUSEHOLDS ELIGIBLE FOR LIHEAP OF 91,993,582 TOTAL HH IN UNITED STATES

Poverty level	No. HH	Percent total HH
Greater of 60 percent SMI[1] or 150 percent poverty	24,136,925	26
150 percent poverty or below	18,718,748	20
125 percent poverty or below	14,796,445	16
110 percent poverty or below	12,335,430	13.4

[1] State Median Income.

Source: 1990 Census, HHS Http://www.acf.dhhs.gov/liheap/census.htm.

LIHEAP is well designed to channel benefits to those most in need, and LIHEAP recipients tend to be on the low end of the poverty scale. For example, in fiscal year 1995 40 percent of households that received assistance were under 75 percent of the poverty level.[6] And although low income households consume 16 percent less heating energy than the average residential household and pay 14 percent less for it[7], energy costs take up a huge proportion of their average $10,048 annual income.[8]

The proportion of energy costs to household income is called the energy burden. In 1995 NCLC completed a study that illustrated the disparity in energy burden between average residential and low income households. We found the burden for the average residential household is 3.8 percent, while low income households pay far more. For example, a TANF household pays an average of 26 percent of their income on energy and recipients of Social Security pay 14 percent.[9]

Impact of LIHEAP Funding Reductions

The proportion of those households that actually receive assistance has decreased as funding levels have plunged in the past four years. For example, in fiscal year 1994, 6 million households received assistance from LIHEAP[10], but by fiscal year 1997 a 30 percent reduction in funds resulted in loss of assistance to approximately 1.7 million households, a 28.4 percent cut back. (See Table II and III). With funding levels falling even lower in fiscal year 1998, a 42.5 percent overall reduction from fiscal year 1994, more households are losing assistance.

Who is hit hardest by these program cuts? A survey by the National Energy Assistance Directors Association (NEADA) released in September, 1997, showed that of the 1.2 million households that lost LIHEAP assistance between fiscal year 1995 and fiscal year 1997, 313,000 had at least one elderly member and 156,000 had at least one disabled member. Of the remaining 731,000 households it is likely that 43 percent, or 314,330, had children.[11]

The NEADA study also found that states have responded to LIHEAP budget cuts in a variety of ways, including "increasing the share of benefits to those with the highest energy burdens and special needs groups including the elderly and disabled, reducing overall program benefit levels, and reducing the eligibility ceiling."[12]

TABLE II.—DECLINE IN LIHEAP FUNDING SINCE FISCAL YEAR 1994

Fiscal year 1994	Regular + Lev/REACH[1] = $1,437,392,360	Percent change from fiscal year 1994	Total (Regular, Lev/REACH + emergency) = $1,737,392,360	Percent change from fiscal year 1994
Fiscal year 1995	$1,319,202,479	−8	$1,419,202,479	−19
Fiscal year 1996	900,000,000	−37	1,080,000,000	−38
Fiscal year 1997	1,000,000,000	−30.5	1,215,000,000	−30

[6] U.S. Dept. of Health and Human Services, Report of Congress for Fiscal Year 1995: Low Income Home Energy Assistance Program, p. 30 Table 12.

[7] Oak Ridge National Laboratories, "The Scope of the Weatherization Assistance Program: Profile of Population in Need" March, 1994, p. 2.5.

[8] Ibid.

[9] National Consumer Law Center, "Energy and the Poor: The Crisis Continues", January 1995 Ch. II.

[10] U.S. Dept. of Health and Human Services, Report to Congress for Fiscal Year 1995: Low Income Home Energy Assistance Program, p. 29.

[11] According to a study by Oak Ridge National Laboratories, "The Scope of the Weatherization Assistance Program: Profile of Population in Need", March, 1994, p. xii, 43 percent of LIHEAP eligible households have children.

[12] Ibid.

TABLE II.—DECLINE IN LIHEAP FUNDING SINCE FISCAL YEAR 1994—Continued

Fiscal year 1994	Regular + Lev/REACH[1] = $1,437,392,360	Percent change from fiscal year 1994	Total (Regular, Lev/REACH + emergency) = $1,737,392,360	Percent change from fiscal year 1994
Fiscal year 1998	1,000,000,000	−30.5	1,000,000,000	−42.5

[1] Funds for leveraging state and local funds and the Residential Energy Assistance Challenge Option.

Source: HHS, www.acf.dhhs.gov/programs/liheap/approp.htm.

TABLE III.—HOUSEHOLDS RECEIVING LIHEAP ASSISTANCE, FISCAL YEAR 1994–97

Program year	HH assisted	Percent change from fiscal year 1994
Fiscal year 1994	6,000,000	NA
Fiscal year 1995	5,500,000	−8.5
Fiscal year 1996–97	4,300,000	−28.4

Sources: For fiscal year 1994–95, HHS Fiscal Year 1995 Report to Congress: LIHEAP, p. 29. For fiscal year 1996–97: National Energy Assistance Directors Association Survey, Sept. 12, 1997.

Decreases in LIHEAP funding have been shown to increase the incidence of utility disconnections. Those that do not receive LIHEAP assistance are almost twice as likely to be shut off.[13] The consequences of disconnections are well documented and include: Health and safety risks associated with alternate heat and lighting sources, such as kerosene heaters and candles; Hunger and malnutrition; Hyperthermia and hypothermia; Eviction and increase in homelessness; and Diminished educational performance by students with high mobility.

Time is Right to Restore LIHEAP Funding

Congress has been successful in bringing the deficit under control. However, LIHEAP has contributed more than its share to this effort, suffering a cumulative loss of $1.1 billion since fiscal year 1985. As the nation moves toward a balanced budget, we must also move toward balance in our priorities, making sure that basic necessities, such as heat in the winter, are available to those who can least afford it. LIHEAP has immense impacts for a relatively small budget, and should be restored to a level of funding that truly protects the health and safety of vulnerable low income Americans.

The Need for Advance Appropriations

The LIHEAP program needs to go into operation prior to the heating season so that state agencies can begin the process of taking applications. They need to know LIHEAP funding levels early in order to implement the program at a time when it can effectively prevent shut off of utility service: during the harshest part of the winter. For this reason, NCLC requests that Congress include an advance appropriation for fiscal year 2000 in its LIHEAP appropriation this year.

Conclusion

The ongoing crisis low income households face in maintaining their utility service has been exacerbated by sharp drops in LIHEAP funding over the past four years. In fiscal year 1999 Congress has the opportunity to restore this program to a level of funding that will avoid disconnections and the threats to health and safety that go with them. We ask Congress to fund the program at a level of no less than $1.437 billion in fiscal year 1999.

[13] NCLC Testimony regarding LIHEAP Appropriations, to House Committee on Appropriations, May 1996.

PREPARED STATEMENT OF PHILLIP FURMANSKI, PH.D., DEAN, FACULTY OF ARTS AND SCIENCE; CHAIRMAN AND PROFESSOR OF BIOLOGY ON BEHALF OF A CENTER FOR COGNITION, LEARNING, EMOTION AND MEMORY AT NEW YORK UNIVERSITY

I appreciate this opportunity to submit testimony before the Subcommittee to discuss a project of scientific research which is not only an important priority for New York University, but which we believe will advance national interests through enhanced scientific understanding of normal brain development as well as the many disabilities, disorders and diseases that erode our ability to think and learn.

Our project addresses the research and programmatic priorities of this subcommittee. We strongly support the goals presented in the Conference Report accompanying the November 7, 1997 Appropriations for the Departments of Labor, Health and Human Services and Education for fiscal year 1998. That report, for example, encouraged the National Institute of Child Health and Human Development to support, and I quote, "research in the area of brain development, mechanisms that underlie learning and memory, the acquisition and storage of information in the nervous system, and the neural processes; underlying emotional memories as they relate to intellectual development and cognitive growth." We thank the Subcommittee for taking the time to consider and give its support to the important research being conducted in this area. We at New York University firmly believe that in the coming decades, a federal investment in mind and brain studies will repay itself many times over.

To implement the Subcommittee's goal, New York University is undertaking to establish a Center for Cognition, Learning, Emotion and Memory. This Center will draw on the University's strengths in the fields of neural science, biology, chemistry, psychology, computer science, and linguistics to push the frontiers of our understanding of how the brain develops, function malfunctions, matures, and ages. In addition, as a major training institute, the Center will help prepare the next generation of interdisciplinary brain scientists.

To establish this Center, New York University is seeking $10.5 million over five years to support and expand the research programs of existing faculty, attract additional faculty and graduate and postgraduate trainees, and provide the technical resources and personnel support that will allow us to create a premier, world class scientific enterprise. Individual researchers in the science programs at NYU compete for investigational support through traditional routes, quite effectively. However, these traditional funding sources do not address the specific need for establishment of a new cross-disciplinary area of scientific study, particularly one that transcends biomedicine, psychology, education, computer science, cognitive science, and linguistics. Nor do they provide the extensive funding necessary for faculty and student support and personnel and technical resources.

Exploration into the fundamental neurobiological mechanisms of the nervous system can help educators, health care providers, policy makers, work force managers, and the general public by enhancing our understanding of normal brain development and function in both children and adults, thereby helping us to detect and correct impediments that affect our ability to learn, to think, and remember, and to mature as productive members of family and society. Research in this area will ultimately contribute to a better understanding of how children learn at different stages; how educators can improve students' retention and memory; how childhood and adult learning is shaped by different cognitive styles; how aging affects memory; and how diseases alter memory.

There are enormous potential applications for early childhood intervention, teacher training, educational technologies, job training, and retraining, and diagnosis and treatment of mental and memory disorders. These applications directly address national concerns which were identified most recently in President Clinton's State of the Union address, and by the Departments of Labor, Health and Human Services, and Education.

New York University is well poised to make important contributions in this area. Founded in 1831, the University today is the largest private university in the United States, with over 49,000 students representing a broad range of backgrounds and coming from every state and over 120 foreign countries. NYU comprises thirteen schools, colleges, and divisions and is known for the excellence of its schools of law, medicine, film, and business; the Institute of Fine Arts; the Courant Institute of Mathematical Sciences; and departments in the Faculty of Arts and Science, notably neural science, chemistry, biology, psychology, French, English, philosophy, anthropology and economics. Located in the heart of the world's most cosmopolitan and diverse city, New York University is a leading national—and in many fields, international—center of scholarship, teaching and research. It is one of twenty-nine private institutions constituting the distinguished Association of American Univer-

sities, and is consistently among the top U.S. universities in funds received from federal sources and from private foundations.

COGNITION, LEARNING, EMOTION AND MEMORY STUDIES AT NYU (CLEM)

The Center for Cognition, Learning, Emotion, and Memory will be an interschool, interdisciplinary unit linking faculty, students, programs and resources from several schools of New York University. These are the Faculty of Arts and Science, Courant Institute of Mathematical Sciences, School of Medicine, School of Education, and Center for Digital Multimedia. CLEM, to be housed at the University's Washington Square campus within the Faculty of Arts and Science, will be the locus for laboratory research and training in fundamental neurobiological, psychological and computational studies of the nervous system. In addition, CLEM will be a point of convergence for faculty and students seeking to incorporate these research perspectives into their own work in education, medicine, and technology, and seeking as well to enrich laboratory research with interdisciplinary collaboration and conceptual bridges.

The new Center will be administratively housed within the NYU Department of Neural Science. This department includes affiliated investigators from biology, chemistry, psychology, physics, computer science, medicine, and mathematics. It is a national center of research and teaching, encompassing a pre-eminent faculty, and generating substantial external funding from federal and state agencies as well as the private sector. The department holds world-class stature in the study of the nervous system as a sensory communications system, as a controller of motor activity and as a neural network that generates the emotional foundation of voluntary behavior. The neural sciences at NYU have attracted millions of dollars in generous support from, for example, the NIH, NSF, and EPA, the Howard Hughes Medical Institute, the W.M. Keck Foundation, and the Alfred M. Sloan Foundation. Its faculty have won prestigious awards, being named National Institutes of Health (NIH) Merit Awardee, Howard Hughes Medical Institute Investigator, National Science Foundation (NSF) Presidential Faculty Fellow, McKnight Foundation Scholar in Neuroscience, and MacArthur "Genius" Fellow. The department cultivates productive linkages with investigators from other disciplines, educational institutions, and research sectors. Thus, linkages between neural scientists, and educators in the NYU School of Education, clinicians in the NYU School of Medicine, and software designers, computer scientists, and graphic artists in the NYU Center for Digital Multimedia facilitate the application of scientific discoveries in the classroom, in the clinic, and in new technologies.

The new Center for Cognition, Learning, Emotion, and Memory Studies will bring the University's many strengths in these areas more fully to bear on the challenges and opportunities that multi disciplinary studies present. The Center will provide an organizational identity, core resources, and common focus for the university's efforts. For students, it will provide an educational forum to apply knowledge gained in one discipline to problems in other disciplines. For researchers, the Center's synergistic linkages between basic science departments, biomedical departments, and mathematical and computational units will encourage intellectual cross fertilization and will permit the consolidation of individual efforts in multi disciplinary but in conceptually coordinated efforts. For colleagues in the fields of education, medicine, and technology, the Center will facilitate connections with laboratory scientists and enhance the translation of research knowledge into health care, educational, and commercial applications. The enhanced research and training that will be possible at the Center will attract public and private funding above and beyond the substantial funds, honors and recognition already awarded to the University's researchers, and will support the Center's continued growth and development.

THE CASE FOR THE NEW CENTER AT NEW YORK UNIVERSITY

New York University has the resources necessary for the successful creation and operation of a major multi disciplinary research and training center. There is top-level administrative leadership, a commitment to science, intellectual and administrative resources, established frameworks for interdisciplinary and interschool collaboration, strengths in neuro-biological, psychological and computational sciences, and standing in the international scientific community. The Faculty of Arts and Science, which encompasses the College and the Graduate School, has a preeminent faculty of 560, an annual operating budget of $197 million, a student population of approximately 9,200, and over 450,000 square feet of dedicated space apart from shared University facilities, making it a vital center of teaching and research. The science enterprise is especially vigorous, the result of a decade-long multi-million dollar development plan to renovate research and teaching laboratories and recruit

distinguished junior and senior faculty, a pioneering science curriculum for undergraduate non-science majors, extensive research experiences for undergraduate science students, and an enhanced graduate student training program of supervised research and teaching assistantships.

New York University has, as part of its multi-year science development plan, created a world- class and widely recognized neuroscience program. Neural science at NYU is particularly well known for research in visual processing and perception, theoretical neurobiology, molecular and developmental neurobiology, and cognitive neuroscience. It has outstanding researchers and well-established strengths in visual neuroscience, auditory neuroscience, cognitive science, neuromagnetism, neurochemistry, neurobiology, behavioral neuroscience, mathematical modeling, and computer simulation. Recently, these faculty have begun to unravel the biological mechanisms underlying cognition, learning and memory. As an example, NYU scientists have made important contributions to visual processing, deriving the most successful methods available for studying nonlinear interactions in neuronal information processing; emotion, giving the first real glimpse into the neuroanatomy of fear; neural development, with landmark work on the vision system; and the neural bases for auditory function, including neural sensitivity to auditory motion stimuli.

With these strengths, New York University is strategically placed to create a new and distinctive center that will produce a new understanding of the brain, and new ways of using that knowledge for improving human health and welfare. The Center for Cognition, Learning, Emotion, and Memory will capitalize on our expertise in physiology, neuroanatomy, and behavioral studies, and will build on active studies that range from the molecular foundations of development and learning to the mental coding and representations of memory. The Center will encompass diverse research approaches, including mathematical and computational modeling, human subject psychological testing, use of experimental models, and electrophysiological, histological, and neuroanatomical techniques. Examples of the kinds of research that will be conducted are taken from our current research efforts, which are now dispersed in the departments of biology, chemistry, neural science, psychology, and computer science: Neural scientists are investigating the anatomical and physiological pathways by which memory can be enhanced; the conditions that facilitate long-term and short-term memory; and the brain sites where all these memories are processed and stored. Neural scientists, working with computational scientists, are using digital imaging to characterize normal and pathological mental processes in humans. Developmental biologists are studying the molecular basis of development and learning. Vision scientists are studying form, color and depth perception; visual identification; the varieties of visual memory; and the relationship of vision and perception to decision and action. Neural scientists are studying the neuroanatomy and physiology of emotion. Physicists are taking magnetic measurements of brain function that trace the decay of memories. Behavioral scientists are studying learning and motivation, acquisition of language, memory and aging Neurobiologist and psychiatrists are conducting clinical studies of patients with nervous system disorders, especially memory disorders. These existing researchers are well recognized by their peers and have a solid track record of sustained research funding from federal agencies and private foundations.

As we move through the last years of the "Decade of the Brain," NYU, through this new Center, is strategically positioned to lead and contribute to accomplishment of the goals of this important initiative. Establishment of this Center requires support to bring together investigators in the different disciplines that address cognition, learning, and memory. Centralized core resources are required to facilitate collaboration and add efficiency to the research and training functions. New faculty who specifically bridge the disparate areas of knowledge and expertise need to be hired and "set up." Support must be provided to attract students to this new area and to promote work in this area, particularly for those from groups traditionally underrepresented in the sciences.

While other academic institution are also conducting research into brain studies, New York University has special strengths in important emerging research directions that are central to this Subcommittee's goals, as stated in its November 1997 Conference Report. To elaborate, vision studies at NYU follow an integrated systems approach that has been shown to be the only successful approach to unraveling this complex system, and that has established NYU as an internationally known center for neuroscience studies in vision. The interest in vision, a key input to learning, is associated with focused studies on the learning process, particularly, the interaction with memory and behavior. These researchers are exploring hard and exciting questions: How does vision develop in infancy and childhood? How does the brain encode and analyze visual scenes? What are the neural mechanisms that lead to the visual perception of objects and patterns? How do we recognize letters and

numbers? How do perceive spaces, depth, and color? How we does the brain move from vision and perception to planning and action? How does the brain process what we see?

NYU scientists are also at the frontier of studies in the neuroanatomy and physiology of emotion, a new area of exploration that complements studies of how perceptions, thoughts, and memories emerge from brain processes. Work recently conducted at NYU and elsewhere has established the biological basis of emotions and the patterns by which they are expressed within the neural circuits that crisscross the brain and project through the body. The new studies have found that there are multiple systems in the brain, each having evolved for different functional purposes, and each producing different emotions. For instance, emotions of fear evolved to help animals survive and reproduce in hostile environments; the amygdala, a tiny structure in the brain, reacts to stimuli and triggers a physiological response, including a rush of adrenaline, a process which constitutes the "emotion" of fear. Work being conducted at NYU also suggests that the neural circuits supporting the expression of emotions were highly conserved through evolution. They persist, unconsciously, in our daily behavior, and shape our reactions to events well before we rationally and consciously process the event.

Scientists at NYU are using behavioral testing physiological recording of neural activity, and neuroanatomical user tracing to ask, what are the neuroanatomical pathways for the formation of emotions and emotional memories? How do we learn and remember emotions? These studies have crucial applications for education, health care, and social welfare, and address such questions as: How can emotions, such as fear, facilitate or undermine the learning process? Do emotionally stressful situations affect our ability to remember facts, retrieve information, perceive events and objects? How can we enhance memory in stressful situations? How can we better diagnose and treat emotional disorders—which commonly characterize psychiatric disorders?

RESEARCH APPLICATIONS

Research conducted in the Center for Cognition, Learning, Emotion and Memory Studies will have diverse applications for health, education, and social welfare.

Early Childhood and Education: Research into the learning process as it relates to attention and retention holds important implications for early childhood development. Although most of the human brain development is completed by birth, the scientific findings on brain development generated by researchers at NYU point clearly to windows of learning opportunity—that open and close—with important implications for when children best learn. Understanding how, when and under what conditions learning proceeds can lead to practical applications for parents, care givers and educators. In the midst of a national debate on education reform, thousands of educational innovations are being considered without the advantage of a fundamental understanding of the learning process. CLEM researchers, coupled with educational psychologists and their expertise in normal childhood development , can contribute to a better understanding of how parents can stimulate their children's cognitive growth, how children learn at different stages and use different styles, how educators can accommodate those styles, and how educational technology can be harnessed to stimulate interest and increase retention and memory. Findings can be quite specific, pointing for example, to critical or sensitive periods for acquiring particular skills in, for example, basic numeric concepts, writing, or foreign language. These findings are crucial to national efforts in early childhood education, and improve teaching and learning in the elementary grades.

At NYU, these research efforts will be enhanced by our scholars and research conducted in our School of Education, and our Center for Digital Multimedia, which brings together educators, laboratory scientists and software designers who explore how interactive multimedia technologies enhance learning and develop prototype teaching models.

Advances in Biomedical and Behavioral Research: Research conducted in our Center will by its nature address the loss of memory through aging or disease (including Alzheimer's), as well as disorders of emotional systems that commonly characterize psychiatric disorders. Many of the most common psychiatric disorders that afflict humans are emotional disorders—malfunctions in the way emotional systems learn and remember—and many of these are related to the brain's fear system. Neurobiological studies of emotion and emotional memory in the brain will generate important information about the brain systems that malfunction in, for example, anxiety, phobias, panic attacks, and post-traumatic stress disorders. Research into the brain mechanisms of fear will help us understand where our emotions come from, why these emotional conditions are so hard to control, and what goes wrong

in emotional disorders. Ultimately, the research will generate clues for prevention and treatment of emotional disorders, focusing perhaps on the ways in which unconscious neural circuitry can in effect, be altered or inhibited.

Job Training and Retraining: Research into the fundamental processes of cognition and learning, emotion and memory will help address the persisting challenge which the nation faces in training new recruits to the labor force, preparing welfare recipients to move into the labor force, retraining workers dislocated from downsized industries, and retraining workers in new technologies. Basic scientific research into neural and psychological mechanisms can help rationalize job training programs and increase their effectiveness.

Mr. Chairman, this concludes my testimony. I fully support the goals of this Subcommittee, and I thank you for the opportunity to testify before you today.

PREPARED STATEMENT OF SCOTT ALLSWANG, CHAIRMAN OF THE BOARD OF TRUSTEES, CROHN'S AND COLITIS FOUNDATION OF AMERICA, INC.

Mr. Chairman, thank you very much for the opportunity to present the views of the Crohn's and Colitis Foundation of America (CCFA) regarding fiscal year 1999 appropriations for the National Institutes of Health (NIH), and the Centers for Disease Control and Prevention (CDC).

My name is Scott Allswang and I currently have the honor of serving as the chairman of the CCFA Board of Trustees. Founded in 1967, the Crohn's and Colitis Foundation of America is a non-profit research organization dedicated to finding the cause of, and cure for, Crohn's disease and ulcerative colitis. The Foundation is committed to a nationwide coordinated research program aimed at conquering these chronic and devastating intestinal diseases that continue to baffle medical science.

Crohn's disease and ulcerative colitis are serious inflammatory diseases that affect the gastrointestinal (GI) tract. Crohn's disease may occur in any section of the GI tract but is predominately found in the lower part of the small intestine and the large intestine. Ulcerative colitis is characterized by inflammation and ulceration of the innermost lining of the colon. Because Crohn's disease and ulcerative colitis behave similarly, they are grouped together as inflammatory bowel disease (IBD). Both diseases present a variety of symptoms including; severe diarrhea, crampy abdominal pain, fever, and rectal bleeding.

It is estimated that over 2 million people are afflicted with either Crohn's disease or ulcerative colitis, roughly half of that number for each disease. Unfortunately, IBD impacts disproportionately on young people, with most cases being diagnosed before age 30. However, it is not uncommon for patients to be diagnosed in their sixties, seventies or later in life. Most IBD patients require long term medical therapy and multiple surgeries. Thus, while not considered a fatal illness, IBD is a debilitating, chronic condition that can lead to intense suffering and morbidity.

My involvement with CCFA began in 1989, the year that my teenage son Jason was diagnosed with Crohn's disease. I have watched him persevere despite the devastating symptoms, potent treatments, and numerous hospital stays that keep interrupting his young life. Soon after Jason's diagnosis, I started volunteering my time to the local chapter of CCFA. I made a commitment that I would do all I could to help. When you have a way to fight back, you don't feel helpless anymore. Jason became involved as well, and throughout the years, we have recruited other volunteers to join us. As a co-owner of an insurance company, I also have provided numerous hours of consultation for IBD patients on issues related to insurance. All over the country, people who suffer from IBD and the friends and family who love them are giving themselves to CCFA, much like Jason and myself.

INFLAMMATORY BOWEL DISEASE RESEARCH

Mr. Chairman, I would like to take this opportunity to express CCFA's deep appreciation for this Subcommittee's long-standing support of NIH and CDC. I would also like to convey a special word of thanks to Senator Reid for his invaluable support of IBD research over the years. Moreover, I would like to thank you Mr. Chairman, for your leadership in providing the National Institutes of Diabetes and Digestive and Kidney Diseases (NIDDK) with a 7.4-percent increase in fiscal year 1998. Together with the National Institute of Allergy and Infectious Diseases (NIAID), NIDDK supports the majority of IBD research within NIH.

Although we have made significant progress in recent years in the fight against Crohn's disease and ulcerative colitis (due in great part to NIDDK's 10-year IBD Strategic Plan implemented in 1993), IBD remains among the most challenging disorders affecting the digestive tract. The two million people and their families currently living with IBD are pinning their hopes for a better life on medical advance-

ments made through NIH and CCFA sponsored research. For this reason, CCFA strongly supports the concept of doubling the NIH budget over the next five years. Regarding fiscal year 1999, the CCFA joins with the Ad Hoc Group for Biomedical Research Funding in recommending a 15-percent increase for NIDDK, NIAID, and NIH overall as a first step toward achieving this goal. Moreover, the CCFA encourages the Subcommittee to increase IBD research funding within NIDDK and NIAID from the current $17 million to $35 million over the next five years.

Throughout its 30 year existence, CCFA has recognized the importance of working closely with NIH. Virtually all IBD researchers funded through NIDDK and NIAID are former CCFA grant recipients. This unique partnership has enabled us to sharpen the cutting edge of an innovative IBD research grant awards program and CCFA co-sponsored scientific symposiums.

Some of the most promising IBD research in recent years has focused on translating findings from studies conducted on animal models to humans with IBD. These animal models have enabled researchers to form the current hypothesis that Crohn's disease and ulcerative colitis are caused by a malfunctioning immune system, wherein components of the patient's immune system over-react to normal intestinal bacteria. We know that people are susceptible to this malfunction because of their genetic makeup but further research is necessary to determine which bacteria are responsible, how these bacteria interact with the intestine's immune system, and which immune system components are involved.

We are also trying to identify the genes that are responsible for making people susceptible to IBD. It is believed that there are several types of each disease, and hence, multiple genes are involved. Once we understand which immune system components and genes are responsible in the different subgroups of Crohn's disease and ulcerative colitis, we can use this knowledge to create new and improved treatments.

Finally, Mr. Chairman, I am pleased to report that due in part to CCFA's Basic Research Agenda and our partnerships with NIDDK and NIAID, research findings are being translated with greater speed into new therapies for IBD patients. By working together we have begun to alleviate the intense pain suffered by people with IBD, but there is a great deal more that needs to be accomplished. Our progress thus far gives us tremendous hope for the future, however, the study of new and promising research pathways is dependent upon increased federal funding for IBD research at NIH.

COLORECTAL CANCER PREVENTION

Mr. Chairman, in addition to coping with either Crohn's disease or ulcerative colitis, a sub-set of IBD patients are at high risk for developing colorectal cancer. As you may know, colorectal cancer is the third most commonly diagnosed cancer for both men end women in the United States and the second leading cause of cancer-related deaths. Because many IBD patients are highly susceptible to this disease, CCFA has a long history of actively promoting the benefits of colorectal cancer screening.

Although colorectal cancer is almost entirely curable when detected early, recent studies have shown a tremendous need to (1) inform the public about the availability and advisability of screening and (2) educate health care providers with respect to colorectal cancer screening guidelines. The recently initiated National Colorectal Cancer Screening Awareness Program at the Centers for Disease Control and Prevention will address these needs by coordinating with national partners like the CCFA to develop an information program emphasizing the value of early detection. CCFA hopes that this new program will do for colorectal cancer screening rates what CDC's Breast and Cervical Cancer Screening Program has done for mammography and Pap smear screening compliance. Mr. Chairman, CCFA encourages the Subcommittee to provide CDC with $5 million (an increase of $2.5 million over fiscal year 1998) in fiscal year 1999 for this vital campaign.

CONCLUSION

As we near the end of the 20th Century, the scientific community is on the verge of tremendous breakthroughs in biomedical research. The development of new technologies coupled with our growing understanding of the genetic code have led us to an unprecedented point in the understanding of human disease. With respect to Crohn's disease and ulcerative colitis, CCFA truly believes that we have reached a turning point in the fight against these devastating disorders. Thanks to this Subcommittee's continued support of NIH and CDC, CCFA is optimistic that the future will yield better treatments and eventually a cure for IBD.

Mr. Chairman, once again thank you very much for the opportunity to present the views of the Crohn's and Colitis Foundation of America. If you have any questions or would like further information please do not hesitate to contact us.

PREPARED STATEMENT OF THE COALITION OF NORTHEASTERN GOVERNORS

The Coalition of Northeastern Governors (CONEG) is pleased to provide testimony for the record to the Senate Subcommittee on Labor, Health and Human Services, Education, and Related Agencies as it considers fiscal year 2000 advance appropriations for the Low-Income Home Energy Assistance Program (LIHEAP). The CONEG Governors appreciate the support provided by the Subcommittee in maintaining this important program, and urge the Subcommittee to provide advance funding at the level of $1.1 billion for fiscal year 2000. In addition, we are requesting that additional funding authority be provided to allow for the release of emergency funds for unforeseen circumstances such as price spikes in natural gas or heating oil, severe winter weather and other potential emergencies.

During the current fiscal year, almost 1.5 million very low income households in the Northeast states will receive LIHEAP assistance. About 40 percent of these households are disabled or elderly. Many live on fixed incomes or are making the difficult transition from welfare to work. Two-thirds of the region's LIHEAP recipients are very poor with annual incomes of less than $8,000 per year. For many of these recipient households, annual income is not sufficient to pay high winter heating bills, even in periods of economic growth. Many low-income elderly or disabled residents are forced to make a choice between purchasing medicine, food or energy.

LIHEAP funds play a major role in helping to make home energy more affordable for low-income households in the Northeast. The percentage of disposable income spent on energy by low-income households can be significant. Program funds are targeted to those with high energy burdens, averaging 15 percent of household income, approximately four times the rate for all households. The program has been very successful in helping low-income households pay their energy bills, thereby preventing fuel supply shut-offs.

According to LIHEAP Home Energy Data (fiscal year 1995), households using fuel oil usually spend more for home heating than households using natural gas, kerosene, LPG or electricity. In addition to having some of the highest electricity rates in the Unites States, the Northeast also has a high percentage of households that heat with fuel oil. Most Northeastern homes are older and have less efficient furnaces, further compounding the problem for low-income residents. Electric utility restructuring and competition, while bringing lower electric rates to the region, will not fully meet the needs of low-income households which predominately heat with fuels other than electricity.

The availability of advance funding for fiscal year 1999, approved as part of the fiscal year 1998 Labor, Health and Human Services, Education and Related Agencies Appropriations Act, will play a significant role in helping states plan their programs prior to the start of the winter heating season. In the Northeast, the winter heating season often begins before the completion of the annual appropriations process. By providing advance funding, states can plan the orderly allocation of funds, thereby reducing administrative costs. It also allows states to coordinate outreach and prioritize program goals and components more efficiently. Traditionally, 70 percent of LIHEAP funds are spent during the first two quarters of the Federal fiscal year.

States have established programs throughout the Northeast to leverage additional funds from the private sector. These programs include requiring margin-over-rack and oil bid programs to provide the lowest possible prices for heating oil; exploring options for purchasing natural gas through cooperative arrangements with local governments; and initiating partnerships with utilities to provide discounts and avoid shut-offs. For example, New Jersey has initiated the Safety Net Partnership project with utilities to avert shut-offs after the winter moratorium. States are also establishing closer links between energy conservation services and LIHEAP, thereby helping to reduce long-term energy bills. For example, Maine is utilizing its LIHEAP database to identify ''high energy users'' and targets its weatherization program to those households.

States are also exploring the use of summer fill programs to purchase oil during the summer months when prices are low, thereby increasing the purchasing power of program funds. For example, in 1997, New Hampshire's number of emergency LIHEAP cases decreased by 10 percent from the previous year. New Hampshire attributes the decrease to its summer fill program, which enables the state to address fuel needs in advance, while protecting eligible LIHEAP households from potential

winter heating spikes. The reduction in emergencies means reduced administrative costs attributed to processing emergency cases. Furthermore, LIHEAP recipients do not absorb the additional costs associated with emergency deliveries.

LIHEAP is an assistance program that can promote planning and responsibility through the use of innovative initiatives and can be a useful mechanism to facilitate the transition from welfare to work. New Hampshire allows LIHEAP recipients to participate in a program that promotes behavior modification and planning for future energy needs. If a LIHEAP recipient remains current with his/her utility provider or establishes a credit with his/her fuel vendor by the end of the winter season, the program will match the LIHEAP participant's contribution (not to exceed $75). This enables LIHEAP recipients to plan for their fall energy needs and reduce their dependency on LIHEAP.

States have also adopted various administrative strategies designed to minimize the amount of program dollars that are used to operate the program, thereby allowing more funds to be used for assistance. LIHEAP administrative costs are among the lowest of human service programs. States pay less than $25 per household for program administration. Specific examples of innovative administrative strategies include the development of uniform application forms to determine program eligibility, establishment of a one-stop shopping approach for the delivery of LIHEAP and related program services, and the use of mail recertification. For example, New Jersey has initiated a program to streamline its service delivery process by sending payments directly to the utilities.

CONEG is pleased to have had the opportunity to share its views with Chairman Specter and rest of the Subcommittee, and stands ready to provide any additional information about the importance of LIHEAP in meeting the home heating needs of low-income, disabled and elderly residents of the Northeast.

PREPARED STATEMENT OF ROBERT E. MCAFEE, M.D., CHAIR, ON BEHALF OF THE JOIN TOGETHER NATIONAL POLICY PANEL ON ADDICTION TREATMENT AND RECOVERY

TREATING ADDICTON: AMERICA'S NO. 1 HEALTH PROBLEM

Mr. Chairman, members of the subcommittee, my name is Dr. Robert E. McAfee, and I am to pleased to provide remarks on behalf of the National Policy Panel on Addiction Treatment and Recovery, convened by Join Together.

I would like to thank you, Mr. Chairman, for this opportunity to offer our recommendations on treatment for addiction. Speaking for my colleagues on the Join Together Policy Panel, I hope that this hearing initiates a productive congressional dialogue on this issue that culminates in the recognition that the alcoholism and drug addiction are diseases, that they are treatable, and that when we make an investment in helping those who are dependent on alcohol and drugs to recover, our entire society benefits.

When I was asked by Join Together to chair this panel of national experts and local advocates on substance abuse and justice system issues, I did so with the hope that we might recommendations that would be helpful to policy makers and to health care professionals in meeting our responsibilities and providing sound health care.

Having had the opportunity to hold a public hearing, to interview experts, people in recovery, mayors and other officials, our panel urges that we move with dispatch to prepare and implement a strategy to overcome the discrimination that until now has marked the care for alcohol and drug dependent members of our communities.

Our panel offers six recommendations for meeting this treatment disparity. Today I would like to urge the members of this subcommittee to consider carefully our first recommendation:

Treatment for alcoholism and other drug addiction must be covered as a health benefit on an equal basis with treatment for other diseases.

It is time for substance abuse treatment to be pulled into the mainstream of health care.

In effect treatment should be made broadly available to all who suffer from addiction. The panel believes in this concept of equal coverage as a matter of fairness, and as a principle of sound public policy. Further, it should apply to everyone, whether they receive health care in the public system or the private system.

For this to happen, it is essential that health care providers and insurers acknowledge addiction as a chronic, primary, relapsing disease, and treat it as any other such condition, be it hypertension, diabetes or arthritis. Likewise, health care purchasers, in particular employers and governments, must demand that full coverage of treatment be included as a basic element of any health benefit.

Even though addicted persons can go through treatment and achieve at least temporary abstinence, some find it difficult over time to avoid relapse. Many people who achieve sustained remission do so only after a number of cycles of treatment and relapse. Understanding this is key to overcoming the stigma of substance abuse and to making treatment part of the health care mainstream. Preventing relapse, and maintaining recovery, requires support from our workplaces, families, schools and religious institutions. For many, these institutional supports have already eroded, and must be initiated or reinvigorated. This means linkages are necessary between these institutions and the treatment site.

Achieving parity

For substance-abuse treatment to be brought up to par with treatment of other chronic diseases, three goals must be met:

—There must be full coverage of substance abuse treatment as a basic health care benefit.

—There must be sufficient capacity to treat those in need.

—There must be access to a variety of substance abuse treatment modalities when and where they are needed.

A. Parity in coverage

For those who need treatment, often the biggest obstacle is cost. For many, lack of health insurance stands as a brick wall between them and treatment services. Even for the insured, coverage sometimes excludes substance abuse treatment or, at best, provides for only bare-bones services.

Unfortunately, the levels and availability of treatment services have in many cases declined over the past decade. The reason for this, in large part, is practices by health care payers that have led to cuts in treatment services by:

—Setting arbitrary limits on the duration or type of treatment;

—Emphasizing short-term savings over long-term outcomes;

—Reducing or eliminating treatment services;

—Putting insufficient emphasis on quality and individualization of care; and

—Using gatekeepers who are poorly trained in substance abuse treatment and have a self interest in keeping costs down.

Purchasers of health insurance, particularly employers and government, may not even be aware of these reductions in substance abuse services, believing that what they contracted for is being delivered. In fact, greater health care savings are likely to be achieved by expanding substance abuse treatment, not restricting it. Particularly at the workplace, employers stand to gain far more by expanded treatment services, in the form of reduced absenteeism, lower training costs and enhanced productivity.

Thus, the first step towards achieving parity is to include primary care and specialty treatment for substance abuse in all basic health benefits, with appropriate services for family members, including children. This would probably cost insurers and managed-care providers nothing; the direct cost offsets would be at least equal to or greater than the cost of adding treatment. By not fully covering treatment, managed-care providers are costing themselves and their subscribers millions.

Employers should not wait for managed-care providers and health insurers to act; they should demand coverage of substance-abuse treatment as a condition of doing business. As employers and major purchasers of health care, it is in their own self interest to do so. Coverage for a high quality of addiction treatment should be made an express term of agreements between purchasers of health care benefits and managed-care providers.

For poor and elderly people, Medicaid and Medicare should likewise provide for substance abuse treatment at least on a par with other chronic diseases. State contracts with managed care providers should require this. State governments should set aside funding to provide treatment for the uninsured. Some revenue for this could come from taxes on alcohol and nicotine. Steps must be taken to ensure that people who rely on the public health care system have access to treatment.

As state governments implement policies to move welfare recipients into the workforce, they must also devise programs to address this population's health needs, particularly as they relate to substance abuse, and to provide related housing and child-care services. Effective implementation of the nation's welfare-to-work reform will be placed in jeopardy if appropriate treatment is not coordinated with this initiative.

A second step in achieving parity of coverage is to expand the scope of covered treatment to include the full continuum of services necessary to achieve appropriate outcomes and sustain recovery. This extends from inpatient detoxification and counseling to outpatient treatment and relapse prevention, and includes health and mental health services, educational and vocational programs, family treatment and sup-

port services. Treatment decisions, therefore, must be made using objective guidelines derived from research and clinical practice, and treatment must be sufficiently flexible to match the needs of the individual and the severity of the illness. Coverage must also provide for simultaneous treatment of substance abuse disorders and their physical and psychiatric comorbidities.

For care providers, this means abandoning generic approaches to treatment in favor of more individualized therapies. Research indicates that the longer an individual remains in treatment, the better the results. The course, length, intensity and type of treatment in any given case should be determined based on individual diagnosis and clinical necessity, as determined using objective guidelines. Any limits on treatment days, visits or payments should be made based on appropriate principles as with other chronic diseases. For example, some patients need inpatient care for part of their recovery. These individuals shouldn't be required to "fail" in other treatment settings first before being placed in the most appropriate level of care.

B. Parity in capacity

To make addiction treatment the equal of treatments for other chronic diseases, treatment capacity must also be enhanced. Capacity for providing treatment must be expanded to meet the needs of both the private and public systems.

At our panel's public hearing in Chicago, witnesses from both the private and public treatment systems testified to the limited access to available treatment slots. In Illinois alone, in 1996, there were an estimated 764,000 people in need of treatment, but the state could accommodate only 116,000. At any one time in Illinois, there is an active list of 1,500 individuals waiting for treatment. No one knows how many others gave up or never even tried.

This lack of capacity for substance abuse treatment exists in stark contrast to the medical system's capacity to treat other diseases. If you fell this morning and needed your hip replaced, you could have it done this afternoon. But if you suffered relapse of an addiction, you might have to wait four weeks before getting help.

Expanding coverage of substance abuse treatment would go a long way toward expanding capacity. Just as supply rises to meet demand, more money for treatment services would result in wider availability of services. But waiting for the market to respond to the demand would take time, and even then would require new staff, more training and constructing new facilities.

Even as we seek to expand capacity, we must recognize that treatment resources are likely to continue to lag behind demand for years. Unless and until there are sufficient resources to meet demand, we must come up with a plan to better allocate existing treatment resources. In effect, we must develop a triage system, parsing out resources to those most in need.

C. Parity in access

The third greatest obstacle to getting treatment for those who need it is access. High cost and limited capacity, of course, are themselves barriers to access, but other barriers exist as well. Among them:

—A lack of timely treatment. When a client presents for detoxification, immediate services should be available. This requires the elimination of waiting lists and of delays in authorizing treatment.

—A lack of geographic proximity. This is an obvious problem in many rural communities, but even in cities, whole neighborhoods may be without any treatment services, may lack services that match the need, or may be unable to reach treatment due to inadequate public transportation.

—A lack of linguistic, cultural, ethnic or gender competence.

Treatment must be made linguistically, culturally, geographically and psychologically accessible. This means that every community should have access to a full range of treatment services. This does not mean that all services must be provided within the community; only that those in the community have somewhere nearby to turn for meeting their needs. Emergency treatment and detoxification services should be available around the clock for all citizens, regardless of ability to pay. Treatment staff must be trained to make their services easy to use and understand. They must be trained about issues of culture, ethnicity and gender, and they must be prepared to provide treatment in the client's dominant language.

A significant factor in ensuring access to substance abuse treatment is its integration into the health and mental health care systems. Screening for, assessing and intervening in substance abuse should be part of general medical and mental health practice. Most importantly, substance abuse must be recognized as a primary disease and all primary-care physicians, nurses, psychologists and social workers must be trained to identify substance abuse—and the children of substance abusers—and

to order appropriate referral. We must reach a point in our perception of this disease where heath and mental health care providers understand that failure to diagnose it under some circumstances would be considered malpractice. Once again, the business sector is ideally situated to demand substance abuse screening from its health providers. Treatment of addiction at any stage is economical for employers, but the earlier it is diagnosed, the more likely treatment is to be successful.

Hovering over all of this is the stigma of substance abuse. Addicted people are judged to be bad, weak-willed, and often criminal. Many people either do not understand, or reject, the biological basis of the addiction. We take what is at essence a health problem and write it off as moral failure. We rely on the criminal justice system for solutions. We pass off substance abuse as someone else's problem, when in fact it touches all of us.

In conclusion, Mr. Chairman, no matter what we may think about people who are dependent on or who abuse alcohol or drugs, we are wrong to push them aside. Substance abuse hurts everyone, if not directly, then indirectly through higher crime, unnecessary health care expenses, added law enforcement costs, lost workplace productivity and personal and family hardship.

The solution to our nation's drug and alcohol problem is for public policy leaders to recognize alcoholism and addiction for what they are—chronic diseases, with biopsychosocial causes and manifestations, whose prevalence has created a public-health crisis—and to respond appropriately by making treatment broadly available to all who suffer from them. Such policies would have immediate and far-reaching effects, not only in reducing substance abuse and improving health, but also in making our communities safer, lowering our taxes, improving workplace productivity and reducing health care costs.

By "treatment," we mean the broadest sense of the word—a continuum of care that begins with diagnosis and access to appropriate behavioral, pharmacological and spiritual care, but that continues on to support the recovering addict in training for work, completing school, finding housing, and restoring families. To achieve this requires the full support of the community, assisted by federal, state and local services and resources coordinated across governmental and institutional lines. For communities that make this effort, the payoff in improving everyone's lives will be well worth the effort.

I thank you, Mr. Chairman, for this opportunity to again offer remarks to this subcommittee. I would like to close my statement by offering the six recommendations of our panel, and provide the names of the distinguished colleagues who have worked with me to prepare and present them to communities across the country.

I have also directed that our final report, Treatment for Addiction: Advancing the Common Good , be provided to each member of this subcommittee. If I, or Join Together, based at the Boston University School of Public Health, can provide additional information, I hope you and your staff will not hesitate to call upon us.

PREPARED STATEMENT OF CYRUS M. JOLLIVETTE, VICE PRESIDENT FOR GOVERNMENT RELATIONS, UNIVERSITY OF MIAMI

Mr. Chairman and Members of the Subcommittee: I am pleased to submit testimony on behalf of the University of Miami (UM) and Florida State University (FSU). Both of the institutions have long enjoyed your support, and my colleagues in Florida are deeply appreciative of your leadership, Mr. Chairman, and the Subcommittee's confidence. We recognize that you and your colleagues on the Appropriations Committee face difficult choices as you prepare for the Subcommittee's priorities for fiscal year 1999 and we know that you will continue to make the difficult choices with the best interests of the nation guiding your decisions. My colleagues and I hope that you will find it possible to fund the important initiatives detailed below in the fiscal year 1999 appropriations cycle.

We would like to highlight two high priority areas: the Risk Assessment and Intervention Lyceum proposal—a collaboration between the University of Miami School of Medicine and Florida State University; and the Minority Cancer Prevention, Control, and Treatment Initiatives. A copy of the statement by Dr. Clyde McCoy, Professor and Chair of the Department of Epidemiology and Public Health at the University of Miami, on behalf of the collaboration and the risk assessment proposal, is attached. We would once again thank the Subcommittee for the opportunity to testify and request your favorable consideration of the proposal.

High priority minority cancer prevention, control, and treatment initiatives

The Miami-based resources of the University's School of Medicine, the Sylvester Cancer Center, one of the oldest and for decades the only comprehensive cancer cen-

ter in Florida, its Courtelis Research and Treatment Center, the Batchelor Children's Center Bone Marrow and Cord Blood Transplantation Pediatric Oncology Project, and its Early Detection Breast Cancer Program (EDP) Consortium in collaboration with Jackson Memorial Hospital make this concentration and coordination of resources, facilities, staff, research, education and treatment one of the most unique resources in the country in confronting and combating cancer in minority and ethnically diverse populations. They have an absolutely unique patient and data base, unparalleled in the nation for minority cancer. They have developed a three-part, comprehensive initiative designed to assist in minority cancer control, prevention and treatment and are requesting $7 million for this three-part campaign: (1) Model Minority Cancer Prevention and Control Program; (2) The Pediatric Oncology and Bone Marrow/Cord Blood Transplantation Initiative; and (3) the Early Detection Breast Cancer consortium. We urge the Department of Health and Human Services (HHS) to implement this far-reaching, multi disciplinary and coordinated campaign in minority cancer, control, treatment and prevention.

(1) Model Minority Cancer Prevention and Control Program.—The University of Miami School of Medicine, its Sylvester Cancer Center—which served for decades Florida's only comprehensive center—the Courtelis Center for Research and Treatment and the Bachelor Children's Center together possess a set of unique resources which can be brought to bear in cancer prevention, treatment, and control, especially among minority populations.

They have a unique, and unparalleled ethnically diverse, minority patient population base which affords them, in turn, a unique source of data, incidence trends and treatment outcomes information, prevention and control guidance that can be of invaluable assistance to our national health and research agencies. There is not other concentrated patient base that would afford the nation's research agencies with such a precise mirror of minority and ethnically diverse populations. We propose to maximize the effectiveness of the work with this critical population base by expanding and further targeting our work in Early Detection, Primary and Secondary Prevention Research, Genetic and Molecular Epidemiology Research, and by expanding the overall capacity of The Courtelis and Sylvester Centers.

We seek $3.5 million in targeted support for the Model Minority Cancer Prevention and Control Program through the National Cancer Institute and the Office of the Minority Research. We would respectfully request the following language:

"The Committee notes the unique resources of the Sylvester Cancer Center and The Courtelis Center for Research and Treatment in focusing on minority and ethnically diverse patient populations. Indeed, there is probably no other data as comprehensive on both African- American and Hispanic cancer patients. The Committee recommends that the NIH consider entering into a $3.5 million cooperative agreement with these centers to fully access and maximize the effectiveness of this critical resource in cancer prevention and control."

(2) The Pediatric Oncology Initiative.—The second and interrelated initiative is the Miami-based Batchelor Project in Pediatric Bone Marrow and Cord Transplantation. As noted above, the concentration of cancer research and treatment facilities and resources at the Miami School of Medicine, make us one of the leading sites in the nation, in our work on Minority Pediatric cancer control and treatment. Two-thirds of all patients are African-American and Hispanic. Our cord blood supply for minority children is virtually unparalleled.

We are requesting $2 million in fiscal year 1999 funding for this component.

(3) Minority Breast Cancer Initiative/The Early Breast Cancer Detection Program (EDP).—Breast cancer is a problem of major public health importance in Miami-Dade County. While late stage breast cancer disease decreased by 21 percent in Florida, late stage breast cancer disease increased by 32 percent in Miami-Dade County. Thirty (30) percent of the 600,000 female cancer cases anticipated in 1998 will be breast cancer; and one in every 8.5 cases of breast cancer in Florida will be diagnosed for Miami-Dade County residents. Breast cancer has become a public health crisis.

Working with the Sylvester Foundation and Sylvester Center, Jackson Memorial Medical Center, the University of Miami School of Medicine, a consortium of primary health care providers and the American Cancer Society, the University of Miami-based EDP seeks $1.5 million per year for five-year massive and comprehensive effort to more than triple the screening capacity of the EDP consortium.

We seek to achieve at least 50 daily screenings, and reach in excess of 12,500 women each year. Indeed, medically under-served minority women who are not screened for breast cancer are at extremely high risk concerning the rapid progression of this disease. Breast cancer screening has been proven to identify early, smaller lesions which are more treatable and at lower cost and result in a higher quality of life. Mammography provides an example of a proven technology for reduc-

ing late stage and increasing early stage breast cancer detection, and the University of Miami/Jackson Memorial Medical Center is effectively delivering this technology especially among the medically under-served.

However, the ability of the current Early Breast Cancer Detection Program (EDP) to meet the Miami-Dade County demand is deteriorating quickly due to the lack of funds. The waiting time for women seen by the EDP at some primary health care centers has increased to six months. There are more than 150,000 medically underserved women over the age of 40 in Miami-Dade County who are potentially in need of the UM/JMMC early detection program services. Under our proposal, the number of women screened from an average of 15 per day to 50 per day—or 12,500 per year.

The Cuban Heritage Collection

Finally, the University of Miami is seeking $4 million over five years from the Department of Education for a unique and historic initiative: The Cuban Heritage Collection. The University proposes to create a first-ever, multi-media resource of Cuban research and training materials. The Cuban Heritage Collection will be housed in an area specifically designed to permanently store, display, and provide non-destructive access to all aspects of Cuban history and culture, especially as it is reflected in the United States, and will be based on the University's existing, large and valuable Cuban collection. The Cuban Heritage Collection will have six major components:

—(1) A Scholarly Collection of National and International Standing;
—(2) A Broad Spectrum Collection reflecting the History and Culture of Cuba and Cubans;
—(3) A Working Collection for Teaching, Learning, and Research;
—(4) A Multi-Media and Multi-Format Collection;
—(5) An Archive for Permanent Housing of Unique Materials; and
—(6) A Collection Housed in a New Facility reflecting Cuban Culture. The University proposes to secure $1 million in matching funds from the State and private sources.

PREPARED STATEMENT OF CLYDE B. MCCOY, PROFESSOR AND CHAIR, DEPARTMENT OF EPIDEMIOLOGY AND PUBLIC HEALTH, DIRECTOR, HEALTH SERVICES RESEARCH CENTER

Mr. Chairman and Members of the Subcommittee: I appreciate the opportunity to present testimony on behalf of the University of Miami as well as our in-state research and education partner, Florida State University. We are deeply appreciative of your leadership, Mr. Chairman, and of the Subcommittee's confidence. We are especially appreciative and deeply thankful for the supportive language from your Subcommittee over the past two years and look forward to your continued support for this unique collaboration in fiscal year 1998. I fully understand and appreciate that at no time in the past have you and your Congressional colleagues faced more challenges and more constraints, thus we appreciate even more your willingness to consider the important and unique research in education partnership between two of our more prominent Universities. As the former campaign manager for Tom Luken, who served on the Hill for over 18 years, I was personally impressed with the dedication, commitment, and hard work that all of you put into serving this great country of ours. We feel strongly that the unique challenges that you face have never been greater than at this particular time in history, but there has never been a time in history when there has been a greater opportunity for the world to share in the accumulation of knowledge that could have healing and unifying consequences for all human populations. People around the world thirst and hunger for our democratic way of life which, in large part, is based upon scientific enterprise, which allows us to be a knowledge based and democratic society which prizes knowledge and objectivity, for supporting the health and economy of our political processes. We scientists are most appreciative to you for funding the most science-based society ever.

The University of Miami and Florida State University Risk Assessment and Intervention Consortium is dedicated to reducing the medical and social costs of health care through the development of cost-efficient, effective delivery interventions. All scientific enterprise faces major challenges today and we feel the proposed University of Miami/Florida State University Risk Assessment and Intervention Consortium will bring together scientists from a broad array of traditional research disciplines to face these challenges in a transdisciplinary and timely manner.

In the last 50 years, tremendous strides relative to health and environment have been made in the biomedical, physical, psychological, economic, and social sciences

to improve the world's health and environment. It now appears that the next major breakthroughs for improving quality of life and reducing socioeconomic costs lie at the intersections between scientific disciplines and not at the core of these sciences. Presently, these various sciences and the institutes that fund them, work too independently from one another to optimally address the broad and inter-related nature of these problems, and most scientists do not fully consider specific policy implications. Furthermore, traditional scientific research does not allow for the investigation of the most threatening risks in the most timely manner. My own scientific research is somewhat unusual in that I have conducted research and published in three broad disciplinary areas of cancer, HIV, and substance abuse. This perspective of more than 25 years made me yearn for a greater scientific enterprise that allows us to reach across these various disciplines in order to investigate problems more quickly and to apply the findings in a much more rapid manner.

We feel that our Consortium will provide a partnership between science and government that will assure the most optimal and cost-effective quality of life. The Consortium will identify individuals and risk groups that are at risk for specific adverse conditions, assess the manifestations of their risk and associated mechanisms and then communicate information about possible interventions and regulations to address such risks.

Therefore, we feel that the model most capable both scientifically and administratively of combining disciplines to address policy implications for intervention, regulation, and control is that of compliance risk assessment. Risk assessment, as a field, incorporates scientists from a wide range of disciplines and directs their attention specifically to controlling, regulating, or intervening with populations at risk. At present, there is no identifiable, broad-based institution we know of that concentrates solely upon the full and complex range of risks utilizing multi- disciplinary and transdisciplinary science. The Consortium will be in a perfect position to improve quality of life, decrease mortality and morbidity and will also, through identifying risks earlier and by intervening earlier, be in a position to save many billions of dollars through the application of knowledge about early intervention.

We know that intervention with effective prenatal programs saves a tremendous amount of money that otherwise would be spent on children after birth. The same could be said for early intervention at other points throughout the life cycle. Our own personal research experiences with the early detection of breast cancer have demonstrated through the screening of over 30,000 medically underserved women using an efficient mobile van visiting more than 12 primary health care centers that these programs not only save lives, but also save dollars. As is true for cancer, we already possess a great deal of knowledge that could be used to develop interventions as well as preventive strategies for many other diseases that present tremendous challenges throughout the world, such as HIV. Applying this accumulated knowledge could effect savings of billions of dollars for state, local, and national government, not only in the health arena, but also in preventing social and health pathologies of juveniles and young adults, as well as middle aged and older citizens. Early interventions would affect costs savings not only for public health systems, but also for the juvenile and criminal justice systems, the educational and welfare systems, as well as to private insurers and non-profit and volunteer organizations, many of which support interventions. With the increasing costs of institutionalization and public subsidies, every person whom we prevent from being institutionalized or dependent on public subsidies will not only save governmental dollars, but will also add to the economy of the country. Just as important, the quality of life for these individuals, their families, and their communities, as well as society at large, will be improved. It is becoming ever more apparent that we, as a nation, cannot afford to ignore prevention and early intervention strategies since crisis management is much too costly in terms of quality of life and unnecessary expenditures of dollars.

Our proposed organization will be cross interdisciplinary boundaries to accomplish goals that, for the most part, presently are hampered by too much independence of the various sciences and institutes conducting such science. We, however, have an opportunity to recognize the enviable talents of academic scientists within our broad-based risk consortium which will forge novel and, hopefully, permanent collaborations between universities and policy makers.

We thank you very much for your valuable time and stand ready to serve you in any way possible.

PREPARED STATEMENT OF THE UNIVERSITY OF MEDICINE AND DENTISTRY OF NEW JERSEY (UMDNJ)

We respectfully present testimony of the University of Medicine and Dentistry of New Jersey (UMDNJ), the largest public health sciences university in the nation. The UMDNJ statewide system is located on five academic campuses and consists of 3 medical schools and schools of dentistry, nursing, health related professions and biomedical sciences. It also comprises a University-owned acute care hospital designated as the State's Level One Trauma Center, three core teaching hospitals, an integrated behavioral health care delivery system, a University-owned managed care network and affiliations with more than 100 health and educational institutions statewide. No other institution in the nation possesses resources which match our scope in higher education, health care delivery, research and community service initiatives with state, federal and local entities.

We appreciate this opportunity to bring to your attention some of the University's priority projects which we believe are consistent with the mission of this committee. The following is an outline of each of these initiatives for your consideration.

INTERNATIONAL CENTER FOR PUBLIC HEALTH

The International Center for Public Health is a strategic initiative that will create a world class, infectious disease research and treatment complex in University Heights Science Park, Newark, New Jersey. Science Park is located in a Federal Enterprise Community neighborhood. The International Center will have substantial local, regional, national and international impact as it addresses many critical social, economic, political and health related issues. The Center is a $78 million anchor project that will launch the second phase of a 50-acre, $350 million mixed-use urban redevelopment initiative, University Heights Science Park. The facility will total 161,600 square feet and house three tenants: The Public Health Research Institute (PHRI), the University of Medicine and Dentistry of New Jersey's (UMDNJ) National Tuberculosis Center, one of three Federally funded TB centers, and the UMDNJ New Jersey Medical School Department of Microbiology & Molecular Genetics. The International Center for Public Health is a priority project for UMDNJ, Rutgers University, the New Jersey Institute of Technology, Essex County College and the City of Newark.

The core private tenant for the International Center is PHRI. PHRI is an internationally prestigious, 57-year-old biomedical research institute that conducts a broad range of infectious disease and public health research. A major PHRI research focus is the study of antibiotic resistance to life threatening bacterial organisms, and the development of new antibiotics. Among its many accomplishments over the years, PHRI has contributed to the development of smallpox vaccine, developed a new diagnostic assay for influenza, conducted early experiments on oncogenes, cloned the gene responsible for toxic shock syndrome, and identified the multi-drug resistant TB strain "W". PHRI's current research centers on molecular pathogenicity, drug discovery, drug resistance, diagnostic and vaccine development, and gene expression. Scientific disciplines include virology, immunology, biochemistry, genetics, cell and structural biology, and regulation of cell development. Presently, PHRI supports a staff of 110, including 20 Principal Investigators. These numbers will double in the move to the International Center.

UMDNJ will be the primary medical center linkage and academic affiliation for the Public Health Research Institute. The New Jersey Medical School National Tuberculosis Center at UMDNJ, one of only three model Tuberculosis Prevention and Control Centers in the United States funded by the CDC, will add an important clinical component to the International Center, since many TB patients also manifest other infectious diseases. The TB Center was founded in 1993 as a response to the national resurgence of antibiotic resistant tuberculosis strains. At the time, Newark had the nation's second highest rate of TB cases for a major city. Rounding out the International Center's initial tenants will be the UMDNJ-New Jersey Medical School's Department of Microbiology & Molecular Genetics. The Department's relocation will add a staff of 100 to the Center's critical mass of microbiology research. Currently the 17-member faculty conducts research in control of cell proliferation; cellular aging; transcriptional, post-transcriptional, and transcriptional regulation; mutagenesis; DNA replication and recombination; chromosome structure and segregation; human molecular genetics; and molecular pathogenesis of viruses, bacteria and parasites.

Together PHRI, the National TB Center and the Department of Microbiology & Molecular Genetics are creating a world class research and treatment complex that will have substantial local, regional, national and international impact. Other collaborators in the development of the International Center include the New Jersey

Department of Health & Senior Services (NJDHSS) and the pharmaceutical industry. Responsible for overseeing all statewide public health initiatives, NJDHSS will contract with the International Center to have cutting edge molecular epidemiology services provided to the State of New Jersey. Expanding the strategic use of molecular epidemiology to direct public health activities will facilitate prompt identification and containment of emerging and re-emerging pathogens. New Jersey's major biomedical companies will also participate in the International Center. An infectious disease consortium will be developed to serve as a forum for disseminating fundamental research on the underlying molecular processes of infectious disease organisms. This research will contribute to pharmaceutical industry development of new drug therapies for antibiotic resistant microorganisms. Private industry R&D facilities contiguous to the International Center are also being explored.

The International Center for Public Health (ICPH) is a creative and unique public/private partnership located in University Heights Science Park, Newark, NJ, that will combine: infectious disease research pharmaceutical industry participation, international, State and regional public health collaborations, high school urban and minority science education initiatives, urban economic and community redevelopment, and high technology job creation in a federally designated Enterprise Community.

Through the leadership and direction of the Governor Christine Todd Whitman, a Memorandum of Understanding (MOU) was signed between the State of New Jersey, UHSP, UMDNJ and PHRI in October 1997. The MOU commits $60 million of State loan and grant funds toward development of the $78 million International Center for Public Health. Science Park is working closely with the New Jersey Economic Development Authority, through whom project bonds will be issued and 14-acres of land acquired. Presently the Science Park partners and International Center for Public Health tenants are seeking the remaining $16 million from Federal and private sources during 1998. Groundbreaking is scheduled for March 1999.

University Heights Science Park is requesting $3 million from the Senate Appropriations Subcommittee on Labor, Health & Human Services and Education for fiscal year 1999 to support the Phase II development of Science Park: the construction of the International Center for Public Health. Such support will leverage Phase II development that totals $138M, and creates nearly 3,000 direct and indirect construction and permanent technology jobs. These funds will be used specifically for construction related project costs.

CHILD HEALTH INSTITUTE OF NEW JERSEY

Disorders of health affecting infants and children exact a terrible toll, in both human suffering and economic impact, on the child, family and the community. Consequently, State and Federal public policy prioritizes efforts to prevent or treat disorders of infancy and childhood. The prevention of conditions such as mental retardation, muscular dystrophy, sickle cell disease or cystic fibrosis has nearly incalculable benefits to society. Neither New Jersey nor New York hosts a research center designed and developed specifically to address issues of child health.

The University of Medicine and Dentistry of New Jersey- Robert Wood Johnson Medical School (UMDNJ-RWJMS) proposes to develop the Child Health Institute of New Jersey (CHINJ), a comprehensive biomedical research center focused on the health and wellness of children. In this program, medical researchers will direct efforts towards the prevention and cure of environmental, genetic and cellular diseases of infants and children.

The Institute will be located in New Brunswick and linked physically and programmatically with both UMDNJ-RWJMS and the Children's Hospital at Robert Wood Johnson University Hospital (RWJUH). This organization reinforces the relationship between essential biomolecular research and the treatment, prevention and cure of disorders of infancy and childhood. Locating the Child Health Institute in New Brunswick promotes the development of new partnerships among the Institute, the Medical School, the teaching hospitals affiliated with UMDNJ-RWJMS, and with the multinational pharmaceutical, biotechnology and chemical interests throughout New Jersey.

The CHINJ will act as a magnet for additional growth in research and healthcare program development in New Brunswick and New Jersey. New Brunswick provides a central location in the state that offers ease of access and proximity to major highway systems and mass transit; this is essential, as no similar program exists in either New York or New Jersey. The state of New Jersey, which has significant concerns in the areas of infant mortality, neonatal HIV infection and pediatric cancer, will benefit directly and enormously from the unique presence and impact of the Child Health Institute of New Jersey.

The Institute will focus research on the molecular and genetic mechanisms which direct growth, wellness, and disease. Examples of the Institute's research foci include: the identification and functional analysis of genes contributing to developmental disabilities and abnormal development; developmental pharmacology relating growth and maturation to the processes that regulate drug metabolism, developmental toxicity, and resistance or susceptibility to toxic agents; genetic and environmental influences on developmental immunology; the molecular mechanisms underlying brain growth and development; and tissue degeneration and regeneration.

The Child Health Institute of New Jersey builds on existing significant strengths in genetic, environmental, and neurosciences research within the UMDNJ-Robert Wood Johnson Medical School and associated joint UMDNJ-Robert Wood Johnson Medical School-Rutgers University research institutes. For example, the Environmental and Occupational Health Sciences Institute (EOHSI) is a National Institute of Environmental Health Sciences (NIEHS) recognized center of excellence which investigates environmental influences on normal and disordered functions; The Cancer Institute of New Jersey (CINJ), a National Cancer Institute-designated Clinical Cancer Center, studies disordered cell growth; The Center for Advanced Biotechnology and Medicine (CABM) characterizes gene structure and function.

The proposed Child Health Institute of New Jersey, which is formally chartered with defining developmental mechanisms, will complement and focus developmental programs within these Institutes and other areas of the University of Medicine and Dentistry of New Jersey.

The University of Medicine and Dentistry of New Jersey seeks a $5 million infrastructure development and targeted program assistance for the Child Health Institute of New Jersey. As indicated above, the program has already received initial funding support from Johnson & Johnson and the Robert Wood Johnson Foundation in the amount of $850,000. Efforts to obtain additional private support are underway and will be ongoing.

The Dean Gallo Prostate Cancer Institute

Prostate cancer is a particularly devastating problem in New Jersey. With the highest population density in the country, at 1,000 people per square mile, we are ranked 10th of all the States in mortality prostate cancer. African Americans diagnosed with prostate cancer are twice as likely to die from it, and New Jersey is ranked 8th in the nation for this disease in this ethnic group. There is no available curable treatment for prostate cancer once it recurs, and when it does, it is uniformly fatal. The objectives of the Dean Gallo Prostate Cancer Institute are:

—Regionally, to provide the highest standard of care, including NCI-approved trial therapies, to all residents of the area who suffer from prostate cancer. In addition, we will provide outreach and education in the community to generate early detection of the disease.

—Nationally, to make significant contributions to the nation's war on this disease through basic science discoveries on how prostate cells become malignant, ways to prevent transformation to cancer, how prostate cancer cells evade therapies, and the development of novel treatments for advanced stages of the disease.

The Cancer Institute of New Jersey (CINJ) is the only NCI-designated Clinical Cancer Center in the State. It is affiliated with the University of Medicine and Dentistry of New Jersey (UMDNJ), and is located at that institution's Robert Wood Johnson Medical School in New Brunswick, New Jersey. CINJ has over 200 members including 35 staff physicians, physician/scientists, and basic science researchers. Because of the devastating problem of prostate cancer in the state and in the nation, CINJ has determined to make the development of a cure for this disease one of its major goals. To accomplish this we have initiated the development of the Dean Gallo Prostate Cancer Institute, named for Congressman Dean Gallo, who was a tireless supporter of the people of New Jersey. He believed in making our state stronger by collaborating with his colleagues to secure federal funding for initiatives that improve the quality of life for all citizens. Tragically, he died of prostate cancer in 1994 after being diagnosed in an advanced stage of the disease.

CINJ is physically located in New Brunswick but has statewide presence through its hospital partners and affiliates. CINJ has grown rapidly through the cooperative efforts of these partners and affiliates, generous grant support from the Robert Wood Johnson Foundation, Johnson & Johnson, as well as many other New Jersey based foundations and corporations.

To address the specific portion of our objective to make treatment available to all area residents, the Dean Gallo Prostate Cancer Institute will be incorporated into the statewide network of affiliated hospitals and providers. This network allows CINJ to facilitate treatments and research for prostate cancer. Patients with advanced, incurable, prostate cancer may therefore be enrolled into clinical trials at

several locations throughout the state. This not only allows us to treat more patients with novel therapies but also increases our ability to rapidly evaluate these therapies. CINJ is also working with local clinics and agencies to develop treatment plans for uninsured sufferers of prostate cancer.

The proposed budget for the Gallo Institute is $9.4 million to be spent over a 5-year period. We expect to raise substantial funds through private, corporate, and other resources. We therefore seek an allocation of $5 million to facilitate the establishment of this important resource. These funds will not be used for bricks and mortar, but to secure the resources necessary to conquer this disease.

Institute for Disability Prevention and Wellness

Today, 1 out of 7 Americans—38 million people—have a disability; approximately 30 million Americans live with chronic pain. Millions suffer limited mobility brought about by injury, disease, and the natural process of aging. The effects are staggering: job related disorders themselves account for 1.9 billion days of restricted activity, 600 million days of bed rest, and $13 billion in health care costs. The impact of disability increases with the years, so that 40 percent of the population over age 65 is affected.

The University of Medicine and Dentistry of New Jersey—School of Osteopathic Medicine (UMDNJ-SOM) proposes to develop the Institute for Disability Prevention and Wellness (IDPW), an integrated basic science and clinical research program focused on the areas of pain and mobility. Two age groups are specially targeted: The working age adult, for whom these problems impact economic productivity, and the geriatric population particularly at the end of life for whom the quality of life can be improved by small changes in functional abilities.

The Institute will be located in Stratford New Jersey and linked physically and programmatically with the UMDNJ-SOM, particularly programs in primary care, geriatrics, and basic science. It will focus on clinical and translational research and on development of clinical researchers with a dedication to primary care, and prevention and treatment of disability. By developing preventive models and new standards of care, it will arm primary care clinicians with the most recent knowledge and up to date methods to diagnose and treat chronic conditions at the most effective and least expensive stage. It will also allow these primary clinicians to effectively counsel their patients on avoidance of injury and disability by adoption of lifestyle practices fostering health and wellness. Through this unique emphasis on improving primary care, the Institute has the potential to influence the course—and the cost—of healthcare well into the next century.

—To establish a center to prevent and reduce disabilities that impact mobility and physical functioning. In the osteopathic tradition, the center will use intervention techniques drawn from all aspects of medicine, including manual therapy as well as medication and exercise.

—To promote primary and secondary wellness through lifestyle and behavioral modification, thereby reducing the morbidity, mortality and disability associated with chronic disease. For example, by developing new methods of treating muscle weakness or fatigue the Institute will be able to develop programs that will be applicable to persons who suffer from a wide variety of conditions.

—To improve physician education at the medical student, resident, and faculty level by maintaining a link between clinically relevant problems and basic and applied research. Involvement in clinical trials is a key to the educational effort, as well as to the development of the treatments themselves.

—To provide preventive services for patients suffering from chronic disease with the emphasis on quality of life and end of life issues.

—To establish an extramurally funded research program, drawing on State and Federal as well as private resources.

We seek $4 million to develop an Institute for Disability Prevention and Wellness that will focus on education, research and training in geriatrics, primary care and osteopathic medicine.

PREPARED STATEMENT OF THE NATIONAL HEMOPHILIA FOUNDATION

Thank you for the opportunity for the National Hemophilia Foundation (NHF) to submit testimony to the Chairman and Members of the Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies. NHF is a national voluntary health organization dedicated to improving the health and welfare of people with hemophilia, von Willebrands disease, and other bleeding disorders. The federally-funded hemophilia and hematologic programs provided for in the annual Labor, Health and Human Services Appropriations Bills are of great im-

portance to the hemophilia community and to the general public who rely on the safety of the nation's blood supply. NHF appreciates the Committee's continuing support in advancing the research, treatment, and consumer-based patient outreach needs of the hemophilia community.

Hemophilia is a lifelong hereditary blood clotting disorder affecting an estimated 20,000 persons in the United States. Throughout their lives, people with hemophilia are dependent on clotting factor to supply a missing protein, which allows their blood to clot normally. As such, the hemophilia community continues to be the first marker in the event of any complication or virus that contaminates the blood supply. Historically, the hemophilia community has been impacted by a number of viruses through the blood supply. While HIV has been the most devastating, other viruses continue to plague the hemophilia community, including hepatitis.

Last year the Committee included in its fiscal year 1998 report a series of actions to be taken by the Public Health Service agencies to improve surveillance, research, patient notification, and outreach efforts in addressing blood safety concerns. Programs funded by the Committee also provided for hemophilia and bleeding disorder programs aimed at HIV/AIDS risk reduction and clinical studies, prevention of the complications of bleeding disorders, and research for a cure for hemophilia and related disorders.

ADVANCING HEMOPHILIA RESEARCH AND BLOOD SAFETY

With regard to programs appropriated under the Labor, Health and Human Services, Education Appropriations Bill, NHF strongly believes that research efforts should continue to:

—Develop gene therapy technologies for hemophilia as an alternative to blood-based products,

—Strengthen our knowledge about the treatment of and prevention of the complications of hemophilia, von Willebrands disease, and other bleeding disorders, and

—Substantially improve surveillance, patient notification, and outreach efforts to address blood safety concerns.

GENE THERAPY FOR THE TREATMENT OF HEMOPHILIA

For persons with hemophilia, gene therapy offers a potentially much less expensive treatment option that would end decades of dependence upon blood-derived products. In a recent report to Congress, the National Institutes of Health (NIH) highlighted hemophilia as one of the diseases most likely to be treatable through gene therapy and as a potential model of how gene therapy may be utilized to treat other genetic disorders.

Over the past few years, the House and Senate Labor, Health and Human Services, Education Appropriations Subcommittees have encouraged the National Heart, Lung, and Blood Institute (NHLBI) to continue support for hemophilia gene therapy research. This year NHF is requesting Appropriations support to:

—NHLBI: Provide an additional $2.5 million, doubling the level of support for the hemophilia gene therapy program. This will allow not only for renewal but also expansion of the hemophilia gene therapy grant program; and provide funding of an biannual scientific conference to advance hemophilia gene therapy research.

—NHGRI/NIDDK: Coordinate research efforts between NHLBI and the National Human Genome Research Institute (NHGRI) and the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK), working with the National Hemophilia Foundation, to pursue research on gene expression and immunity needed to make gene therapy technology available to the hemophilia community.

RESEARCH TO PREVENT COMPLICATIONS OF HEMOPHILIA

Because of the hemophilia community's dependence on blood products, hepatitis C continues to be a serious ongoing concern. More than 80 percent of all persons with hemophilia in the United States. have been exposed to hepatitis C through the use of clotting factor. NHF requests Appropriations language encouraging:

—NIAID/NIDDK: Increased funding of research on hepatitis at the National Institutes of Allergy and Infectious Disease (NIAID) and NIDDK, including research on optimal treatment regimes, access to clinical trials, development of a vaccine, and improved diagnostic testing for hepatitis C, as well as studies on the impact of multi-drug therapy on the liver. Committee report language should indicate

that concern regarding the impact of hepatitis C on the hemophilia community is a priority.

—NHLBI: Continued research support on preventing the complications of hemophilia, von Willebrands disease, and other bleeding disorders.

BLOOD SAFETY

During the 1980's, over half of all persons with hemophilia in the U.S. were infected with HIV through the use of contaminated blood products. While blood products are now inactivated for HIV, blood products remain susceptible to viruses and pathogens.

For the last two years, the House and Senate Appropriations Committees have included in their reports accompanying the Labor, Health and Human Services, Education Appropriations Bill and the Agriculture, Rural Development, Food and Drug Administration Bill, a series of actions to be taken by the Public Health Service to substantially improve surveillance, patient notification, and outreach efforts in addressing blood safety concerns. These directives have led to marked improvements in our nation's response to potential threats to blood safety.

CDC: The Labor, Health and Human Services, Education Appropriations Subcommittees for several years have provided funding support for the Centers for Disease Control's (CDC's) hematologic and hemophilia blood safety initiative, including efforts in blood safety and the prevention of complications of hemophilia. NHF requests that an additional $1 million be made available to:

—Fully implement a nationwide surveillance system utilizing the network of hemophilia treatment centers and a serum bank to monitor, detect and warn of adverse events in the blood supply.

—Establish a cooperative CDC/Food and Drug Administration (FDA) early warning system to ensure immediate investigation of and action on, any possible viral contamination in the U.S. blood supply or blood products.

—Expand hematologic outreach for the prevention of the complications of hemophilia, von Willebrands, and other bleeding disorders.

MCHB: NHF requests report language, calling for the Maternal and Child Health Bureau to maintain funding support for the 140 facilities that comprise the hemophilia treatment centers network in order to (a) sustain their treatment outreach to persons with hemophilia and (b) ensure their participation with CDC and FDA on blood safety surveillance and patient notification efforts.

Thank you for the opportunity to provide this statement to the Committee.

PREPARED STATEMENT OF DAVID KARLSON, EXECUTIVE DIRECTOR, SOCIETY OF GENERAL INTERNAL MEDICINE

Good morning, before I go into my prepared remarks, I'm going to ask you to step back and to imagine yourselves 10 years from now, sick, with a chronic illness. You still have a lot of life ahead of you, and you want to spend as little of it as possible in the hospital. You are being cared for by a doctor who is in training today. But that doctor hasn't been taught to care for your special needs in a home or outpatient setting, and worse yet, doesn't have at his or her disposal evidence about the most appropriate treatment that will lead to the best outcome for your problem. That's a real scenario-one that will occur, unless we fund AHCPR and Title VII programs at a level that will let them do their job.

I am pleased to be here today on behalf of the Society of General Internal Medicine, an organization representing the nearly 3,000 physicians who are the primary care internal medicine faculty of every medical school and major teaching hospital in the United States. SGIM members prepare medical students, residents and others to be primary care doctors for the 21st century and they conduct research that improves primary care delivery and patient care.

Today I'd like to talk with you about two programs, AHCPR and Title VII.

As you probably know, AHCPR funds support scientific study of the health care delivery system, providing the knowledge base that enables consumers, providers, the managed care industry, and others to function optimally in the health care system. Title VII provides outpatient and community- based training for those in academic institutions around the country, permitting the up-to-date training of primary care physicians for the 21st century. We believe that is in the nations' interest to increase funding for both of these programs.

TITLE VII PROGRAM

Let's talk first about health professions training. As you know, medical practice has changed drastically over the last two decades, moving from a primarily hospital setting to the outpatient arena, and it will change even more in the next 10 years. In our teaching, we struggle daily to teach through evidence, rather than anecdote. After all, you want your care to be based on evidence-not anecdote.

Unfortunately, our primary way of funding graduate medical education-that is, through Medicare, provides little support for training outside the hospital. This is a major impediment to training physicians who are prepared to practice in current and future environments and manage the ever growing population of patients with chronic illness. The funding level only works well if we want to train most doctors to practice in the past.

General Internal Medicine/Pediatrics Title VII programs provide the major source of funding primary care training, permitting us to prepare health care professionals for 21st century practice, and to train them to care for underserved populations, which will in all likelihood still be with us.

SGIM is particularly proud of the track record of the Title VII-supported General Internal Medicine grant programs. Over 69 percent of HRSA-funded internal medicine program graduates go on to primary care practice after graduation—nearly twice the rate of internal medicine programs without Title VII funding. Further, over 40 percent of internists trained through Title VII-supported programs have established practices in medically underserved communities in the past two years. You should know that the appropriation for the General Internal Medicine program in fiscal year 1998 was insufficient to permit the funding of new or competing renewal applications. While we recognize that your support has allowed these programs to survive at all, we urge you to fund Title VII at a level that actually lets it get the job done.

AHCPR

Let's shift gears, and talk about AHCPR. As you probably know, the Agency for Health Care Policy and Research is one of 3 science agencies in the federal budget that are necessary to maintain and improve the health of our nation. NIH develops new laboratory-based knowledge that will someday be translated to clinical application at the bedside. The CDC provides the science for public health. Despite this, you and I hear all the time the cries of alarm at the state of our health care system. There's a serious disconnect here. It is AHCPR that supports the discovery of new knowledge that can improve the health care system, and can identify the highest quality, most cost effective ways to get scientific breakthroughs into the health care delivery system in America. Yet, it is an agency that is seriously underfunded.

Just like at the NIH, some of the best work comes from investigator initiated programs, but inadequate funding means that the AHCPR can support only a very small handful of individual investigators. Many like myself no longer even bother to prepare grant proposals for the AHCPR because the funding prospects are so bleak. Since 1994, the AHCPR has cut the number of funded investigator grants by over 50 percent. Ultimately, this translates into denied opportunities for the American public, and for you, the Congress, to make wise policy choices and save money. It may mean that we don't have the evidence to best treat your problem 10 years from now, and will have to rely on anecdote instead.

On a positive note, let me give you a couple of examples of recent research released by the Agency, because it is this type of research that both improves quality of care and cuts health care costs, that a funding increase could support.

Middle ear infection is the most frequent diagnosis requiring antibiotics for children in the United States. AHCPR-supported research at the University of Colorado found that common ear infections in children with less expensive antibiotics, instead of more expensive ones could save millions of dollars a year without changing recovery rates. The study estimated that in one state alone, and one program alone, the Colorado Medicaid program could have saved almost a half million dollars by implementing this change in treatment.

Research supported by AHCPR also leads to the development of new technology that can be applied to make the functioning of the health care system more efficient. Recently, a tool to predict whether someone with chest pain is actually having a heart attack has been shown to reduce unnecessary coronary care unit admissions by 30 percent. This translates into 250,000 fewer critical care admissions or $3 billion savings per year in the U.S.-by all standards a great return on investment.

In the past few years, the AHCPR has worked with private managed care companies to develop methods that can be used by average consumers to rate their local managed care plans. The Agency has also worked with the Health Care Financing

Administration to improve way to assess beneficiary needs and satisfaction, for both the managed care and the fee-for-service system.

AHCPR also support work in rural communities, where different solutions to keep primary care providers in rural areas have been identified.

Just as the National Institutes of Health trains investigators to conduct basic research, the AHCPR trains physician-scientists to examine how our health care system works, and to develop more cost- effective approaches to make our population healthier and produce better health care outcomes. Both the Institute of Medicine and the National Academy of Sciences have called for at least tripling the numbers of health services researchers trained.

In summary, the AHCPR's research programs are focused on topics of major concern to the Medicare and Medicaid programs and enable Congress and the public to discriminate between what we do, and what we know when we make health care decisions. In just one example alone, I've shown you how a small part of a $150 million investment, translates into cost savings of $3 billion. Its a great example of fiscal responsibility. On behalf of SGIM, I strongly urge you to provide a substantial increase to the AHCPR to expand its activities. Budget Recommendations

Mr. Chairman, our funding recommendation for the Title VII Internal Medicine/ Pediatrics programs is for $25 million this year. This will allow for growth within the program, but it will take closer to $50 million if you are serious about actually getting the job done in the future. Our recommendation of $306 million for the entire Title VII program reflects the recommendation of the Health Professions and Nursing Education Coalition.

For the AHCPR, we will ask you to provide the funding necessary to repair the damage done over the past three years to the investigator-initiated grant program and to the training program. We recommend an AHCPR budget of at least a $175 million—a $32 million increase. We urge that this entire increase be allocated to the extramural investigator-initiated grant program, with 2 million set aside for new training programs.

I would like to close by thanking this Subcommittee for its strong support of the Title VII program and the AHCPR. I would be pleased to respond to questions.

PREPARED STATEMENT OF RALPH G. YOUNT, PRESIDENT, FEDERATION OF AMERICAN SOCIETIES FOR EXPERIMENTAL BIOLOGY

Mr. Chairman, Mr. Harkin, Members of the Subcommittee: I am Ralph Yount, professor of biochemistry at Washington State University. I am a basic scientist who works on the mechanism of muscle contraction. My research has been funded for 37 continuous years by NIH. I serve this year as the President of the Federation of American Societies for Experimental Biology, usually referred to as FASEB. Founded in 1912, FASEB is the largest organization of life scientists in the United States with a combined membership of more than 52,000 researchers. It is in my role as President of FASEB that I appear before you today to testify in support of the goal of a 15 percent increase for the National Institutes of Health in fiscal year 1999 as the first step in doubling funding over the next five years.

Let me note at the outset that the Federation is very pleased by the budget request submitted by the President, and by his strong statements in favor of biomedical research during the State of the Union address. While we are hopeful that Congress can go even further than the President has proposed, we appreciate that this is the first time since the "War on Cancer" was proposed in 1971 that a President has so aggressively supported funding for the NIH.

Following the lead of this Subcommittee, and in particular its Chairman, it appears that the President and our champions on the Appropriations Committees—Senate and House, Republicans and Democrats—all now support a significant increase for NIH this year. We join with you in a common effort to convince the full Congress that this goal is fully justified and achievable.

FASEB believes the Congress should review NIH funding decisions in the context of the remarkable accomplishments that past investments have produced, as well as the substantial evidence which exists of unrealized scientific opportunities. Half a century of public investment in the NIH has fostered the development of a biomedical research enterprise, which is the envy of the world. The scientific investigations supported by NIH have given birth to the biotechnology industry, fueled the activities of the pharmaceutical industry, altered the daily course of health care in this country for every American and are even changing the nature of agriculture. The list of recent discoveries is remarkable.

Three examples illustrate the range of progress being made every day:

—NIH supported research led to development of defined fragments of DNA on chips, the so-called gene chips which promise to revolutionize the detection of certain gene-based diseases, such as breast cancer.
—NIH researchers have identified a crucial enzyme, telomerase, which plays a significant role in cancer, normal growth and possibly the fundamental process of human aging.
—A recent NIH funded molecular genetics study has led to a possible method for resensitizing bacteria, critical to dealing with the spread of antibiotic resistant strains of these dangerous organisms.

The tragedy of these examples is that so many more breakthroughs are possible. In 1998 NIH will be able to fund only about three out of ten proposals approved by study sections. The success rate for new investigators who have not previously had a grant is substantially lower—only slightly better than 1 in 10. These are abysmal and discouraging odds. We believe these unfunded applications and unfunded researchers represent the best argument for increased support for the NIH.

FASEB comes to you not only as an advocate for more money, but also to express our views on the priorities for most effectively utilizing a substantial increase in NIH funding. These proposals are not "etched in stone" but represent a starting point for discussions within the NIH and this committee. Briefly, FASEB recommendations are that increased funding be invested in the following areas:

—Fund increased numbers of research grants developed through the existing system of investigator initiated projects, selected through rigorous competitive review by scientific peers;
—Adequately fund research projects by increasing the average size of grants;
—Raise stipends for pre- and post-doctoral trainees to a living wage;
—Modernize the research infrastructure—including facilities, instruments and clinical research support mechanisms;
—Support a wide variety of new scientific partnerships, including more extensive direct support by NIH for relevant studies in chemistry, physics, mathematics and computational science;
—Develop and support mechanisms for more rapidly translating research findings from the laboratory to the clinics and beyond; and
—Increase the average length of grants to create a more stable research environment.

Mr. Chairman, these are FASEB's suggestions as you and the NIH begin the difficult task of deciding how best to invest the increased resources for biomedical research that we all hope can be found. We have also made other policy recommendations in our formal report previously submitted to the committee, which we hope you will review carefully.

In conclusion Mr. Chairman, we at FASEB believe this represents the best opportunity in a generation to expand our country's historic effort to improve America's health, using the tools of science. FASEB recognizes the challenge this represents and we pledge to use all the resources available to us to convince the Congress to support the budget allocation needed to make our mutual goal a reality.

Mr. Chairman, this concludes my statement.

PREPARED STATEMENT OF MARY WOOLLEY, PRESIDENT, RESEARCH!AMERICA

Chairman Specter and members of the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Research!America thanks you for the opportunity to provide this written testimony on the President's fiscal year 1999 budget request. The testimony will specifically comment on the requested increases in funding for scientific research, in particular research conducted at the National Institutes of Health (NIH).

Research!America, a national not-for-profit public education and advocacy alliance, is dedicated to making medical and health research a much higher national priority. On behalf of its more than 350 members—individuals, academic institutions, corporations and voluntary organizations—Research!America is proud to serve as a voice for citizens on the issue of medical research. The bottom line is that citizens want more research funded than is called for in the President's 1999 fiscal year budget.

Since 1992, Research!America has commissioned both national and state-based public opinion polls and has regularly conducted focus groups to explore attitudes and identify citizens' issues and concerns regarding research. The poll results have consistently shown that citizens place their trust in research and research-based institutions to make the discoveries that will translate hope into cures, treatments and preventions.

Along with the American Medical Association, the Ad Hoc Group for Medical Research, the National Health Council, the Biotechnology Industry Organization (BIO) and the many others concerned, Research!America is convinced that because we have in place an army of gifted researchers, and because the opportunity in science is at an extraordinary level, Now is the time to substantially increase funding for the National Institutes of Health. Now is the time to make the commitment toward doubling funding for medical research over the next five years.

The public supports this increase as is evident from the results of our most recent polls completed in March of this year which found that in the aggregate, 60 percent of citizens surveyed say they favor doubling funding for medical research. Research!America has now asked citizens in Alaska, Connecticut, Louisiana, Michigan, Missouri, Ohio, Pennsylvania, Virginia, Washington, West Virginia and Wisconsin about doubling funding for medical research and the majority of citizens in every one of these states say they favor such a proposal. A national poll conducted by the Wall Street Journal and NBC found that, by a better than two to one margin (or slightly better than our findings), the public favors doubling the current NIH budget of 13-plus billion dollars over a five year period.[1]

With the commitment of this subcommittee, accompanied, if necessary, by innovative additional funding mechanisms, doubling the NIH budget over five years can become a reality. Research!America has tested several possible mechanisms for identifying additional monies to supplement appropriated dollars to accomplish the doubling goal. One possible mechanism, currently hypothetical on the national level but in use in some states, is to allow taxpayers who will receive a tax refund to designate some of that refund to a special fund for medical research. In our national poll conducted in 1995, 60 percent said they would be willing to donate a portion of their tax refund—with the median amount donated being $23. According to 1997 Internal Revenue Service figures, about 80 million taxpayers—two-thirds of those filing returns—expected to receive a 1996 refund. If all 60 percent from our poll followed through with their intent and donated an average of $23 each, 48 million taxpayers would donate $1.1 billion for research.[2]

Another mechanism, very timely in light of attention on a possible tobacco settlement, is Research!America's finding that 68 percent (aggregate) of those surveyed say they favor a proposed increase of $1.50 per pack of cigarettes over three years with about 30 percent of the annual proceeds used to fund medical research.

A third mechanism involves the projected budget surplus. Citizen priorities for surplus-generated dollars has been tested by various polls of late. When Louis Harris and Associates asked citizens this past November how they felt about money from a budget surplus being used for additional spending on current programs, 81 percent said they would support surplus dollars going to medical research.

While citizens strongly support increased funding for medical research, they do not want doubling the budget of the National Institutes of Health to come at the expense of other health and science programs.

When coupled with medical knowledge gained from basic and clinical research, behavioral and health services research can lead to effective prevention programs in communities across this nation. The eradication of small pox, the decrease in the incidence of AIDS in the United States, the use of t-pa to prevent the side effects of stroke are just a few examples of what can be accomplished when medical and public health research are working together. Research!America polls show that citizens value public health programs, which include prevention research, and health services research. It is not surprising that there is such strong interest in prevention and outcomes research, since everyone would agree that the ultimate goal is to eradicate, not just ameliorate, dreaded diseases like cancer, AIDS, diabetes, heart disease and stroke. This public mandate translates to achieving stronger support for the Centers for Disease Control and Prevention and the Agency for Health Care Policy and Research, in tandem with increased support for the NIH.

My final point is based on a finding from our polls that strongly supports federal investment in basic research. It is important to emphasize that all science—not just medical and health science—needs strong support in order for our national goal of better health and well-being to be met. New ideas and breakthrough technologies in fields such as engineering, physics, mathematics and chemistry have been instrumental to progress in the life sciences in the past; this important synergy must be nurtured as we move into the next millennium. Proposals for increased funding for basic science conducted under the auspices of several federal agencies including the NIH and the National Science Foundation must be sustained if we are to meet our nation's goals.

---

[1] Wall Street Journal, February 12, 1998: 64 percent favor; 25 percent oppose.
[2] Internal Revenue Service, April 1997.

Doubling the NIH budget in five years is the right first step in achieving the great promise of research. Doubling the NIH budget in five years would allow the 105th Congress to place its stamp on history, contributing in never-before-possible ways to the health and quality of life of all Americans. In poll after poll, the message is clear that citizens back you, their Senators, when it comes to seizing the opportunity that science offers at this moment in our history.

The Research!America alliance is pledged to continue working to ensure that research has the chance to deliver on its promise. Through our polls and our 435 Project we are working in communities across the nation to answer citizens' questions about research and to encourage them to speak up in support of use of their tax dollars for this critical priority. Concurrently, we are connecting researchers to citizens so they can share their work with their home town communities and in so doing demonstrate their accountability for the taxpayer dollars they spend. Nothing less than the health and well-being of my family, and yours and every family in America is at stake; we put our trust in our elected officials to make the investments today so tomorrow we will speak of cancer, premature heart disease, AIDS, diabetes and a host of other dreaded diseases, as finally conquered by American scientific know-how.

PREPARED STATEMENT OF DR. M. SUSAN SMITH, ON BEHALF OF THE REGIONAL PRIMATE RESEARCH CENTERS PROGRAM

Chairman Specter and Members of the Subcommittee: We the directors of the seven Regional Primate Research Centers thank you for the opportunity to submit written testimony on behalf of the Primate Centers Program. The seven Centers are located across the country in California, Georgia, Louisiana, Massachusetts, Oregon, Wisconsin and Washington, and each is affiliated with a distinguished university. The Centers receive support as part of the National Center for Research Resources of the National Institutes of Health (NCRR-NIH).

Congress acted with great foresight in 1960 to establish the national Regional Primate Research Centers Program, in recognition of the importance of nonhuman primates in biomedical research. The funds appropriated to build the seven centers have been an excellent investment. As we look back over the nearly forty years since their establishment, it is clear that these Centers have provided specialized and unique scientific capabilities not available through any other program within the Department of Health and Human Services. The Centers are our nation's single major resource for the conduct of research which is dependent upon the use of nonhuman primates. With the ever increasing complexity and sophistication of research questions and methodologies, the Primate Centers Program is even more important today than when the centers were established.

It is difficult to overemphasize the importance of nonhuman primates, monkeys and apes, in biomedical research. These animals share more than 90 percent of their genetic makeup with humans. This close genetic similarity makes the nonhuman primate an ideal animal model for the study and understanding of human health and disease processes. Nonhuman primates are often the vital link between basic research on one hand and human application on the other. In some cases, there is no suitable animal model, other than the nonhuman primate, for study of a disease. An example is AIDS, for which the nonhuman primate is the best and most appropriate animal model. Important scientific advancements resulting from nonhuman primate research abound in fields of neuroscience, reproduction, infectious diseases and developmental biology, among others. The seven Centers provide the resources, including the nonhuman primates, scientific expertise and specialized facilities and equipment, to conduct this research. Without the Centers, high priority biomedical research programs requiring nonhuman primates and supported by the NIH could not proceed. These include programs in AIDS and other infectious diseases, aging, cancer, neurodegenerative disorders such as Alzheimer's disease, senile dementia and Parkinsonism, heart disease, infertility, mental health disorders, organ transplantation, osteoporosis, Lyme disease, drug addiction, reproduction and behavior. These research programs address basic mechanisms underlying human health and disease, as well as development of therapy and methods of prevention of disease.

The research programs on AIDS at the Regional Primate Research Centers serve as an example of the Centers' unique ability to respond to our nation's health needs. When AIDS was first recognized in the early 1980's, there were few laboratory animal models available to begin studies of this disease. Within a year of emergence of AIDS, the Regional Primate Research Centers identified a comparable disease in Asian monkeys, and shortly after the discovery of HIV, the virus which causes AIDS, the Centers identified a similar virus termed SIV or simian immunodeficiency

virus. This virus produces a disease remarkably similar to AIDS and is recognized as the best animal model to study these types of viruses. More recently, the vaccine development programs within the Centers provide new hope of identifying a vaccine that may have the potential of preventing the disease. The Centers are also engaged in research to prevent the AIDS virus from being transmitted from HIV-infected mothers to their babies. Without the Regional Primate Research Centers, it is very likely that these important advances in the treatment and prevention of AIDS would not have occurred.

A new area of research at the Centers has the potential to revolutionize the use of nonhuman primates in biomedical research. This research involves the use of the technique called "nuclear transfer" to produce genetically identical animals. The availability of genetically identical nonhuman primates would provide a powerful resource for biomedical research because it would eliminate genetic variation during experimental manipulation and allow for greater statistical validity with fewer animals. Such a primate resource would be analogous to the inbred strains of mice that have greatly facilitated studies on biological mechanisms, disease processes and the development of new treatments such as gene therapy. Research at the Centers has proven the feasibility of using nuclear transfer to produce genetically identical nonhuman primates, and current studies are underway to develop the technology so as to produce large numbers of these valuable animals. There are a number of new opportunities that would arise from the availability of genetically identical nonhuman primates. (1) Gene therapy and vector development. This animal model would permit the use of genetic manipulations to study molecular processes and treatments of human disease. (2) Immunologic studies. The elimination of genetic variability would permit important new studies of autoimmune diseases, organ or cell transplantation, and HIV vaccine development. (3) Genetic versus environmental factors as contributors to disease. Without the confounding influence of genetic variability, it will be possible to determine the contribution of stress, the environment or nutrition to a variety of conditions, such as cardiovascular disease or behavioral abnormalities.

In addition to their roles as research centers, the Regional Primate Research Centers also serve as national resources to the biomedical community at large and as centers of primatology. As national resources, the seven Regional Primate Research Centers are indispensable to approximately 1500 scientists from universities, research institutes and laboratories across the country, as well as scientists from around the world, whose research requires nonhuman primates. The Centers provide the essential elements, such the animals, scientific and technical expertise, materials and facilities, necessary to conduct their research programs. For the most part, these scientists' research missions serve all of the categorical institutes of NIH and are dependent on the Regional Primate Research Centers. The scope and diversity of their research and the number of institutions served stress the importance of the resources of the Regional Primate Research Centers to the national biomedical research effort. In addition to serving investigators on-site, the Center's tissue distribution programs direct more than 10,000 specimens per year to laboratories throughout the country.

As centers of primatology, the Regional Primate Research Centers house the largest and most diverse collections of nonhuman primates in the world. The Centers provide access to some 16,000 nonhuman primates, representing 21 species, that have been proven to be valuable for biomedical research. Many of the species are threatened with extinction, are embargoed from importation, and are of unique genetic background or possess other distinctive biologic characteristics which makes them irreplaceable. This resource can never be duplicated. The Centers also maintain breeding colonies for which much of the biomedical research community is dependent. As centers of primatology, the Regional Primate Research Centers also contribute to our understanding of these extraordinary animals with respect to their biology, diseases and husbandry requirements, knowledge that is essential for their preservation and their judicious use in biomedical research.

The support for the research programs at the Centers is derived largely from the categorical institutes of the NIH. However, the support for the infrastructure of the Centers is provided through the NCRR, NIH. The infrastructure of the Centers provides the necessary resources to support the research programs. Appropriations for the Regional Primate Research Centers have not kept up with inflation during the past 10 years. In fact, in absolute dollars, appropriations have barely risen in some years, whereas they have actually declined in others. When the high costs of biomedical research are taken into account, the budget for the seven Centers has been eroded. This has inevitably led to reductions in resources made available to the biomedical research community. This "no growth" funding pattern has greatly hindered the Centers' ability to expand its current research programs and will be detrimental

to the development of new research opportunities. During this time of expanding resources in support of NIH, we ask that appropriations for research resources not be neglected. We request that this Committee in its budget deliberations take action to reverse the current funding pattern for the Regional Primate Research Centers. We are currently operating on a budget that is approximately 20 percent below the NIH-peer reviewed and approved recommended levels. We ask you to increase the funding for the Primate Center Program, which will not only be an investment in the seven Centers, but will also benefit the biomedical research interests of essentially all of the divisions of NIH.

We would like to thank the Committee for their support in providing NCRR with construction funds, which have been specifically designated for the Centers during the past two years. It is essential that this source of funds for new construction be continued if the Centers are to maintain their state-of-the-art facilities and equipment. With many of the facilities at the Centers nearing 30–40 years of age, it is imperative that we retain our ability to obtain funding for new construction that is necessary to support new scientific opportunities into the next century.

Respectfully submitted,

Dr. M. Susan Smith, Director, Oregon Regional Primate Research Center, Oregon Health Sciences University, Beaverton, OR; Dr. Andrew G. Hendrickx, Director, California Regional Primate Research Center, University of California, Davis, CA; Dr. Ronald D. Hunt, Director, New England Regional Primate Research Center, Harvard University, Southborough, MA; Dr. Peter J. Gerone, Director, Tulane Regional Primate Research Center, Tulane University, Covington, LA; Dr. William Morton, Director, Washington Regional Primate Research Center, University of Washington, Seattle, WA; Dr. Joseph W. Kemnitz, Interim Director, Wisconsin Regional Primate Research Center, University of Wisconsin, Madison, WI; Dr. Thomas Insel, Director, Yerkes Regional Primate Research Center, Emory University, Atlanta, GA.

Prepared Statement of the National Association of Nutrition and Aging Services Programs

Chairman Specter and members of this Senate Appropriations Subcommittee: Thank you for the opportunity to provide written testimony to you regarding the Older Americans Act. I am Mary Podrabsky, a provider of Congregate and Home-Delivered Meal services in Seattle, Washington. I am also President of the National Association of Nutrition and Aging Services Programs (NANASP), a membership organization of direct service providers of meals and other nutrition services across America. It is on behalf of NANASP that I present this testimony.

First, Chairman Specter, I wish to thank you for your historical leadership and support for all the programs of the Older Americans Act and in particular the effort you championed last year to secure increased appropriations for these vital community based services. Your work and the work of this subcommittee has had an impact that is felt and greatly appreciated in communities, large and small, in every State, Territory and Tribal Land in this Country.

The Older Americans Act, as you know, provides a wide range of home and community based services for persons sixty years and older. These include such services as adult day care, transportation, information and assistance, elder abuse protections, nursing home ombudsman services, senior employment, chore services, services for native Americans and Hawaiians, legal assistance, and congregate and home-delivered nutrition services. The Older Americans Act has established over the past thirty-three years an aging network comprised of the Administration on Aging, State Units on Aging, local Area Agencies on Aging and thousands of service provider organizations, who with paid and volunteer staff, provide millions of older Americans with needed services. It is through the provision of such services that America is growing old with dignity, pride and maximum independence.

This hearing, however, is not about creating a network of quality aging services. That work has already been done and has evolved over the last three decades. This hearing is about increasing the capacity of that network and of aging service programs to meet the needs of a rapidly growing senior population. It is also about spending limited national resources wisely. Providing increased funding to support Older American Act programs, I think, accomplishes both goals.

Congregate and Home-delivered Nutrition Services, the two primary services provided by NANASP members, are arguably the two most visible services of the Act. Congregate meals are served at over 15,000 meal sites throughout the country, pro-

viding 127 million meals a year to 2.3 million people. Home-delivered meal programs, more commonly referred to as Meals-on-Wheels, provided 115 million meals to nearly 1 million homebound seniors.

Nutrition Programs, authorized through Title III and, more recently Title VI, of the Older Americans Act, are now in their 25th year of operation and are considered a wonderful success story. During the last reauthorization of the Act, the U.S. Congress authorized the Department of Health and Human Services to conduct a comprehensive two year evaluation of the Elderly Nutrition Program to include both congregate as well as home-delivered nutrition services. The results of this exhaustive evaluation, conducted by Mathematica Policy Research, Inc. of Princeton, NJ, were published in June, 1996. The results "show that the Elderly Nutrition Program has succeeded in accomplishing its mission of improving the nutritional intakes of elderly people, as well as in decreasing their social isolation." The evaluation also "shows that the program is evolving to meet the changing needs of older people brought on by shifting demographics and changes in the health care system and public policy environment." Finally, the evaluation results state that "the Elderly Nutrition Program is a highly successful program that has a positive influence on an overwhelming majority of its participants."

Congress stipulated in the Older Americans Act that services would be targeted to certain individuals by stating that "preference will be given to providing services to older individuals with greatest economic need and older individuals with greatest social need, with particular attention to low-income minority individuals." The same Mathematica study cited above found that "about one-third of Title III congregate participants and one-half of Title III home-delivered participants have incomes at or below the DHHS poverty threshold." Also, with regard to minority targeting, the study concluded that "overall, racial and ethnic minorities constitute 27 percent of congregate and 25 percent of home-delivered participants" and that "almost all Title VI participants are members of minority groups, compared with 14 percent of the overall population age 60 and older." Furthermore, "nearly four times as many Title III participants and nine times as many Title VI participants are low-income minorities, compared with the overall population age 60 and older."

Okay! The program works. It does what it is supposed to do. That places it in pretty select company, but does that necessarily mean its funding should be increased? I would say no, not necessarily, but there is more. For every federal Title III dollar spent on congregate nutrition services an additional $1.70 is raised from other sources. The amount of leveraging is substantially higher for Title III home-delivered nutrition services. This kind of leveraging of public dollars in congregate and home-delivered meal programs make this a wise investment and a model public/private partnership.

To be eligible to receive home-delivered meals, a participant needs to be, with few exceptions, not only sixty years of age or older, but also homebound. Often, the receipt of a meal is the only service required for these individuals to be able to remain in their own home. Home-delivered meals can be provided to a home bound person for an entire year for less than the cost of one overnight stay in the hospital! Audrey Baker , blind and recovering from a broken back, whose story is told in the attached article, must not be forced to wait any longer for meals. And Helen McCleery of San Diego, described in the same article, should not be required to find her food in dumpsters. It is just possible that for those in need of this service, it may be one of the best spent health care dollars.

For most Nutrition Services providers in the Country, home-delivered meals are increasing at a rate that far exceeds their capacity to meet the need. Four out of ten programs show a waiting list for home-delivered meals. One out of ten congregate meal providers have waiting lists, but there are not sufficient funds in these programs to establish new sites or to perform outreach efforts to locate isolated older persons in need of the services available at the congregate meal sites.

Funding for the programs and services of the Older Americans Act have simply not kept pace with the increasing costs of providing the services and this at a time of historical low inflation.

This fact, coupled with the steadily increasing numbers of frail older persons in need of the services, has stretched program capacity to its limits. There are no savings to be achieved by reducing services provided in the home and community if the only option remaining is more expensive institutional care. We must, as a Nation, provide for the most appropriate, least expensive service option possible at the earliest possible time. Only then can we be assured that we are spending dollars wisely. As we turn to face the new millennium, let us be able to face our mothers and grandmothers as well.

PREPARED STATEMENT OF PATRICIA DEITCH, CHIEF EXECUTIVE OFFICER, PHILADELPHIA HEALTH SERVICES, ON BEHALF OF THE NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

Mr. Chairman and Members of the Subcommittee my name is Patricia Deitch. I am the Chief Executive Officer of Philadelphia Health Services. On behalf of the National Association of Community Health Centers, I am pleased to provide the Subcommittee with testimony in support of the urgent need to increase funding to $926 million for fiscal year 1999 for the Consolidated Health Centers Program (i.e., community, migrant, homeless, and public housing health centers). Health centers share a common mission of providing quality and cost-effective health care to patients in urban and rural medically underserved areas, and it is for this mission and service to the nation that we ask the Subcommittee's continued strong support.

First, I would like to thank the Subcommittee for its support of the consolidated health centers program over the past two years. Under the leadership of Chairman Specter, appropriations for the program have increased by $68 million in that period one in which the Subcommittee had to face many difficult choices among worthwhile programs. We are particularly indebted to Senator Christopher Bond and Senator Ernest Hollings for their efforts on our behalf during the last two years. We also would like to extend our best wishes to Senator Dale Bumpers in his final year of a tremendous career in public service. Arkansas health centers will miss his leadership and health centers throughout the nation will never forget his strong support of our program.

The $68 million increase this committee has approved for health centers over the past two years is an investment towards providing services to uninsured patients and previously unserved patients. However, much more work needs to be done. The $68 million increase has only enabled health centers to serve approximately 250,000 people which is less than one percent of the nation's approximately 42 million uninsured people. Rising number of uninsured patients, coupled with eroding grant, Medicaid and other revenues, place health centers in a financial squeeze which literally threatens their viability. Most existing health centers have not seen an increase in their grant dollars for the past eight years, yet are being inundated with escalating numbers of uninsured. In the past three years alone, the number of uninsured people seeking care at health centers has increased by over one million.

The financial squeeze health centers are experiencing is forcing many to cut services, staff and/or hours in order to remain operative. Nowhere are these trends more evident than in the State of Pennsylvania and at my health center, Philadelphia Health Services (PHS). We serve over 23,000 patients in our two Philadelphia locations. Between 1996–1997, we have had a 6.4 percent decrease in our total revenue, while the number of uninsured patients has increased by 46 percent. The number of uninsured grew eight times faster between 1996–1997 than the previous year. In addition, we have experienced a 7.6 percent reduction in Medicaid revenues between 1996–1997. Medicaid losses for PHS will contribute to a $600,000 deficit in fiscal year 1998.

In an effort to minimize the negative impact of Medicaid changes and declining revenues, PHS took several steps to contain costs while working toward identifying ways to increase revenues. For example, after closing our in-house laboratory due to financial constraints, we eliminated several necessary lab tests. Patients must now go to the costly hospital emergency room to receive a lab test. We have also had to discontinue our school-based wellness centers which provided on-site preventive, diagnostic educational services to junior high elementary children. In addition, our doctors were once able to visit patients that have been admitted into area hospitals to evaluate their conditions. Unfortunately, we have been forced eliminate this practice.

In the past three years, PHS has been forced to eliminate 19 positions including a pediatrician, physician assistant, an internist, health educator, and a nurse. We are unable to eliminate any additional staff without jeopardizing primary health care we deliver to our patients. The cuts in personnel have resulted in life altering consequences for our patients. For example, since we have had to eliminate the health educator's position, our patients can no longer receive intensive diabetes education after their doctor's visit. One of our patients recently diagnosed with the disease was prescribed oral medication and dietary changes. One day she was rushed to the emergency room with extremely elevated blood sugar level. She was admitted to the hospital to bring down her blood sugar level, was placed on insulin, and received 2 hours of instruction from a diabetic nurse as a hospital inpatient. Had our health center been able to retain our health educator and continue to provide intensive diabetes education, this patient would have received necessary education when

she was first diagnosed, and possibly the trauma and expense of a hospitalization could have been avoided.

Without an increase in grant funding, PHS will not be able to generate the revenue needed to continue providing our full scope of services beyond next year.

The problems PHS is facing are echoed nationwide. There are 981 community, migrant, homeless and public housing centers and FQHC look-alikes serving over 2,500 communities across America. Together, these health centers care for over 10 million children and adults in every state, Commonwealth and Territories, and the District of Columbia. Health centers are local non-profit, community-owned health care programs serving low-income and medically underserved urban and rural communities with few or no resources. Health centers are governed by volunteer members of the community who have an interest and take responsibility to ensure that responsive and affordable health care is provided to all who need it. Patients are charged on a sliding fee scale to ensure that income or lack of insurance is not a barrier to care. Federal grants subsidize the cost of care provided to the uninsured and the cost of enabling services (such as translation and outreach) not covered by Medicare, Medicaid, or private insurance—services which make the care provided by health centers cost-effective and responsive.

Health centers are staffed with interdisciplinary teams of more than 6,000 physicians (98 percent of whom are board certified), as well as nurses, dentists, other health professionals and community residents. Health centers offer a wide range of primary and preventive medical and dental care, including: diagnostic laboratory and radiologic services, pharmaceutical services, immunizations, well-child examinations, preventive dental care, family planning, and prenatal and postpartum care. Health centers also provide health education, community outreach, transportation, and support programs (including literacy and other education programs) in collaboration with other organizations and agencies like schools, Head Start programs, and homeless shelters.

Without health centers, residents of inner-city and rural underserved areas would face great unmet health care needs. Health center patients include uninsured low-income persons, minorities, rural residents, high-risk pregnant women and children, migrant and seasonal farm workers, persons with AIDS, persons with drug and alcohol problems, homeless persons and families, the frail elderly and other high-risk groups. Health centers have special expertise in meeting the unique needs of these most vulnerable populations and are often the only source of non-hospital, community-based primary care for them.

The following reflect the profiles of health center patients:

—Health centers serve one of every six low income children (4.5 million children).

—In 1995, the 400,000 births to health center patients accounted for one of every 10 births (and one of every five low-income births) in the United States.

—One in every 10 uninsured persons in the United States uses health centers.

—Health centers are the family doctor for one in 10 rural Americans.

—One of every eight low income Americans uses health centers.

—Almost 7 million minority persons are health center patients.

—Health centers are the provider of choice for one of every 10 people covered by Medicaid.

—Health centers care for one of every four homeless persons.

There are over 42 million uninsured Americans who suffer financial, geographic or cultural barriers to health care. This number of uninsured Americans is growing rapidly, at a rate of 100,000 per month. Studies have shown that this number could reach 50 million or more over the next five years. Nearly three-fifths of the uninsured are members of low-income working families who cannot afford to buy health insurance, and must rely on the safety net for health care primarily health centers or costly emergency rooms.

Many studies have concluded that health centers, in the process of providing primary care to medically uninsured and underserved communities, achieve real and significant cost savings. Through fewer hospital admissions and less frequent use of costly emergency care for routine services, health centers save the American health care system almost $12 billion annually.

Few government programs have made as significant a contribution to low-income families as cost-effectively, or in high quality a manner as health centers. For example:

—Health centers create jobs and provide an economic base: Health centers employ more than 50,000 persons, many of whom are community residents. They also help to retain other local businesses and stabilize neighborhoods by bringing in other forms of community or economic development. Health centers generate over $14 billion in annual economic activity in many of America's most economically depressed urban and rural communities.

—Health centers make a difference in the health of people: Studies of health centers credit them for a 40 percent reduction in infant mortality, improved immunization and prenatal care rates, and increased use of preventive health services among their patients.
—Health centers triple the value of investment: Every $100 million invested in health centers brings an additional $200 million in other resources into communities, and helps 1 million people (including 350,000 uninsured persons) get the care they need.

Despite achieving remarkable progress in responding to the rapidly changing health care environment, health centers increasingly are feeling the strains brought on by the continuing erosion of private insurance coverage, stagnant or shrinking public subsidies, and the pressures of a restructured marketplace now driven by competitive forces. Over the past three years, centers have added more than one million new uninsured patients to their rolls. This growth in new uninsured health center patients is widespread and underscores the declining ability of providers in all communities to continue to serve the uninsured. This situation is certain to worsen causing more uninsured and low-income people to seek care at health centers.

In addition, the changes in the Medicaid program have reduced the amounts available to health centers. Health centers lost almost 400,000 Medicaid patients last year, principally because of State Medicaid managed care efforts. The most perplexing part of this is the fact that much of the loss is due to state auto-enrollment (or default assignment) procedures, in which health center patients who failed to choose a managed care plan were involuntarily assigned to plans that did not include their center in their provider network. At least 650 patients were lost at my Philadelphia centers alone. Also, with the increased enrollment of Medicaid patients in managed care, health centers around the country are receiving decreased reimbursement for serving Medicaid patients. And, beginning in fiscal year 2000, the Balanced Budget Act will phase out and eliminate cost-based reimbursement for Medicaid patients. Even though health centers are re-engineering their service delivery systems to become more efficient, we are caught in a tightening vise of reduced levels of reimbursement and increased numbers of uninsured. Health centers will again have to use grant dollars to subsidize the care of Medicaid patients.

During testimony to the House Appropriations Subcommittee on Labor, Health and Human Services and Education hearing the Health Resources and Services Administrator, Dr. Claude Earl Fox, stated that the problem requires immediate attention by the Congress in order to ensure the future viability of health centers. Dr. Fox stated that grant dollars need to be increased or Medicaid dollars going to health centers need to be increased to address the situation. He also stated that in his professional judgment, health centers need a $200 million increase in fiscal year 1999 to maintain operations and meet the growing demands for services. In addition, Dr. Marilyn Gaston, Director of the Bureau of Primary Care, stated that five percent of health centers are bankrupt and between five and 10 percent more will be soon as a result of the financial squeeze affecting health centers.

The National Association of Community Health Centers believes additional federal investment is needed to ensure the availability of primary and preventive health care in medically underserved communities, and priority should be given to strengthening and preserving the existing health center infrastructure. Health centers have been faced with the challenge of caring for an ever- increasing number of people seeking care in an era of stable or declining resources and shortages of primary care health professionals. As the number of uninsured persons increases, there must be a system in place that will provide essential health care services, especially for the most vulnerable, underserved people in our communities and in our nation. The health center system is already in place; it is cost-effective, efficient, accountable, and it works. We urge you to maintain and build on it.

As you consider the fiscal year 1999 appropriations, we request that you consider for the Consolidated Health Center Program (i.e., community, migrant, homeless and public housing): $926 million.

Mr. Chairman, we know that you and members of the Subcommittee have a very difficult task ahead of you this year because of the strict limits on available funds. We have labeled our recommended funding levels as an investment in a proven system of care to foster wellness and prevention. If funded adequately, the continued presence of health centers and the availability of basic health services will contribute to a healthier, more productive America.

Health centers were founded with a vision of community and consumer empowerment, and their experience over that past 30 years provides an object lesson on how consumer involvement can succeed where other models fail. Invest in health centers, build upon what has worked, look at the long history and success of the program

and continue to invest in programs that mobilize communities to solve problems at the local level.

Once again, Mr. Chairman and Members of the Subcommittee, I thank you for the opportunity to present you with my testimony.

PREPARED STATEMENT OF DR. RODNEY MEAD, PROFESSOR OF ZOOLOGY, DIRECTOR OF NIH IDeA PROGRAM, UNIVERSITY OF IDAHO

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to submit this testimony regarding the National Institutes of Health's Institutional Development Award (IDeA) program on behalf of the Coalition of EPSCoR States.[1] I am Rodney Mead, and I am Professor of Zoology and Director of the NIH IDeA Program at the University of Idaho.

Let me begin by expressing my thanks to Senator Larry Craig for his strong support of the IDeA program. IDeA works to improve Idaho's biomedical research capability, and we are deeply grateful for Senator Craig's efforts to ensure that the NIH has a truly effective IDeA program for the benefit of Idaho and of our nation.

The 1993 NIH Revitalization Act (Public Law 103–43) authorized the NIH to establish a program to broaden the geographic distribution of health research funding. The IDeA program is similar to the Experimental Program to Stimulate Competitive Research (EPSCoR), a program established by the National Science Foundation to improve our nation's science and technology capability.

The IDeA program funds merit-based, peer reviewed research and works to enhance the competitiveness of research institutions located in states with historically low aggregate success rates for grant applications to the NIH. For fiscal year 1998, the NIH has identified the following states as eligible for IDeA funding: Alaska, Arkansas, Delaware, Hawaii, Idaho, Kansas, Kentucky, Louisiana, Maine, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New Mexico, North Dakota, Oklahoma, Rhode Island, South Dakota, South Carolina, Vermont, West Virginia Wyoming and the Commonwealth of Puerto Rico.

The fiscal year 1999 budget request for IDeA is $5.2 million. The Coalition of EPSCoR States respectfully requests that the Subcommittee appropriate $15 million for IDeA in fiscal year 1999.

Let me begin by telling you how IDeA is improving Idaho's biomedical research capability. Idaho has received two IDeA awards totaling $500,000, all of which has been matched dollar for dollar by the state of Idaho. The federal funding has been equally divided between the University of Idaho (UI) and Idaho State University (ISU), and has been used to upgrade the biomedical research infrastructure at both institutions.

Funds from the first award were used by both universities to create, equip and staff core molecular biology research laboratories. These core laboratories are designed to provide technical support, training and access to multi-user equipment that was not previously available. These services are made available to all biomedical researchers on both campuses. At UI, the core molecular biology laboratory is staffed by a full time Ph.D., whose position is now permanently funded by state funds.

The second award has been used to purchase a state-of-the-art equipment for three core laboratories (molecular biology laboratory, confocal microscope laboratory, and the experimental laboratory animal facility). The phosphoimaging/gel documentation instrument purchased last year has received extensive utilization by biomedical researchers from five different departments on the University of Idaho campus. In addition, the first of several sets of specialized caging systems, which permit the housing of rodents in a germ-free environment were purchased. This year we are purchasing a sophisticated UV microscope for the confocal microscope laboratory that will greatly expand the capabilities of several of our biomedical researchers. The instruments in this core research laboratory are extensively used by members of the WAMI medical faculty. For example, Dr. Michael Laskowski makes extensive use of the confocal microscope in his studies of the growth and regeneration of mammalian nerves.

These core research facilities are currently being used by biomedical researchers in the Departments of Biological Sciences, Animal Science, Food Science and Toxicology, Microbiology, Molecular Biology and Biochemistry, and by the Washington, Alaska, Montana, Idaho (WAMI) medical faculty at the University of Idaho. The

---

[1] Alabama, Arkansas, Idaho, Kansas, Kentucky, Louisiana, Maine, Mississippi, Montana, Nebraska, Nevada, North Dakota, Oklahoma, Puerto Rico, South Carolina, South Dakota, Vermont, West Virginia, and Wyoming.

core molecular biology laboratory at ISU is principally being used by biomedical researchers in the Department of Biological Sciences and the College of Pharmacy.

The creation and enhancement of these research facilities have led to at least six important results. They have:

—(1) provided access and training in the proper use of very expensive multi-user equipment that was not previously available. Use of this equipment has significantly reduced the amount of time required to acquire, analyze, graphically display data, and obtain publication quality images. This equipment has both enhanced the quality of the data that were are able to obtain and has increased the productivity of Idaho's biomedical researchers. This has increased the productivity of Idaho's biomedical research community, including Dr. Holly Wichman, who has made extensive use of the imaging system to acquire rapidly preliminary data that she included in an NIH research grant application regarding the evolution of viruses. This grant has just been funded by the NIH;

—(2) expanded the research capabilities of faculty and students by providing training in new and rapidly changing molecular biology technologies used in biomedical research. This has allowed faculty, students, and post-doctoral trainees to undertake research projects that were previously impossible due to inexperience with the new techniques required to investigate complex biomedical problems;

—(3) reduced the time required to establish these new techniques in investigators' laboratories and provided unlimited access to methodological trouble-shooting expertise that was formerly not available without impinging upon other researchers' time and good will;

—(4) enhanced the chances of Idaho's biomedical researchers of obtaining NIH research grants by providing them with increased technical capabilities and the opportunity to demonstrate their ability to use these new techniques by collecting preliminary data which are so vital in convincing grant reviewers that they have the facilities, technical expertise and actual ability to do what is proposed. For example, I obtained preliminary data which ultimately convinced an NIH panel to approve funding of a grant to investigate factors necessary for promoting changes in the uterine environment that may be essential for successful implantation of mammalian embryos;

—(5) enhanced the ability of UI and ISU faculty to provide state of the art training to future biomedical researchers. Several of our graduate students have obtained training and used equipment in the molecular biology laboratory to conduct and complete their thesis research. Results of these studies have been presented at recent national scientific meetings and manuscripts have been or are being prepared for submission for publication in leading scientific journals. Specific examples include:

—Ms. Carrie Bickle has completed a study regarding changes in the length of the ends of chromosomes (telomeres) during aging in mice;

—Mr. Doug Hirzel completed a study of changes in uterine concentrations of leukemia inhibitory factor during the peri implantation period of pregnancy; and

—Mr. Todd Garwood has reported on the isolation and changes of DNA binding proteins.

—(6) resulted in Idaho universities being better able to compete for the brightest young biomedical researchers. For example, UI has hired a faculty member (Dr. Debora Stenkamp) who studies the developmental and molecular biology of color vision. Access to equipment and technical help was an important factor in her decision to accept this position at UI. Dr. Stenkamp was just awarded her first NIH research grant.

These accomplishments indicate that the intent of Congress and the goals of the IDeA program are being met, and that Idaho's biomedical researchers are becoming better equipped and better able to compete for research funding. The capability of Idaho's universities to provide state of the art training to our country's biomedical researchers has been and is continuing to be enhanced by this effective program.

In previous years the National Center for Research Resources (NCRR), which funds the IDeA program, issued program announcements soliciting applications from IDeA eligible states to provide support for research activities that stimulate improvement in the biomedical research capacities of the institutions. In response to Congressional language included in the fiscal year 1998 Appropriation Committees Reports, NCRR has modified IDeA. The program will now support: (1) high quality applications for Shared Instrumentation Grants, using meritorious requests that have already been submitted to the SIG program; and, (2) using the Shannon Awards as a model, NIH will fund investigator-initiated proposals from IDeA eligible states with scores that fall near but below the funding cut-off in the regular In-

stitutes programs. For fiscal year 1998 funds, no specific solicitation to the IDeA eligible states will be issued for either of these awards.

Congress appropriated $13.6 billion for the NIH in fiscal year 1998; for the NCRR Congress appropriated over $453 million. The Coalition of EPSCoR States applauds the Congress for this commitment to biomedical research and encourages Congress to continue funding biomedical research at as high a level as possible. We also ask Congress, and especially this Subcommittee, to consider the importance of making sure all parts of the country are able to contribute to the important research mission of the NIH. We encourage the Subcommittee to provide $15 million for NIH IDeA in fiscal year 1999.

I thank the subcommittee for the opportunity to submit this testimony.

PREPARED STATEMENT OF G. BROCKWEL HEYLIN, DIRECTOR, GOVERNMENT AFFAIRS, THE AMERICAN ASSOCIATION OF COLLEGES OF NURSING

This statement presents the fiscal year 1999 appropriations recommendations of the American Association of Colleges of Nursing (AACN) for nursing research and education. AACN represents over 520 baccalaureate and graduate nursing education programs in senior colleges and universities across the United States.

AACN thanks the members of this subcommittee for the fiscal year 1998 funding levels for the National Institute of Nursing Research (NINR) at NIH. AACN also is grateful for the subcommittee's commitment to the Nurse Education Act (NEA) (Public Health Service Act Title VIII), Scholarships for Disadvantaged Students (in PHSA Title VII), the Agency for Health Care Policy and Research (AHCPR) and others. These needed funds are being well spent to improve the public health.

Overall Recommendations: For NINR, AACN recommends an increase of $63.5 million over fiscal year 1998 to $127 million. For AHCPR, AACN asks for an increase of 10 percent to $161.08 million. For fiscal year 1999 for the NEA, AACN respectfully requests an increase of 8 percent over fiscal year 1998 to a level of $70.9 million. For SDS, we seek an increase also of 8 percent over the fiscal year 1998 level to $20.2 million. AACN endorses the fiscal year 1999 overall NIH recommendation of the Ad Hoc Group for Medical Research Funding. AACN agrees with the recommendation of the Health Professions and Nursing Education Coalition for fiscal year 1999 of $306 million for PHSA Titles VII and VIII. AACN also advocates appropriate fiscal year 1999 funding levels for Higher Education Act programs that serve nursing students at the undergraduate and graduate levels, such as Pell Grants, Perkins Loans, Federal Work-Study, TRIO, and GAANN.

National Institute of Nursing Research

AACN urges the subcommittee to increase the fiscal year 1999 funding for NINR to $127 million. This doubling of resources is essential for several reasons.

One, NINR is "fighting success" in terms of its research and research training programs. The research being conducted and disseminated is extremely relevant and is making a difference to public health issues such as health promotion, caring for the increasing numbers of chronically ill individuals and their families, dealing with the acute care nature and high technology of our hospitals, and understanding how health care systems influence client/patient outcomes in terms of quality and cost. There is more and more demand for such research.

Two, nursing science has advanced rapidly with numerous sophisticated clinical intervention studies underway, which are resource intensive and require years of study. Such intervention studies are at the heart of the science for nursing practice since we can understand best which interventions are most effective. These studies are quite expensive compared to laboratory research because of the involvement of human subjects and other factors.

Three, the research training needs for nursing are quite high, unlike other biomedical sciences, according to the 1994 Institute of Medicine Biomedical Personnel Needs Report. A number of graduate programs are not fully staffed with doctorally prepared faculty. In addition, there is a graying of nurse researchers and a strong need to prepare and bring to maturity a sizable cadre of nurse scientists in the future.

NINR has the smallest funding level of any NIH institute and all but one of NIH's 3 centers, despite the fact that nurses are the central human component in the delivery of care and management of health care for most patients in hospitals and communities. In fiscal year 1998, NINR received an increase of only 6.8 percent although the NIH at large was increased by 7.1 percent. NINR's funding base is less than one-third the level of the next higher funded NIH institute. A small percentage increase on such a low base equals a very small dollar increase for the science of

nursing practice. Nursing is relevant to virtually every condition and disease within the health care delivery system.

Nursing research makes a difference, as the following examples demonstrate

Arthritis: About 11 percent of the U.S. Hispanic population suffers from arthritis. An NINR funded project at the Stanford Arthritis Center in California brings the benefit of previously English language only measurement scales to the Latino community. The project includes pain management and exercise for Spanish speakers through community outreach, classroom education, a manual, and audiovisual aids. The project concept is being expanded for use with Chinese patients.

Early Hospital Discharge: Today's shorter hospital stays may save money but they mean that patients are sicker at discharge and need more support at home. NINR funded a project for comprehensive discharge planning and follow-up programs using visits and telephone contact by advanced practice nurses. The study improved patient outcomes and decreased the cost of care and the likelihood of readmissions. Originally developed with a focus on high-risk mothers and low birth weight infants, the model is being expanded to elderly patients with complex medical conditions and to prenatal care.

Pain: The permutations and intensities of pain trouble patients and challenge caregivers. NINR funded research has discovered that, for women, a particular type of pain medication, kappa-opioids, more effectively reduce high levels of pain than morphine type drugs and with fewer negative side effects. The study also found that with the test drugs, pain relief lasted longer than with traditional medications. Now, the study seeks to ascertain dose response levels and whether hormones play a role in pain responses.

Other Examples: NINR's research agenda focuses on helping patients deal with pain, maximizing the quality of life of people living with chronic conditions or the physical disabilities of stroke, avoiding low birth weight babies, and maternal and child health. Indeed interdisciplinary research partially funded by NINR increases the value of NIH research and is complementary to biomedical research. For instance, several Pennsylvania studies are studying critical illness in the elderly and elderly frail rural populations. A Texas grant seeks to reduce the number of teen pregnancies. University of Illinois-Chicago NINR project is examining ways to strengthen respiratory muscles in patients with chronic obstructive pulmonary disease. A University of Arkansas NINR grant has produced ways to improve knowledge on the ability of nursing home residents to achieve their activities of daily living thus reducing their need for assistance. A Florida Atlantic University project seeks to find ways to improve the quality of life and to reduce the care costs for Alzheimer's disease patients by using exercise and special monitoring. A Johns Hopkins University (MD) NINR project has investigated several interventions to reduce the risk of high blood pressure in young black men, a common concern in this population. A University of Mississippi Medical Center project funded by NINR is supporting an interdisciplinary research team to examine treatment of blood clots and tumors. NINR grants to schools in New York are examining childhood asthma and the side effects of chemotherapy. And a University of Wisconsin project is examining high risk pregnancy.

The Core Centers program sponsored by NINR funds extramural research at several institutions to focus on major areas of professional nursing practice. They include symptom management (University of California San Francisco), care of the chronically ill (University of Pittsburgh [PA] and University of North Carolina, Chapel Hill), serious illness (University of Pennsylvania), gerontological nursing interventions (University of Iowa), and women's health (University of Washington). These Core Centers gather established investigators into an interdisciplinary team to benefit from the synergy of collaboration that will exceed what individually funded investigators might be expected to produce. The Core Centers were also designed to build and strengthen the research infrastructure of personnel and physical facilities and to promote outreach activities to disseminate findings and implications. While the Centers are relatively new, they have provided valuable knowledge on patient care issues.

End-of-life care

Recently, NINR was assigned to serve as the lead institute on research related to palliative care, involving complex care, pain management, and psychosocial issues for terminal patients and the families of critically ill patients. With a population that is aging dramatically, these are major areas of concern to the health care system. NINR's base of knowledge in pain management and palliative care, positions it well to handle this important responsibility. Last fall, NINR and other NIH entities convened an interdisciplinary and inter-intramural conference on Symptoms in

Terminal Illness. It has joined with other NIH entities to stimulate research interest in the subject. Research is critical to addressing these issues; by providing NINR with the financial tools it needs they will be addressed.

In fiscal year 1997, NINR awarded 64 competing and 95 non-competing (renewal) grants; in fiscal year 1998, NINR expects to award 50 competing and 121 non-competing grants, reflecting the shift to longer term and continuing research awards typical of a mature institute supporting a cadre of mature and productive research. But NINR's success rate, 20 percent, that is the proportion of peer reviewed, approved awards that actually receive funding, is below the NIH average, 28 percent. One reason is that NINR funds proportionately more clinical research than most NIH institutes, and research that involves actual human subjects is more expensive. But this alone cannot explain NINR's lower success rate. The problem is primarily its small funding base.

The contributions that NINR funded research are making are substantial, but they could be even greater with an adequate financial base. AACN requests the Subcommittee to boost NINR funding of NINR to $127 million. Such a figure is still far less than the fiscal year 1998 figure of $200 million for the National Institute of Deafness and Communications Disorders which was established almost at the same point in time. (AACN is not criticizing the higher funding of other institutes; it offers this point only for comparison.) A greater funding base for NINR is critical to supporting a critical mass of researchers and research activity that is producing breakthroughs of major importance to society in patient care, outcomes and cost effectiveness appropriate to nursing, the largest health care profession. With past strong congressional support for women in science, this is an excellent opportunity to increase research relevant to the public health of women and all Americans. With over ten years at NIH, NINR has the administrative structure, strategic plan and experience to be able to wisely and efficiently administer more spending authority.

Agency for Health Care Policy and Research

AACN recommends a 10 percent increase over fiscal year 1998 for AHCPR to $161.08 million in fiscal year 1999. AHCPR's mission is critical to wise utilization of health care dollars because it seeks to discover and to publicize the most effective health care interventions.

The Nurse Education Act

The NEA is the key source of federal financial support for nursing education programs and nursing students. Nursing students educated with NEA support often become the nurse scientists that conduct research for NINR and other NIH entities. The NEA provided stipends in 1997 to almost 37 percent of 12,769 full-time graduate nursing students in 267 grants totaling $15.6 million. For example, Professional Nurse Traineeships (Section 830), provided assistance for masters and doctoral students in Pennsylvania ($910,424), Wisconsin ($339,935), North Carolina ($370,773), Washington ($418,555), Mississippi ($180,226), Hawaii ($61,875), Iowa ($80,880) New Hampshire ($69,164), Texas ($917,281) and South Carolina ($185,465). The NEA funds programs to educate APNs and future nursing faculty (NEA Sections 821, 822 and 831) and seeks to help disadvantaged students attain nursing education (Section 827). NEA funds supported about half of the doctorally prepared nursing faculty teaching today. Future nurse researchers often receive one or more types of NEA support as they increase their academic skills.

Scholarships for disadvantaged students

AACN recommends a funding level for fiscal year 1999 for SDS of $20.2 million, an 8 percent increase over fiscal year 1998. By statute, 30 percent of SDS appropriations are reserved for nursing students. Schools with proportionately greater numbers of minority students are given additional funds. For fiscal year 1996 (most recent data), 4,101 nursing students received about $5.6 million in SDS support, and 2,601 or 63.4 percent were minorities. Federal funds can help to increase the diversity of the profession.

(The NEA and SDS are the subject of reauthorization legislation moving through Congress [S. 1754, Frist/Kennedy]. This bill would increase program flexibility and provide one authorization figure for NEA programs, but would support continuation of present legislative foci as well.)

National Health Service Corps

AACN suggests a 5-percent increase over fiscal year 1998 for the National Health Service Corps Scholarship and Loan Repayment programs (PHSA Title III) to $82.074 million. This program seeks to attract health professionals to areas with shortages of such providers. Many of those areas are rural, and have difficulty attracting and retaining caregivers.

CONCLUSION

In summary, AACN respectfully recommends the following appropriations for fiscal year 1999:

	Millions
National Institute of Nursing Research	$127
Nurse Education Act	70.9
Scholarships for Disadvantaged Students	20.2
Agency for Health Care Policy and Research	161.08
National Health Service Corps Scholarship/Loan	82.07

PREPARED STATEMENT OF VICKI KALABOKES, CHIEF EXECUTIVE OFFICER, NATIONAL ALOPECIA AREATA FOUNDATION

Chairman Specter and members of the Senate Subcommittee on Appropriations for the Departments of Labor, Health and Human Services, and Education, I am Vicki Kalabokes, chief executive officer of the National Alopecia Areata Foundation (NAAF).

First, I would like to take this opportunity to thank you for your leadership and support. We are making progress because of the hard work of many researchers, the leadership of many professionals, and, most importantly, the vision of this committee and it's chair. Our work isn't finished, but we are making progress.

The National Alopecia Areata Foundation (NAAF) is the largest organization in the nation dedicated to finding a cure for alopecia areata. It also provides support for those with alopecia through a publication program and support groups. The support groups provide information and direction to thousands of people with alopecia areata. As a support group leader I am sometimes the first person, outside of the medical community, that a person turns for help and information. Frequently people call who are scared, misinformed, and afraid. The support group provides a forum to reach out to others, problem-solve and grow.

The National Alopecia Areata Foundation is also a member of, and currently the headquarters for, the Coalition of Patient Advocates for Skin Disease Research. The Coalition, which operates as a voluntary organization and as such receives no public or private money, provides an umbrella to over 21 "lay" skin groups. These groups represent millions of people who suffer from a wide range of skin diseases. We work together for two reasons. First, to provide information to others about why research is needed. And secondly, so that we may push for a wide-ranging research agenda. Many of us believe that diseases such as alopecia, lupus and others are the result of a malfunctioning immune system. When the key is found to one of our diseases then it is likely that many of the other diseases represented in the coalition will be cured. By working together we will make a difference. Alopecia areata is a disease that strikes over four million Americans. It is the loss of hair. For some it is a quarter size patch that can be easily covered, for others it is the loss of every hair follicle on their body. Young children get alopecia areata most often. It strikes members of all ethic groups. The loss of hair has several types of impacts. Hair provides significant protection for the body. The loss of eyelashes means that even the simple act of opening and closing ones eyes to keep the dust out is a difficult process.

However, alopecia is not simply a physical problem, it has surprisingly serious psychological demands. For many people, when they first discover their hair falling out they are devastated. They think that they are the only ones in the world with the disease. Frequently when they go to their doctors they discover that even their physicians have little idea of what is happening, why it is happening, or even if others suffer from it. For some treatment options stop there, while for others they begin the long process of finding someone who knows something about the condition.

Unfortunately in our society the lack of information is not the only problem. Frequently people with alopecia believe that they are vulnerable to the stares and grimaces of those around them. People have lost their jobs. A noted news anchor lost his on-air job because he was suddenly perceived as being unappealing. This lack of being appealing (either real or perceived) causes many people to lose confidence in themselves and they begin to withdraw from society.

Recently, one parent called concerning her daughter who has alopecia areata and she was asking for help to stop the harassment that the daughter was experiencing at school. Another parent called who has alopecia areata and had just discovered that her daughter is developing it too. As this parent talked more about her child, she expressed the fears of many parents who have alopecia areata; they don't want their children to suffer from the turmoil and fears that they had to endure. Both parents wanted to know what they should or even could do.

Fortunately, there are people who can help, and in many of our support groups people learn how they can help themselves both cosmetically and psychologically. They learn that they are not alone and that they can do something about their sense of vulnerability and isolation. But the real solution will be when we find a cure for alopecia areata.

Over the past ten years the Foundation has raised and provided almost $1.5 million for research studies. Our privately funded research studies have been studying the genetic structure of hair, the function of the immune system, and supporting non-human research studies looking for the cause of alopecia. Several weeks ago the press hailed a major discovery of a "hairless gene." This gene was discovered by one of our Foundation's funded researchers. We can do much more if we fund research programs with the National Institutes of Health.

Part of our research program is to continue to work with the National Institute of Arthritis, Musculoskeletal and Skin Disorders to create a research agenda. In 1990 and in 1994 NIAMS and NAAF conducted two international research workshops on what is known about alopecia areata. One of the many results from this joint program was that NIAMS funded a significant study on the structure of the disease. Another result was the discovery of animals with alopecia—thus NAAF was able to support the first non-human host of the disease.

On November 5, 1998, we will be holding the Third International Workshop on Alopecia Areata, with NIAMS. This workshop, as with the earlier meetings will bring researchers, clinicians, and patients together from around the world to study what progress has been made and how new studies should be structured. The convening authority of NIAMS is critical for this sharing of knowledge. However, its long-term value will be seen because of the unique relationship that has been developed with NIAMS and NAAF.

Working together in this unique private-public partnership is a significant step towards finding a cure. We hope to continue this relationship with NIAMS providing limited funds for critical studies, while we continue to work to support the research effort as well. With this partnership we have been able to sharpen the research agenda so that we are looking at questions that are building on a wider and more informed base of knowledge.

The National Alopecia Areata Foundation and the 20 other lay skin disease groups in the Coalition of Patient Advocates for Skin Disease Research ask that you continue to support NIAMS. We are asking for an increase of 15 percent. This increase would allow the Institute to increase its ability to fund more research projects and support more programs that will help the over 60 million people who are impacted by skin diseases. We also support the proposal of the Ad Hoc Group for Medical Research Funding, which calls for a 15-percent increase in funding for the NIH in fiscal year 1999 as a first step toward doubling the NIH budget over five years. We recognize that difficulty in achieving this goal under the current spending limits, and encourage the Congress to explore all possible options to identify the additional resources needed to support this increase.

We also believe that work done in any of the disease areas represented by the Coalition of Patient Advocates for Skin Disease Research, will have a profound impact on the lives of over 60 million Americans who suffer from one or more than one of the diseases that NIAMS is charged with investigating. We also believe that when a cure is found for any of these diseases that there is a good chance that it will help in finding a cure for many of the other skin diseases.

Again thank you for your vision and concern. Without your support this unique private/public partnership would only be a dream, with your help it will result in a cure.

I look forward to answering your questions.

PREPARED STATEMENT OF DR. RAYMOND E. BYE, JR., ASSOCIATE VICE PRESIDENT FOR RESEARCH, FLORIDA STATE UNIVERSITY

Mr. Chairman, thank you, and the Members of the Subcommittee, for this opportunity to submit testimony. I would like to take a moment to acquaint you with Florida State University. Located in the state capital of Tallahassee, we have been a university since 1947; prior to that, we had a long and proud history as a seminary, a college, and a women's college. While widely known for our athletics teams, we have a rapidly emerging reputation as one of the Nation's top public universities. Having been designated as a Carnegie Research I University several years ago, Florida State University currently exceeds $100 million per year in research expenditures. With no agricultural or medical school, few institutions can boast of that kind of success. We are strong in both the sciences and the arts. We have high qual-

ity students; we rank in the top 25 among U.S. colleges and universities in attracting National Merit Scholars. Our scientists and engineers do excellent research, and they work closely with industry to commercialize those results. Florida State ranks seventh this year among all U.S. universities in royalties collected from its patents and licenses. In short, Florida State University is an exciting and rapidly changing institution.

Mr. Chairman, let me describe four projects that we are pursuing this year. The first is a collaborative project between FSU and UM dealing with risk assessment activities related to several health issues. Several proposals have been completed and are being sent to the Directors of the National Institutes on Health (NIH), National Institute for Drug Abuse (NIDA), and the National Institute of Child Health and Human Development (NICHHD). The proposal to NIH seeks funding to provide an overarching capability to respond to requests from several institutes in the overall risk assessment area. This would be consistent with report language included in the fiscal year 1998 Committee reports. These funds will establish a joint FSU-UM Risk Assessment and Intervention Center that will provide invaluable data to a wide range of health and health-related federal agencies that deal with health and other human outcomes. An amount of $750,000 is being requested to establish such a Center. No new legislative language will be sought in fiscal year 1999. Based on pending proposals at NIH, the collaborators are requesting support at the $2 million level from the Department of Health and Human Services (HHS). State matching funds will be sought from the Florida legislature.

Florida State University (FSU) and the University of Miami (UM) are also collaborating to establish a joint Program in Aging and Health Promotion dedicated to research on the issues of health and health care facing an aging population. Florida is the ideal state for such a project given the high proportion of people over 65 in the population and the presence of these two research universities with outstanding programs in this area. The resources include UM's School of Medicine and FSU's Pepper Institute on Aging and Public Policy as well as FSU's Center for Population Studies. The Center will become a focal point for national, state, and local research on such issues as Medicare's transition to managed care; the provision of long-term care for the frail elderly including models to integrate acute and long-term care; and the impact of immigration on the racial and ethnic structure of the older population of the future. Partners will include the Florida Department of Elder Affairs and other state agencies. Private foundation support is also being sought. The initial step in securing federal funding will be project funding for a research development proposal to the National Institute on Aging (NIA). We will be seeking approximately $1 million in fiscal year 1999 from NIA, and matching state funding will be sought.

A third collaborative project between FSU and UM will look at the effectiveness of early childhood programs in preparing children for school. There are several major early childhood services: Head Start, Pre-K, childcare, and early intervention programs. Although these programs vary substantially in terms of staff, cost and quality, little is known of the differences in their effectiveness as school readiness programs. We propose to answer these questions by comparing the school readiness of children enrolled in early childhood programs characterized as effective based on the literature, with that of children enrolled in sub-optimal programs. This research will also help to determine whether inclusive programs, currently advocated for children with disabilities, are equally effective for children with all types of disabilities. We are seeking $2 million in fiscal year 1999 from HHS for this project.

Another project that we are seeking funding for in fiscal year 1999 is for course materials for training purposes that could be based upon materials developed by the British Open University (BOU). Florida State University and the British Open University signed an agreement to jointly develop educational materials with FSU faculty playing key roles as mentors/teachers for the users of these materials at various training sites. New technologies will be employed in this effort, and innovative approaches in utilizing these technologies in classrooms and other training settings will be emphasized. We are working closely with the Leon County School District (FL) in creating a model program effort. Our consortia will be seeking funding from the Department of Education and its Technology Innovation Challenge Grants program. We anticipate a $1 million effort in fiscal year 1999 and $5 million over five years.

Mr. Chairman, these activities discussed will make important contributions to solving some key problem and concerns we face today. Your subcommittee's support for research activities across your jurisdiction is greatly appreciated. Those investments are crucial one for our Nation's future. Thank you again for this opportunity to present these views for your consideration.

PREPARED STATEMENT OF RITCHIE L. GEISEL, PRESIDENT, RECORDING FOR THE BLIND AND DYSLEXIC [RFB&D]

Mr. Chairman, Mr. Cochran, members of the subcommittee, I am Ritchie Geisel, President of Recording for the Blind and Dyslexic (RFB&D), whose headquarters are located in Princeton, New Jersey, with thirty-two recording studios throughout the United States. It is on behalf of RFB&D that I submit this statement in support of our request for continued federal support of our mission as the nation's primary producer of recorded textbooks for people of all ages who cannot use standard print because of a visual, perceptual or physical disability.

First, I want to thank the members of the subcommittee for the continuous support that you have given RFB&D since our first federal assistance, which began in 1975. This support, plus the support we receive through private philanthropy, allowed us this year to circulate more than 245,000 textbooks, free of charge, to approximately 50,000 borrowers. In 1990, the number of borrowers was less than half that number. Increased federal support has been key to our ability to reach an increasing number of students, including an increasing number of severely dyslexic students.

Historically, RFB&D was founded in 1948 as a service for returning blind veterans of World War II, and has grown into a national, private, volunteer-based organization serving as the national education library for people who cannot read standard print because of a disability. Located in Princeton, New Jersey, its volunteer readers are spread throughout the United States, as are its library users.

RFB&D distributes textbooks and other educational materials in accessible audio and digital sound and text formats. Our tape and digital library continues to grow with more than 75,000 titles and is constantly updated to meet the needs of our student and professional users. Our books are provided free of charge to students of all ages, after a small registration fee, with students permitted to borrow as many texts as required for their course of study.

Our request to the subcommittee for fiscal year 1999, is for an appropriation of $6,500,000, an increase of $500,000 over the amount provided by the Congress last year. This federal subsidy, which is approximately 25 percent of our total budget, will be used for two significant initiatives:

—1. Expanding the number of student borrowers through an aggressive outreach program: By the year 2000, only three years from now, the number of borrowers is expected to exceed 80,000 students dependent on us for their textbooks. Since these students are entitled by both the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA) to appropriate educational materials, RFB&D believes that our federal appropriation represents an appropriate contribution towards this cost. Our highly trained readers are volunteers knowledgeable in the field in which they read; therefore, RFB&D is able to meet this need at a fraction of what it would cost government, whether local or federal, if it were required to produce these textbooks on their own.

—2. Converting RFB&D's recording system from analog tape to digital format: RFB&D is well along in this 3-year project to convert its recording operations to the new digital technology. This change will have two principal advantages. First, it will allow visually impaired and dyslexic students to search and move around within a book in the same way that sighted students do. Second, it will permit books to be circulated on CD–ROM and electronically through the Internet. During 1998, RFB&D has further refined its core digital technology and begun the process of revamping its 32 recording studios located throughout the United States in order to begin recording digitally.

Mr. Chairman, RFB&D and its student users are grateful for the support the committee has provided in the past, and are hopeful that you will be able to approve our request for $6,500,000 for fiscal year 1999. This level of support will assist RFB&D as it continues our joint efforts to serve the educational needs of disabled students throughout the United States.

RECORDING FOR THE BLIND AND DYSLEXIC (RFB&D)

[Special education, technology, and media services]

Fiscal year	Base	Outreach	Total
1998 appropriation	$6,000,000	.....	$6,000,000
1999 President	6,000,000	.....	6,000,000

RECORDING FOR THE BLIND AND DYSLEXIC (RFB&D)—Continued

[Special education, technology, and media services]

Fiscal year	Base	Outreach	Total
1999 RFB&D request	6,000,000	$500,000	6,500,000

RECORDING FOR THE BLIND AND DYSLEXIC

	1990	1995	1998	2000 (estimate)
Students	23,287	37,176	49,515	80,000
Books loaned	143,020	214,621	245,274	400,000

Recording for the Blind and Dyslexic (RFB&D), located in Princeton, New Jersey, is the nation's primary producer of recorded textbooks for people of all ages who cannot use standard print because of a visual, perceptual or other physical disability. Books from its master tape library are loaned, free of charge, to users throughout the United States. RFB&D is supported principally through private, charitable giving and volunteer labor, but has received support from the Department of Education continuously since 1975. In 1998, 245,274 books are expected to be sent to 49,515 users, and RFB&D has recently committed to a doubling of the number of blind and dyslexic student borrowers by the year 2000. (See table above.)

In fiscal year 1998, RFB&D received increased funding from Congress to support two significant initiatives: (1) substantial expansion in the number of student borrowers served by the organization, and (2) development and application of digital technology as a tool to improve the usefulness of its recorded books for students. Congress approved these increased resources as part of its continuing partnership with RFB&D, and both projects are proceeding on schedule. RFB&D is well along in its 3-year project to convert its recording operations from an analog tape system to new digital technology. This change will have two principal advantages. First, it will allow visually impaired students to search and move around within a book in the same way that sighted students do. Second, it will eventually permit books to be circulated on CD–ROM and electronically through the Internet. During 1998, RFB&D has further refined its core digital technology and begun the process of revamping its 32 recording studios located throughout the United States in order to begin recording digitally. The process of expanding the number of students receiving books is proceeding, and an additional 6,225 borrowers have been added this past year. RFB&D believes this process can be further accelerated through an expanded outreach program which has already been implemented and will be expanded in fiscal year 1999.

The $500,000 increase requested for RFB&D for fiscal year 1999, is compatible with the long range financial plan developed at the Appropriations Committee's request and submitted to Congress on January 31, 1997. The amount requested represents approximately one-fourth of the organization's operating budget with the remaining funds generated from private sources.

Prepared Statement of the National Rural Health Association

The National Rural Health Association (NRHA) thanks Chairman Specter and members of the Committee for the opportunity to submit for the record the association's fiscal year 1999 funding requests for programs important to our nation's rural health care delivery system. We believe we can offer you and your Committee a unique and insightful look at the health care needs of rural frontier America.

The NRHA is a national nonprofit membership organization that provides leadership on rural health issues. The NRHA works to create a clear national understanding of rural health care, its needs and effective ways to meet them. Our mission is to improve the health of rural Americans and to provide leadership on rural health issues through advocacy, communications, education and research. As you are well aware, rural areas are unique. They differ from urban areas in their geography, population mix and density, economics, lifestyle, values and social organization. Rural people and communities require programs that respond to their unique characteristics and needs.

The NRHA membership is a diverse collection of individuals and organizations, all of whom share the common bond of an interest in rural health. Individual mem-

bers come from all disciplines and include administrators, physicians, nurses, dentists, non-physician providers, health planners, researchers, educators and policymakers. Organization and supporting members include hospitals, community and migrant health centers, state health departments and university programs.

The NRHA appreciates this opportunity to discuss several programs we feel are particularly crucial to the quality of rural health care services. However, attached is a more detailed letter containing all the NRHA's specific program funding level requests for fiscal year 1999, which was sent to Chairman Arlen Specter and Ranking Member Tom Harkin on March 11, 1998.

Before discussing specific programs, the NRHA wants to express its strong opposition to any special projects being funded in this year's appropriations bill from funds appropriated for the Rural Health Outreach, Network Development and Telemedicine Grant program and the Rural Health Research Grant program. While the projects that were earmarked in last year's bill were both innovative and important, the NRHA believes that any program increases should be made available in their entirety to the competitive grant process, which was the original intent of Congress.

The National Health Service Corps (NHSC) is one of the NRHA's partners in several of our initiatives to recruit and retain more health care providers in underserved rural communities. The NHSC is long overdue for a funding increase after having received only level funding the last several fiscal cycles, and the NRHA urges the Committee to increase the Corp's funding to $155 million. This funding increase is desperately needed so the NHSC can expand its outreach efforts in educating rural communities regarding the options the Corps can provide and targeting a portion of the existing pool of health professionals toward service in underserved communities. In 1996, the NHSC placed 1,371 health care professional in rural areas of which 771 were primary care physicians. However, there are still many communities that cannot provide essential health care services on their own. Since its inception 25 years ago, the NHSC has been an essential lifeline for providing health professional services to those communities most in need.

For example, Dr. Ralph Taube began his practice with the Tigerton clinic in Tigerton, WI, in 1979. His NHSC obligation was completed in June 1982, but he remained in the community for another nine years. For twelve years he provided medical care to the community and was joined by another physician who still provides care in Tigerton. Without the initial support of the NHSC, the small clinic might not have been able to recruit for and stabilize the practice that provided much needed support for the people of this community.

The Cornerstone Care facility in Greensboro, PA, has been able to expand their services to two other communities, Rogersville, PA, and Burgettstown, PA, because of the commitment of the current medical director Nathan Duer. Dr. Duer was an NHSC scholar who remained in the community after serving his four year commitment to the NHSC. His continual presence has allowed the practice to stabilize and build to what is now a three site network with both medical and dental services.

In Onawa, IA the NHSC has placed two physicians, Dr. Gerald Stanley and Dr. Curtis Mock, who have been working together for almost ten years establishing a system of health care services for the community. Dr. Stanley and Dr. Mock are in the process of expanding their system of care to another satellite with the two physician assistants and physician placed in Onawa by the NHSC in recent years. This team of health care providers in Onawa is also active at the state level ensuring that access to quality health care in rural America continues to improve. Dr. Mock is on the State Board of Directors for Rural Health Clinics and Dr. Stanley is on the State Board of Directors of the Iowa Academy of Family Practice and has been recently nominated for the NHSC Physician of the Year Award.

The Balanced Budget Act of 1997 (BBA) provides numerous opportunities to improve access to quality health care services to rural and frontier Americans. It is imperative, however, that Congress provide the financial resources necessary to ensure the full and proper implementation of these provisions. One such program, which the NRHA strongly supports, is the Medicare Rural Hospital Flexibility program. This program was created by the BBA to improve access to essential health care services through the establishment of Critical Access Hospitals (CAHs) and rural health networks. The program creates an important alternative to small rural hospitals that provides regulatory relief and more equitable financing options by assisting states in proactively respond to market changes, remove any restrictive standards and authorities, support network development and regional approaches to health care and support hospitals that want to respond to ongoing market reforms. The NRHA strongly urges the Committee to provide the $25 million annual appropriation authorized by the BBA. This money would provide states with the necessary resources to develop and implement a rural health plan, develop networks, designate CAHs and improve rural Emergency Medical Services.

The NRHA requests that the Committee provide $50 million for the Rural Health Outreach, Network Development and Telemedicine Grant program. This program, which was reauthorized in 1996, provides important grant opportunities to rural communities. The Rural Outreach Grant program includes grants for developing formal, integrated networks of providers that may offer a range of primary care and acute care services. Network development grants are designed to develop organizational capacity in the rural health sector through formal collaborative partnerships involving shared resources and possible risk-sharing.

One outreach grant in Lock Haven, Pennsylvania, provides health promotion classes and health screening programs throughout rural Clinton County. Health screening services, conducted in local fire halls include checking for hypertension, diabetes, elevated cholesterol levels, skin cancer and other conditions. Clients are referred to appropriate sources of care as needed. The grant also supports health education classes on such topics as diet, exercise, nutrition and diabetes control.

Marshalltown, Iowa, which is providing medical and dental services to underserved children, youth and families through a school-based outreach program, is another innovative outreach grant project. Using a mobile medical clinic, services are rotated among four elementary schools. Hundreds of elementary school children have received primary medical care and dental services through this project. The grant has also established an emergency prescription drug reimbursement program for low income students and their families.

Additionally, the program will continue to offer grants to rural communities working to provide health care services through new and innovative strategies including mobile primary care outreach programs for migrant and seasonal farmworkers and telemedicine. Since 1991, approximately 300 rural communities have benefited from innovations in health care service delivery from grants totaling $170 million. The program also currently funds 18 telehealth/telemedicine projects.

The NRHA strongly recommends a $15 million appropriation for Rural Health Research, which provides funding for research programs, the Rural Information Center Health Service (RICHS), telemedicine grants and the National Advisory Committee on Rural Health. This grant program currently supports six Rural Health Research Centers that provide policy relevant research, including work on rural hospitals, health professionals, delivery of mental health services and functioning of managed care systems.

RICHS began in 1990 as a joint project of the Office of Rural Health Policy, HHS, the National Agricultural Library and the Department of Agriculture. It serves as a national clearinghouse for those seeking information referrals about rural health issues and answers requests on specific rural health issues. The knowledge gained from all these important research efforts is an important contributor to the success of all the above mentioned programs in improving access to quality rural and frontier health care services.

In many cases, the only health care entity providing primary and preventive health care services to a rural community is a community health center (CHC). Overall, CHCs provide services to eight million residents of underserved areas. About 60 percent of health centers and 50 percent of the users are from rural areas. CHCs have been proven to significantly improve a community's health especially when it provides maternal and child health care services as well as child immunizations. The NRHA urges the Committee to provide $926 million for the Consolidated Health Centers program for fiscal year 1999 to continue improving the health status of our country's underserved populations.

We also urge you to include specific language in your Committee's final report directing $5 million from the National Health Service Corp's allocation for State Offices of Rural Health. The State Offices of Rural Health coordinate statewide rural health activities, offer technical assistance to communities to develop health care programs and are also actively involved in efforts to recruit and retain health care providers in rural areas.

The NRHA wishes to thank the Chairman and Members of the Committee again for the opportunity to submit for the record the NRHA's fiscal year 1999 funding requests. It is important that the work already done continue to be built upon to create a healthier life for rural and frontier Americans. However, due to the geographical, distance and financial restraints that many rural and frontier areas face, this progress depends upon the assistance of all levels of government. The NRHA stands ready to work with your Committee and the Congress to ensure access and quality of essential health care services continue to improve for our country's rural residents.

PREPARED STATEMENT OF DR. WILLIAM H. MAHOOD, PRESIDENT, DIGESTIVE DISEASE NATIONAL COALITION

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to submit written testimony regarding the federal government's support for digestive disease research and prevention programs at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the Centers for Disease Control and Prevention (CDC).

I am Dr. William Mahood, a practicing gastroenterologist in Abington, PA and the president of the Digestive Disease National Coalition (DDNC). Founded in 1978, the DDNC is a voluntary organization comprised of 22 professional and patient organizations concerned with the many diseases of the digestive tract. The Coalition has as its goal a desire to improve the health of millions of Americans who suffer from both acute and chronic digestive disorders

Mr. Chairman, the social and economic impact of digestive diseases is enormous. Digestive disorders afflict approximately 62 million Americans, resulting in 50 million visits to physicians, 10 million hospitalizations, 230 million days of restricted activity, and nearly 200,000 deaths annually. The total cost associated with digestive diseases has been conservatively estimated at $56 billion a year.

With these devastating numbers in mind, I would like to take this opportunity to thank you Mr. Chairman for your past support of the National Institutes of Health and the Centers for Disease Control and Prevention. Regarding the coming fiscal year, I would like to briefly discuss the following: (1) digestive disease research at NIDDK (2) colorectal cancer prevention activities at CDC, (3) viral hepatitis research and prevention, and (4) irritable bowel syndrome.

DIGESTIVE DISEASE RESEARCH AT NIDDK

Millions of Americans suffering from digestive disorders are pinning their hopes for a better life—or even life itself—on medical advances made through research supported by the National Institute of Diabetes and Digestive and Kidney Diseases. Recent breakthroughs in our understanding of hemochromatosis, Crohn's disease, pancreatitis and other digestive abnormalities reinforce the need for continued support of NIDDK.

For fiscal year 1999, the DDNC recommends that NIDDK receive a 15 percent increase over last year. This percentage translates into $131 million over fiscal year 1998 and would bring NIDDK's total appropriation to $1 billion. At this point Mr. Chairman, I would like to make clear that although the DDNC strongly supports the concept of doubling NIH's overall budget in the next five years, we do not believe that these increases should come at the expense of other important Public Health Service programs.

COLORECTAL CANCER PREVENTION

Turning from biomedical research at NIH to disease prevention and control at CDC, I would like to say a few words about CDC's newly established program promoting colorectal cancer screening.

Colorectal cancer is the third most commonly diagnosed cancer for both men and women in the United States and the second leading cause of cancer- related deaths. Although colorectal cancer is almost entirely curable when detected early, recent studies have shown a tremendous need to (1) inform the public about the availability and advisability of screening and (2) educate health care providers with respect to colorectal cancer screening guidelines. The recently initiated National Colorectal Cancer Screening Awareness Program at the Centers for Disease Control and Prevention will address these needs by coordinating with national partners like the DDNC to develop an information program emphasizing the value of early detection. The digestive disease community hopes that this new program will do for colorectal cancer screening rates what CDC's Breast and Cervical Cancer Screening Program has done for mammography and Pap smear screening compliance.

Mr. Chairman, as the DDNC representative to CDC's colorectal screening program, I have seen first hand the ambitious plan that CDC has to reduce the incidence of this devastating disease. As a result, the DDNC encourages the Subcommittee to provide CDC with $5 million (an increase of $2.5 million over fiscal year 1998) for this vital campaign.

VIRAL HEPATITIS RESEARCH AND PREVENTION

Mr. Chairman, viral hepatitis is one of this country's most dangerous and prevalent infectious diseases. More than 5 million Americans are currently infected with

chronic hepatitis B or hepatitis C. Overall 128,000 new cases are reported each year. Because chronic viral hepatitis can result in severe liver impairment, liver transplantation (at a cost of approximately $250,000 per patient) often becomes the only treatment option available for many individuals. Already, chronic hepatitis C accounts for nearly one third of all liver transplants being performed in the U.S. It is estimated that there are up to 10,000 deaths annually from hepatitis C and the CDC projects that this number may triple by the year 2010.

The DDNC is pleased that NIDDK convened a Hepatitis C Consensus Development Conference last March. We believe that priority should be given to supporting the research recommendations developed by the consensus panel, particularly the development of vaccines for hepatitis C. Also, we urge making existing hepatitis B vaccines readily available to at-risk populations through an expansion of CDC's vaccination program.

IRRITABLE BOWEL SYNDROME

Finally, Mr. Chairman, I would like to provide the Subcommittee with some information on one of the most common and perplexing digestive disorders, irritable bowel syndrome (IBS). IBS is a chronic complex of disorders that malign the digestive system affecting 10–15 percent of the general population annually. These disorders strike people from all walks of life and result in a significant toll of human suffering and disability. Although IBS is one of the most common GI disorders people are often very isolated by their condition.

In a recent U.S. Householder Survey of Functional Gastrointestinal Disorders, Prevalence, Sociodemography and Health Impact, irritable bowel syndrome accounted for 10 percent of the total gastrointestinal disorders population, 46 percent of which required the supervision of a gastroenterologist. This care alone results in millions of dollars in health care costs every year. In addition, individuals who suffer from IBS will miss 13.4 days of work annually as opposed to the 4.9 national average, further contributing to higher health care costs and loss of productivity. IBS alone has recently been called a multi-billion dollar problem by the gastrointestinal community. I would like to thank Senator Kohl for his past interest in this area and remind the Subcommittee that much more can be done and should be done through the NIDDK to address the needs of the millions of Americans suffering from IBS.

Mr. Chairman, once again, thank you very much for the opportunity to present the views of the Digestive Disease National Coalition.

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF ADDICTION TREATMENT PROVIDERS

The National Association of Addiction Treatment Providers, Inc. is very honored and proud to participate in this hearing on "Addiction and Recovery". For the past twenty years, NAATP has been the preeminent association representing the interests and concerns of private sector addiction treatment providers across this country. This organization represents some of the highest quality and most well recognized treatment programs, as evidenced by the attached Board of Directors list, throughout the United States.

Perhaps no other subject generates as much discussion, debate, disagreement, hostility and confusion as does the topic of addiction. Hardly any citizen of this country would argue that addiction, in some form, has not touched their family or a family close to them. However, the responses to this primarily public health issue have been confusing and often misguided. Our public policy initiatives have oscillated between an attempt to ignore the disease to punishment for those with the disease of addiction. In our attempt to simplify a complex issue, we have often not taken the time to understand this disease for what it is a chronic re-occurring disease that does respond to treatment.

The National Association of Addiction Treatment Providers recognizes that the current public debate on addictions has focused on a significant number of issues including, demand reduction, illegal vs. legal, criminal justice component, outcome expectations, health care off-set dollars, etc. Without diminishing the importance of these issues, NAATP wishes to comment on the treatment side of the equation. The National Association of Addiction Treatment Providers begins with the premise that Alcoholism and other Drug Dependencies is diagnosable, the disease responds to treatment and that through appropriate quality treatment and a life-long monitoring process, this disease like any other chronic disease can be managed. Therefore, recovery becomes possible!

The one hundred and forty members of the National Association of Addiction Treatment Providers, Inc. believe that their contribution to the continued national debate on this issue will be best served with a focus on treatment. In this regard, NAATP is committed to helping to promote and provide the most current, accurate and reliable information possible on addiction treatment.

NAATP believes that the single strongest deterrent to an informed discussion of this issue are the stigmas and myths associated with the diagnosis and treatment of alcoholism and other drug dependencies. The overt and covert discrimination is rampant! The National Association of Addiction Treatment Providers supports the passage of Federal Legislation that would eliminate discrimination that currently exists in private health insurance plans. The artificial establishment of lifetime dollar caps and yearly limited treatment episodes for addiction treatment which are not included or in place for other diseases is blatant discrimination. In 1997 Senator Paul Wellstone (S. 1147) and Representative James Ramstad (H.R. 2409) introduced legislation that would end this discrimination. In a recent study completed by Milliman & Robertson Premium Estimates for Substance Abuse Parity Provision for Commercial health Insurance Products (September 2, 1997) it was found that the cost for this "act of justice" would be 0.5 percent or less than $1 per member per month. NAATP supports the rapid and complete passage of this legislation so as to take the first steps toward dealing with the stigma and discrimination that have plagued this disease.

If we are indeed going to commit ourselves to providing treatment to those individuals and families whose lives have been ravaged by chemical dependency then we must take note of and address the following issues:

Treatment efficacy.—The efficacy of treatment for alcohol and other drug problems is clearly established. Outcome studies for the treatment of addictions have clearly documented that treatment is effective and beneficial both to the individual, her or his family, and society. Recent studies have shown that addictions do conform to the common expectations of chronic illness and that addiction treatment has outcomes comparable to other chronic conditions. A key issue with chronic conditions is compliance with the prescribed treatment plan. The likelihood of requiring additional treatment within a 12-month period following initial treatment is generally higher for diabetes, hypertension and asthma than for alcoholism and other drug dependencies.

Economics of treatment.—Accessibility to addictions treatment is a major issue. At present, demand for addiction treatment services is considerable. Current reimbursement for care both in public and private sector combined, are not sufficient to meet the demand for treatment appropriately. Hence, accessibility to treatment is often non-existent or truncated. It has been the experience of the National Association of Addiction Treatment Providers and its members (both former and present) that over the past ten years nearly 50 percent of the addiction treatment beds have disappeared. This reduction in beds has been directly related to the availability and accessibility of treatment funds to pay for such treatment. Therefore, due considerations must be given to ensure that appropriate fiscal resources necessary for addictions treatment are available.

Accountability.—Accountability for treatment, i.e., who receives care, what kinds of resources they receive and sufficiency of treatment, are key issues. Managed care has changed the equation of the past in that treatment decisions are no longer the sole domain of health care providers. Therefore, standards to monitor the performance of managed care entities and meaningful oversight mechanisms are essential if accessibility is to be promoted and the positive cost-benefits of treatment are to be realized. Likewise, existing clinical and performance standards for treatment provides need to be promoted and monitored to ensure treatment efficacy.

The National Association of Addiction Treatment Providers and its members will continue to forge new treatment methodologies, new treatment measures and new partnerships with other professionals to ensure that the addiction treatment delivered is of the highest possible quality and provides the best opportunity for life long recovery.

Therefore, NAATP is committed to:

—Actively working to reduce the stigma associated with the disease of Alcoholism and other Drug Dependencies;

—Providing accurate information as to who the persons in treatment and needing treatment really are (replacing the myth with a person);

—Seeking accessible and affordable treatment for all persons diagnosed with the disease of alcoholism and other drug dependencies;

—Developing appropriate outcome measures so as to continue to demonstrate the value of addiction treatment; and

—Building a national database on addiction treatment.

PREPARED STATEMENT OF THE NATIONAL COUNCIL ON REHABILITATION EDUCATION

The Rehabilitation Act of 1973, as amended in 1992, has significant implications for Title III, Section 302 (Training) and the resultant Title I and Title III appropriations for the period from fiscal year 1992 through fiscal year 1997. In the 1992 Amendments, the following changes impact the nature, scope, breadth, and distribution of the Title III Training appropriations:

—Section 21 focuses on the need for recruitment, development, and retention of underrepresented and unrepresented individuals and requires the set-aside of 1 percent to meet these needs;

—Section 803 of Title VIII requires specialized training for distance education through telecommunications, Braille training, parent information and training, Impartial Hearing Officers training, and recruitment and retention of urban personnel;

—Title I strengthens the requirements for a comprehensive system of personnel development, increasing congressional expectations on State agencies to upgrade the qualifications of personnel consistent with comparable State and professional standards (i.e., a graduate degree, licensure, or national certification);

—The Amendments increased Section 130 programs for Native American reservations, services for independent living (Title VII-B), and the expansion and development of independent living centers (Title VII-C), resulting in the need for preparation of additional personnel entering the field of rehabilitation and requiring continuing education for currently employed personnel; and

—The Amendments allocated a minimum of 15 percent of all Title III appropriations for State agency in-service training grants.

In addition to these legally mandated training requirements, numerous studies were commissioned by the Rehabilitation Services Administration (RSA), the National Council on Disability, and the National Institute on Disability and Rehabilitation Research, and were completed by rehabilitation personnel and professional organizations over the past fifteen years (Pelavin, 1991; Menz, 1989; Roberts, 1984; and Crisler, 1991), which have substantiated the existing shortages for current rehabilitation personnel and the need for future rehabilitation personnel. A number of Institutes on Rehabilitation Issues (i.e., Human Resource Development, 1991; Serving the Underserved, 1992; and Counseling and Guidance, 1993) have substantiated the need for qualified personnel throughout the State-Federal system and in special areas of priority needs. These studies further supported the contention that many agencies are experiencing significant loss of personnel through retirement and turnover. In the late 1980's and 1990's, State agencies have lost much of their institutional memory and talent related to the full implementation of the Rehabilitation Act and its subsequent Amendments.

These statutory requirements and personnel and research studies are further impacted by increases in SSI and SSDI recipients and the authorization and implementation of the Americans with Disabilities Act. The needs of persons with disabilities to obtain employment remain high (Harris, 1994). While legislation mandates increased employment opportunities for persons with disabilities and improved quality and productivity of rehabilitation services, there is a critical disparity between the current level of appropriated Title III funds and the level of funding necessary to prepare new professionals and provide continuing education for rehabilitation personnel to empower them to comply with these mandates.

The legislative mandates, the demands for rehabilitation services by adult consumers with disabilities, and the need for new personnel to meet expansion of program directions, replace retirements, and meet the turnover needs of personnel have created a critical demand for the continuing education of existing personnel and the educational preparation of new personnel.

REALITIES OF THE RESOURCES AND RSA POLICIES

From fiscal year 1993 through 1998, the Federal appropriations for Title III was $39,629,000,000. This reflected level funding, while the Title I appropriations increased from $1,873,476,000 to $2,231,528,000, an increase of 19 percent. Coupled with the above demands, the rise in inflation, and the escalating costs of purchased educational services, the level funding for the past six fiscal years actually resulted in a significant reduction of resources and purchasing power.

RSA policies and the Federal regulations changed during the fiscal years of 1993 to 1997. These changes involved an administrative policy for level funding for each year of a multi-year grant or cooperative agreement. In essence, for a 5-year grant or cooperative agreement, there are no cost- of-living increases. Many long-term training grants have been capped at a maximum of $100,000 per year, with a further mandate that at least 75 percent of all dollars must be directly related to stu-

dent tuition and fees or stipend support. The latter requirement has been mandated by Department of Education regulations for 34 CFR 386.

In the area of continuing education, the General Regional Rehabilitation Continuing Education Programs (General RRCEPs), which were first funded in 1974, have received level funding for the period from 1992 to 1997. The only increases have been task-specific addendums (i.e., diversity, employment, and streamlining) for a finite period. In the September 1997 Request for Proposal, the seven regional General RRCEPs which are competing for five-year funding are required to continue level funding for another five years. This category of training and the individual cooperative agreements will have received level funding for a ten-year period—with no reduction in outcomes and, in some cases, increased expectations.

In 1995, RSA consolidated funds from a number of community rehabilitation long-term training grant categories and phased in Community Rehabilitation Program Regional Rehabilitation Continuing Education Programs (CRP-RRCEPs) over a three-year period (1995 through 1997). The ceiling is $500,000 per year per each regional program for the five-year period of the cooperative agreement. There are no increases to compensate expanded training needs or inflation.

Clearly, although the resources have remained constant in actual dollars, they have actually been reduced in purchasing power through erosion from inflation, cost-of-living increases, regulatory parameters, and expanded needs and expectations of consumers and rehabilitation service providers.

While there are methods to increase efficiency, there are also the realities of actual cost demands. These demands include increases in tuition and fees, travel, and inflation. A program comparable to Title III, Training, within the U.S. Department of Education, the Office of Special Education and Rehabilitation Services, is the training authorized under the IDEA. Table 1 reflects the appropriated levels of Federal funding for training during a two-year period (FY 1995 and 1996).

TABLE 1—COMPARISON OF IDEA AND REHABILITATION ACT APPROPRIATIONS FOR FISCAL YEAR 1995–96 FOR STATE GRANTS AND TRAINING/PERSONNEL DEVELOPMENT [1]

Fiscal years	Title I State VR funds	Title III funding	Percent for training	State grants—IDEA	Personnel development	Percent for training
1995	$2,054.145	$39.629	1.93	$2,998.812	$114.254	3.67
1996	2,118.834	39.629	1.83	3,000.000	113.50 4	3.64

[1] Personnel development for IDEA includes personnel development, parent training, the clearinghouses, and the regional resource centers, which are categories within Title III of the Rehabilitation Act. All funds are reflected in millions of dollars.

As reflected in Table 1, during the same two Federal fiscal year periods (1995 and 1996), the education and training appropriations within the IDEA received significantly higher funding levels. There is a substantial discrepancy between the two training programs in terms of actual dollars and the percent of appropriations for State grants. The support for personnel development, based on a percentage of the total allocation for direct services, is almost double for IDEA when compared to the State-Federal system of rehabilitation. In actual dollars the difference is in excess of $70 million.

CONCERNS FOR THE FUTURE APPROPRIATIONS OF TITLE III OF THE REHABILITATION ACT, AS AMENDED

The quality of services available for consumers with disabilities will be severely diminished without a significant change in the philosophical, legal, and fiscal approaches to the comprehensive system of personnel development.

Therefore, to establish the base for an effective system of personnel development that will enable quality employment outcomes for adults with disabilities, the following resolution is proposed:

Whereas the Rehabilitation Services Administration training dollars have remained the same since fiscal year 1993, and

Whereas there have been inflationary increases and increases in the number of individuals needing training and education, and

Whereas the 1992 Amendments to the Rehabilitation Act and related regulations require master's degree-prepared rehabilitation counselors and other qualified rehabilitation personnel to deliver vocational rehabilitation services, and

Whereas training dollars must be spread across an increasing number of disciplines, and

Whereas many staff members who entered into employment in the late 1960's and early 1970's are now aging out of the vocational rehabilitation system,

Whereby be it recommended by the National Council on Rehabilitation Education that the Rehabilitation Services Administration seek an increase of the appropriations for fiscal year 1999 to $50 million. This figure is derived from the cost-of-living adjustments that were afforded to Title I of the Rehabilitation Act from 1993 through 1998 (19 percent) and from parity with the IDEA personnel development authorization.

There should be an explicit mandate that the focus of training efforts in Title III be linked to employment-related outcomes. The portion of Title VIII related to distance learning needs to be expanded to enable present and future rehabilitation personnel to remain current and technologically competent.

In addition to the proposed increase in appropriations, modifications are needed in the regulations and administration of Title III by the RSA. These changes should include the expansion of the terms and conditions for the payback provisions for stipend support. The current provisions are placing undue burdens on the universities for reporting and recordkeeping, which often extend beyond grant periods. With the development of public-private partnerships, the move toward deregulation, and privatization of services, the current definitions for graduates are restrictive. Finally, the policy for level funding of multi-year projects should be refined and adjusted to meet the needs of the students and employed trainees, the sponsoring organizations, and the public program.

SUMMATION

The comprehensive system of personnel development is a positive mandate under the law and has far-reaching implications for organizations providing services through, and preparing personnel for, the public program of rehabilitation. However, without a proactive approach to appropriations that ensures that there will be sufficient funds for the future, the personnel development of new professionals and continuing education of current personnel will continue to fall critically short of the need. The legislative intent is clear—what remains in question is sufficient funding to meet the intent. Persons with disabilities deserve and should expect the highest quality services provided by competent, professional personnel.

PREPARED STATEMENT OF DR. JOHN F. NEYLAN, THE AMERICAN SOCIETY OF TRANSPLANT PHYSICIANS [ASTP]

ENHANCING TRANSPLANTATION MEDICINE IN THE UNITED STATES

Thank you for the opportunity to be here today and to present testimony on behalf of the American Society of Transplant Physicians (ASTP). I am John Neylan, President-Elect of the ASTP, and Director of Transplant Out-Patient Services at Emory University.

The American Society of Transplant Physicians is composed of 1,100 physicians, surgeons and scientists. The practices and careers of our members focus on the broad fields of transplantation medicine and immunobiology and span across many medical and surgical specialties. The ASTP represents the largest group of transplant professionals in the United States.

We are pleased that the Institute of Medicine (IOM) has invited a cross section of professionals and other interested individuals from the transplant community. No single institution or organization can affect significant change alone. If we are to continue to advance the field, it will be accomplished only through a partnership among all interested parties. The progress achieved over the past ten years is clearly a result of this kind of collaborative effort. For example, the volunteer-run Organ Procurement and Transplant Network (OPTN) administered by the United Network for Organ Sharing (UNOS) has developed a sophisticated national system for organ sharing.

The transplant community has persuaded the Congress to extend anti-rejection drug benefits for kidney transplant patients from 12 to 36 months under the Medicare entitlement. There have also been steady improvements in clinical practice which have reduced transplantation morbidity and mortality. Surveys confirm that an overwhelming percentage of Americans are aware of and are in favor of the "gift of life," though family refusal continues to be a significant impediment. Required request laws have been enacted in all 50 states. The organ procurement organizations (OPOs) have been responding to increased demands for efficiency and productivity and have consolidated from 120 to 64. And finally, the funding for transplant-related biomedical research at the National Institutes of Health (NIH) has increased in the past decade.

As we have heard this morning, enhancing transplantation requires a myriad of strategies including increasing organ donation, developing fair and equitable allocation principles, recognizing the concerns of special populations, building upon scientific and technical advances, and securing adequate access and funding for all patients in need of organ or tissue transplants. I would like to build upon this morning's discussion by presenting two very important and timely issues for your consideration. First I will discuss the ASTP's development of standardized listing criteria for determining when to list a patient on the national transplant waiting list. Second, I will provide a cursory review of the Society's assessment of the recommendations put forth by the original Task Force on Transplantation as a means in which to determine the public policy needs facing us today.

Organ allocation, without a doubt, has engendered the most contentious public policy debate regarding transplantation in years. Throughout this debate, it has been observed that the variation in criteria physicians use to list a patient for transplant has contributed to the inconsistencies in waiting times among patients across the country. Furthermore, there is concern that, because of long waiting times in certain regions, there is a pressure on transplant programs to list patients early, before they actually require transplantation, a practice referred to as "waiting list inflation." While many other factors contribute to these regional differences including OPO productivity and the available supply of local donors, the increasing discrepancy between the short supply of donor organs and expanding list of patients in need has spurred a growing demand to ensure that the organ allocation system is efficient and equitable.

In early 1997, the ASTP successfully joined transplant physicians, surgeons, government agency representatives, UNOS, patients, ethicists and managed care providers on the NIH campus for a series of organ-specific conferences. These conferences addressed the scientific basis supporting specific minimal listing criteria. Transplant programs were surveyed before each conference to identify areas of consensus and areas of controversy. The initial work in this area by UNOS provided the spring board from which the Society has subsequently developed recommendations for national, standardized criteria for placing patients on the organ-specific transplant waiting lists.

Time does not permit me to review each of the listing criteria, however, a set of these has been made available in your handouts. A few key points are worth noting. It was agreed by the participants of the conferences that when a program places a patient on the waiting list, it should signify that the program would be prepared to transplant that patient immediately. Patients should not be placed on the waiting list only because it is perceived that he or she will likely need an organ transplant at some indeterminate point in the future. It was agreed that the minimal listing criteria should be simple, practical, based on existing published or, in some cases, unpublished clinical research, and have received broad agreement among the transplant community. The criteria should be readily verifiable and regularly reviewed to be modified where appropriate.

Recently, a modified version of these recommendations was approved by the UNOS Board of Directors. These and other steps must be taken if we are to maintain the public's trust in the organ allocation system. This trust is absolutely essential if altruistic organ donation is to grow to the levels required to meet the needs of transplant recipients in the future. The consensus-building process used in the development of these listing criteria is an example of how the system can work. The ASTP encourages the IOM to carefully scrutinize the process for establishing public policy in organ allocation and other areas. We support an approach, where those actively involved in transplantation come together to review scientific evidence, reach a consensus, and make recommendations. As I mentioned in my introduction, the ASTP, in it's own efforts to forecast the future needs of transplantation, conducted an internal review of the Task Force on Transplantation's recommendations. As you are aware, the Task Force was created by statute with the passage of the National Organ Transplant Act in 1984. We believe the more than 70 recommendations put forth by the Task Force presents a national blueprint from which most public policy decisions have been made in the past decade. From a public policy perspective, we felt much could be learned from revisiting these recommendations to determine what has been accomplished, what remains a work in progress, and what has been left undone.

The ASTP Public Policy Committee and the Board of Directors recently completed a position paper that created a "scorecard" that compared 1986 Task Force recommendations with the state-of-the-art today. Each of the recommendations was reviewed and scored according to present day results. Enclosed in your handouts, is a copy of the ASTP's White Paper on Transplantation which reviews our conclusions and describes areas of needed improvement. The White Paper addresses four spe-

cific areas: organ donation, organ allocation, access to transplantation and biomedical research. Our agenda is ambitious, but, we are confident that each and every recommendation is attainable. In the remaining time, I will outline a number of key points.

ORGAN DONATION

The transplant community is acutely aware that nearly 10 patients die each day while waiting for an organ. Despite improvements in the organ retrieval system, allocation simply has not kept pace with demand. In 1990, there were 21,914 patients on the waiting list; today, there are over 51,000 patients on the waiting list representing an increase of 133 percent over six years. Tragically, the number of donors has increased by only 43 percent over the same period. The reasons for the lack of transplantable organs are numerous, but family refusal as I mentioned earlier is the leading cause for the loss of potential donors, averaging over 40 percent. Recently, the Institute of Medicine recommended that, "Increasing the donation of kidneys receive the highest priority in the coming decades."

The ASTP urges federal and state governments, providers, professional organizations and patient communities to work together in translating the extremely high public awareness of the benefits of organ donation into a pro-active national effort to increase the actual practice of this altruistic act.

ORGAN ALLOCATION

Many of the Task Force organ sharing recommendations have been implemented through a single, national OPTN. UNOS continues to work towards a fair and equitable national allocation scheme, however, as we have noted, there are still unresolved questions and problems. The ASTP proposes:

—The Scientific Registry should develop policies to make the system more user friendly concerning access to data and its use.

—A mechanism is needed to minimize the persistent problem of organ discard rates. In 1995, 1,200 kidneys, 500 livers and 250 hearts were procured and ultimately discarded.

—The Task Force recommendation to regionalize histocompatibility typing should be implemented to reduce unnecessary and duplicative effort and expense.

—The Congress needs to embrace the OPTN guidelines developed by UNOS and enact long overdue legislation to reauthorize the Transplant Act so that authority will finally be in place to appropriately administer the system of organ sharing.

ACCESS TO TRANSPLANTATION

The issues surrounding access to transplantation are complex and controversial. To build upon and enhance the existing system we propose:

—Uniform medical listing criteria for each solid organ category (heart, liver, lung, pancreas and kidney) should be developed. Patients who meet the accepted criteria should be allowed access to transplantation, regardless of their ability to pay. As managed care grows, the ASTP sees a need for the federal government to assert its leadership to assure that each managed care plan provides equal access to transplantation.

—The government should extend Medicare coverage and payment for anti-rejection drugs for the life of the graft.

—With Medicaid reform, the federal government should assure that all states have uniform eligibility and coverage criteria for transplantation.

—To ensure that patients make informed choices regarding transplantation, the HCFA and private insurance carriers should annually advise patients of their treatment options.

—National education programs targeted to minorities should be developed to educate these under-served groups about the "gift of life" as well as the medical consequences of a transplant. It is imperative that there be a thoughtful review of previous minority education programs coupled with this effort.

—There is disturbing evidence that transplant recipients experience employment discrimination. The Congress should schedule hearings to determine the extent of discrimination in employment, insurance coverage, etc. and move to amend the Society Security Act, the job training program, and the Vocational Rehabilitation Act to eliminate such discrimination and design programs to ensure appropriate access to employment medical benefits.

—The special issues and specialized needs of children should be given a high priority. All funding sources, including Medicaid and Medicare, private insurance

and HMOs must recognize the additional costs necessary for the appropriate provision of transplantation care to children, particularly infants and the very young.

BIOMEDICAL RESEARCH

Research is central to all of the transplantation issues previously addressed. We submit that increased funding for transplantation research will lead to solutions that will save lives. Both the Task Force and an IOM report recommended that research receive high priority. While research initiatives since 1986 have made progress in all of the areas cited by the Task Force, the ASTP believes that we are now on the threshold of many important breakthroughs in the areas of rejection-immunosuppression, tolerance and xenografts.

Next to issues related to the supply of organs for patients on the waiting lists, those of basic and clinical research are of the highest priority. Clinical and basic transplantation funding at the NIH must be increased. We propose that Congress, through the authorization and appropriations process, expand the general transplantation research authority of NIH. In particular, we recommend that Congress designate a number of high priority initiatives at the NIDDK, the NIAID and the NHLBI. We also recommend that the NIAID be designated as the lead coordinating institute for the NIH transplantation research effort in the next decade, The Decade of Transplantation.

I have submitted a copy of the White Paper for this hearing's record. We plan to distribute this paper to members of the Congress, selected government agencies, and others in the transplant community. The ASTP invites the IOM and all other interested groups to comment and reflect on the recommendations presented in this white paper. We would welcome the opportunity to work with the Institute to publicly explore these issues further. I urge each of you to read the document. We believe it is a blueprint for The Decade of Transplantation.

The ASTP is enthusiastic about the potential for a variety of important studies on organ transplantation in the United States today. We strongly endorse an IOM study that would evaluate the field, identify problems and trends and suggest solutions. It has been more than ten years since the Congressionally mandated (Public Law 98–507) Department of Health and Human Services report of the Task Force on Organ Donation issued its report and more than seven years since the landmark Institute of Medicine report, Kidney Failure and the Federal Government. There is much to do to ensure that every person on the waiting list has the opportunity to obtain the benefits of organ transplantation. We believe that we are at a crossroads, and that the time is right to unite our community to enhance transplantation as we approach the beginning of the new millennium. The ASTP stands ready to assist in every facet of the process.

Thank you.

PREPARED STATEMENT OF DR. DAVID L. HEYMANN, WORLD HEALTH ORGANIZATION

THE NEED FOR GLOBAL SURVEILLANCE AND MONITORING FOR INFECTIOUS DISEASES

The challenge

Infectious diseases remain a global problem in the late twentieth century. Global surveillance is an urgent necessity to protect the health of people throughout the world. There is reason to believe that the emergence of previously unknown diseases and the re-emergence of old ones is increasing. One-third of the 52 million deaths in the world in 1995 were due to infectious diseases, and this ratio remained the same in 1996 and 1997. Infectious diseases spread when adequate financial and human resources are not devoted to infectious disease control and when microbes in animals find suitable conditions to jump the species barrier and infect humans. Factors responsible for the increase in infectious diseases include social changes such as mass population movements, rural-to-urban migrations and accelerated urbanization, population growth, rapid transport, global trade, new food technologies, and new life styles as well as environmental changes such as altered land use patterns and irrigation that increase the risk of human exposure to animal reservoirs and vector-borne infections. A new outbreak may first appear in a circumscribed area, but with expanding global travel and trade, the disease can span entire continents within days or weeks as influenza periodically demonstrates. The diseases that have crossed, or threaten to cross, international borders menace international public health security. Today these infectious disease outbreaks and epidemics are

not only costly to the economies of the countries in which they occur, but are also a concern for all countries because no country is safe from infectious disease.

For example, during 1997:

—Major cholera epidemics spread throughout eastern Africa, affecting hundreds of thousands of people in more than ten countries over several months; trade sanctions were unnecessarily placed on fish exports from these countries resulting in severe economic impact on their fragile economies;

—Yellow fever fatalities were reported in seven countries in Africa and South America;

—Meningitis caused major epidemics in Africa, with over 70,000 deaths reported in the 1996–1997 season;

—More than 15,000 cases of typhoid fever with resistance to first line antibiotics occurred in Tadjikistan;

—Epidemic typhus resurged in Burundi with over 30,000 cases and untold deaths;

—An avian influenza virus emerged in humans in Hong Kong, killing six out of eighteen people, and was carefully monitored for its potential to be the next pandemic influenza threat;

—Rift Valley Fever afflicted thousands of people, killing hundreds and many of their livestock in Kenya and Somalia;

—The prevalence of hepatitis C continues to increase in countries where blood is not screened prior to use and where sterilization of medical equipment is faulty;

—Lassa fever, with high mortality, re-emerged in Sierra Leone;

—An outbreak of dengue fever occurred in Cuba for the first time since the 1981 epidemic;

—The investigation of an unexpectedly large human monkeypox outbreak in Africa raised new issues about this important disease and the safety of smallpox vaccination in the era of AIDS;

—The number of cases of new variant Creutzfeldt-Jakob Disease reached twenty-four in the United Kingdom and France combined with the continuing threat of bovine spongiform Encephalopathy (BSE or mad cow disease), and the United Kingdom's economic loss from BSE was estimated to have reached 5.7 billion U.S. dollars;

—Eschericia coli 0157 continued to surface in industrialized countries including Japan and the United States;

Vancomycin-resistant Staphylococcus aureus was identified in Japan for the first time, and later in the United States.

The solution

The concern of industrialized countries such as the United States, where prevention and control efforts have dramatically decreased infectious disease mortality, is international public health security: ensuring that infectious diseases which are occurring elsewhere do not spread internationally across their borders.

The concern of developing countries is to detect and stop infectious diseases early, thus avoiding high mortality and negative impacts on tourism and trade. Yet, developing countries are constrained by the lack of appropriate technologies and the difficulty of financing the necessary interventions on a sustainable basis.

The solution, which addresses the interests of both the industrialized and developing countries, is to combine their efforts to strengthen detection and control of infectious disease. The major requirements for the prevention and control of infectious diseases globally and nationally are:

—1. Strong global and national epidemiological surveillance and public health laboratories to detect infectious diseases, to provide data for analyzing and prioritizing health services, and to monitor and evaluate the impact of control efforts plus global monitoring and alert systems to bring together laboratories and disease surveillance systems from all countries to share information internationally through electronic and printed media.

—2. Sustainable and well-managed infectious disease control programs which effectively diagnose infectious diseases and administer vaccines, curative drugs, and other interventions where and when they are needed.

—3. Continuing research and development of simple-to-use and robust vaccines, antimicrobial drugs, and laboratory tests for effective surveillance, prevention, and control of infectious diseases.

WHO's global strategy and collaboration with CDC

To combat the spread of infectious disease a global framework is needed to build up the necessary networks for surveillance and control of infectious diseases. The World Health Organization works to build such a global framework and effective

networks through its Division of Emerging and other Communicable Disease Surveillance and Control (EMC).

WHO has responded to the threats of infectious disease by developing a four-part strategy for international surveillance.

First, WHO has instituted a global monitoring and alert system for communicable diseases that brings together laboratories and disease surveillance systems from all countries to share information internationally through electronic and printed media. Revision of the International Health Regulations (IHR) is underway and will be proposed for adoption by the World health Assembly in 1999. The new International Health Regulations will require Member States to report a spectrum of communicable disease syndromes of international public health importance in addition to the three specific diseases covered at present. These proposed new regulations are now being field-tested.

Second, WHO rapidly and widely disseminates global information collected from national Ministries of Health, WHO Collaborating Centers, and governments via electronic means and the WHO World Wide Web site. EMC also has an electronic alert system designed to help facilitate expert verification of unconfirmed outbreak information on a confidential basis.

Third, WHO helps in establishing national and regional preparedness for communicable disease prevention and control. EMC provides manuals, standards, and guidance to national centers. The weak link in current global monitoring capacity is the collection of clinical/epidemiological data. At present, few countries have an adequate national infectious disease monitoring system, and most are extremely weak. Some of the most important geographical regions in terms of disease emergence, are the weakest, and this situation needs to change.

Finally, WHO encourages international preparedness for communicable disease prevention and control, which supports and augments national and regional preparedness while national systems improve their capabilities.

The key to global surveillance and control of infectious diseases has been a collaborative effort between WHO and its partners, including national-level agencies like the Centers for Disease Control and Prevention (CDC), which play a critical role in continuing domestic surveillance and control which minimizes the risk of international transmission of infectious diseases.

WHO's goal is to strengthen national preparedness in all countries, which will require a substantial long-term commitment of human and material resources by many partners to strengthen the infrastructure and processes for disease control and surveillance in poorer countries. WHO's role has been to reinforce global laboratory-based surveillance by providing training and support to existing WHO Collaborating Centers and laboratories. WHO gives seed funding for development and distribution of diagnostic reagents and designates new centers and laboratories to fill geographic gaps. CDC already provides valuable assistance in quality assurance to WHO supported laboratories monitoring bacterial, viral, parasitic and zoonotic diseases throughout the world. CDC also provides expert training in epidemiology and other areas of public health, working with WHO and other international partners.

WHO has improved global epidemiological surveillance and facilitated rapid reporting of and response to infectious disease of international public health importance. Surveillance has specifically focused on developing a system to detect and investigate unusual infectious disease outbreaks, whether naturally occurring or intentionally caused. WHO has been working with the monitoring group of the Biological Weapons Convention (BWC) to make sure that all diseases of concern to BWC are included in these surveillance guidelines. WHO Member States and WHO's network of regional offices, country representatives, and technical partners such as CDC are now being linked electronically for verification and response. The response mechanism permits rapid and coordinated international investigation and containment of infectious disease outbreaks of international importance. WHO-coordinated international response broadens international cooperation so that no country is required to shoulder the entire burden of responding to an infectious disease outbreak of international importance. Without such a coordinated international response, many disease outbreaks could have resulted in extensive international spread.

EMC is strengthening global surveillance through adding new collaborating partners to the network of WHO Collaborating Centers in infectious disease and/or the anti-microbial resistance (ARM) monitoring network. WHO is working to incorporate military laboratories which often have good capabilities even in poorer countries, together with WHO Collaborating Centers into the global monitoring system for diseases and antimicrobial resistance.

Increased support to CDC for international collaboration with WHO would permit more rapid strengthening of surveillance and control capabilities worldwide, espe-

cially in poor countries. By permitting rapid detection and containment of infectious diseases when and wherever they occur, the risk of their entering the United States of America is minimized. Together, WHO and CDC will be working to advance all of the elements of current efforts to strengthen the global monitoring system to ensure international public health security.

PREPARED STATEMENT DAVID B. MOORE, COORDINATOR, HEALTH PROFESSIONS AND NURSING EDUCATION COALITION

The Health Professions and Nursing Education Coalition (HPNEC) is pleased to submit its recommendations for fiscal year 1999 funding for the health professions and nursing education programs authorized under Titles VII and VIII of the Public Health Service Act. HPNEC is an informal alliance of over 40 organizations comprising a variety of schools, programs, and individuals dedicated to educating professional health personnel. All members of HPNEC are united in our belief that these programs are essential to the development and training of health professionals and that these programs are critical to our nation's efforts to provide professional health services to underserved and minority communities.

The members of HPNEC are encouraged by the Administration's recognition of the importance of these programs as reflected in the President's fiscal year 1999 budget. The budget illustrates the Administration's understanding that the federal government must take a leadership role in ensuring the supply, distribution, diversity, and quality of this nation's health care workforce. The Administration's budget proposal emphasizes the importance of having health care professionals in areas where they are most needed, and highlights strategies to achieve this goal: increasing the number of health providers from minority backgrounds; fostering community- based education; and enhancing service to underserved communities.

HPNEC recommends that Titles VII and VIII receive an appropriation of $306 million for fiscal year 1999. This recommendation is a 5 percent inflationary increase over the amount Congress appropriated for these programs in fiscal year 1998. This appropriation is necessary to maintain current efforts to address our nation's rapidly changing health care system.

These programs are designed to meet the nation's needs for an expanded supply of primary health care providers and public health professionals. The original purpose of Titles VII and VIII were to train more health professionals in fields experiencing shortages, improving the geographic distribution of health professionals, and increasing access to health care in underserved areas. However, the need for these programs will become increasingly critical to ensure that the medical innovations and new technologies that will result from increased support for research will be properly applied to individuals in or most needy communities. With your support, these programs will continue to achieve these missions by providing support for the health professions in the form of loans, loan guarantees, scholarships to students, and grants and contracts to institutions. In this rapidly changing health care environment, it is crucial Title VII and Title VIII programs receive an appropriation of $306 million for fiscal year 1999 in order to meet the mission set out in their original authorization.

The following pages describe each of the health professions and nursing education programs authorized under Titles VII and VIII. Examples of the positive impact of these programs are provided in italics.

TITLE VII

Title VII programs provide opportunities for health professions students to train and provide primary and preventive care to people of medically underserved communities

LOANS FOR DISADVANTAGED STUDENTS [SECTION 721]

Loans for Disadvantaged Students go to eligible health professions schools allowing them to provide loans to disadvantaged individuals. Schools receiving funds must carry out programs for recruiting and retaining students from disadvantaged backgrounds and recruiting minority faculty. The fiscal year 1997 appropriation was $6.717 million; the fiscal year 1998 appropriation is $6.741 million. The Health Professions Student Loan Program has helped approximately 700 students at Ohio State University over the past three years. These loans have kept students from having to borrow alternative loans or having to increase the use of unsubsidized loans to meet their Cost of Attendance. This has enabled students to not only reduce their debt, but have loans with better terms when repayment occurs. Rita Spring,

Financial Aid Officer for the College of Veterinary Medicine, recently spoke with John Groah, a 1996 graduate from the College of Veterinary Medicine. He received not only Health Professions Student Loans, but Loans for Disadvantaged Students while at Ohio State. John was from McConnelsville, Ohio, a rural part of southern Ohio and considered part of the Appalachian Mountain region. John has returned home to McConnelsville and is engaged in a practice with one other Veterinarian. John feels that he would not have been able to graduate from Veterinary School without the help of these two programs. He is doing well and is contributing to his community.

SCHOLARSHIPS FOR STUDENTS OF EXCEPTIONAL FINANCIAL NEED [SECTION 736]

Exceptional Financial Need (EFN) scholarships are awarded by allopathic medical, osteopathic medical, and dental schools to students who can demonstrate extreme financial hardship. Each scholarship consists of payments equivalent to the student's tuition and other educational expenses, such as books and laboratory fees. Students who accept EFN scholarships must agree to enter and complete a primary-care residency and serve in a primary-care career for five years after finishing the residency. The fiscal year 1997 appropriation of $11.33 million resulted in nearly 650 scholarships for needy students; the fiscal year 1998 appropriation is $11.371 million.

Dr. Gary Schluckebier, and Exceptional Financial Need Scholarship recipient, graduated from the Indiana University School of Dentistry in 1995. Upon graduation Dr. Schluckebier served one year in an inner-city clinic in Chicago, Illinois providing oral health services to HIV/AIDS patients. Dr. Schluckebier now has a general dentistry practice in the small economically depressed town Michigan town of Niles. Scholarships for Disadvantaged Students [Section 737]

While African Americans represent 12 percent of the population of the United States, only 2 to 3 percent of our nation's physicians, dentists, pharmacists, psychologists, and veterinarians are African American. Historical data documents that African Americans and other minority health care professionals are more likely to serve in underserved communities in primary-care settings. This program provides funds to health professions and nursing schools for scholarships for disadvantaged persons from all ethnic backgrounds to help defray the cost of education at the baccalaureate and graduate levels, thereby encouraging the recruitment and retention of these individuals. More than 4,980 health professions students received scholarships through the fiscal year 1997 appropriation of $18.676 million; the fiscal year 1998 appropriation is $18.737 million—30 percent of this appropriation is reserved for nursing students.

FACULTY LOAN REPAYMENT AND FELLOWSHIPS [SECTION 738]

This program repays loans for and provides added training to minority individuals from disadvantaged backgrounds who serve on the faculty of health professions schools. The fiscal year 1997 appropriation of $1.061 million benefited 23 faculty members; the fiscal year 1998 appropriation is $1.065 million

CENTERS OF EXCELLENCE [SECTION 739]

Section 739 recognizes the need to increase the number of minorities in the health professions and to improve the health status of minorities. The Centers of Excellence program seeks to strengthen our national capacity to educate minority students by offering special support to institutions that train many of America's minority health professionals and serve as the primary source of health care to minority populations. Funding for Centers of Excellence supports programs to improve student recruitment, retention, training, and research at predominantly minority institutions. The education of nearly 3,520 students at 22 institutions was enhanced by the fiscal year 1997 appropriation of $24.718 million; the fiscal year 1998 appropriation is $24.798 million.

The Tuskegee University School of Veterinary Medicine has utilized Centers of Excellence funding to gradually increase faculty salaries to 85 percent of the national average, making Tuskegee more competitive in recruiting faculty. Tuskegee has also increased its number of library personnel and updated its audiovisual tutorial holdings. Centers of Excellence funding has contributed to Tuskegee becoming a national leader in recruiting and training students specializing in the human health aspects of veterinary medicine. These specially trained veterinarians combat diseases such as E. coli that threaten public health.

DISADVANTAGED ASSISTANCE [SECTION 740]

Grants made to health professions schools under the Health Careers Opportunity Program (HCOP) are used to identify and recruit disadvantaged students, facilitate their entry into school, and help them complete their education successfully. HCOP funds are also used to provide any necessary preliminary education and to pay for scholarships (known as Financial Aid for Disadvantaged Health Professions Students scholarships) and stipends to defray the costs of attendance. HCOP grants supported by the fiscal year 1997 appropriation of $26.785 million assisted 134 projects that served 6,122 students; the fiscal year 1998 appropriation is $26.779 million.

Despite the fact that the provision of health care in this country is undergoing rapid changes, there has been insufficient funding of training programs for health care professionals, such as psychologists who are equipped to deal with behaviorally based social problems (e.g., violence, teen pregnancy, and the spread of AIDS and other sexually transmitted infections). The Wright State University School of Professional Psychology's Minority Access to Professional Psychology (MAPP) is designed to assist individuals from cultural, racial, and other diverse and/or disadvantaged backgrounds to enter and graduate from doctoral training programs in psychology. The three program components are:

—Preliminary education, which targets undergraduate minority and disadvantaged students (at the sophomore levels and above) from area universities and provides them with academic skill-building and enrichment experiences;

—Facilitating entry, which is designed to reduce barriers to minority and disadvantaged students' applying and being accepted for clinical psychology graduate study; and RETENTION, which includes the provision of preventive and remedial academic skill development as well as nonacademic personal and professional development support.

AREA HEALTH EDUCATION CENTERS [SECTION 746]

Section 746 provides grants for the creation and operation of area health education centers (AHECs). The AHEC program provides clinical training opportunities to health professions and nursing students and residents in rural settings by extending the resources of academic health centers to communities in need of health care and education. Through this linkage, AHEC projects, which eventually become self- or state-supported, form networks of health-related institutions to provide educational services to students, faculty, and practitioners, and ultimately to improve health-care delivery. The fiscal year 1997 appropriation of $28.490 million supported grants to 36 AHEC projects that train 21,075 students and residents across the country; the fiscal year 1998 appropriation is $28.587 million.

The University of Florida College of Medicine through coordination with the University of Florida Health Science Center AHEC program has developed a mandatory three-week community primary care rotation for 85 first-year medical students. The program has presence in all 37 north Florida counties in the North Florida AHEC cachment area. This program was made possible by the AHEC system and its federal funding. The program has been in place for 6 years and while it is too early to determine placements in these primarily underserved areas, several other outcomes have developed. The value and positive role these students have played in the various sites across North Florida have resulted in additional rotations for 3rd and 4th year students at the same sites. In addition, rotations for other health professions have developed in these areas. Also, along with the first-year student rotations, the AHEC program was central in establishing rotation sites for primary care residents and nurse practitioners. These latter trainees have added service capacity to the communities they train in since they are licensed practitioners. It is safe to say these programs would not have emerged as rapidly or as successfully without the AHEC component

HEALTH EDUCATION AND TRAINING CENTERS [SECTION 746(F)]

The Health Education and Training Center (HETC) program was created to improve the supply and distribution of health professionals along the border between the United States and Mexico, as well as in other underserved areas to population groups that have demonstrated serious unmet health care needs. HETC projects employ educational incentives to attract and retain health care personnel and incorporate a strong emphasis on wellness through public health education activities. Each project also supports at least one training and education program for physicians and one for nurses to provide a portion of the clinical training for students

in the service area. The fiscal year 1997 appropriation of $3.752 million assisted ten projects; the fiscal year 1998 appropriation is $3.765 million.

Nova Southeastern University College of Osteopathic Medicine (NSU-COM) serves as the lead institution of the Florida Border Health Education and Training Centers Program, a partnership of the four medical schools in Florida, which focuses on the State's diverse and complex immigrant, migrant, and minority patient populations. This program now provides a unique national model of collaboration between osteopathic, allopathic, private and public schools of medicine. Among the many special training initiatives have been a "Culturally Competent Health Care" Teleconference reaching nearly 600 participants in over 35 sites across Florida. These site encompass providers from health departments, community and migrant health centers, and hospitals in rural and remote communities where a large number of immigrants from Florida's multiethnic and multilingual cultures are served. Because of its success, this Teleconference also resulted in the production of a videotape which is now being used in follow-up workshops and seminars.

FAMILY MEDICINE TRAINING [SECTION 747]

Section 747 family medicine training funds are used to help develop and maintain an infrastructure for the production of family physicians. Funding is used for the establishment of departments of family medicine within medical schools, the development of third-year clerkships in family medicine for medical students, the training of family practice residents, and development of teaching and education skills for family medicine faculty. The General Accounting Office and others have acknowledged the importance of this Title VII funding in the creation and maintenance of family medicine departments and divisions in medical schools.

The fiscal year 1997 appropriation of $49.3 million funded 322 projects, including grants to school to support predoctoral training; to hospitals to support graduate training for 950 students in family medicine; to various institutions engaged in facility development activities; and for the establishment and maintenance of family medicine departments. The fiscal year 1998 appropriation is $49.42 million.

Medical College of Georgia. A number of years ago the department was awarded an innovative residency curricula grant to develop academic community partnerships with a network of rural health clinics in a four county area—an area that was a Health Professional Shortage Area, unable to keep private physicians, and economically depressed. The success of that grant is in the development of self-sustaining rural health clinics as teaching sites with residents and students providing care under the auspices of a teaching physician. Physicians graduating from this program have subsequently been hired to direct these sites and have stayed for the long term providing continuity of care, and living in the communities that they serve.

GENERAL INTERNAL MEDICINE AND GENERAL PEDIATRICS TRAINING [SECTION 748]

General internists and pediatricians are two additional and important generalist specialties. Section 748 provides funds directly to general internal medicine and general pediatrics training programs, which together train the most medical students. In an effort to produce more generalists, these training programs expose students to generalist role models in community and ambulatory settings, where most generalists are likely to practice, and encourage general faculty development programs that produce future generalist teachers and role models.

Pediatrics has historically been a generalist dominated field of medicine with over 70 percent of practicing pediatricians engaged in primary care practice. Faced with increases in the incidence of AIDS, substance abuse, adolescent pregnancy and other health concerns, future pediatricians will be expected to manage both acute and chronic health programs, care for children and adolescents with disabling conditions, and provide counseling for problems that are psychosocial or behavioral in nature. Section 748 grants in pediatrics have supported training in a variety of diverse ambulatory and community-based sites including nontraditional settings such as, juvenile detention centers, homeless shelters, child nutrition programs, child care centers and community health centers. The fiscal year 1997 appropriation of $17.68 million supported nearly 1506 residency positions in general internal medicine and general pediatrics and nearly 1,000 faculty positions in these two areas of medicine. The fiscal year 1998 appropriation is $17.678 million.

With Title VII funds, the Department of Pediatrics at Harbor/UCLA Medical Center (a county-funded institution serving mainly underserved indigent Hispanic patients) expanded services, developed new programs, and trained physicians who have remained general pediatricians in inner city underserved communities of California. Approximately 100 such pediatricians have been trained, and these general-

ists provide comprehensive and preventive care to a large number of vulnerable and economically disadvantaged children.

GENERAL DENTISTRY RESIDENCIES [SECTION 749]

General Dentistry Residency Training provides dentists with the skills and clinical experiences needed to deliver oral health care to the full community of patients. General Dentistry programs include off-site rotations in community-based settings such as community health centers, nursing homes, geriatric day care facilities, state institutions, and children's hospitals. Because the General Dentistry program emphasizes primary care, dentists are trained to deliver a broader range of services to their patients and as a result, consistently refer fewer patients to specialists. This is especially important to the underserved populations that often face financial and logistical barriers making specialized care unobtainable. Eighty-seven percent of the dentists that receive General Dentistry Training remain in primary care. Programs have consistently met the statutory preference of demonstrating that graduates establish their permanent practice or spend a significant portion of time working in underserved communities. However, there are not enough of these residency slots for dental school graduates seeking this training. The General Dentistry Residency Training program does not increase the supply of dentists, but provides enhanced training for primary care dentists. The need to increase these training opportunities was supported by the 1995 Institute of Medicine Report on Dental Education. The fiscal year 1997 appropriation of $3.785 million supported 41 General Dentistry Residency Training programs.

The fiscal year 1998 appropriation level is $3.798 million.

The General Dentistry Residency program at Meharry Medical College School of Dentistry in Nashville, Tennessee, is currently in the second year of a three-year federal General Dentistry Residency grant. A significant feature of the Meharry program is the involvement of the General Dentistry residents as a part of an interdisciplinary health care team delivering medical and dental care to rural populations in west Tennessee. Over 40 percent of the General Dentistry program graduates continue to practice in medically underserved communities throughout Tennessee and the United States.

PHYSICIAN ASSISTANTS [SECTION 750]

Section 750 authorizes grants for schools of medicine and osteopathic medicine, as well as colleges and universities, to meet the costs of projects to develop and operate or maintain accredited programs for the training of physician assistants and faculty. Programs under this section are oriented toward primary care and stress educational experiences in both rural and urban areas that are medically underserved or facing shortages of qualified health professionals. The fiscal year 1997 appropriation of $6.376 million provided 38 awards for the training of 3,250 physician assistants nationwide; the fiscal year 1998 appropriation is $6.398 million.

The establishment of the Physician Assistant Program has enabled Western University to develop and implement a 20-week cross-cultural medicine curriculum designed to provide physician assistant students with the skills needed to practice in culturally diverse communities. In addition, the program has been designed to provide clinical practicum in primary care and increase the clinical rotation time in primary care from 12 to 16 weeks. As a result of Title VII funds, Western University PA students consistently score the highest on State Board exams.

PODIATRIC PRIMARY CARE RESIDENCIES [SECTION 751]

Grants are awarded under Section 751 for assistance with the costs of training podiatric physicians to provide primary health care services. Funds awarded through this section help podiatric residency training programs implement new primary-care projects and provide financial assistance to residency trainees enrolled in these programs. Thirty-nine podiatric physicians in five projects were supported by the fiscal year 1997 appropriation of $677,000; the fiscal year 1998 appropriation is $679,000.

PUBLIC HEALTH TRAINEESHIPS, SPECIAL PROJECTS, AND PREVENTIVE MEDICINE [SECTIONS 761–3]

Public health professionals will play a unique role in the evolving managed care environment, and health agencies and organizations at national, state, and local levels will rely even more heavily on University graduate schools of public health and other public health and preventive medicine projects to provide leadership in the form of comprehensively trained public health professionals.

Section 761 provides Traineeships for individuals pursuing courses of study in fields experiencing severe shortages of public health professionals, such as dental public health, epidemiology, environmental health, biostatistics, managed-care administration, and risk analysis. Section 762 authorizes the extension of grants to schools of public health for projects in the areas of preventive medicine, health promotion and disease prevention, and improving access to and quality of health services in medically underserved communities. Section 763 provides funds to schools of medicine, osteopathic medicine, public health, and dentistry for the development and maintenance of preventive medicine and dental public health programs, and extends financial assistance to residents enrolled in such programs.

Preventive medicine physicians and dentists are uniquely trained in both clinical medicine or dentistry and public health, and seek to find the most cost-effective ways to reduce the risk of diseases, disabilities, and death in individuals and population groups. Support through Title VII is necessary to alleviate the serious shortage of public health professionals such as dental public health specialists; in 1994, for example, there were only 116 such board-certified specialists and only 12 graduates from the 19 accredited programs.

The fiscal year 1997 appropriation of $7.998 million supported 69 projects and awards, approximately 123 preventive medicine and dental residents, and more than 987 public health trainees. The fiscal year 1998 appropriation is $8.025 million.

Section 762 (Special projects) funded a project with the Tulane University School of Public Health and Tropical Medicine to develop a community health strategic plan. A task force of more than 60 members of the university, community, non-profits and public agencies came together to create a community health strategic plan to establish partnerships which truly address community needs. Outcomes of this program include the establishment of a school-based adolescent mental health clinic, expansion of primary care facilities to low- income neighborhoods, school health clinics to promote healthy lifestyles for children, and a five-year study in 24 elementary schools to assess school-based interventions in promoting healthful behaviors. As an outgrowth of this program, the school formed a faculty advisory committee, and began an academic program in community health. The School of Public Health has also instituted a program in social mobilization to teach community leaders how to empower their communities for action.

ALLIED HEALTH PROFESSIONS ADVANCED TRAINING AND SPECIAL PROJECTS [SECTION 766–7]

Section 766 authorizes the awarding of grants to schools, universities, and other educational entities for establishing and expanding post baccalaureate programs for the advanced training of allied health professionals, as well as for providing traineeships and fellowships for students who agree to teach in an allied health profession. Section 767 provides funding for developing or expanding programs that will increase the number of individuals trained in allied health professions. The fiscal year 1997 appropriation of $3.832 million supported 34 special projects in allied health; the fiscal year 1998 appropriation is $3.845 million.

Several grant recipients have developed model programs to identify and recruit non- traditional students, including minorities and recent college graduates in science, into allied health professions. The University of Maryland School of Medicine developed a national model to assist in recruiting and retaining minority and disadvantaged students. The retention rate of individuals participating in the program is 92 percent to 100 percent.

HEALTH ADMINISTRATION TRAINEESHIPS AND SPECIAL PROJECTS [SECTION 771]

Health administration training programs exist in a wide variety of settings, including medical schools, schools of allied health, schools of public health, and even in schools of business. They play an integral role in training the present and future management of our evolving health care system.

Section 771 authorizes a program of traineeships, as well as special projects in which grant applications are peer-reviewed. Special emphasis is placed on programs that focus more heavily on underserved communities. Preference is given to students who are committed to careers in underserved areas with public or nonprofit private entities requiring the specific training provided in health administration programs. The fiscal year 1997 appropriation of $1.095 million supported 38 awards and 365 health administration trainees. The fiscal year 1998 appropriation is $1.099 million.

GERIATRIC EDUCATION CENTERS AND FELLOWSHIPS AND GERIATRIC OPTOMETRY TRAINING [SECTIONS 777 (A, B, AND (C)]

Funding for geriatric training has not kept pace with the rising demand for specialized services necessary for a rapidly aging population. Evaluations of the adequacy and availability of health- care personnel to meet the needs of elderly Americans through the year 2020 have revealed a shortage of adequately-trained faculty to educate future health-care providers in geriatrics. Specifically, increased funding is needed to support multi-disciplinary geriatric education centers (GECs) and geriatric training programs (GTPs). Both types of programs are effective in providing opportunities for health-care personnel to develop skills for providing better, more cost-effective health care for older Americans.

GECs include short-term faculty training, curriculum and other educational resource development, and technical assistance and outreach, and are affiliated with educational institutions, hospitals, nursing homes, community-based centers for the aged, and veterans' hospitals. GTPs provide fellowships for medical and dental faculty and provide for curriculum development, the hiring of faculty and the first three months of fellowship training.

Section 777(c), Geriatric Optometry Training, authorizes grants to schools and colleges of optometry to support projects in postgraduate geriatric care training for optometrists who will teach geriatric optometry; to provide residencies, traineeships, and fellowships to participants; and to establish new affiliations with nursing homes, ambulatory-care and senior centers, and other public or nonprofit private entities.

The fiscal year 1997 appropriation of $8.88 million supported 31 GECs and 8 Faculty Fellowship Programs; the fiscal year 1998 appropriation is $8.911 million.

University of North Texas Health Science Center Texas College of Osteopathic Medicine (UNTHSC) has a two year faculty training program in medicine and dentistry that includes research, administration, clinical, and teaching experiences in aging. By July, 1997, the program will have graduated three dentists and 1 physician. The program requirements include providing services through community-based programs to minority elderly and indigent elderly populations. Over the past three years, a dentist, nurse manager, Director of nursing, physician, and administrative coordinator have enjoyed the benefits of a educational experience in geriatrics education. There are needs for continued support of GEC's to increase interdisciplinary training in Geriatrics to meet future population demands.

RURAL HEALTH INTERDISCIPLINARY TRAINING [SECTION 778]

Rural health interdisciplinary training projects are designed to assist individuals in academic institutions in establishing long-term collaborative relationships with health care facilities and providers in rural areas. Projects funded under this authority use new and innovative methods to train practitioners to provide services in rural areas, demonstrate models and methods designed to provide access to cost-effective comprehensive health care, and enhance the amount of relevant research conducted concerning health care issues in rural areas. Twenty grants and contracts were made with the fiscal year 1997 appropriation of $4.153 million.; the fiscal year 1998 appropriation is $4.167 million.

HEALTH PROFESSIONS RESEARCH [SECTION 781]

Section 781 provides funding to public and nonprofit private educational entities for conducting research on various health professions issues. The issues on which research has been authorized include the extent to which educational indebtedness influences the specialty choice of medical students; the effects of federally-funded educational programs for minority and disadvantaged individuals; the effectiveness of state licensing authorities in protecting the public health through investigations and disciplinary actions; and the extent and impact of federal policies and medical school curricula on the percentage of physicians and other health professionals graduating from health professions schools and selecting a primary care career. The fiscal year 1995 appropriation of $600,000 supported 11 contracts and awards; there was no appropriation for fiscal year 1996. The fiscal year 1997 appropriation was $450,000; the fiscal year 1998 appropriation is $452,000.

CHIROPRACTIC DEMONSTRATION PROJECTS [SECTION 782]

Section 782 provides funding to chiropractic schools for carrying out demonstration projects in which chiropractors and physicians collaborate to identify and provide effective treatment for spinal and lower-back conditions. Funding may only be extended to a project in which a school of medicine or osteopathic medicine will par-

ticipate jointly. The fiscal year 1997 appropriation was $1.025 million, which provided for three awards; the fiscal year 1998 appropriation is $1.029 million.

HEALTH PROFESSIONS DATA ANALYSIS [SECTION 792]

Section 792 authorizes the Secretary of Health and Human Services to establish a program to collect, compile, and analyze data on health professions personnel. The program includes a uniform health professions data reporting system. The Secretary also has the authority to conduct or enter into contracts with states and not-for-profit entities for the conduct of analytic and descriptive studies of the health professions, including evaluations and projects of the supply of and need for health professionals by specialty and geographic location. The fiscal year 1997 appropriation was $236,000, which supported 12 contracts and awards; the fiscal year 1998 appropriation is $237,000.

TITLE VIII (THE NURSE EDUCATION ACT)

The Nurse Education Act helps schools of nursing and nursing students at all levels prepare a workforce for a changing health care delivery system. The NEA encourages moving the educational level of the professional nurse to the baccalaureate level (60 percent of RNs have less than a BSN today) due to the complexities of caring for sicker, often older, and chronically ill patients. The NEA is a major thrust toward educating more advanced practice nurses such as nurse practitioners (NPs), certified nurse midwives (CNMs), clinical nurse specialists (CNSs) and Certified Registered Nurse Anesthetists (CRNAs). The NEA also funds studies on workforce needs to help plan for the future.

There is a preference in most Nurse Education Act programs for institutions that have been particularly effective in placing graduates in practice in medically underserved communities, such as rural areas and inner cities. The NEA appropriation for fiscal year 1998 was $65.6 million

SPECIAL PROJECTS [SECTION 820]

Section 820 provides funds to: increase nursing enrollments; initiate nurse managed centers to deliver primary care to medically underserved populations as part of a clinical training experience; support continuing education for nurses practicing in medically underserved communities; and to help paraprofessionals acquire professional nursing education. The fiscal year 1997 appropriation of $10.381 million funded 61 special projects; the fiscal year 1998 appropriation is $10.600 million and should fund about the same number.

An estimated 50 percent of the currently operating nurse managed centers were developed or expanded under this section. These clinics deliver essential primary health care services to a diverse population in elementary schools, senior citizens centers, housing complexes, homeless shelters and via mobile units such as the University of Maryland School of Nursing's Wellmobile. Section 820 also supports projects to increase the use of technology in nursing practice.

ADVANCED NURSE EDUCATION [SECTION 821]

Section 821 represents program support for schools offering master's and doctoral programs for graduate students on track to become clinical nurse specialists, public health nurses, nursing school faculty, and acute care nurse practitioners (education for primary care nurse practitioners in supported by Section 822). Nearly 1,300 graduate students benefited from 60 grants totaling $12.249 million in fiscal year 1997; the fiscal year 1998 appropriation is $12.410 million and will fund about the same number of awards.

A University of Pittsburgh School of Nursing project funded through this section combines education regarding the acute care skills of a clinical nurse specialist and primary care skills of an NP and recruits applicants from rural and underserved areas (26 out of 88 enrolled are from such places). This section supports 10 programs in psychiatric-mental health nursing. The section supports 70 percent of doctoral programs preparing nursing faculty. (Funding for doctoral programs is limited to 10 percent of appropriations for this section.)

NURSE PRACTITIONER/CERTIFIED NURSE-MIDWIFE [SECTION 822]

Section 822 supports grants to schools for starting, maintaining, or expanding advanced practice programs educating primary care nurse practitioners and certified nurse-midwives. The section gives special consideration to programs that train NPs and CNMs for practice in Health Professional Shortage Areas. The fiscal year 1997 appropriation of $17.278 million supported 69 awards benefiting 1540 NPs and

CNMs; the fiscal year 1998 appropriation of $17.64 million will result in about the same number of awards.

This section funded 60 percent of nurse practitioner programs preparing for practice in primary care. Medicaid patients represent a quarter of the patient population for forty four percent of certified nurse practitioners. A majority of nurse-midwives have been educated in programs supported by this section, and 89 percent of nurse-midwives serve low-income women.

OPPORTUNITIES FOR NURSING STUDENTS FROM DISADVANTAGED BACKGROUNDS [SECTION 827]

Section 827 funds nursing school activities to recruit, counsel, remediate, and assist faculty in helping, disadvantaged students in completing nursing education programs. A small stipend is part of 50 percent of awards. The fiscal year 1997 appropriation of $3.799 million aided 1,000 nursing students in 22 programs; the fiscal year 1998 appropriation of $3.878 million will fund about the same.

Schools receiving support from this section average 35 percent minority students, compared to schools not in the program at 19 percent. Over the past 5 years, this section has helped increase overall minority nursing student enrollments by 25 percent. One program in rural North Carolina is part of an academic pipeline to facilitate disadvantaged students in attaining a BSN degree. Two Texas programs helped increase the clinical competence of disadvantaged students and boost their graduation rates. The NEA has supported 3 minority congresses to consider ways to increase the minority presence in nursing practice and teaching.

TRAINEESHIPS FOR THE ADVANCED EDUCATION OF PROFESSIONAL NURSES [SECTION 830]

Section 830 funds individual stipends for master's and doctoral students (funding for doctoral limited to 10 percent of total appropriations for the section) such as nurse practitioners, certified nurse midwives, nurse educators, public health nurses or in clinical nursing specialties, with a preference for those who are residents of Health Professional Shortage Areas. The graduate education of more than 5,580 nurses at 267 schools was supported by the fiscal year 1997 appropriation of $15.662 million; the fiscal year 1998 appropriation of $15.985 million will be distributed to students by 278 schools.

This section provided stipends to about 37 percent of full time graduate nursing students, including 20 percent of funded nurse practitioner programs and 42 percent of nurse- midwifery programs. In some cases, these stipends make it possible for a student to attend school full time, producing these much sought after professionals more quickly. (Over half of master's in nursing students are part time.)(Funding for doctoral students is limited to 10 percent of the appropriations for this section.)

NURSE ANESTHETISTS [SECTION 831]

Section 831 assists programs that teach registered nurses to become Certified Registered Nurse Anesthetists (CRNAs), with a concentration on meeting the needs of rural areas by requiring clinical experience there and by preferring residents of Health Professional Shortage Areas. The section provides grants for institutions to develop and operate programs, to improve faculty, and to offer traineeships to students. A fiscal year 1997 appropriation of $2.678 million benefited 1,107 nurse anesthesia students (over 75 percent of total students) and 66 programs; the fiscal year 1998 appropriation of $2.774 million will have about the same impact.

CRNAs administer 65 percent of anesthetics administered each year and are sole providers in 70 percent of rural hospitals. This section also helped programs obtain training sites for students who are required to have a minimum of 800 hours of clinical training.

LOAN REPAYMENT FOR SERVICE SHORTAGE AREAS [SECTION 846]

Section 846 repays up to 85 percent of nursing student loans in return for at least 2 years of practice in an area of nursing shortage, such as Indian health, public hospital, migrant, rural or community health center, or other public facility that has a critical shortage of nurses. In fiscal year 1997, 213 awards were made from an appropriation of $2.157 million. In fiscal year 1998, appropriations of $2.183 million will produce about 200 new awards.

Ninety percent of loan repayment participants are in pubic hospitals providing inpatient care. The three states with the highest number of loan repayment nurses are Louisiana, (74), Mississippi (18) and North Dakota (12). Other states with substantial numbers of nurses in loan repayment are Hawaii (7), Georgia (8), Alabama (6), Nebraska (12), South Carolina (8), and Texas (7).

In closing, Titles VII and VIII of the Public Health Service Act help the nation meet the need for an expanded supply of primary health care providers and public health professionals. For both institutions and students, the educational process is a carefully planned and carried out undertaking that depends upon stability of financial support. Federal funds are a vital part of this effort because they focus on innovative approaches to changes in the health care delivery system and help to prepare those who deliver basic care to underserved people. The solution is to fund Titles VII and VIII in accordance with the need. In this rapidly changing health care environment, it is crucial Title VII and Title VIII programs receive an appropriation of at least $306 million for fiscal year 1998 to meet their missions.

The members of HPNEC appreciate the opportunity to comment on these vital programs and look forward to working with the Subcommittee in support of them.

PREPARED STATEMENT OF NANCY MUNRO, RN, MN, CCRN, THE AMERICAN ASSOCIATION OF CRITICAL CARE NURSES [AACN]

Thank you Chairman Specter and Members of the Subcommittee for the opportunity to present written testimony. I am Nancy Munro, Clinical Nurse Specialist at Georgetown University Hospital. I am pleased to present testimony on behalf of the American Association of Critical Care Nurses (AACN) in support of funding for the National Institute of Nursing Research, the Agency for Health Care Policy and Research, and the Title VIII Health Professions Programs.

AACN is a not-for-profit service association dedicated to the welfare of people experiencing critical illness or injury. AACN was founded in 1969 and has grown to become the world's largest specialty nursing organization with nearly 73,000 members representing the United States and 35 countries. AACN has 270 chapters, located in every state and overseas.

Our goal should be to translate the promise of scientific discovery into an improved quality of life for all Americans. To accomplish this, we must continue to invest in medical research and the NIH. Towards this end, I encourage the Subcommittee to support the recommendation of the Ad Hoc Group for Medical Research Funding which calls for a 15 percent increase in the NIH budget for fiscal year 1999. This represents the first step towards doubling the NIH budget over the next five years. And within this increased appropriation, AACN will work to ensure that NINR receives its fair share of the increase.

AACN strongly supports NINR's goals of health care effectiveness, cost effectiveness, and assuring that the scientific agenda has a human aspect and translates research findings into applications that improve the nation's health.

As nurses who provide care to the critically ill, one of the most important things we can do for our patients is provide relief from their pain and suffering. Nursing affords a unique vantage point from which to examine the way pain affects patients and their caregivers. Pain is also a costly health problem, prompting nearly 40 million visits to health care providers each year and costing our nation over $100 billion annually in lost productivity and health care expenses.

Over the past year, NINR has reported two groundbreaking advances in pain research—one showing gender differences in response to analgesics and a second indicating that sedatives given before surgery can actually block the action of medication given to relieve pain after surgery.

AACN currently sponsors Thunder Project II, a large-sample, multi-site research project in partnership with seven other nursing organizations. The purpose of the research is to examine pain perceptions and responses of acutely or critically ill pediatric and adult patients to selected producers. Data collection is underway, and it is anticipated that it will be completed by early 1999. To date, over 200 sites are enrolled in the U.S., Canada, Australia, and the U.K.

AACN also supports NINR's leadership in improving end-of-life-care. NINR recently held a state-of-the-science conference on "Symptoms in Terminal Illness" to address end-of-life issues in four areas—pain, dyspnea, cognitive disturbances, and cachexia.

AACN firmly believes that research is needed to develop a scientific basis for critical care nursing practice and to achieve a broad understanding of the role and impact of critical care nurses on patient outcomes. Many research projects funded by AHCPR are gradually helping our communities refocus healthcare so that it is truly driven by the needs of patients and their families. AACN is pleased that the President's budget includes $171 million for AHCPR, a $25 million increase over fiscal year 1998.

As you know, in 1990, Congress passed the Patient Self Determination Act which AACN believes has made significant progress in educating Americans about their

right to make their own health care choices. This is of particular interest to AACN in light of the Robert Wood Johnson study that followed 9,000 critically ill patients and found discrepancies between patient's end-of-life care directions and their actual treatment.

AACN is currently working to educate consumers about the Patient Self Determination Act and its importance. The Committee's support for AHCPR has provided AACN with the resources to design a community outreach program to improve completion rates for advanced directives. AACN's program, in conjunction with UCSF, Research on Advance Care Planning Including Advanced Directives, has a specific emphasis on an education program stressing definition and documentation of care preferences so that in the event of catastrophic illness or injury, individual care preferences can be honored.

Additional funds have been received to complete the project as a result of AHCPR funding in fiscal year 1998.

AACN believes that education is fundamental to professional growth and to excellence in clinical practice and optimal patient outcomes. Practitioners must commit to life-long learning to assure they remain competent in fulfilling their obligations to the patients and families they serve.

According to the Bureau of Labor Statistics, the demand for health professionals is expected to grow by 47 percent by the year 2005, with the need for advanced practice registered nurses among the greatest. In addition, an Institute of Medicine study on the role of nursing staff in hospitals found that a more advanced, or more broadly trained registered nurse (RN) workforce would be needed in the future. Such training is currently provided under the programs funded under Title VIII of the Public Health Service.

AACN is pleased that Congress provided an increase for Health Professions training overall in fiscal year 1998, and encourages Congress to once again demonstrate its support for these important programs in fiscal year 1999.

In closing, Mr. Chairman and members of the Subcommittee, I would like to thank you again for your support for nursing research and the NIH.

Prepared Statement of Ellen Glesby Cohen, President and Founder, Lymphoma Research Foundation of America

Thank you Chairman Specter and esteemed members of the Subcommittee for the opportunity to present written testimony before the Subcommittee. My name is Ellen Glesby Cohen. Even in my wildest dreams, I never thought that I would be in this honored position of testifying before Congress on matters of life and death. That was before my own health turned into a matter of life and death and made me realize how many millions of Americans will be helped or even healed by the decisions you have the power to make.

I am here today as the Founder and President of the Lymphoma Research Foundation of America, the nation's largest lymphoma organization dedicated to providing comprehensive information and support to lymphoma patients, their family and friends. The Lymphoma Research Foundation of America also finances research into better and safer treatments for the third most rapidly-rising cancer in America. I would like to share with you the story of my own battle with Lymphoma as a way of illustrating for you just how crucial your work is. Although this disease claims the lives of more victims every day and understanding lymphoma could shed light on many other diseases, funding for lymphoma research amounts to just 2 percent of the National Cancer Institutes' budget.

I am going to speak from my heart today so that you know how much we are looking to this Subcommittee for the hope and strength we need to persevere in our battle against this killer called lymphoma.

In 1987, my dear husband, Mitch, and I were the proud parents of an 18-month-old daughter and we were waiting for our son to be born. We were also building an addition to our home. My husband's internal medicine practice was growing and I was a busy TV commercial producer.

Life was good except for the nagging tiredness I was constantly feeling. It also seemed that I got the flu or a cold every time I turned around. The lymph nodes in my neck kept swelling up and my feet were so swollen that I had to buy new shoes. I went to the doctor, but blood tests didn't reveal anything suspicious.

My son, Joshua, was born in October of 1988. When I didn't bounce back from the birth, and lumps kept growing on my neck, my husband sent me to an oncologist. She took one look at me and sent me straight to the hospital for a biopsy. A week later, we had an answer, but it wasn't the answer we wanted to hear.

I had Lymphoma. Cancer of the lymph system. And it isn't curable. At the time, I wasn't even 40 years old.

My doctors told me to go on with my life. Sure, I was sick, they said, but not sick enough to receive aggressive treatment at the time. But how do you act like nothing is happening to your family when cancer is lurking in your body?

Somehow, we made it through a year and a half. Eventually, I developed a 99-percent obstruction in my nasal pharynx and I could hardly breathe. I also had a large mass in my abdomen. It came time for me to experience chemotherapy and within days of that first treatment, I was back in the hospital with a collapsed immune system. I had just five white blood cells left in my body. I didn't even have the strength to hug my children. Eventually, the therapy did its job. But it wasn't medicine that gave me the will to fight. It was the statistics behind this devastating illness.

Lymphoid malignancies strike upwards of 85,000 Americans each year and there is a 50-percent mortality rate. It is one of the most rapidly rising cancers in our country today yet it seemed that no one knew much about it. Even the scientific community was not sure what caused it and there was no national organization funding research, educating the public or supporting patients.

I had to do something. So I picked up the telephone and began calling everyone I could think of. Each phone call led me to someone else—another doctor, another lymphoma patient. Those conversations convinced me that I could start a nonprofit organization that could make a difference, not just for myself but for the health of all Americans.

You see, this disease knows no boundaries. Anyone can get it. A former First Lady. A former senator. A professional hockey player. Two of my neighbors. Even voters who cast their ballots for the esteemed members of this subcommittee. You should be aware that many of the states you represent have some of the highest rates of lymphoma in the country. Approximately 600,000 Americans today are living lymphoid malignancies. Some days, it feels like I hear from all of them. I have to fight back the tears when I hear from a 23-year-old graduate student in Illinois who tells me she is relapsing after only a year of remission and she's running out of effective and safe treatment options.

I started the Lymphoma Research Foundation of America to raise money, but what's priceless is the hope we have raised. We started the first Lymphoma-specific support groups, Internet site, patient helpline and quarterly newsletter. To date, the Lymphoma Research Foundation of America has funded 43 Lymphoma research projects totaling more than $1.25 million at top cancer centers and universities across the country.

Lymphoma is a growing, serious public health problem for all Americans. Recent research shows that there are links between understanding the causes of lymphoma and understanding the causes of many other cancers, including leukemia, lung, colon, breast and prostate cancer. We are finding that there are several crucial scientific issues that require immediate attention, such as the link between viruses and bacteria with lymphoma, and the role of environmental toxins in triggering lymphomas.

The Lymphoma Research Foundation of America has achieved a lot, but this disease is a formidable opponent and strikes in the very prime of our lives. Of all cancers, lymphoma is the fourth-largest killer of men ages 25 to 60 and the fifth-largest killer of women in that same age group. Sixty percent of all childhood malignancies are lymphoma or related diseases.

Those statistics grow deadlier every day. I, myself, am now facing the grim prospect of another round of chemotherapy and I wonder how much more my body can endure. I keep reminding myself—and every Foundation member I speak with—that some of the new treatments that have come out of our research programs are promising. But it's so hard to keep hope alive without increased government support.

The good news is that scientists believe that lymphoma research will unlock the secrets to many other cancers. That is why, for Fiscal 1999, Mr. Chairman, we seek this Subcommittee's continued support in funding the research essential to finding a treatment and cure for lymphoma. In furtherance of this goal, we request that Congress: Increase Appropriations for the National Institutes of Health.

Lymphoma Research Foundation of America endorses the call of the Ad Hoc Group for Medical Research Funding for a doubling of the budget of the National Institutes of Health within the next five years.

However, we realize the difficulty—if not impossibility—of achieving this goal entirely with the current spending caps for discretionary spending. Accordingly, we believe that the Administration and Congress should identify additional resources to reach these goals, such as adjustments to spending caps, increasing tobacco revenues, and investing part of the potential budget surplus.

As a first step the Lymphoma Research Foundation of America joins the Ad Hoc Group, along with other research organizations, in supporting a 15 percent increase for the NIH in Fiscal 1999.

For the National Cancer Institute, which funds the bulk of lymphoma research at the NIH, Lymphoma Research Foundation of America supports the Institute's Fiscal 1999 Bypass Budget Request of $3.191 billion, which represents a $644 million increase over the Fiscal 1998 appropriated level. The 1999 Bypass Budget will enable the National Cancer Institute to sustain its current research investment, identify and invest in new research opportunities, and invest now in future research opportunities.

For all the reasons mentioned above, its link with other cancers, the potential role of environmental factors, and the alarming rise in its incidence, the Lymphoma Research Foundation of America requests that the Subcommittee include in its Fiscal 1999 Committee Report language calling for:

—Increased appropriations for lymphoma research.

—Use of all available mechanisms for expanding the scope of lymphoma research, including convening a scientific workshop to examine the current state of research on lymphoma and exploring opportunities for additional study, use of program announcements and Requests for Applications on lymphoma-specific research topics.

—Research into potential environmental and other factors responsible for lymphoma.

Thank you for the opportunity to tell you my story. Thank you for your hard work and for your consideration. And thank you for the hope that you have given me and to all lymphoma patients and their families.

PREPARED STATEMENT OF MICHAEL Q. FORD, EXECUTIVE DIRECTOR, THE NATIONAL NUTRITIONAL FOODS ASSOCIATION

Mr. Chairman and members of the subcommittee: My name is Michael Ford. I am Executive Director of the National Nutritional Foods Association (NNFA), a trade association representing some 2,500 health food stores and some 800 manufacturers, distributors and suppliers of natural health products, including organic and natural foods, natural ingredient cosmetics and dietary supplements.

Congressional mandate mirrors citizen demand

National interest in access to and reliable information on safe, effective vitamins, minerals, herbs, amino acids and other dietary supplements has grown steadily since the Dietary Supplement Health and Education Act (DSHEA) unanimously passed the House and Senate to become the law of the land in 1994.

Approximately 100,000,000 Americans are taking dietary supplements, spending, by some estimates, as much as $11.5 billion a year in health food stores alone. Americans are looking to safe, natural alternatives to prescription drugs to treat and prevent disease, and to maintain good health by supplementing inadequate diets with vitamins and minerals.

Nutrients can prevent chronic disease

We are entering a new era of recognition of the value of natural pathways to good health. For example, the Food and Nutrition Board of the National Academy of Sciences, which devises Recommended Daily Allowances for nutrients for the Food and Drug Administration, has issued the first of a series of reports presenting revised nutrient intake guidelines. Originally introduced in 1941, RDAs were intended to prevent classical nutrient deficiency diseases nearly extinct in the U.S. today, such as scurvy, beriberi and rickets. Now, these reports are revising and expanding RDAs to reflect compelling evidence which supports the use of nutrients to help prevent chronic disease, such as osteoporosis. We agree with the Chairman of the Food and Nutrition Board, who characterized this approach as "a major leap forward in nutrition science."

Similarly, the recent report of the President's Commission on Dietary Supplement Labels endorses continued research on the benefits of dietary supplements in health promotion and disease prevention. The Commission hails the increasing research-based documentation of the benefits of dietary supplements in maintaining health and preventing chronic disease and other health-related conditions, and calls for continuation of this welcome trend. NNFA entirely supports the Commission's recommendation that, "the public interest would be served by more research that assesses the relationships between dietary supplements and maintenance of health and/or prevention of disease."

Herbs and botanicals are beneficial, cost-effective

In addition to support for these kinds of exciting new findings on the health benefits of nutrients, NNFA urges the Committee to support research on medicinal herbs and botanicals, also classified as dietary supplements under the DSHEA. The results of a study on ginkgo biloba, published recently in the October 22, 1997, ''Journal of the American Medical Association,'' indicates that administration of this herbal extract, recognized for centuries in Chinese medicine for its ability to stimulate and improve blood circulation in the brain, could delay the onset of Alzheimer's Disease for up to 6 months. This could represent tremendous savings of lives and dollars from a disease which costs society $90 billion a year. Other studies show saw palmetto more effective than prescription medicine at reducing benign prostate enlargement, with far less expense and no reportable side effects.

Millions of Americans are turning daily to herbal remedies and seeking primary health care from the alternative, holistic providers who prescribe them. There is an urgent need for a dramatic increase in support for research on herbs and botanicals, justified by consumer demand and the Congressional intent expressed in DSHEA. The Dietary Supplement Commission report recommends that, ''Federal agencies continue to support research on the health benefits and safety of dietary supplements. Research should be expanded beyond the traditionally supported areas associated with vitamin and mineral supplements and include research on some of the more promising botanical products used as dietary supplements.'' NNFA wholeheartedly agrees.

Ours is one of the few cultures in the world for whom the prevention and treatment of disease with non-prescription herbal medicines is the exception rather than the rule. This is largely due to the fact that foreign research oftentimes is deemed unacceptable by the Food and Drug Administration for use in justifying health claims for herbs and botanicals. We urge the Committee to provide the adequate funding for research on the safety and benefits of medicinal herbs.

Full funding for the NIH Office of Dietary Supplements

The Office of Dietary Supplements (ODS) was established at the National Institutes of Health by DSHEA, to stimulate, coordinate and disseminate the results of research on the benefits and safety of dietary supplements in the treatment and prevention of chronic disease. Though authorized at $5 million per year by DSHEA to carry out its lofty mission, ODS has been woefully underfunded at less than $1 million per year and fewer than 2 full-time employees (FTEs). Despite these severe financial constraints, ODS has done an admirable job in attempting to meet its mandate. While this is commendable, the Congressional mandate for ODS is yet unmet. NNFA agrees with the President's Commission on Dietary Supplement Labels that the ODS must be fully-funded. Says the Commission report, if fully-funded, ''ODS could play a valuable role in providing consumers with information about dietary supplements including [the] promotion of scientific studies on potential roles of dietary supplements in health promotion and disease prevention. Appropriations as authorized by DSHEA are essential if ODS is to meet [the] mandates of the Act.'' ODS deserves this Committee's support and that of the NIH itself.

Office of Complimentary and Alternative Medicine

In 1992, Congress directed the National Institutes of Health to establish the Office of Alternative Medicine with the expressed task of assuring objective, rigorous review of alternative therapies to provide consumers reliable information. While funding for the Office has grown since its creation, the fiscal year 1998 funding of $20 million provided for this office, now known as the Office of Complimentary and Alternative Medicine (OCAM), is an infinitesimal percentage of the overall NIH budget. Furthermore, the OCAM budget is insignificant in comparison to the dramatic growth of the American public's interest in and use of alternative therapies.

Indeed, findings from the ''National Survey of Alternative Medicine Use,'' published in the January, 1993 New England Journal of Medicine, reveal that Americans made an estimated 425 million visits to alternative medical therapy providers in 1990, exceeding the 338 million visits made to all US primary care providers that year. The survey also showed that out-of-pocket expenditures associated with alternative therapies totaled $10.3 billion in 1990, approaching the $12.8 billion in out-of-pocket expenses incurred for all U.S. hospitalizations during the same period.

NNFA not only supports increased funding for OCAM, but feels it is critical that this office also be granted increased authority to initiate research projects and develop its own peer review panels. To this end, the NNFA strongly supports legislation to elevate the Office of Complimentary and Alternative Medicine to a Center at the National Institutes of Health, as proposed by Congressman Peter DeFazio's H.R. 1055, the National Center for Integral Medicine Establishment Act.

Demonstration projects at AHCPR and HFCA

The Agency for Health Care Policy and Research (AHCPR) is often directed by the Committee to pursue projects designed to research the cost-effectiveness attendant to novel approaches to the treatment and/or prevention of illness. The time is right for investigation of the worthiness of certain dietary supplements, based on well-designed, cost-effectiveness research.

Every year, treatment of chronic conditions and illnesses—from flus and colds to hypertension to dementia and Alzheimer's disease—generates enormous publicly and privately funded health care expenditures. There exists an opportunity to trim such burgeoning costs through prevention and/or treatment of these chronic ailments—or delay of their onset—with safe, effective, low cost dietary supplements. NNFA is confident that basic research at NIH can lead to appropriately structured, cost/outcome research at AHCPR which would demonstrate the value of dietary supplements in comparison to contemporary medical intervention. This evidence can, in turn, lead to HCFA projects to determine if a policy of reimbursement could be established.

Despite the growing popularity and demand for herbs and nutritional supplements, and their widespread use for prevention and intervention of chronic illness, precious few large-scale outcome studies on American populations are available to give health professionals the information they need to make decisions on alternatives to contemporary medical approaches. Echinacea and golden seal have been shown to be effective in preventing and treating colds and flus; ginkgo has been show to forestall dementia and the onset of Alzheimer's disease; herbal/nutritional combinations have been shown to provide control for hypertension without the side effects which cause many patients to stop using their prescription medicine; similarly, saw palmetto effectively shrinks benign prostate enlargement without side effects affecting normal body function.

NNFA believes that a sufficient body of botanical and nutrient research may exist in certain instances, to whet AHCPR's appetite and to warrant Congressional consideration of cost-effectiveness studies in this area.

NNFA urges the Committee to consider directing AHCPR to work with the Office of Dietary Supplements and the Office of Complimentary and Alternative Medicine to review the existing outcome research on dietary supplements. The AHCPR could then investigate the feasibility, under appropriate protocols, of developing cost-effectiveness projects designed to compare the value of herbs and other dietary supplements in the treatment and prevention of chronic illness to typical medical approaches. The areas I have mentioned are but a few of the many possibilities which urgently present themselves for research and evaluation. Once the necessary biomedical and cost-effectiveness research have been completed, NNFA urges the Committee to direct HCFA to investigate the potential reimbursement for promising alternative therapies and treatments involving nutritional supplements and herbs.

A sound investment in the health and well-being of all Americans

Science and experience ably demonstrate a wealth of benefits attendant to the regular use of vitamins, minerals, amino acids, enzymes, herbs and botanicals—all classified by DSHEA as dietary supplements. Dietary supplements are allowing millions of American consumers to take charge of their own good health by safely and effectively preventing and treating a host of illnesses and conditions. The body of research supporting use of these products is impressive, but sorely requires immediate and dramatic expansion. NNFA urges the Committee to undergird the Congressional mandate expressed in DSHEA by investing in the scientific research which holds the key to our knowledge of the remarkable importance and value of dietary supplements.

Thank you.

PREPARED STATEMENT OF ROTARY INTERNATIONAL

Chairman Specter, members of the subcommittee: Rotary International appreciates this opportunity to submit written testimony in support of the polio eradication activities of the U.S. Centers for Disease Control and Prevention. Rotary International is a global association of nearly 29,000 Rotary clubs, with a membership of over 1.2 million business and professional leaders in 158 countries. In the United States today there are some 7,500 Rotary clubs with over 400,000 members. All of our clubs work to promote humanitarian service, high ethical standards in all vocations, and international understanding.

Rotary is submitting this testimony on behalf of a broad coalition of child health advocates, including the March of Dimes Birth Defects Foundation, the American

Academy of Pediatrics, the Task Force for Child Survival and Development, and the U.S. Committee for UNICEF, to seek your continued support for the global program to eradicate polio. First, Rotary International and our coalition would like to express our sincere gratitude. For 1997, you recommended that $47.2 million be allocated for the polio eradication activities of the Centers for Disease Control, and for fiscal year 1998 you again recommended this same amount, and the full Congress ratified your recommendations in both years.

This investment makes the United States the leader among donor nations in the drive to eradicate this crippling disease. The target year is 2000. Fewer than 1,000 days remain to defeat this disease in the 60 nations where the polio virus still causes death and disability. The eradication of polio, achieved through your leadership, will not only save lives, but will also save our financial resources.

Eradicating polio will save the United States at least $230 million annually

Although polio-free since 1979, the United States currently spends at least $230 million annually to protect its newborns against the threat of importation of the polio virus. Globally, over 1.5 billion U.S. dollars are spent annually to immunize children against polio. This figure does not even include the cost of treatment and rehabilitation of polio victims, nor the immeasurable toll in human suffering which polio exacts from its victims and their families. Once polio is eradicated, tremendous resources will be unfettered to focus on other health priorities.

Progress in the global program to eradicate polio

Thanks to your appropriations, the international effort to eradicate polio has made tremendous progress during the past two years.

—Preliminary estimates are that reported polio cases for 1997 will be approximately 3,600, one-half the number of cases reported only 2 years ago. This dramatic decline is due to the tremendous success of National Immunization Days (NIDs) in South Asia and Africa. Worldwide, reported cases have decreased from over 38,000 cases in 1985, when Rotary began its PolioPlus Program—a decline of over ninety percent! Acute Flaccid Paralysis (AFP) surveillance, which is critical to the process of certification of a polio-free world, is improving, and health authorities in polio-endemic countries are now better able to assess the challenges remaining to eradication.

—In 1996, 154 countries reported no polio. That number is expected to rise in 1997. About 60 countries, however, remain polio-endemic.

—The global eradication strategy is working. Seventy-five countries conducted NIDs in 1997, protecting 450 million children against polio—more than one-half of the world's children under the age of 5.

—During its third year of NIDs, India was able to immunize 130 million children on December 7, 1997, and again on January 18, 1998—the largest public health events in history. Pakistan, Bangladesh, and six other countries coordinated their NIDs with India's to achieve the maximum effect over the entire region.

—Despite economic difficulties, more than 40 African countries conducted National or Sub-National Immunization Days during 1996–97, as part of the continent-wide "Kick Polio Out of Africa" campaign championed by South African President Nelson Mandela, reaching nearly 70 million children. Forty-nine African countries are undertaking NIDs in 1997–98. Polio-free zones are emerging in both Northern and Southern Africa.

—The three-year "Operation MECACAR" (Middle East, Caucasus, Central Asian Republics) immunization campaign has been deemed a success, virtually eliminating polio from 19 contiguous countries stretching from the Middle East to Russia. For 1997, polio cases reported from WHO's European region have been confined to Tadjikistan and Turkey.

—As a result of 3 years of successful NIDs, China reported no laboratory-confirmed indigenous polio cases in 1996 or 1997. In 1997, reported polio cases in the Western Pacific were confined to the Mekong Delta of Cambodia and Viet Nam, with no cases reported for more than a year. We are optimistic that we have seen the last case of polio in the Western Pacific, but continued vigilance is necessary to confirm this. The entire region has started on the process of certifying polio eradication.

The role of the U.S. Centers for Disease Control and Prevention

In this Subcommittee's fiscal year 1998 report, you commended the CDC for its active leadership in the global polio eradication effort, and recognized the real prospect of eradicating polio by the year 2000. As a result of the $47.2 million Congressional appropriation, in 1998 the CDC is:

—Supporting the international assignment of nearly 50 long-term epidemiologists, virologists, and technical officers to assist the World Health Organization and polio-endemic countries to implement polio eradication strategies.
—Providing $30 million to UNICEF for polio vaccine and operational costs for NIDs in more than 50 countries in Asia, Eastern Europe, the Middle East and Africa. Many of these NIDs would not take place without the assurance of CDC's support.
—Providing over $7 million to WHO for surveillance and NIDs' operational costs, primarily in Africa. As successful NIDs take place, surveillance is emerging as a critical need, to determine where polio cases are continuing to occur. Good surveillance can save resources by eliminating the need for extensive immunization campaigns if it is determined that polio circulation is limited to a specific locale.
—Training virologists from all over the world in advanced poliovirus research. The CDC's Atlanta laboratories serve as an international reference center and training facility.
—Helping to persuade countries such as Afghanistan, Somalia and Sudan to plan and conduct NIDs despite ongoing civil conflict. Warring factions have agreed to "days of tranquillity" in order to allow immunization campaigns to occur.

The benefits of polio eradication

Increased political and financial support for childhood immunization has many documented long-term benefits. Polio eradication is helping countries to develop public health and disease surveillance systems useful in the control of other vaccine-preventable infectious diseases. Already, much of Latin America is free of measles, due in part to improvements in the public health infrastructure implemented during the war on polio. As a result of this success, measles has been targeted for eradication in the Americas by the year 2000. The disease surveillance system—the network of laboratories, computers and trained personnel built up during the Polio Eradication Initiative—is now being used to track measles, Chagas, neonatal tetanus, and other deadly infectious diseases. The campaign to eliminate polio from communities has led to increased public awareness of the benefits of immunization, creating a "culture of immunization" and resulting in increased usage of primary health care and higher immunization rates for other vaccines. It has improved public health communications and taught nations important lessons about vaccine storage and distribution, and the logistics of organizing nation-wide health programs. Lastly, the unprecedented cooperation between the public and private sectors serves as a model for other public health initiatives.

Resources needed to finish the job of polio eradication

The World Health Organization now estimates that in 1998 approximately $220 million in external funds is needed to help polio-endemic countries carry out the polio eradication strategy. For 1999, an estimated $248 will be needed. To date, however, only $160 million has been committed by external donors for 1998, leaving an estimated shortfall of $60 million. In the Americas, some 80 percent of the cost of polio eradication efforts were borne by the national governments themselves. In Africa, many nations can contribute only a small percentage of the needed funds, meaning that foreign donors must meet up to 100 percent of the polio eradication costs. We are asking that the United States continue to take the leadership role in meeting this shortfall.

The United States' commitment to polio eradication has stimulated other countries to increase their support. Belgium, Canada, Finland, France, Italy, Korea, Norway, Sweden and Switzerland are among those countries which have followed America's lead and have recently announced special grants for the global Polio Eradication Initiative. Japan and Australia are major donors in Asia and the Western Pacific, and Japan has recently expanded its support to polio eradication efforts in Africa. And both Denmark and the United Kingdom have made major grants that will help ensure that India is able to vanquish polio by the target year 2000.

By the time polio is certified as eradicated, hopefully no later than 2005, Rotary International will have expended well over $400 million on the effort—the largest private contribution to a public health initiative ever. Of this, $304 million has already been allocated for polio vaccine, operational costs, laboratory surveillance, cold chain, training and social mobilization in 119 countries. In 1997, realizing the increased role which external donors need to play in order to ensure that polio eradication is not jeopardized due to lack of resources, The Rotary Foundation committed an additional $34 million to its PolioPlus fund. More importantly, we have mobilized tens of thousands of Rotarians to work together with their national ministries of

health, UNICEF and WHO, and with health providers at the grassroots level in thousands of communities.

Fiscal year 1999 budget request

For fiscal year 1999, we respectfully request that you provide $67.2 million for the targeted polio eradication efforts of the Centers for Disease Control and Prevention. This is an increase of $20 million over the fiscal year 1998 level of $47.2 million, and $20 million more than the President's fiscal year 1999 budget request, which was submitted before WHO released the latest estimates of unmet polio eradication needs. The additional $20 million is needed to meet the enormous costs of eradicating polio in its final stronghold—sub-Saharan Africa. Of this amount, $6 million would be used to purchase and deliver more oral polio vaccine for NIDs, while $5 million would be used for technical and operational support of NIDs in difficult countries such as Liberia, Somalia, and the Democratic Republic of the Congo. A further $9 million would go to develop an Africa-wide polio surveillance system, and strengthen and expand the existing network of regional and national laboratories. Without this additional appropriation, we may not be able to eradicate polio in Africa by the target date.

Humankind is on the threshold of victory against polio, and we must not miss this window of opportunity. Poliomyelitis will be the second major disease in history to be eradicated. The world celebrated the eradication of smallpox in 1979, and no child anywhere in the world will ever suffer from smallpox again. The annual global savings of nearly $1 billion per year in smallpox immunization and control costs far exceed the approximately $300 million that was spent over ten years to eradicate the disease. The United States was a major force behind the successful eradication of the smallpox virus, and has recouped its entire investment in smallpox eradication every 2½ months since 1971. Even greater benefits will result from the eradication of polio.

Polio eradication is an investment, but few investments are as risk-free or can guarantee such an immense return. The world will begin to "break even" on its investment in polio eradication only 2 years after the virus has been vanquished. The financial and humanitarian benefits of polio eradication will accrue forever. This will be our gift to the children of the 21st century.

Thank you for this opportunity to testify.

PREPARED STATEMENT OF ROBERT WILSON, THE WILSON FOUNDATION ON NEUROFIBROMATOSIS

Thank you, Chairman Specter and members of the Subcommittee for the opportunity to submit testimony on the need for a continued Federal commitment to research for Neurofibromatosis (NF), a terrible genetic disorder closely linked to cancer, brain tumors and learning disabilities affecting over 100 million Americans.

I am Robert Wilson, President of the Wilson Foundation, a private charitable foundation. My 11 year old son, Michael, suffers from a severe case of Neurofibromatosis. I have been working for many years with NF groups from around the country, the growing NF scientific community, members of Congress, and the National Institutes of Health. I appear before you today on behalf of Michael and the 100,000 other Americans who suffer from NF, as well as the tens of millions who suffer from NF's related diseases.

As a result of your support for biomedical research, each year that I appear before your Subcommittee I bring exciting news of a breakthrough in NF research that moves us closer to a treatment and cure for this terrible disease. Once again, I am able to report to you a major breakthrough since last year which holds promise not only for the individuals suffering from NF, but also for the 100 million Americans who suffer from cancer, brain tumors, and learning disabilities with which NF is closely connected.

Last Spring, researchers at Cold Spring Harbor Laboratory and Massachusetts General Hospital in Boston have determined for the first time that the NF–1 gene in fruit flies is linked to learning and memory. The studies showed that the protein made by the NF–1 gene is part of the c-AMP pathway, the pathway which is known to control learning and memory, while at the same time still being implicated with NF's cancer fighting tumor suppressor functions. This major breakthrough leads to new opportunities for drug and genetic therapies for NF patients, experiments for which have already begun on the fruit fly. Cold Spring Harbor Laboratory stated in its Spring/Summer 1997 newsletter that such research stands to benefit "a vast segment of the human population, including those afflicted with learning disabilities, Alzheimer's disease, and other dementias".

NF, incorrectly but commonly known as elephant man disease, involves the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer, and death. It is the most common neurological disorder caused by a single gene. While not all NF patients suffer from the most severe symptoms, all live their lives with the uncertainty of knowing whether they too will be severely affected because NF is a highly variable and progressive disorder.

Dr. Samuel Broder, former Director of the National Cancer Institute, stated that NF was at the "cutting edge" of cancer research. This cancer connection was at the heart of two major conferences on NF held in October 1995 and July 1997 at Cold Spring Harbor Laboratory in New York, one of the world's leading cancer and neuroscience research laboratories headed by Dr. James Watson, the co-discoverer of DNA. These Conferences brought together basic researchers, clinicians, biotech and pharmaceutical companies from around the world to find a treatment and a cure for NF. These conferences have been hailed throughout the research community as a turning point for NF. After the first conference, more than 20 leading NF researchers worked for over one year preparing a detailed blueprint for finding a treatment for NF. This document has been well received at NIH and many researchers are calling for this document to be used as a model for how NIH should fund research.

The future promise of NF research is based upon past successes. Let me highlight the enormous advances in NF research that have occurred since 1990:

—The discovery of the NF1 and NF2 genes and gene products;
—Determining that NF is closely linked to many of the most common forms of human cancer, brain tumors, and learning disabilities which affect over 100 million Americans;
—Determining the function of the NF genes and gene products, including their tumor suppressor, memory, and learning disability functions;
—Developing animal models for NF1 and NF2;
—Developing a diagnostic blood test and pre-natal testing for NF;
—Commencing a national trial drug treatment program for NF patients which can serve as the infrastructure for future clinical trials;
—Determining the connection between the phenotype /genotype in NF; Substantially increasing the number of NF researchers;
—Commencement of drug and genetic treatment experimentation on fruit flies with defective NF genes

The enormous promise of NF research—and its potential to benefit millions of Americans in this generation alone—has gained increased recognition from Congress and the National Institutes of Health. For fiscal year 1999, this Subcommittee's continued support will be critical to expanding on the basic and clinical research described above which is essential to finding a treatment and cure for NF. Specifically, this can be accomplished through a four-part NF research agenda:

Increase appropriations for NIH. Our goal should be to translate the promise of scientific discovery into an improved quality of life for all Americans. To accomplish this ambitious goal, we must continue to invest in medical research and the NIH. Sustained growth for the NIH is necessary to seize the tremendous opportunities brought about by previous research successes, build upon past scientific achievements, address present medical needs, and anticipate future health challenges. Towards this end, I encourage the Subcommittee to support the recommendation of the Ad Hoc Group for Medical Research Funding, a coalition of nearly 200 patient and voluntary health groups, medical and scientific societies, academic and research organizations, and industry, which calls for a 15 percent increase in the NIH budget for fiscal year 1999. This represents the first step towards doubling the NIH budget over the next five years. I urge members of this Subcommittee to join with their colleagues who have introduced legislative vehicles for achieving this ambitious but critical goal.

Increase appropriations for NF research. In addition to holding the promise of improving the lives of the thousands of individuals who suffer from NF, recent research has demonstrated that NF research stands to benefit the 100 million Americans who suffer from cancer, brain tumors, and learning disabilities. Therefore, I urge members of this Subcommittee to increase funding for NF research at NIH.

Continue cooperation and coordination between NCI and NINDS through targeted NF research programs. In your fiscal year 1998 Report, this Subcommittee encouraged NCI and NINDS to coordinate efforts and to pursue an aggressive program in basic and clinical research on NF. I applaud NCI and NINDS for the coordination that has occurred to date, and encourage the Committee to continue to urge continued expansion and coordination for NF research through the use of: Requests for

Applications, as appropriate; Program Announcements; the National Cooperative Drug Discovery Group Program; and Small Business Innovation Research Grants.

Target funding for the implementation of the clinical research initiatives generated at the Cold Spring Harbor Conferences. As developed by Cold Spring Harbor Laboratory at its NF Conference in October 1995, NF should become the model for scientist-initiated proposals to fund clinical treatment research for specific diseases which offer the potential for significant advances in broader areas, such as tumor suppressor genes. The Committee should encourage NIH to explore this new and exciting avenue in promoting dramatic advances in select research areas.

In closing, Mr. Chairman, with only a small investment, dramatic advances in NF research have been made with far reaching implications for many other diseases. Many of the worlds leading NF researchers, such as Dr. Frances Collins, Director of the National Human Genome Project; Dr. Bruce Korf of Harvard Medical School; Dr. Vincent Ricardi of the NF Institute in Los Angeles; Dr. David Guttman of Washington University School of Medicine; and Dr. Michael Wigler of Cold Spring Harbor Laboratory, among others, now believe that with an increased investment and a research agenda focused on all aspects of the NF research portfolio, from basic research in the labs to drug development and genetic therapy, a treatment and cure for NF can be found in the next few years.

I would like to end with a statement that appeared in a recent edition of Cold Spring Harbor Laboratory's newsletter which focused on major breakthroughs in NF research: "the hope is that the day may come when doctors can flip critical switches to repair the broken circuits in each of these disorders and diseases. Such life-changing therapies will be the reward for years of enthusiastic basic research." I believe, Mr. Chairman and members of the Subcommittee, that with your continued support, that day will soon be here.

PREPARED STATEMENT OF KATHYE GOROSH, PROJECT DIRECTOR, THE CORE CENTER

Committee on Appropriations Submitted to the Subcommittee on Labor, Health and Human Services and Education U.S. Senate Washington, DC

Mr. Chairman, thank you for the opportunity to present this testimony for the record on behalf of the "Enhanced Provider and Patient Education Initiative" proposed at the CORE Center in Chicago, Illinois. To address the national need for a model of "real time" education and training for HIV care providers at all levels and for patients, the CORE Center is proposing the establishment of the "Enhanced Provider and Patient Education Initiative."

This initiative will create a model technology-based system for the education of specialty and community-based providers and the education and treatment of patients. It will address an existing national need for the effective integration of educational programs to enhance provider performance and, importantly, to incorporate patients into the decision making process. It will create a system of education and care which takes advantage of the new scientific landscape and is centered around an information system. It will demonstrate the ability of computerized networks, with real time performance feedback, to improve the quality of and access to care, to increase compliance and to control cost.

As you know, the development of new and more effective drugs has allowed people to remain healthier longer and to delay the progression from HIV to AIDS. Nevertheless, it remains critical that we stop the spread of HIV as well as provide early and comprehensive care to those already infected. Effective education and compliance management programs are the only way to prevent the behaviors that lead to the spread of resistant strains of HIV. As a result, quality care will be provided in a cost-effective manner providing thousands of HIV infected individuals with an improved quality of life and enabling them to remain productive members of society.

While there have been dramatic new developments in HIV care due to new and more powerful medications, including a 13 percent decrease in the death rate from AIDS reported by the Centers for Disease Control and Prevention (CDC), these therapies have not been as effective in the indigent inner-city urban population. For example, according to the Department of Medicine at Long Island Jewish Medical Center in New Hyde Park, New York, in 1996 increased cases of AIDS related opportunistic illnesses were reported for heterosexual African American and Hispanic men and women. This disparity in opportunistic infection trends between population groups most likely reflects differences in access to the full range of new therapies now available and a lack of targeted outreach, education and compliance enforcement efforts aimed at high risk populations and at those lifestyles which contribute significantly to the transmission of HIV.

In contrast to the general decline in the number of AIDS related illnesses and deaths, the CDC has reported a continuing increase in new cases of HIV/AIDS among people of color.

In November 1997, medical experts at the United Nations reported that new infections are occurring worldwide twice as fast as just one year ago at 16,000 per day, up from 8,200 per day, with 30.6 million living with HIV throughout the world. For children under age 15, the UN estimates that 1,600 children are infected each day, up from last year's estimate of 1,000 per day. In addition, it is estimated that 1,200 children die of AIDS each year, up from the prior estimate of 1,000.

In the United States, the numbers are equally as chilling. Research is showing that the epidemic continues to shift to people of color, women and children. Since 1993, there has been a 3 percent increase annually in the national prevalence of AIDS. Recent data have shown that:

—One in 250 people in the United States is infected with HIV;

—One in four of all new HIV infections in the U.S. are estimated to occur in young people between the ages of 13 and 20;

—Every hour 2 to 4 Americans under the age of 20 become infected with HIV;

—27 to 54 adolescents are infected with HIV every day;

—2,354 adolescents ages 13—19 have been diagnosed with AIDS as of December 1995;

—Among adolescent women with AIDS, 80 percent are African American or Hispanic; and,

—AIDS is the leading cause of death of people between the ages of 25 and 44 in African Americans and Hispanics.

In addition to the growing numbers of individuals being infected with HIV, continuing trends show that the rate of increase is greatest among injection drug users and through heterosexual transmission.

Recent research has shown that the disproportionate incidence of HIV/AIDS among inner-city, minority populations is due in large part to low rates of compliance and lack of effective community-based, comprehensive, health education systems and programs for providers and patients.

Low rates of compliance can most often be attributed to the following:

Cost

The costs for HAART therapy is enormous, as much as $10,000—$15,000 per patient per year. This figure does not include other costs for care or daily medications. There is great concern among people living with AIDS that access to care for all people be assured.

Although the federal program, AIDS Drug Assistance Program (ADAP), is designed to provide financial assistance for uninsured or underinsured HIV/AIDS patients in purchasing required medications, it has been unable to keep up with the increasing demands;

Testing

Many individuals are hesitant to be tested for HIV and go undetected. As a result, patients go without care until the symptoms become evident and they are in need of immediate services;

Compliance

Many HIV infected patients are unwilling or unable to get timely clinical care or to adhere to complex and difficult drug regimens. Often patients have little or no understanding of newer therapies and their potential benefit, resulting in low levels of compliance.

While many piecemeal health education systems for HIV/AIDS exist throughout the United States, there are none that are taking full advantage of today's cutting-edge scientific landscape. It is well known that the adoption of computerized clinical information systems in health care lags behind the use of computers in most other sectors of the economy. There is no HIV educational system that provides care, clinical assistance and interactive education, while integrating the patients and community-based providers into the care giving and decision-making process. Especially given today's technological advances, this is a striking deficiency in health education systems for HIV/AIDS.

At this critical time in the evolution of the long-term treatment of HIV/AIDS, it is important that we focus on the creation and implementation of comprehensive educational systems of care for individuals affected by HIV/AIDS. This focus will improve treatment and prevention efforts, increase the rate of the early detection of HIV, increase the rate of treatment compliance and ultimately decrease the spread of HIV. It is critical that the federal government focuses its resources on creating

comprehensive HIV education systems that fully integrate specialists, community-based providers and patients and evaluate the outcomes of those systems.

The CORE Center believes that the most effective educational system is one which uses today's state-of-the-art technology and creates interactive systems of education that provide real-time feedback and enables providers to optimize care for HIV/AIDS patients. That is why the Center is proposing to establish the "Enhanced Provider and Patient Education Initiative" a model technology-based system for the education of specialty and community-based providers and the education and treatment of patients.

We are at a critical point in the care of patients with HIV/AIDS. We have achieved major goals in our basic science understanding of the course of HIV disease and have applied this understanding to the care of patients

Successes in the treatment and care of HIV/AIDS have led to increased numbers of AIDS patients surviving longer and once again becoming productive members of society. Hospital admissions for AIDS care are down, and clinics are experiencing dramatic increases in the demand for out-patient services. Although science has taken big steps toward making AIDS a long-term manageable disease, by no means do we have a cure for the largest public health crisis of the century.

Additionally, given the frequently changing scientific landscape and related improvements to available therapies and care protocols, it is difficult for specialty-care providers, and more so for community-based care providers, to keep abreast of the most recent advances in care and medication usage. Lack of access to up-to-date information also hinders compliance of patients in their therapy and clinic schedules.

There is no successful system in place that provides caregivers and patients the education and scientific tools needed to ensure that they make the most of the advances in care.

Patients need to be educated regarding their drug therapies and other care options available to them. Because many inner-city patients are unable or unwilling to routinely access the local primary health care system, this education and compliance is very difficult.

Moreover, the treatment of patients with HIV/AIDS in Chicago and other urban areas is made more difficult by the large number of patients receiving care and the large number of potential patients whose infections have not been recognized who will ultimately need care.

Compliance for patients in lower socioeconomic populations has been more difficult to achieve. Unfortunately, incomplete compliance with medication regimens greatly increases the risk of the emergence of strains that are resistant to the newest therapies thus increasing the likelihood of the spread of HIV/AIDS.

Specialists alone are not able to provide primary care for all affected patients, especially those in underserved communities. This means that other providers need to be trained in the complicated care of patients with HIV/AIDS to insure that the new HIV medications are used appropriately and to the greatest benefit for all patients.

To be effective, these community providers must have current medical data and protocols at their fingertips. They must be able to access immediate expertise to ensure the most accurate interventions and care for patients. Today, due to weaknesses in the HIV/AIDS care infrastructure, they are often unable to access this type of critical information or feedback in a timely and effective fashion.

The Enhanced Provider and Patient Education Initiative will focus primarily on methods of optimizing the delivery of care through the real time education of specialists, nurse practitioners, physician's assistants, and community-based providers caring for people with HIV/AIDS. The secondary goal is to screen patients with other sexually transmitted diseases for infection with HIV and to initiate therapy at an early stage of HIV disease.

The CORE Center's proposed initiative will be composed of four elements:

I. EDUCATION

There is growing evidence that use of practice guidelines and disease management systems can help direct and improve care given to patients. In the complicated arena of HIV care, where multiple antiretroviral regimens are available and where interactions with other medications are common, the use of such protocols is particularly important.

The CORE Center's Enhanced Provider and Patient Education Initiative will disseminate expert consensus-derived protocols for the care of patients in the CORE Center and in the community. It will use a comprehensive technology-based education system to implement a program for health care providers, including specialists, generalists, nurse practitioners, and physicians assistants, to optimize care of

HIV/AIDS. This system will provide education services both in the CORE Center and to the community clinics associated with the Cook County Bureau of Health Services.

Through the use of current state-of-the-art, interactive computer technology, this initiative will allow providers to order medications and laboratory tests through an interactive computer system which will direct therapy by computerized educational screens that appear sequentially during the ordering process. These educational screens will assist providers in prescribing the most effective, economical and comfortable therapies for patients

Computer facilitated review of patient care will be performed daily by using computer flagging systems to ensure that care conforms to guidelines and by expert review of computerized records that will be transmitted to the CORE Center from affiliated clinics on a daily basis.

Feedback will be provided for caregivers based on the reviews described above. This will create a continuous improvement loop. Guidelines and additional education efforts will be redesigned on a continual basis using the results of computer facilitated reviews of patient care. The process will be used for educating patients at each visit, teaching patients about HIV disease and related issues and integrating patients into the decision making process. It will improve compliance with the use of social service interventions for the CORE Center's indigent population.

Computer kiosks stationed throughout the CORE Center will allow patients to review information on AIDS treatment, to formulate questions, and to interact with other patients.

II. EARLY INTERVENTION

The CORE Center will evaluate early intervention programs in terms of their effectiveness and successful coordination with the full continuum of care. This program element will target HIV screening of inner-city populations with sexually transmitted diseases so that advances in HIV care can be made available as early as possible in the course of HIV infection and help to stop the increase in the numbers of HIV cases reported daily.

The CORE Center will include a screening clinic for patients with sexually transmitted diseases. Currently, only 10 percent of the more than 10,000 patients seen yearly at Cook County Hospital with STDs undergo screening for HIV infection. The CORE Center will provide HIV testing and counseling of all patients who are seen for treatment of STDs.

The CORE Center will assess the impact of early intervention programs on the stage of illness at which patients enter into care in the CORE Center. Specifically, patients will be seen earlier in the course of HIV infection which will improve their chance of responding to therapy. In addition, the CORE Center will provide HIV testing and counseling for all patients who are seen for treatment of STDs.

III. COMPLIANCE

The Center will implement an aggressive compliance program to insure application of sound treatment principles and protocols, medication compliance and clinical follow-up.

Provider compliance with treatment guidelines will be measured, corrected, and reinforced through innovative use of provider order entry systems, as noted above in the education program. Patient compliance will be reinforced through participation in the development of treatment plans, through clinical pharmacy teaching sessions, and through the use of medication reminder devices. The CORE Center is currently developing a variety of compliance programs and believes that patient will be an important source of patient empowerment and "buy-in" to care.

IV. OUTCOMES MEASUREMENT

The Center will implement an aggressive and comprehensive outcomes measurement program that will measure patient outcomes and cost of care by different community provider groups in the CORE Center and the community. This HIV/AIDS cost and outcomes data, which does not currently exist for any AIDS treatment program, will be extremely useful. Importantly, this initiative will also measure improvement rates in provider compliance with recommended guidelines and measure the cost for achieving improved compliance with treatment protocols.

In closing, Mr. Chairman, the CORE Center believes that this technology-based education initiative is a prototype for national efforts to meet the educational challenges presented by infectious diseases, especially, HIV/AIDS. As such, the CORE

Center is seeking $6.9 million over five years for the establishment of the Enhanced Provider and Patient Education Initiative.

Again, I appreciate the opportunity to submit testimony for the record and to share with you and the other members of the subcommittee the details of this unique initiative. We look forward to continuing to work with you and your subcommittee as well as the Administration in support of this initiative.

PREPARED STATEMENT OF THE TRI-COUNCIL FOR NURSING

This statement presents the fiscal year 1999 appropriations recommendations for nursing education and research of the Tri-Council for Nursing. The Tri-Council is composed of four major national nursing organizations:

—The American Association of Colleges of Nursing representing over 520 baccalaureate and graduate nursing education programs in senior colleges and universities;

—The American Nurses Association with 178,000 registered nurse members in 53 constituent state and territorial associations;

—The American Organization of Nurse Executives representing 5,000 nurses in executive practice; and

—The National League for Nursing on behalf of 1,674 education agency members representing all levels of nursing education, 42 constituent state leagues representing 40 states, 104 health care institutions, 67 academic nursing centers and non-academic agencies, and 6, 842 individual members, including consumers, nursing school faculty, and nurse practitioners in community nursing centers.

The Tri-Council thanks the members of this subcommittee for the fiscal year 1998 funding levels for the programs critical to nursing education and research: the Nurse Education Act (NEA) (Public Health Service Act Title VIII), Scholarships for Disadvantaged Students (in PHSA Title VII), the National Institute of Nursing Research (NINR) at NIH, the Agency for Health Care Policy and Research (AHCPR) and others. We can assure you that these needed funds will be well spent to improve the public health.

For fiscal year 1999 for the NEA, the Tri-Council respectfully requests an increase of 8 percent over fiscal year 1998 to a level of $70.92 million. For SDS, we seek an increase also of 8 percent over fiscal year 1998 to $20.235 million. For NINR, we recommend a 15 percent increase over fiscal year 1998 to $73.136 million. For AHCPR, we ask for an increase of 6 percent over fiscal year 1998 to $155.221 million. For the National Health Service Corps Scholarship and Loan Repayment programs we seek an increase over fiscal year 1998 of 5 percent to $82.074 million.

The Nurse Education Act

The NEA is the key source of federal financial support for nursing education programs and nursing students. Although it has a student loan program open to undergraduates, the NEA primarily seeks to encourage preparation of advanced practice nurses (APNs) for underserved populations. APNs include nurse practitioners, certified nurse midwives, clinical nurse specialists and certified registered nurse anesthetists. These well-trained professionals are highly sought after by hospitals, community based health care centers and other providers. The NEA funds programs to educate APNs and future nursing faculty (NEA Sections 821, 822 and 831), offers modest stipends to master's and doctoral students (Section 830), and seeks to help disadvantaged students attain nursing education (Section 827). NEA Section 820, Special Projects, encourages linking training to the delivery of primary care for underserved people, assists continuing education in rural areas, and encourages schools to increase enrollments. NEA Section 846 offers repayment of academic loans for nurses that agree to practice in areas of nurse shortage such as public hospitals, community health centers, American Indian facilities, and public health services. (The NEA reauthorization underway in the form of S. 1754 may streamline the law and expand its focus, but existing functions will likely continue.) NEA funds serve as federal leverage to reward schools and students for meeting workforce needs of our rapidly evolving health care system. NEA programs have incentives for schools to train for work with underserved populations. Whatever that system ultimately becomes, nursing professionals will provide needed healthcare services.

ACCOMPLISHMENTS OF THE NEA

NEA funds

—Assisted the development and expansion of 60 percent of current educational programs readying nurse practitioners for primary care. 95 percent of NP grad-

uates work in primary care and 44 percent of NPs had at least 25 percent Medicaid patients;
—Supported the development of APN education for specialty HIV/AIDs tracks;
—Supported about half of the doctorally prepared nursing faculty teaching today;
—Helped schools to address current and developing care issues such as HIV/AIDS, elderly, school health, high risk perinatal care, rural health, and home health;
—Fostered programs to prepare nurses to meet the healthcare system's need for nursing professionals to address sicker patients in tertiary care sites, people living longer with chronic conditions, and the often complex health care needs of an increasingly elderly population;
—Expanded the scope of nursing's use of technology for telehealth, distance learning and information collection and analysis;
—Provided stipends in 1997 to almost 37 percent of 12,769 full-time graduate nursing students in 267 grants totaling $15.6 million (for example, $910,424 went to 20 Pennsylvania programs);
—Significantly increased the number and retention of minority nursing students and faculty, boosting the number of minority nursing graduates by 25 percent over the past 5 years;
—Helped train Certified Registered Nurse Anesthetists (who are sole providers of anesthesia services in 70 percent of rural hospitals) and contributed to the upgrading of the anesthetist faculty and to graduate degrees to meet the strong demand for these professionals;
—Facilitated development and/or operation of 50 percent of currently operating nurse managed health care centers that serve diverse populations of minorities, elderly, schools, housing complexes and homeless people;
—Supported 80 percent of certified nurse midwifery (CNM) programs, and 89 percent of CNMs serve low-income women;
—Provided funds for 10 graduate programs in psychiatric-mental health nursing; and

Sponsored and collaborated on research on nursing workforce to help maintain a relevant educational focus and preparation level.

SOME EXAMPLES OF NEA PROJECTS

A Pennsylvania Acute Care Nurse Practitioner program combines primary health care skills with acute care clinical skills and is designed to attract students from medically underserved areas. An NEA project at the Marquette University College of Nursing in Milwaukee, Wisconsin developed a Pediatric Nurse Practitioner/Clinical Nurse Specialist programs to address the preventive and primary health care needs of children living in poverty in a medically underserved area. Another NEA grant at the University of Arkansas College of Nursing supports a Family Nurse Practitioner program that focuses training on underserved rural populations and has placed over half of its graduates there. Another NEA grant seeks to increase the numbers of disadvantaged and minority nursing graduates at Prairie View A&M University in Texas. NEA funds support a nursing center in Kansas City Missouri managed by The Research College of Nursing that delivers primary health care services 6 days a week to the 520 children and their families at Blemheim Elementary School. The NEA facilitates a pioneering program at Howard University (Washington, DC) to teach homeless people to become successful nursing professionals. Several NEA programs use special mentoring and academic assistance to help nursing students complete their courses of study and then return to underserved areas to practice nursing. The University of Maryland School of Nursing operates 7 school based health centers in metropolitan Baltimore with NEA funds as well as 2 Wellmobiles on Maryland's rural Eastern Shore.

The scope and breadth of NEA projects is impressive. Continued funding ensures that these good works will be maintained and possibly expanded. The need for BSN graduates is expected to increase; meanwhile, APNs are in great demand everywhere. The fact is that the NEA is the sole source of federal support for APN education.

SCHOLARSHIPS FOR DISADVANTAGED STUDENTS

The Tri-Council recommends a funding level for fiscal year 1999 for SDS of $20.235 million, an 8 percent increase over fiscal year 1998. By statute, 30 percent of SDS appropriations are reserved for nursing students. Most of the nursing SDS money, about $5.6 million in fiscal year 1998, goes to baccalaureate students. Schools with proportionately greater numbers of minority students are given additional funds. For fiscal year 1996 (most recent data), 4,101 nursing students re-

ceived SDS support, and 2,601 or 63.4 percent were minorities. While baccalaureate nursing programs have done reasonably well in attracting minority students (19.5 percent of baccalaureate enrollments in 1997, according to AACN's most recent data), the SDS funds do make a difference for the students. Nursing needs federal help to increase the diversity of the profession.

NATIONAL INSTITUTE OF NURSING RESEARCH

NINR is one of the smallest NIH entities, despite the fact that for many patients in or out of hospitals, nurses are the major factor in their care and management of health care. The Tri-Council strongly urges the subcommittee to increase funding for NINR by at least 15 percent over fiscal year 1998 to $73.136 million. This level will enable nursing science to begin to conduct the scope of research essential to achieving breakthroughs in patient care, outcomes and cost effectiveness appropriate to nursing, the largest health care profession. NINR's research agenda concentrates on helping patients deal with pain, maximizing the quality of life of people living with chronic conditions or the after effects of stroke, avoiding low birth weight babies, maternal and child health and other conditions. Indeed, interdisciplinary research funded by NINR increases the value of NIH research.

Recently, NINR was assigned to be the NIH lead institute on "End-of-Life Care," involving complex care, pain management, mental issues for terminal patients and emotional issues for critically ill patients' families. Not only is this an issue we all must someday face, but also with a population that is proportionately getting older, it will be of major concern to many more people in the years to come. The way to address this issue is to research it; the way to research it is to provide NINR with the financial tools it needs to handle this task. For this reason, the Tri-Council urges the subcommittee to ensure that funding for NINR meets the percentage of increase that NIH receives. In fiscal year 1998, NINR was given only 6.4 percent, while NIH got 7.1 percent. This puts a small institute like NINR at a disadvantage because the need for nursing science is huge. The Tri-Council recommends at least a 15 percent increase over fiscal year 1998 for NINR in fiscal year 1999.

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

The Tri-Council recommends a 6 percent increase over fiscal year 1998 for AHCPR to $155.221 million in fiscal year 1999. AHCPR's mission is critical to wise utilization of health care dollars because it seeks to discover and to publicize which procedures and practices work and which don't. Among other things, AHCPR is developing a new Web based clearinghouse for clinical practice guidelines and funds a group of Evidence Based Practice Centers to examine specific medical and health concerns in detail. To spend health care dollars wisely, America needs a strong AHPCR.

NATIONAL HEALTH SERVICE CORPS

The Tri-Council suggests a 5 percent increase over fiscal year 1998 for the National Health Service Corps Scholarship and Loan Repayment programs (PHSA Title III) to $82.074 million. This program seeks to attract health professionals to Health Professional Shortage Areas. Many of those areas are rural, and have difficulty attracting and retaining caregivers.

CONCLUSION

In summary, the Tri-Council for Nursing respectfully recommends the following appropriations for fiscal year 1999:

Tri-Council for Nursing recommended appropriations for fiscal year 1999

	Millions
Nurse Education Act	$70.920
Scholarships for disadvantaged students	20.235
National Institute of Nursing Research	73.136
Agency for Health Care Policy and Research	155.221
National Health Service Corps scholarship/loan	82.074

PREPARED STATEMENT OF TOM LAPAHE, COUNCIL DELEGATE, PINON HEALTH CENTER PROJECT, PINON, NAVAJO NATION (ARIZONA)

In the early 1980's, the Pinon and Whippoorwill Chapters and the surrounding communities initiated plans to design and construct the Pinon Health Facility to be located in Pinon, Navajo Nation (Arizona). The purpose of establishing a health center in Pinon is to provide community members direct and immediate access to adequate health and emergency care services to save lives. Although the development of the Pinon Health Center Project (Project) has been progressing for quite some time, the Project continues to experience funding shortfalls.

Pinon is geographically located in the middle of the Navajo Nation—a considerable distance from major growth areas such as Chinle, Window Rock, and Tuba City. The nearest health facility that provides general health care, inpatient accommodations, and emergency services is the Chinle Comprehensive Health Care Facility, approximately 50 miles from Pinon. The Pinon community has grown considerably in the past ten years. Construction of new school facilities, construction of a dormitory housing 600 students and additional housing development has contributed to community expansion. There are over 1,500 students in the elementary and high school. Pinon, as a result of this expansion, has become one of the primary communities where a considerable number of Navajo families have relocated from the Hopi Partitioned Lands tripling the population.

Due to increasing population, the community is planning future infrastructure development to accommodate needs. Upgrading health care service delivery is a necessary and critical part of this development. The current Pinon Health Clinic will need to be expanded to meet the increasing demand for a comprehensive health facility that will equal the medical services provided by the hospital in Chinle. Currently, the Pinon Health Clinic is open from 8 a.m. to 4 p.m., three days of the week. This requires those seeking emergency medical treatment to travel to Chinle to seek needed medical attention when it is not available at the Pinon Clinic. During normal weather conditions, persons will travel 45 minutes, or 50 miles, from Pinon to Chinle to seek medical assistance. During inclement weather, persons residing on the far west end of the Pinon community have to travel additional miles on impassable roads to get into Pinon, then drive to the Chinle hospital. This situation extends travel time up to one and a half-hours and in severe emergency situations, critical life saving time is lost. Once the project is completed, people of Pinon and the surrounding communities will no longer have to risk their lives to receive minor and major health care at the current clinic.

An estimated $34.2 million is required for construction of the health facility and is considered the fourth priority of the National Indian Health Services Construction Priority list for outpatient facilities. In addition, approximately $1.04 million is needed to complete the design phase that was funded in fiscal year 1990. In fiscal year 1989, $50,000 was appropriated by the US Congress for the initial stage of the Project's design and $84,000 was appropriated again in fiscal year 1990, however, additional monies are needed in fiscal year 1999. The Navajo Nation Council's Health and Social Services Committee has endorsed the aforementioned dollar amounts as outlined in Resolution HSSCF–24–98.

If moneys are not secured to complete the design phase and budgeted to begin construction of the health facility, overall cost will escalate and the project will be further delayed. I strongly believe the health, welfare, safety and accessibility to quality health care are at stake and may be jeopardized.

The Pinon community greatly needs this project to move forward—tragic loss of life has already been experienced due to the lack of emergency facilities and the distance form Pinon to Chinle. Without the Pinon Health Care Facility, families will continue to confront loss of life due to lack of a nearby health facility. To immediately reduce tragic losses and contain the escalating costs, Congress must appropriate funds in fiscal year 1999 to complete the design phase and the Clinton Administration must budget for the construction of the Pinon Health Facility at Pinon, Navajo Nation (Arizona) next fiscal year.

PREPARED STATEMENT MICHAEL E. DEBAKEY, M.D. AND THE HON. PAUL G. ROGERS ON BEHALF OF THE FRIENDS OF THE NATIONAL LIBRARY OF MEDICINE (NLM)

On behalf of the Friends of the NLM, it is our pleasure to submit a statement for the record on the need to double funding for the National Institutes of Health over the next five years, and particularly to double support for the National Library of Medicine (NLM), the world's largest and most prestigious medical and scientific library located at the NIH.

We are Michael DeBakey, Chancellor Emeritus and Professor of Surgery at Baylor College of Medicine in Houston, Texas, and Paul G. Rogers, Chairman of the Friends of the NLM. The Friends of the NLM is a national nonprofit organization whose mission is to increase awareness and use of this preeminent national treasure, the NLM. Our membership includes medical societies and associations, health sciences schools, medical librarians, health professionals and companies that share our vision. The motto of the Friends is The More You Know, The Better You Heal, and that is perhaps an apt point on which to begin.

We appreciate this opportunity to offer our perspective on the current state of the nation's medical research and, in particular, on the spectacular emergence of information technology as a new essential component of the whole biomedical research enterprise.

UNLOCKING THE MYSTERIES OF DISEASE AND HEALTH

As America approaches the turn of a new century, we are poised on the brink of a revolutionary new era in medical knowledge. Mysteries about the nature of the human body and its disorders that have baffled medical scientists for centuries are beginning to be revealed. Major new breakthroughs in genetics, molecular biology, human biochemistry, and many related fields, are converging to unlock our understanding of and treatments for cancers, diabetes, Alzheimer's, AIDS, and many other diseases. This knowledge explosion in medicine has only just begun. As we approach the millennium, these advances hold the promise of dramatically increasing our ability to improve the quality of human life.

Many of these exciting breakthroughs are inextricably tied to the emergence of new information technologies. Researchers around the world now have instantaneous access to the latest biomedical knowledge thanks to MEDLINE and other online databases of the National Library of Medicine. Medical and scientific research now and in the future begins at the computer screen, enabling our research dollars to go further and avoid wasteful duplication of effort.

While we are submitting this statement specifically to address the vital programs of the National Library of Medicine, we strongly support the efforts to double funding for all of the National Institutes of Health over the coming five years. We simply can think of no better investment of public resources.

Thanks to America's wise investment in a broad array of biomedical investigation, the NIH has become the world's preeminent medical research institution, the engine of cutting-edge investigation of human afflictions and the repository of vast stores of scientific information available to researchers and laypersons around the globe.

THE NLM: LINCHPIN BETWEEN COMMUNICATION TECHNOLOGIES AND HEALTH

As ardent champions of the importance of making available scientific information to the public as well as to medical practitioners and researchers, we would like to draw your attention to the ways in which digital technology is enhancing the value of public investment in the NIH.

The National Library of Medicine, located in Bethesda and a part of the NIH, has been a leader in developing and applying the latest in communications technologies to improve health. From the birth of the computerized MEDLARS system in the 1960s, to the introduction of the online database, MEDLINE, in the 1970s, to today's DNA databases and World Wide Web based services, the Library has played an increasingly central role in the life of American medicine.

Last year marked a stunning milestone for the NLM in this regard. In June, 1997, beginning with a packed Capitol Hill press conference led by Vice President Al Gore and Senators Arlen Specter and Tom Harkin, the Library launched free, public use of MEDLINE via the World Wide Web [WWW]. As you may know, prior to that time the database—which is the world's largest medical database—was open only to registered users who paid a search fee.

We are delighted but not surprised to report to you that MEDLINE use has risen tenfold since that time, to more than 300,000 searches a day. Researchers, medical practitioners, and students are rightly thrilled with MEDLINE's easy-to-use, free search capabilities. What is particularly extraordinary, is that almost one-third of those who are accessing the service are simply citizens seeking health-related information. With this in mind it is noteworthy that NLM is enriching MEDLINE with carefully selected consumer health newsletters published by medical schools and government agencies.

We are particularly proud of the outreach efforts the NLM has taken to educate the public about the potential of online medical knowledge to save lives. For example, both ER and Chicago Hope television shows have recently used story lines that involve MEDLINE searches. The stories have been based on actual true stories

where vital, life-saving information was found because a simple literature search was undertaken by the doctor. You may have seen the ER episode where a boy arrives in the emergency room and has a "numb chin". This baffling symptom is diagnosed as lymphoma when nurse Hathaway performs a MEDLINE search. The real situation happened in an Atlanta community health clinic.

We agree with The Speaker of the House, Newt Gingrich, who wrote in Roll Call column a few weeks ago that "the development of a universal system of knowledge accessible to both professionals and patients" is, in conjunction with increased funding for medical research, the linchpin of "a dramatically healthier and financially smarter" health care system for the 21st century.

The new free MEDLINE demonstrates the validity of the Speaker's vision for the future: A consumer-oriented system in which individuals take greater responsibility for maintaining their health begins with access to current credible information about diseases and disease prevention.

MEDLINE is the hub of the emerging health information system. Since making MEDLINE free via the Web last summer, more than 100 medical journals now have direct links to the existing database enabling searchers to access full text of the article. And, that effort will only increase in the future, making MEDLINE an increasingly valuable and vital source of comprehensive biomedical information.

Clearly the NLM will need significantly more resources to reach out to both health care professionals and the public about free MEDLINE.

NLM'S ROLE IN IMPROVING HEALTH CARE

We have highlighted the role of MEDLINE in expanding the return on the public's investment in medical research. But we certainly believe that health care practitioners themselves are primary beneficiaries of the new information technologies. It was not too long ago that research findings took years to wend their way into clinical practice. Today computer-literate members of the medical community around the globe can access state-of-the-art research information almost as soon as it is published.

It is impossible to overstate the significance of the change such access represents over the traditional system in which doctors practice the medicine they learned in medical school. Even at the current rate of new developments, practitioners' knowledge becomes outdated in less than a few years. And, the pace of advances is only going to increase in the years ahead.

To quote Speaker Gingrich again: "Thirty years from now, we will have somewhere between 10 and 1,000 times the amount of information we have today on the human body. Therefore, another goal [of medical-research funding] should be the transmission of knowledge to the practitioner within no more than 12 to 18 months of discovery."

We concur in this vision for rapid information flow between research and practice, and believe MEDLINE is the wellspring.

DIGITAL IMAGING AND THE NEXT GENERATION INTERNET

In its Visible Human Project, the NLM has developed another breathtaking application of information technologies: a digital "library" of CAT, MRI, and cryosection images, at one millimeter intervals, of the male and the female body. Begun in the last decade, this project is producing CD–ROMs and related materials for teaching and research that are now being used throughout the world. We are particularly proud that more than 1,000 commercial and nonprofit licenses have been issued by the NLM to use this free public database of images.

In addition, we are proud of the NLM's leadership in the federal government's Next Generation Internet Project, and overall efforts to use advanced telecommunications to improve health. This initiative, which involves a number of federal agencies and academic institutions, will experiment collaboratively with telecommunications technologies to increase the speed of data transmission by up to 100 times current levels while ensuring data integrity, security, and reliability. Success in this venture promises to propel the advance of telemedicine and telehealth, with its need for absolute reliability and data-heavy image transfers, into a new level of usefulness as a tool in medical practice.

Already NLM has invested significantly in telemedicine projects that are beginning to bear fruit. Just a few weeks ago a Boston newspaper ran a feature about how an NLM-sponsored telemedicine project in that city was helping new mothers care for infants whose precarious health requires special attention.

The Next Generation Internet also will allow NLM's National Center for Biotechnology Information to create high-speed, reliable connections between the Center and contributing genome sequencing centers and the worldwide participants in

the National Cancer Institute's Cancer Genome Anatomy Project. A new database containing the entire genome of the malaria-causing mosquito would also be created. High-speed connectivity is necessary if we are to process the avalanche of data coming out of the mapping centers, develop new computational analysis software, and provide effective access to scientists around the world. Most importantly, the "next generation" NLM will be able to make accessible images and other complex data as well as text materials to online researchers.

SUMMARY

We hope this brief account suggests our reasons for agreeing with leading members of Congress that it is indeed appropriate and essential to double federal funding of the National Institutes of Health and the National Library of Medicine over the next five years.

This is a moment of unparalleled possibility in the history of medical science, and we believe there is no better way to improve the lives of all Americans than to increase investment in the work of preventing and treating disease.

We believe the investment in NIH, and particularly for the National Library of Medicine, will result in the best health care and quality of life. Thank you.

PREPARED STATEMENT OF VICKI KALABOKES, CO-CHAIR COALITION OF PATIENT ADVOCATES FOR SKIN DISEASE RESEARCH [CPA-SDR]

Mr. Chairman and members of the subcommittee, my name is Vicki Kalabokes. I am the co-chair of the Coalition of Patient Advocates for Skin Disease Research [CPA-SDR]. The Coalition wishes to express its sincere thanks to you, Mr. Specter, and to members of the Subcommittee for your unwavering support of the NIH and biomedical research. The Coalition also thanks you for providing us with the opportunity to submit written testimony.

The Coalition of Patient Advocates for Skin Disease Research joins with our colleagues in the Ad Hoc Group for Medical Research Funding and the NIAMS Coalition to request an increase of 15 percent for the National Institutes of Health (NIH) in fiscal year 1999. This increase would provide the first year installment towards an effort to double the budget of the NIH over the next five years.

Although research into the basic mechanisms of skin disease is supported throughout the NIH, it is the mission of the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS) to address the causes, treatment and prevention of diseases of the skin. An increase of 15 percent would provide the NIAMS with a budget of $316 million in fiscal year 1999.

The Coalition is comprised of over 20 national lay skin disease organizations. The member organizations of the CPA-SDR are supported by patients and their families, Americans who live with skin disease daily. For the majority of patients served by our member organizations, treatment options continue to remain limited or, in some cases, nonexistent. The skin diseases represented by the CPA-SDR are chronic, costly, disfiguring, and sometimes fatal.

It is estimated that over 60 million Americans are treated each year for skin disease; skin disorders are among the ten most frequent reasons for physician visits annually. Skin disease is the most common cause of chronic illness in the United States and its economic cost is staggering—over $7 billion every year.

Funding for biomedical research at the NIAMS has significantly advanced our understanding of the skin, its important role in our immune system, and the structure and function of connective tissue. While much progress has been made, much more must be understood if we are to take the breakthroughs from the lab to the bedside.

Let me now discuss with you recent important breakthroughs in skin disease:

—The basic molecular mechanisms for two very serious, blistering skin diseases, epidermolysis bullosa (EB) and pemphigus, has been uncovered. In addition, scientists have also elucidated the molecular mechanism in a variant of EB that is associated with muscular dystrophy. This discovery provides scientists with a new understanding of muscle physiology in relation to muscle wasting disorders.

—The efforts of this Subcommittee has provided for many breakthroughs in the treatment of lupus. Now special prevention and education programs are in place to screen young minority women most at risk for this terrible disease. It is hoped that the screening process will allow physicians to diagnose this disease in its earliest stages, drastically reducing costs and improving outcomes.

—Tissue banks have been established for several skin diseases, including psoriasis, EB and ichthyosis. These pioneering efforts will lead to advances in therapies and ultimately cures for these diseases.

—Researchers now know that port wine stains form during the first 2–8 weeks of gestation. Additional research is needed to elucidate the role of angiogenesis in these stains.
—Researchers at the NIAMS and the National Cancer Institute have significantly advanced our understanding of skin cancer, the most common form of cancer in the United States. We now know that a gene is responsible for a rate inherited disorder, basal nevus syndrome and acquired basal cell carcinoma.
—Ichthyosis is a family of rare diseases in which there is abnormal development of the outermost layers of the skin. Researchers have made an important discovery—the genes for many of the molecules involved with the structure of our skin are clustered on chromosome 1. This area of chromosome 1 is called the epidermal differentiation complex.
—During the past year, the locus for pseudoxanthoma elasticum (PXE) was isolated. A recent international meeting on PXE was sponsored by the NIAMS and helped to define the next steps toward treating this disease. This may be a small step in understanding the complexities of PXE, but it provides the first glimmer of hope that a cure can be found.

Despite our progress, many extraordinary grants remain unfunded. Historically, the NIAMS has been below the NIH average with regard to success rate. This means that the NIAMS has funded fewer meritorious grants than many other institutes. Increased funding for the NIAMS will allow the institute to support more research grants in key areas of opportunity.

The Skin Diseases Research Core Centers are another important part of the NIAMS effort to unlock the many remaining mysteries of skin disease research. The CPA-SDR thanks the members of this Subcommittee for your support of these centers. In addition to the core centers, NIAMS has also announced that research initiatives in scleroderma would be eligible for funding under the SCORs program.

A skin disease research center grant provides funds for integrating, coordinating, and fostering interdisciplinary cooperation of a group of established investigators conducting research programs of high quality that relate to a common theme in skin disease. These centers bring together related facilities within six large, prestigious medical universities to pursue interdisciplinary research on skin diseases. By providing more accessible resources, these special grants ensure greater productivity at a given grantee institution. Indeed, a recent review of the centers programs supported by the NIAMS points to the skin disease core centers as a model for future efforts.

In addition to basic research funding, the members of the CPA-SDR are very concerned about support for clinical, patient-oriented research and for research training funds. We were pleased to learn of the high priority that Dr. Stephen Katz, the NIAMS Director, has placed on these areas. Translating the great discoveries of the bench to the bedside is critical, if we hope to improve the quality of life for skin disease patients. Furthermore, we must do everything that we can to encourage brilliant minds to consider a career in skin disease research. Funding for the NIH must include funding for increases in training stipends and encourage more experienced scientists to mentor new investigators.

We, the Coalition of Patient Advocates for Skin Disease Research, thank you again for your support and ask for your continued support in fiscal year 1999. Your commitment has meant so much to the many families that cope with chronic skin disease each and every day.

DISCLOSURE

The Coalition of Patient Advocates for Skin Disease Research receives no federal funding. The National Alopecia Areata Foundation, for which Ms. Kalabokes serves as executive director, received less than $5,000 from the Combined Federal Campaign.

PREPARED STATEMENT OF THE AMERICAN MEDICAL ASSOCIATION

MEDICARE RESOURCE-BASED PRACTICE EXPENSE—MEDICARE USER FEES

The American Medical Association (AMA) would like to submit the following statement for the record regarding the implementation of resource-based practice expense relative values, and the Administration's proposal to implement user fees in the Medicare program.

Medicare resource-based practice expense

The Balanced Budget Act of 1997 (BBA) included important provisions regarding the Health Care Financing Administration's (HCFA) development of resource-based practice expense values. Due to major problems with HCFA's initial proposal for resource-based practice expense values, the AMA strongly supported the BBA provisions extending the implementation date for the new payments and requiring that HCFA revise its proposal to incorporate accurate cost data. We were also pleased that Congress directed the General Accounting Office (GAO) to evaluate HCFA's methods and data and the potential impact of the payment changes on beneficiary access. The AMA continues to support the change to resource-based values, so long as they reflect the actual costs of clinical practice.

Since enactment of the BBA, we have been impressed with the dedication of both GAO and HCFA staff to meeting the Act's requirements. Project teams from both agencies have consulted frequently with AMA staff, particularly with regard to potential use of data from the AMA's annual survey of physicians in the new values. We believe that the GAO has developed an excellent report, and its recommendations are consistent with AMA policy.

The AMA is encouraged that HCFA's recent Report to Congress, also required by the BBA, suggests that HCFA is likely to adopt many of the modifications recommended by the GAO. Many of the GAO recommendations encourage HCFA to conduct sensitivity analyses and explore alternative options. The GAO does not recommend that HCFA use one specific alternative for the new values; however, and HCFA's report suggests that HCFA also is weighing multiple options. The AMA believes that HCFA should publish several different methodological options in its May 1998 proposed rule. The options could vary in the degree to which the practice expense values are based on the expert panel data or on data from the AMA's Socioeconomic Monitoring System (SMS).

Although the SMS was not designed to support the development of relative values and the sample sizes for some specialties are not large enough to produce statistically valid responses, it has become clear that no other valid and reliable cost data are currently available. With a response rate greater than 60 percent, the SMS is of high quality and is the only existing practice expense database derived from a randomly selected national sample. The SMS core survey has been conducted since 1982 by respected survey research firms and its validity is well-recognized. Therefore, the AMA, the GAO, and a number of medical specialties now agree that HCFA should make use of specialty-specific data from the SMS.

This use of specialty-specific data would be a marked departure from HCFA's June proposal, which used the SMS data only to establish the total proportion of direct and indirect practice costs. The SMS reveals significant practice cost differences among specialties, however, including wide variations in the total dollars expended on practice resources per hour worked, as well as on individual cost components, such as medical equipment, staff labor, and materials and supplies.

The AMA also agrees with the GAO that use of expert panels is an appropriate way to gather information about procedure-specific, or direct practice costs. However, the way that HCFA used the panel data in its June proposal indicated that even the agency itself had little confidence in the results. A variety of methods were utilized, including a statistical approach called "cross-specialty linking" and a series of across-the-board data "edits" that substantially reduced the cost estimates provided by the expert panels. HCFA did not describe the criteria that it used to judge the relative accuracy of the panel estimates. Nor did it explain its apparent conclusion that only one of the panels produced accurate results. Moreover, in contrast to the process used to construct the physician work values, the cross-specialty linking process for practice expense relied exclusively on statistical methods, with no opportunity for clinical judgment.

Despite our criticism of the way HCFA altered the direct cost data in its June proposal, however, the AMA believes that, if the expert panel data are to be a significant component of the new values, they require some adjustment and should not be used "as is." AMA observers attended all of the expert panel meetings and concluded that the panel estimates of billing costs, and possibly other administrative costs, were of questionable validity. Over the last six months, HCFA has made several well-intentioned but unproductive efforts to evaluate and correct these data. In our estimation, it is now time to move on and try other approaches to obtain accurate billing and administrative cost estimates.

We support the GAO recommendation, therefore, that HCFA either modify its linking approach significantly or eliminate the need for linking by making targeted adjustments to improve the expert panel data's consistency. We also agree with the GAO that the agency should explore the option of including billing and other administrative costs in indirect costs, such as office rent and other overhead costs. This

approach would eliminate the need to rely on panel estimates to measure billing and administrative costs for each procedure, thereby also eliminating the need to adjust or link the panel estimates for these resource costs.

With the expert panel and SMS data, we believe HCFA could develop reasonably accurate values. HCFA's Report to Congress and recent testimony suggests three major options for the revised proposal:

—Use the adjusted expert panel data for direct costs and SMS data on specialty costs per hour worked for indirect costs.

—Use the SMS data on total specialty costs per hour worked as the basis for the new values and use the expert panel data to allocate costs and assign relative values to specific codes within a specialty.

—Use the linked expert panel data for direct costs and use the SMS data to calculate specialty-specific ratios of direct to indirect costs in determining indirect relative values.

If possible, the AMA would like to see all three of these options published in the new proposed rule. Since all three options rely on existing data, the AMA agrees with the GAO that starting data collection over again would needlessly increase costs and delay implementation. While we are eager to see a detailed new proposal explaining how HCFA plans to use the various extant databases, we think it is highly likely that these data will prove sufficient for initial implementation of the new values to proceed as scheduled in January 1999.

Nonetheless, we also appreciate the GAO's recognition of the need for HCFA to engage in some limited additional data collection to validate the expert panel data and expand the information available from the SMS. These supplemental data collection efforts should be initiated before a final rule is issued, continue during the transition period, and be used to refine the initial values. As a first step, we believe HCFA could collect data on administrative and equipment costs from a representative sample of medical practices, firms that provide billing, coding, transcription, and equipment procurement services to practices, and industry groups such as the Medical Group Management Association and the Health Industry Manufacturers Association.

One of the most serious flaws in HCFA's June 1997 proposal was the application of a "behavioral offset" that would have removed more than $1 billion from Medicare's budget for physician services. HCFA actuaries' assumption that physicians would manipulate patient demand to recoup 50 percent of any payment reductions in their services led to a proposed 2.4 percent payment cut for all services. An earlier analysis by Physician Payment Review Commission (PPRC) staff suggested that the actuaries' assumption was incorrect.

Both the Medicare Payment Advisory Commission (MedPAC) and HCFA's Practicing Physicians Advisory Council have now recommended that no behavioral offset be applied when the new practice expense values are implemented. The AMA wholeheartedly endorses these recommendations. There is no reason to expect that physicians will manipulate utilization in response to payment changes. If for any reason utilization experience differs from projections, however, the expenditure target, or Sustainable Growth Rate established under the BBA, will adjust future payment updates to recoup any spending over the target. There is thus absolutely no reason to apply any behavioral offset.

Finally, we think it is important to note that controversy over the development of new practice expense values stems partly from the requirement that total practice costs under the new system cannot exceed practice costs under the old system. The problem with that requirement is that it ignores any increases in practice expenses that may have occurred since the original system was developed. We believe that physician costs have increased, however, in part because hospital restructuring and changing practice patterns have shifted care from the inpatient to the outpatient setting.

For example, a number of cardiovascular services now are frequently provided in the office rather than the hospital. Patients with complex illnesses that once would have required hospitalization are being treated in physicians' offices. Shorter lengths of stay for many surgical procedures have increased the number of post-surgical services and supplies provided in physicians' offices. In addition, it is possible that the volume of physician services may rise as more and more care is provided outside the hospital. Physicians then could exceed the expenditure targets established through Medicare' Sustainable Growth Rate formula, thereby triggering reductions in their future payment levels.

To fairly reimburse physicians for the increased overhead they incur from these changes in the current Medicare environment raises some difficult questions, however. Since virtually all payment changes today are required to be budget neutral, any efforts to compensate physicians for new costs they have assumed must be off-

set with payment cuts elsewhere in the Medicare program. Inpatient hospital services and physicians are paid out of two separate pools of money, however, so unless Congress directs otherwise, the offsetting pay cuts can only be applied to other physician services.

Since physicians are already subject to tighter constraints than other Medicare providers, many could be forced to respond to these additional pressures in ways that could erode the quality of care Medicare beneficiaries now receive. The AMA therefore suggests that Congress direct HCFA or MedPAC to consider whether some redistribution of funds between Parts A and B is needed to accommodate recent changes in the medical delivery system. We urge the Appropriations Committee to call for and appropriate funds for such a study.

Medicare user fees

The AMA is adamantly opposed to a series of so-called "user fees" included in the President's latest budget plan. Let us be clear: these proposals are not really "user fees". Instead, they represent a significant new tax on physicians and other health care providers and are completely at odds with Congressional leaders' goal of reducing or holding the line on taxes.

If enacted, these proposals could reduce Medicare's status with physicians to the same low levels as Medicaid's. Surveys by the Physician Payment Review Commission suggest that Medicare's physician payment rates are nearly a third lower than most private plans' rates. That gap is likely to widen under the terms of last year's Balanced Budget Act (BBA) since the Congressional Budget Office anticipates that over the next five years, Medicare's physician payment rates will fall by 11 percent across-the-board or 19 percent after adjustment for inflation.

Even as their payments have eroded, physicians have been hit year after year with burdensome new administrative duties that increase their overhead and detract from their time with patients. In their effort to root out fraud in federal health programs, government officials have contrived ever more elaborate paperwork requirements that frequently seem to assume that all doctors and hospitals are guilty of fraudulent behavior. At the same time, funds for informing doctors about new rules have shriveled, leaving them vulnerable to potential fraud charges should they misinterpret any of Medicare's 45,000 pages of complex rules and regulations.

To add insult to injury, the President now is asking physicians and other providers to pay for the privilege of dealing with Medicare's extensive paperwork and low payments. Alarmingly, his budget seeks more than $850 million in total and $660 million in new "user fees" or taxes. Between 13 percent to 15 percent of program administration costs would be financed out of the pockets of physicians and other providers. Government expenditures for running Medicare would drop to a paltry 1 percent of benefits or less than 10 percent of what even the most efficient private plans spend.

None of the new taxes or "user fees" would go into education or provider relations and many of the proposals would exacerbate Medicare costs and hassle. For example, under one proposal, doctors would be charged $1 for every duplicate or unprocessible claim. Physicians then would be penalized for resubmitting claims even when payment was seriously overdue or when the contractor had rejected the claim for trivial reasons. Should the Iowa doctor whose claims were denied because the contractor disapproved of his signature really have to pay for the right to go through the hassle of resubmitting all claims?

In another plan, rejected by Congress in the past, the President also wants to charge $1 to process any claim submitted on paper rather than electronically. Budget documents refer to a possible waiver for rural physicians but it is our understanding that the waiver would be so narrowly drawn that few physicians would qualify. Is it fair or wise to ask physicians anticipating retirement in a few years to invest in new computer equipment or leave Medicare? Other than raising money, is there any real purpose to another administration proposal to force physicians to enroll ($100) and re-enroll ($25 every five years) in Medicare?

To make matters worse, the same budget that asks physicians to help finance Medicare's operation also proposes to double prepayment claims reviews. Physicians certainly do not condone fraud and the AMA supports appropriately-designed prepayment reviews. However, past experience suggests that prepayment review sometimes results in automatic and unjustified claims denials. Physicians then will experience yet another increase in the costs of treating Medicare patients as they are forced to appeal all these automatic denials in order to receive the payments that are due them.

The timing for the President's onerous new tax proposal could not be worse. As the government prepares to launch the BBA's Medicare reforms, elderly and disabled patients are likely to look to their physicians for information on the wide

array of new choices and benefits available to them. But physicians coping with lower payments, increased paperwork, and new taxes may be forced to see more patients every day to cover their overhead. Many may find that they do not have time to stop and talk to patients about their new Medicare choices.

If the reforms Congress enacted in the BBA are to fulfill their promise, Medicare needs to spend more money, not less, on program administration. We therefore concur with the Administration that additional resources are needed and we urge lawmakers to move quickly before more key senior Medicare officials leave the program to work in private industry. The true users of Medicare are its 37 million beneficiaries, however, and we submit that the cost of running the program should therefore be shared by all Americans.

To pretend that the program can be adequately and equitably financed through a rash of new taxes on physicians and other providers is an elaborate and dangerous ruse that abdicates this nation's responsibility to its most venerable and vulnerable citizens. Like the Congressionally-created Practicing Physicians Advisory Council, we are unalterably opposed to this outrageous proposal and urge Congress to reject it swiftly and soundly.

The AMA appreciates this opportunity to submit our views for the record. We would be happy to respond to any questions the Committee might have on these important issues.

Prepared Statement of the Association of Maternal and Child Health Programs

Thank you for the opportunity to provide testimony to the Senate Labor Health and Human Services Appropriations Subcommittee. We, at the Association of Maternal and Child Health Programs, appreciate the Subcommittee's support of the Maternal and Child Health Services Block Grant.

For over 60 years, programs authorized within Title V of the Social Security Act, the Maternal and Child Health Services Block Grant, have helped fulfill our nation's strong commitment to improve the health of all mothers and children. State Maternal and Child Health (MCH) programs, supported by the federal Maternal and Child Health Services Block Grant, have demonstrated their ability to adapt through decades of change by responding to the emergence of new diseases, discovery of new vaccines, and evolving health financing and delivery systems while still fulfilling their core mission of improving the health of all mothers and children. Congress has remained committed to this public health program because it provides proven, preventive health care with demonstrated results. These results include reducing maternal and infant mortality, improving the health of newborns, immunizing and screening children to prevent life-threatening diseases, and helping children with disabilities function to their full potential.

The Maternal and Child Health Services Block Grant is the basic framework upon which states have built and maintained their systems of care for women and children. This framework assures access to quality maternal and child health services, including care for children with special health care needs. State MCH programs carry out core public health prevention activities, as well as provide or finance direct services for women and children who lack access to necessary care.

PUBLIC HEALTH PREVENTION

Investment in public health enables Americans to live longer healthier lives by preventing premature death and disability. In order to meet the challenges ahead, Congress must continue to invest in a continuum of public health activity that not only includes biomedical and behavioral research, but also includes investment in targeted health care services, disease prevention, and other cost-effective strategies such as those aimed at improving the health of women and children. As a proportion of overall health expenditures, federal public health activities account for approximately $25 billion of the estimated $1 trillion, roughly 3 percent, spent on health care in the United States.

Investment in public health, including maternal and child health, is cost-effective, preventive in nature, and results in improved health outcomes for mothers and children. For every dollar invested in prenatal care, three dollars are saved in subsequent health costs for the care of a low birth weight baby. MCH programs also assist in the delivery of immunizations to children. Immunizations are widely known to be cost-effective, and for every dollar spent on measles, mumps, and rubella vaccine $21 is saved.

Another important MCH program, newborn screening, prevents chronic diseases and disability through early detection, diagnosis and treatment. Currently, nearly

all 4 million newborns receive screening in order to avert tragic health consequences from genetic, metabolic, hearing and other disorders. In Illinois, 99 percent of its 190,000 newborns are screened for at least 6 disorders including sickle cell anemia. In Hawaii, the expansion of newborn hearing screening has enabled the average age of hearing loss identification to drop from 4 years of age in 1987 to 1 month in 1995. In addition to newborn screening, MCH programs provide early intervention and coordination of care for children with chronic diseases and disabilities. Through these efforts, children are able to function more independently and avoid institutionalization. Florida estimates saving $21,000 per disabled child over a 20 year period because of such early intervention efforts.

Finally, another important public health threat that is receiving increased attention this year is tobacco. Tobacco use and exposure to environmental tobacco smoke pose exceptional and immediate risks to pregnant women, infants, children, and youth. The serious health risks include low birth weight which is the strongest determinant for infant mortality and is associated with a wide range of problems. These health problems include cerebral palsy, epilepsy, respiratory illnesses, and learning disabilities. In 1995, the estimated costs of birth complications attributed to smoking were conservatively estimated at $1 billion. Given the enormous impact of tobacco on maternal and child health populations, state MCH programs have long supported tobacco control policy. They have worked in partnership with community-based groups, other public agencies, and the private sector to prevent and end nicotine addiction. The Association of Maternal and Child Health Programs (AMCHP) supports public health prevention strategies aimed at preventing tobacco use among our nation's pregnant women and youth.

With demonstrated, preventive programs such as prenatal care, immunizations, newborn screening, smoking cessation, and care for children with disabilities, the Maternal and Child Health Services Block Grant is a sound investment in the health of children and pregnant women.

POPULATIONS SERVED

The Maternal and Child Health Services Block Grant directly serves over 17 million women and children. Through grants, contracts, or reimbursements to private and public sector providers, state MCH programs support the availability and accessibility of community health and family support services, especially for the uninsured and underinsured families. These services range from doctors' visits for newborns to specialized treatment for children with special health care needs. Most recent data indicate that MCH programs supported preventive, primary, and speciality services for:

—Approximately 4.8 million women;
—Almost 11.3 million infants, children and adolescents; and
—Approximately 900,000 children with special health care needs.

Beyond direct services, the program reaches a much wider population of women and children through population-based services. These services include sudden infant death syndrome (SIDS) education, injury prevention, lead poisoning prevention, outreach activities, and public education to encourage healthy behaviors. Many parents are familiar with the "Back to Sleep Campaign" aimed at preventing SIDS deaths that was developed in collaboration with the Maternal and Child Health Bureau, the National Institute of Child Health and Development, and the American Academy of Pediatrics. Using the message from this campaign, state MCH programs have conducted public education activities to educate parents about putting their babies to sleep on their backs. SIDS deaths have dropped substantially for the population as a whole, but more research needs to be done to determine why rates have not fallen as much for minority populations.

UNMET NEED

Health status indicators

The health of our Nation's pregnant women and children has improved dramatically over the last 50 years. Advancements in medical technology and improved access to care, have seen reduced in many adverse health outcomes including maternal and infant mortality rates; however, our nation still falls short of its goals, especially for underserved and minority populations. Since 1980, our infant mortality has dropped for both blacks and whites, but there is still a substantial gap between the two.

—In 1980, the infant mortality rate for blacks was two times higher than the white rate. Fifteen years later, this gap has widened. In 1995, the black infant mortality rate was 2.4 times higher than the white infant mortality rate.

Another important indicator in child health is the number of babies born who are low birth weight. Low birth weight infants are at higher risk of death, long-term illness and disability than are babies of normal weight.

—The percentage of low-birth weight infants in the United States increased from 6.8 percent in 1980 to 7.3 percent in 1995.

Clearly, the increase in low birth weight babies is going in the wrong direction. Although important health problems have been alleviated, many still threaten the health of women and children. Smoking rates for adolescents are going up; injuries remain the leading cause of death for children; and women and children are at increased risk for HIV/AIDs.

Children's health insurance implementation and remaining needs

Last year, Congress took significant steps to address some of these health problems through passage of the State Children's Health Insurance Program. This health coverage expansion presents states with tremendous opportunities. During the current implementation stage, most state MCH programs have been working together with Medicaid agencies to figure out what is the best approach to serve the needs of uninsured children.

The Congressional Budget Office estimated that the new law would cover 3.4 million uninsured children when it's fully implemented. Even if every one of these 3.4 million children is enrolled in public insurance programs, and even if the 3 million uninsured children who are eligible for Medicaid sign up for that program, there will remain millions of youngsters—3.6 million to be precise—with no health coverage whatsoever. These 3.6 million young children and adolescents will need the health services that MCH programs and other public health programs provide or they will have no professional health care at all.

Although the State Children's Health Insurance Program fills a tremendous gap in coverage for many children, it does not cover all necessary services, or as I just mentioned, all populations. The new insurance initiative does not provide access to care, by which I mean transportation to clinics, and other services that bridge the gap between "eligibility" and actual service delivery. It does not provide services for uninsured pregnant women or for children with substandard insurance coverage. It does not cover comprehensive services for children with special health care needs.

As a result, a significant number of pregnant women will still need prenatal care and related health services. Without adequate access to these services, pregnant women will be at risk of having babies that are low birth weight or have other serious and potentially long-term health problems. Underinsured children—including those with only catastrophic health coverage through a parent's policy—will still require access to well-baby and well-child check-ups and other preventive services provided by state MCH programs. Finally, the complex medical conditions of children with special health care needs will require additional care by pediatric specialists, and care coordination not likely to be covered by the new children's health initiative. It is estimated that 13.4 percent of low-income, insured families with disabled children had unmet health care needs in 1994. This figure is not likely to change with the expansion of the new health insurance program. Clearly, the needs of pregnant women and children, the underinsured, and children with disabilities must still be addressed by the MCH programs with or without health insurance expansion.

Even as more children gain insurance coverage, MCH programs will continue to:

—Ensure the availability of public and private providers in underserved areas;

—Support and coordinate services for children who have complex medical conditions or disabilities;

—Provide "enabling services" such as home visiting to detect any health problems early on, and to teach parents how to prevent childhood injuries; and

—Get pregnant women and children into care through media campaigns, toll-free hotlines and outreach workers that link them with Medicaid, other insurance sources, and directly with providers.

FUNDING FORMULA/SET-ASIDES

The MCH Block Grant is a permanently authorized discretionary federal grant program. Its current authorization level is $705 million; in fiscal year 1998, $683,000 million was appropriated for the program. Of this $683,000 million, $3 million was earmarked for the traumatic brain injury demonstration project and other initiatives. The Association of Maternal and Child Health Programs recommends that new initiatives such as the traumatic brain injury demonstration project, be funded separately in fiscal year 1999. For appropriations up to $600 million, 85 percent of the appropriation is allocated to the states, and 15 percent is set-aside at the federal level for demonstration, research and training, and service projects. For

appropriations exceeding $600 million, 1989 amendments created a second set-aside of 12.75 percent to fund six types of demonstration projects: home visiting; provider participation; integrated service delivery; non-profit hospital MCH centers; rural programs; and community projects for children with special health care needs. States match $3 for every $4 Federal; many States provide additional funds. States must limit administrative costs to 10 percent; maintain state MCH funding levels at 1989 levels; and spend 30 percent of funds on preventive and primary care for children and adolescents, and 30 percent on services for children with special health care needs.

The MCH Block Grant's two Ufederal discretionary programs or set-asides: are the Special Projects of Regional and National Significance (SPRANS) program and the Community Integrated Service System (CISS) program. SPRANS grants are authorized as special projects that must respond to national needs and priorities, have regional or national significance, and demonstrate some way to improve State systems of care for mothers and children. SPRANS funds are reserved at the federal level for the purpose of supporting projects in five areas of research, training, hemophilia, genetic diseases, and maternal and child health improvement projects. SPRANS grants support technical assistance training and research policy development centers that work to build States' maternal and child health infrastructure and develop tools and information to help States improve the health status of pregnant women and children. While SPRANS grants focus on regional and national priorities, the CISS program targets communities through increasing the capacity for service delivery at the local level and fostering formation of comprehensive, integrated, community-level service systems for mothers and children.

One example of the good use of Federal grants is child care. With three of every children under age 6 in some form of child care setting, it is vitally important that these settings be safe and healthy. To this end, the Maternal and Child Health Bureau awarded nearly all states a grant of $50,000 each as seed money to promote health and safety in child care settings. In North Carolina, the state has used this grant as part of a larger initiative, Smart Start, which is a public—private partnership involving businesses such as Glaxo—Wellcome. The program promotes healthy child care by actually expanding access to health screenings and nutrition services onsite at child care settings, and educating child care workers about proper health and safety. If additional resources were available, states could make further improvements in the training of child care providers in the area of health and safety.

FUNDING RECOMMENDATION

To maintain cost-effective, preventive public health services protecting all our nation's mothers and children, the Association of Maternal and Child Health Programs recommends an appropriation of $705 million for the Maternal and Child Health Services Block Grant for fiscal year 1999. This modest request is approximately a 3-percent increase over fiscal year 1998. While AMCHP recognizes that there are limited federal resources, it should be noted that if the block grant's appropriation were to have kept pace with constant 1980 dollars, its funding level would now be approximately $730 million. With sufficient funding, this program can continue to play a vital role in improving the health status of all children and pregnant women.

PREPARED STATEMENT OF PATRICIA FRANKLIN, MSN, RN, CPNP, PRESIDENT, NATIONAL ASSOCIATION OF PEDIATRIC NURSE ASSOCIATES AND PRACTITIONERS

On behalf of the more than 5,500 members of the National Association of Pediatric Nurse Associates and Practitioners (NAPNAP), I appreciate the opportunity to provide the members of the subcommittee the views of the association and request that our statement be included in the record.

Founded in 1973, NAPNAP is the largest nursing organization dedicated solely to improving the quality of health care of children from birth to the age of 21. Pediatric nurse practitioners (PNPs), are registered nurses with advanced education and training who provide health care services and have prescriptive authority in 49 states. The PNP has completed a program of nurse practitioner (NP) preparation usually offered in schools of nursing as part of the Masters in Nursing Degree Program.

NP's were recognized in the Balanced Budget Act as a primary care providers and are now able to receive direct reimbursement from the Medicare program in all settings. Now more than ever, advanced practice nurses like PNPs are front line, point of contact providers of primary care services to an increasing number of Americans.

PNP's deliver a broad range of health care services to children from birth to age 21—performing physical examinations, treating common childhood illnesses, coordi-

nating care of chronic illnesses in children, and helping families meet other important health care needs. To support the increasing contributions PNPs make to the health care system, particularly in rural and medically underserved areas, NAPNAP requests your favorable consideration of spending levels for the following programs:

—Nurse Education Act: $70.92 million;

—National Institute of Nursing Research (NINR): $73.136 million; and

—National Health Services Corps (NHSC): request that the committee provide the appropriations necessary to assist the NHSC in developing a site assessment tool to evaluate the workforce needs of medically underserved areas and provide funding for necessary health care providers.

NURSE EDUCATION ACT

The Nurse Education Act (NEA) is the sole source of federal support for advanced practice nursing education. Advanced practice nurses (APNs) include nurse practitioners, certified nurse midwives, clinical nurse specialists, and certified registered nurse anesthetists. NAPNAP respectfully requests an 8 percent increase over fiscal year 1998 to a level of $70.92 million with proportionate increases appropriated to Sections 821 and 822, Advanced Nurse Education and Nurse Practitioner/Nurse Midwives, respectively.

APN's are in increasing demand in the health care market, and traditionally have filled the void of primary care physicians in rural and medically underserved areas. Increasing support for a diverse group of advanced practice nurses prepared as primary care providers will further the ability of the government and the profession to meet the health care needs of all Americans.

NATIONAL INSTITUTE FOR NURSING RESEARCH

The National Institute for Nursing Research (NINR) is one of the smallest NIH entities despite the growing responsibility of nurses, especially advanced practice nurses, for the primary care and case management of patients in all settings. In fiscal year 1998, NINR received a budget increase of 6.4 percent over fiscal year 1997, less than the 7.1 percent budget increase for the overall National Institutes for Health. To compensate for the disproportionate increase last year and in line with anticipated fiscal year 1999 NIH spending, we respectfully request that the subcommittee endorse a 15 percent increase in the NINR budget, commensurate with NIH funding levels.

This increase would provide funding sufficient to empower NINR researchers to explore the vast complexities of "end-of-life" care; a research area for which NINR was identified as the lead institute. End-of-life care involves the synthesis of complex care, pain management, and mental health services for patients and their families. Furthermore, NINR represents the largest health care profession—nursing—whose research agenda encompasses breakthrough developments in patient care, outcomes, and cost effectiveness; avoiding low birth weight babies; and maximizing the quality of life of people living with chronic conditions, a population which will grow as the baby boom generation ages.

NATIONAL HEALTH SERVICES CORPS

The National Health Services Corps (NHSC) has traditionally provided the funding necessary to bring vital health care to rural and medically underserved areas. At present, there are 146 counties without a physician, more than 50 percent of which are being served by a NP or a physician assistant (PA). NHSC funding makes this possible; however there are still approximately seventy counties not served by either a physician, NP, or PA.

Furthermore, NAPNAP has grave concerns regarding a shift in the National Health Service Corps policy on the placement of NPs in underserved areas. Traditionally, the program has paid for both family nurse practitioners and pediatric nurse practitioners; however in 1997, NHSC moved to eliminate PNPs from consideration for NHSC scholarships without any assessment mechanism as to whether this best meets the needs of the communities. We strongly urge the committee to direct the NHSC to develop a site assessment tool which assesses the resident characteristics of a community and then provide the appropriate health professional to meet those needs. Without this, the NHSC is left making arbitrary determinations about the providers placed in underserved areas—a disservice to all involved.

On behalf of NAPNAP, I thank the committee for this opportunity to present our views on the vital funding of nursing programs. We look forward to working with you through the appropriations process and welcome any questions, comments, or

concerns you might have. Please do not hesitate to call me should you desire additional information or have further questions.

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF EMERGENCY PHYSICIANS

The American College of Emergency Physicians (ACEP) wishes to thank the Labor, Health and Human Services, and Education Subcommittee of the Senate Appropriations Committee for the opportunity to present its views concerning implementation of a resource-based practice expense payment system.

ACEP is a medical specialty society representing over 19,600 emergency physicians. Emergency medicine is practiced as patient-demanded, broadly available, and continuously accessible care by physicians educated to engage in the recognition, stabilization, evaluation, treatment, and disposition of patients in response to unexpected illness and injury. The patient population is unrestricted and presents with a full spectrum of episodic undifferentiated physical and behavioral conditions.

ACEP supported the provisions enacted as part of the "Balanced Budget Act of 1997" (BBA) to delay the implementation of the new practice expense system and redirect the Health Care Financing Administration's (HCFA) efforts in devising the new system. ACEP also appreciates the oversight that the Subcommittee is providing on this issue in the hearing on March 10, 1998.

As the Subcommittee is well aware, due to concerns that HCFA's June 1997 proposed rule was based upon a flawed methodology, the BBA required HCFA to restudy the issue, taking into account "generally accepted cost accounting principles which (i) recognize all staff, equipment, supplies, and expenses, not just those that can be tied to specific procedures, and (ii) use actual data on equipment utilization and other key assumptions."

However, ACEP is concerned that despite this new Congressional directive, HCFA continues to depend upon a methodology and data that pre-date the enactment of the BBA and which are not based upon generally accepted cost accounting principles and do not utilize actual data. It is difficult for the College to understand how continuing on this path will comply with the requirements of the BBA.

The way is which HCFA calculates and allocates indirect practice expense is an especially important issue for emergency medicine because, as a hospital-based specialty, a substantial proportion of the specialty's practice costs are indirect in nature. However, after reviewing the June 1997 proposed rule and based upon HCFA's subsequent actions, the College believes that the way in which HCFA has chosen to measure and allocate indirect practice costs is seriously flawed.

For the practice of emergency medicine, this raises significant concerns with respect to two categories of expense. These are uncompensated care costs and readiness costs.

Uncompensated care

To accurately and fairly determine the level of practice expense for emergency physicians, it is essential that any new rule recognize certain aspects of emergency medicine, such as the cost of uncompensated care.

For the practice of emergency physicians, uncompensated care is a significant portion of indirect practice costs. This cost becomes even more significant in light of the fact that, in 1986, Congress passed the "Emergency Medical Treatment and Labor Act" (EMTALA), often referred to as the Federal "antidumping" law (section 1867 of the Social Security Act). Under EMTALA, emergency physicians are required to provide services to all persons who seek care in the emergency department, regardless of their insurance status or ability to pay.

As a direct result of this federal mandate, a substantial portion of the services provided by emergency physicians are never reimbursed. This federal mandate applies only to the practice of emergency medicine and is vigorously enforced through HCFA and the Medicare law. Violation of EMTALA can result in $50,000 fines for the physician and expulsion from the Medicare and Medicaid programs. As such, emergency physicians practice under a Federal requirement to provide significant amounts of uncompensated care to patients and face stiff penalties if they fail to do so.

The irony is that while HCFA oversees enforcement of EMTALA, resulting in high levels of uncompensated care for emergency physicians, HCFA has historically refused to consider this cost as a legitimate practice expense that Medicare should reimburse. Although ACEP supports the tenets of EMTALA and has always been dedicated to providing access to care for all those who seek it, HCFA should recognize that there is a financial consequence to sustaining this level of care.

All available evidence suggests that uncompensated care in the emergency department is large and growing. The 1996 National Hospital Ambulatory Medical Care Survey, conducted by the National Center for Health Statistics (NCHS), estimates that 16.8 percent of all visits to the emergency department are "self-pay", a term that reflects the uninsured population and usually results in no payment. In the same study, the NCHS estimates that Medicaid patients make up about 22 percent of the emergency department case mix. As any emergency physician will tell you, State Medicaid payment rates are, for the most part, unreasonably low, and often do not even cover the cost of providing care to Medicaid recipients.

Anecdotal reports from emergency physicians indicate that uncompensated care may account for between 20 and 50 percent of the physician workload, depending on where the physicians practice. Furthermore, the growth of managed care, both in public programs, such as Medicaid, and in the private sector, has led to increased levels of uncompensated care and under-compensated care, with virtually no means by which to shift the costs of such care to other payers.

As HCFA considers a new proposed rule to implement the resource-based practice expense system, ACEP strongly urges the agency and Congress to take into account the costs of uncompensated care.

Readiness costs

Emergency physicians are required to be available on a 24-hour a day, 7 days a week basis. Patients with a variety of injuries and illnesses arrive in the hospital emergency departments at any time of day or night. There is a value to the community and the nation in maintaining these readiness capabilities. As a result of the unscheduled nature of emergency medicine, emergency physicians may spend a portion of their time in an "availability" or "readiness" status awaiting the arrival of patients.

There is substantial economic costs involved in maintaining emergency physician resources on a 24-hour a day basis. Any practice expense approach that pays on an average per-case basis and fails to recognize this unscheduled demand for services is problematic for the practice of emergency medicine, particularly in low volume emergency departments, such as rural areas. The College is increasingly concerned that HCFA does not currently recognize these costs in calculating Medicare work values or practice expense values.

As with the costs of uncompensated care, ACEP urges HCFA and Congress to recognize "readiness" costs in determining the new practice expense payment system.

Conclusion

Emergency physicians are dedicated to providing access to emergency services for all populations, regardless of culture, background, economic status, or ability to pay. However, by mandating through EMTALA that emergency physicians and hospitals provide emergency care 24 hours a day, 7 days a week, Congress also determined that such access should be the law of the land. As a result, both uncompensated care and "readiness" costs are legitimate components of emergency physician practice expense and should be incorporated into HCFA's practice expense methodology. These costs help ensure that high quality emergency medical services are available whenever the need arises.

In sum, ACEP appreciates the opportunity to present our views on this important issue. The College would be pleased to work with the Subcommittee and HCFA to ensure that the new proposed rule accurately and fully recognizes the costs associated with the practice of emergency medicine.

PREPARED STATEMENT OF RONNY B. LANCASTER, M.B.A., J.D., PRESIDENT, ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

Mr. Chairman, thank you very much for the opportunity to present the views of the Association of Minority Health Professions Schools (AMHPS) regarding fiscal year 1999 appropriations for the Departments of Labor, Health and Human Services, Education and Related Agencies. I am Ronny Lancaster, Senior Vice President for Management and Policy at Morehouse School of Medicine, and President of AMHPS.

I would like to begin my statement by thanking this subcommittee for its past support of programs which assist AMHPS institutions. In particular, we very much appreciate the leadership of Chairman Specter.

AMHPS is an organization which represents 12 historically black health professions schools in the country. Combined, our institutions have graduated 60 percent of all the nation's African-American pharmacists, 50 percent of African-American physicians and dentists, and 75 percent of the African-American veterinarians. Our

12 schools are becoming even more ethnically and culturally diverse in terms of Hispanic students and Native American students, and most of these students and graduates matriculate from and are working in the nation's underserved rural and inner-city communities.

While African-Americans represent approximately 12 percent of the U.S. population, only 2–3 percent of the nation's health professions workforce is African-American. Studies have demonstrated that when African-Americans and other minorities are trained in these institutions, they are much more likely to serve in medically underserved areas, more likely to take care of other minorities and more likely to accept patients who are Medicaid recipients or otherwise poor. For this reason, it is imperative that the federal commitment to training African-Americans and other minorities in the health professions remain strong. Clearly, institutions which train disproportionately high numbers of minorities address an important national need.

In spite of our proven success in training minority health professionals, our institutions endure a financial struggle that is inherent in our missions to train disadvantaged individuals to serve in underserved areas. The financial plight of the majority of our students has affected our schools in numerous ways, such that we are not able to depend on tuition as a means by which to respond to the discontinuation of funding or other forms of federal support for health professionals education. Additionally, due to the fact that the patient populations served by the AMHPS institutions have historically been poor, our institutions have not earned money from the process of patient care at the time when the average medical school gets 40 to 60 percent of its operating revenue from patient care.

SPECIFIC KEY PROGRAMS SUPPORTED BY AMHPS

Health professions/disadvantaged minority training

The health professions programs supported by this subcommittee are the only Federal initiatives that are designed to deal with acknowledged health personnel shortages among diverse populations and in geographic areas.

The Minority Centers of Excellence Initiative, the Health Career Opportunity Program, Scholarships for Disadvantaged Students, and other health professions programs recognize and support the institutions that have a mission, commitment and record to addressing those shortages. The support provided for the Centers of Excellence program, represents, very frankly, the difference between keeping the doors open or closed at several historically minority health professions schools.

Our schools and students appreciate the support of this subcommittee in restoring funding for health professions programs in last year's bill. It is our hope that the President's budget proposal for fiscal year 1999 is more favorable than it was last year. Health professions organizations, including AMHPS, are recommending $306 million for fiscal year 1999 for health professions training.

Our association is also encouraging members of this subcommittee to review and co-sponsor H.R. 1895, the Disadvantaged Minority Health Improvement Amendments introduced by Congressman Stokes. H.R. 1895 would reauthorize many of the important health professions training programs, and its passage this year is critical.

National Institutes of Health

The historically minority institutions which I represent today are committed to narrowing the health status gap among minorities when compared to the general population. Our institutions can achieve this national goal by improving our research capabilities through continued development of our research labs, faculty improvement, and other learning resources. Three programs specifically address developing the research infrastructure at our institutions:

The Research Centers at Minority Institutions program at the National Center for Research Resources (NCRR) is helping us develop the research capability to solve health problems disproportionately impacting minorities. Funding for this program should grow at the same rate as NIH overall.

Second, the Extramural Facility Construction program at NCRR can help our schools catch up to our non-minority counterpart institutions by providing us the resources to build adequate research facilities. The subcommittee is urged to provide $30 million for fiscal year 1999 for this program.

Third, the Minority Health Initiative and the Office of Research on Minority Health at NIH each support critical specific disease related research initiatives through the various NIH institutes. We recommend a combined funding level of $80 million for these programs in fiscal year 1999.

Almost every health professions training and research institution in this country was built and developed with a significant contribution from federal sources. At this

stage in our development, minority institutions are prepared to accept and hereby request this same kind of support.

Mr. Chairman, as this subcommittee contemplates a significant increase in the budget for the National Institutes of Health, we believe that an unprecedented opportunity exists to provide the research and infrastructure building support that is necessary to allow our historically minority institutions to conduct research on equal footing with our sister majority institutions. We are recommending the establishment of a $1 billion research endowment initiative at NIH, focused on those individuals and institutions which have a historic commitment to studying and improving minority health status. The purpose of this initiative is to establish research endowments in minority institutions to ensure excellence and continuity in our research efforts.

Centers for Disease Control and Prevention

Minority populations of all ethnic backgrounds are at significantly increased risk of infectious disease, low birth weight, Hepatitis B. sexually transmitted diseases, tuberculosis, and other chronic disorders.

The Centers for Disease Control has taken a leadership role in combating these problems by supporting initiatives to control infectious and chronic diseases among disadvantaged minority populations through CDC's plan, "Addressing Emerging Infectious Disease Threats: A Preventative Strategy for the United States". With additional resources, CDC could begin to support community-based infectious disease prevention programs in each State.

Because of the proximity of minority health professions institutions to disadvantaged, medically underserved communities, CDC can and does play a leadership role in supporting disease prevention and public health education activities in partnerships with our institutions.

Our overall funding recommendation for CDC for fiscal year 1999 is $2.8 billion.

HHS Office of Minority Health

The HHS Office of Minority Health (OMH) has the critical role of trying to ensure that all Public Health Service agencies are focusing appropriate resources on improving minority health status in this nation. Although their task is daunting, progress has been made as a result of OMH leadership.

The OMH is assisting our institutional adjustment to the managed care environment by supporting a comprehensive study entitled Securing the Future of Minority Health

Professions Schools. The study is analyzing the challenges and capabilities of each of our institutions, and offering recommendations to our schools to better compete as patient care entities and as academic health centers.

To continue this study in fiscal year 1999, we are recommending additional funding of $1.5 million for the HHS Office of Minority Health.

Strengthening historically black graduate institutions/higher education

The Strengthening Historically Black Graduate Institutions, Title III, Part B. Section 326 is a program of extreme importance to AMHPS schools. This program allows historically black graduate institutions, including those represented by AMHPS to participate in the Part B programs for strengthening our schools. The funding from this program is utilized by our institutions to establish and strengthen development offices, to begin endowment development campaigns (a definite need of all HBCU's), and to enhance our educational capabilities on the graduate level.

The Higher Education Act Reauthorization added 11 Historically Black Graduate and Professional Schools to Section 326 of Title III, making 16 schools eligible for this funding. In order to accommodate the growth at these new schools and continue the progress being made at existing schools, increased funding is a necessity in the fiscal year 1999 appropriation for this program. A funding level of $30 million is necessary to accommodate the growth of the grant level at each of the Section 326 schools.

Closing

Mr. Chairman, please allow me to offer our sincere appreciation to you and the members of this subcommittee for the support you have provided for our institutions and our students. With congressionally funded programs for minority health and health professions education, we can overcome the disparity in health care in this country. We must be careful not to eliminate, paralyze or strangle the programs that have proven to work. There are success stories, but not enough of them. The lack of participation by minorities in medicine and the sciences is characteristic of a long-term, complex, multi-faceted set of variables which will require a sustained,

vigorous, and visionary commitment from our high schools, colleges, medical schools, and support organizations—and from this subcommittee and the entire Congress.

Once again, thank you for allowing our association the opportunity to present our views.

PREPARED STATEMENT OF JANNINE D. CODY, PH.D., PRESIDENT, THE CHROMOSOME 18 REGISTRY AND RESEARCH SOCIETY

Thank you for allowing me this opportunity to share some of our concerns with you.

My name is Jannine Cody. I am the founder and President of the Chromosome 18 Registry and Research Society, a support group for families affected by chromosome 18 abnormalities. I live in San Antonio, Texas. I am accompanied by members of our Board of Directors from Chicago and Detroit as well as some of our families who live in the DC area.

We are asking you to reevaluate the NIH funding priorities. Nationally, in our fervor to alleviate suffering and to insure a long and healthy life, we have ignored our most needy and vulnerable citizens. We have focused our medical research efforts on prolonging the end of life without equal commitment to giving people with mental retardation and developmental disabilities a complete life. A life of dreams and promise. A life of independence instead of dependence.

Thirteen years ago, my daughter Elizabeth was born with a severe cleft palate and cleft lip and foot abnormalities. A blood test revealed that these problems were caused by a chromosome abnormality called 18q-. This is a mental retardation syndrome caused by a missing portion from the long arm of chromosome 18.

The pediatrician gave us a photocopy from a medical textbook which made the following observation about kids with 18q-. "They are probably the most severely afflicted among carriers of chromosomal abnormalities. They maintain the froglike position observed in infants and are reduced to an entirely vegetative, bedridden life."

As you can imagine this was devastating news. Especially since she seemed so bright and alert. This information was accompanied by a long list of other possible congenital deformities associated with the syndrome. There was VERY LITTLE information about functional development such as growth, motor skills and hearing. There was NO information about increased risk for later onset conditions.

For us, our most immediate concern was repair of her cleft lip and palate. To date, she has had 12 surgeries and is about at the half-way point in the repair process. However, her first 4 surgeries, all before age 3, were all complicated by her failure to heal properly. We now know that her healing problems were caused by growth hormone deficiency which also causes short stature.. The 8 surgeries she has had since being on growth hormone replacement therapy have healed perfectly. She has had to face numerous surgeries to repair the complications resulting from her early failed surgeries because no one ever asked the simple question, "Why are kids with 18q- short?".

Because of Elizabeth, growth hormone deficiency is now known to be a common feature of the 18q- syndrome. And hopefully no future child will have to endure the pain and trauma of unnecessary surgery and abnormal scarring.

It was this finding in my daughter that spurred me to find other parents and to see that research is done to determine the nature of our children's problems. I started The Chromosome 18 Registry & Research Society in an effort to bring families together who are affected by chromosome 18 abnormalities. In order to insure that the research done on these syndromes is clinically relevant and is translated into patient useful information, I earned a Ph.D., in human genetics working on the 18q- syndrome. Our goal is to find treatments and not just supportive care for our children.

Today, my husband and I are trying to understand why two bone grafts to create a continuous gum line have failed. Why the bones in her feet are grown together. What can we do about her dyslexia? In spite of these many obstacles, Elizabeth is now in a hearing impaired 7th grade and her teacher says she is a whiz at history and science. Not exactly the vegetable that was predicted.

This might be my personal story, but the stories of any of our over 700 families are as equally compelling and frustrating.

18q- is only one of many types of chromosome abnormalities. These abnormalities are a leading cause of birth defects because chromosomes play a central role in controlling the cells that make up our body. Chromosomes are the packages of hereditary material that are in every cell of the body and are passed from one generation to the next. Individuals with Down syndrome have three instead of two copies of chromosome 21. There are many other chromosome abnormalities which can involve

all or only a part of any of the 23 pairs of chromosomes. Almost anything you could do to a picture of chromosomes with scissors and glue could really happen, but few are compatible with life.

The majority of people with chromosome 18 abnormalities have one of 5 different syndromes. A missing piece from the long arm of the chromosome is called 18q-, which my daughter Elizabeth has. A missing piece from the short arm is called 18p-. The chromosome can form a ring causing the loss of chromosomal material form both ends of the chromosome and is called Ring 18. Individuals can have an extra copy of chromosome 18 which is called Trisomy 18. An even more unusual rearrangement can result in an extra chromosome 18 which is composed of 2 short arms, giving the individual a total of 4 copies of the short arm. This is called Tetrasomy 18p.

These abnormalities can happen to anyone. There is no known ethnic bias. There are no know causes such as exposure to radiation or chemicals, before or during pregnancy. There is no way to protect your family. It could happen to anyone and it often does. Fifty percent of conceptions are thought to have chromosome abnormalities. However, 90 percent of those with abnormalities do not even implant in the uterus and become a recognized pregnancy. Of those embryos that are viable through early pregnancy the vast majority are miscarried. The abnormalities of chromosome 18 are probably some of the most common because they are more compatible with life. Babies conceived with a chromosome 18 abnormality are more likely to survive long enough to be born.

Many other parent support groups have information about the growth and development of their children. They have growth charts so that parents can see how their child is growing in comparison with other children with that same syndrome. Here is the growth chart for kids with chromosome 18 abnormalities. It is a normal growth chart. We will not settle for less than average, less than normal. If our kids are failing to grow normally, we intend to find out why and to fix it. Palliative and supportive therapy is not enough. We are determined to understand our kids problems and then to solve them, not to merely ameliorate them.

We have been extremely fortunate to have found a group of researchers who have had the vision to see that these are scientifically interesting syndromes. These syndromes are medically uncharted territory. These are syndromes that the age of molecular biology can make understandable. This is a opportunity to make a dramatic difference in the lives of many families.

One of our main organizational goals is to establish a Chromosome 18 Clinical Research Center. We thought that if we could provide money to gather preliminary data on the study of each of the syndromes, then these projects could move on to be Federally funded. We would just have to get the ball rolling. Our families have invested more than $700,000 to generate preliminary results and this has still not been enough. It has not been enough because the pot of NIH money available to study these syndromes in the mental retardation branch of the NICHD is disproportionately small. It is disproportionately small compared to the number of people affected by mental retardation and disproportionately small compared to the proportion of mental retardation caused by chromosome abnormalities.

As a nation, we have focused so intensively on adult onset conditions that we have not given adequate attention to those who have not been given the chance to grow into productive adults, to make adult choices and have adult dreams and aspirations. In 1996, 32 percent of the population was children and adolescents, yet only 14 percent of direct NIH funding was for pediatric research (1). Children's medical research needs have been unmet.

Compounded by that problem, seven and a half million Americans have mental retardation (2) representing 3 percent of the population (3). For fiscal year 1996, 3 percent of the NIH budget was 357 million , yet in that year only 86.3 million dollars were spent on mental retardation research by NICHD. One quarter of what should be spent based on population numbers alone.

However, population numbers alone should not determine the budgetary level of importance. The burden to society must be considered as well as scientific opportunity.

Individuals with development disability and mental retardation create an indisputable burden to society, not just in terms of health care but in special educational needs and in lifelong dependency. Money spent to cure these problems would be an investment in the future and potential of these individuals, and their caregivers, as well as an investment in the future of the nation as a whole.

Chromosome abnormalities represent a significant clinical and social burden. The very nature of chromosome abnormalities means that multiple body systems are affected. Individuals with chromosome abnormalities usually require many medical interventions, not to mention many supportive therapies such as physical, occupa-

tional and speech therapy. This places a burden on families that is often overwhelming. One parent may have to give up a job in order to meet the appointments of all the different medical specialists and therapists. The other parent is often locked into the same job for fear of losing health insurance. This is a recipe for stress, and 22,000 families join these ranks each and every year.

Scientific opportunity does not magically appear, it is bought. The Human Genome Project has bought us the advances necessary to begin to understand and to ultimately treat many human disease including mental retardation. Yet there is proportionately little clinical research on mental retardation or chromosome abnormalities.

Since 50 percent of mental retardation is caused by chromosome abnormalities and chromosome abnormalities have a defined genetic etiology they are the logical starting place for unraveling the mysteries of learning differences and mental retardation. The study of chromosome abnormalities could open many new vistas in cognitive neuroscience.

What we need is for you to realize that by studying chromosome abnormalities you would not just be helping our families, but you would be opening the door to understanding mental retardation and developmental disabilities. Chromosome abnormalities can serve as the key to understanding mental retardation and fulfilling the promise of the Human Genome Project which has provided us with the scientific opportunity.

You would be giving people back not just the end of their life but an entire life. A productive life. A life of independence instead of dependence. We have declared war on cancer so that adults might live a little longer. Now lets declare war on mental retardation so that children might have a full life.

With the promise of increased NIH funding in the air, please consider directing those funding increases in ways which will equalize research for the currently under-served populations such as those with mental retardation and chromosome abnormalities. These are areas of research which have great scientific promise, in a field in which there is currently little expenditure. These syndromes carry a significant social burden with life-long health-care and entitlement costs.

References:

1. A May 7, 1996 letter to Representative John Porter from Representative James Moran.
2. President's Committee on Mental Retardation, Fact sheet
3. Introduction to Mental Retardation, The ARC, September 1993.

Prepared Statement of Wadi N. Suki, M.D., President, American Society of Nephrology

INTRODUCTION

Mr. Chairman and distinguished Members of the Subcommittee, my name is Wadi N. Suki, M.D., and I am the President of the American Society of Nephrology (ASN), the national organization representing 6,500 physicians and researchers who are committed to finding cures for kidney disease. On behalf of the ASN, I would like to thank you for this opportunity to testify before you in support of the National Institutes of Health (NIH) and specifically the National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK), which provides funding for most of the kidney disease research in the United States.

ESRD PATIENT POPULATION CONTINUES TO GROW

Although recent data suggests that the United States is possibly seeing some reduction in the growth of new end stage renal disease (ESRD) patients, the number of individuals being treated for ESRD grew steadily between 1986 and 1993. Since 1993, the rate of increase is down to 7 percent from the 9–10 percent levels that were experienced for most of the pre-1993 era.

Between 1986 and 1995, the number of patients in this country with ESRD, that is total kidney failure, has more than doubled from 114,188 to 257,266. During 1995 alone, a total of 68,870 patients were reported as being newly treated for ESRD in the United States. Chairman Porter, in your state of Illinois, the number of people undergoing therapy for ESRD has doubled over ten years from 5,813 in 1986 to 12,285 patients in 1995. In Mr. Obey's state of Wisconsin, the number of patients undergoing treatment for ESRD increased from 1,939 to 4,649 over that same period. In Mr. Istook's state of Oklahoma, the patient population receiving therapy for ESRD grew from 1,100 in 1986 to 2,865 in 1995. For your review, I have attached

a table to my statement that outlines the dramatic rate of increase of people receiving therapy for end stage renal disease in each state.

In terms of survival, the expected remaining years of life or life expectancies for U.S. ESRD patient groups is on average one-half to one-sixth of the normal life expectancy. In lay persons terms, if you are diagnosed with ESRD, you will die sooner.

What causes ESRD

The causes of ESRD are diabetes, hypertension, glomerulonephritis, and polycystic kidney disease. Hypertension and diabetes affect minorities disproportionately, thus accounting for the higher incidence of ESRD in the minority population. Diabetes is the most common cause of kidney failure in Native Americans, and it leads to kidney failure more often in women than in men. ESRD continues to be a disease that affects African Americans and Native Americans at a rate 3 to 5 times the rate of White Americans. ESRD remains very expensive to treat both on a per patient basis and a program basis. The medical, social, and financial implications of this disease continue to make ESRD a major public health and public policy problem for our country.

Direct cost of ESRD to the Nation

In 1995, the total spending for ESRD treatment in the United States was an estimated $13.1 billion. This includes Medicare payments of $9.7 billion, $2.2 billion for Medicare patients' obligations, and an additional 0.98 billion for non-Medicare patients. In 1995, the average Medicare spending per patient/per year at risk was $40,000 for ESRD.

Current data shows that the growth in the number of ESRD patients remains the primary driver of increased total spending. Between 1991 and 1995, the rate of increase in spending per patient year was only 1.1 percent. Depending on which Consumer Price Index (CPI) is used, the rate of increase in real spending per patient year was either or minus 2 percent. As a result, spending per patient year has either remained constant or has decreased in recent years.

Although the cost to the Federal Government per ESRD patient has remained relatively neutral, the number of patients requiring treatment for ESRD continues to grow. In recent years, the total funding at NIH for kidney disease research has been a little more than two percent of this country's direct cost to treat ESRD. Most of this funding went to the National Institute of Diabetes, Digestive, and Kidney Diseases (NIDDK). This is a very small percentage, yet it is my view and the view of the members of the American Society of Nephrology that an investment in research is the only real opportunity we have to reduce the enormous Medicare costs and human suffering imposed by ESRD.

Advances in research

Nephrology research is currently addressing many issues that affect patients with kidney disease. We are defining the best dialysis regimens in patients with ESRD. In experimental animals, we are exploring treatments to prevent or shorten the course of acute renal failure. We have also cloned the gene responsible for polycystic kidney disease and are now studying the protein to determine how it causes this disease. Genetic defects in other familial diseases have also been identified. Hopefully, these discoveries will lead to new treatments and preventions.

Research is also addressing the mechanisms by which glomerulonephritis is induced, with the hope that this will lead to strategies for prevention. Antibodies against certain inflammatory proteins can arrest experimental focuses of glomerulonephritis. Soon this strategy will have to be tested in man.

Medical research, made possible largely through Congressional support, has given the men, women, and children who suffer from chronic renal failure hope. Thirty-five years ago, ESRD patients died. Dialysis technology was in its infancy, available only for patients with acute reversible rather than total permanent renal failure. Kidney transplants were only a dream.

Since then, millions of Americans have benefited from dialysis or kidney transplants. However, while treatment often prolongs life, ESRD remains a serious medical condition. There is a misconception that the dialysis patient is able to live a full, active life. Sadly, that is not the case.

Dialysis does not simply mean being hooked up to a machine 4 hours a day, three times a week. Dialysis patients commonly suffer bouts of anemia, nausea, fatigue, low blood pressure, chills, and itching (due to impurities in the blood). The body has difficulty adjusting to the frequent changes in toxicity levels, as toxins are removed and then build back up prior to the next dialysis. Many patients suffer depression, due to feelings of vulnerability and illness.

Children with chronic renal diseases present medical challenges not usually seen in adults. Children undergo continued somatic, mental and psychological maturation

even in the face of ESRD. Therefore, an understanding of how these issues of normal development interact with chronic renal disease in the production of abnormal growth and development is the highest priority.

Basic animal research led to clinical studies that have now established that the progression of chronic renal disease can be substantially slowed by: (1) treatment of blood pressure to normal levels; (2) use of specific types of anti-hypertensive drugs, that have kidney-protecting effects in addition to their action to lower blood pressure; and (3) dietary protein restriction. These approaches may well be responsible for the recently noted slowing in the rate of growth of ESRD in the U.S.

Fifteen years of NIH-supported research established the role of increased blood pressure in the kidney itself as an important cause of the loss of kidney function. These findings stimulated a clinical trial that demonstrated that captopril, a drug that lowers blood pressure in the kidney, could also reduce the progression of diabetic kidney disease by about 50 percent, a finding that will save the Medicare program an estimated $2.6 billion over the next 10 years. More clinical trials of this nature are needed.

Additionally, decreasing the anemia that accompanies chronic renal failure by the use of erythropoietin has been shown to reduce the incidence of heart failure in dialysis patients; increase the patient's sense of well being and exercise tolerance, as well as, improve their overall quality of life. Heart disease is the main cause of death in such patients.

Despite the progress we have made and the possibilities on the horizon, the mortality rate for ESRD patients is still very high. Approximately 50 percent of dialysis patients die within a few years after they begin treatment. The life expectancy of a 49-year-old ESRD patient is less than seven years, compared to 30 years for a healthy 49-year-old American.

From bench to bedside

Although solid basic research in the field of Nephrology has led to new discoveries in the prevention, diagnosis and treatment of kidney disease, more needs to be done in the area of clinical trials, studies and translational research (e.g., epidemiology, long-term longitudinal studies). Advances in understanding the mechanism of kidney disease and the discoveries of ways of arresting or modifying experimental kidney diseases will by necessity lead to the need to examine these strategies in patients with clinical kidney disease. This will create a need for professionals trained in the proper conduct, design, and analysis of data for clinical trials. There is also a need for properly trained officials to conduct longitudinal observation studies to better understand the natural history of kidney diseases. Funds will be necessary for training these individuals and for their research following the completion of training. In order to truly understand, diagnose, treat and hopefully cure kidney disease, it is imperative that we make a training investment in bio-staticians, clinical experts, and epidemiologists.

At present, there is only a modest level of clinical trials and trained investigators working to translate new discoveries and information into cures for kidney disease. As with other disease institutes, a cadre of clinical investigators need to be funded and properly trained on how to conduct clinical trials and translational research to take basic discoveries to the next level in finding a cure for kidney disease.

Although some funding does exist to train clinical investigators in the field of Nephrology research, additional resources are imperative if we are to be serious in combating this devastating disease. Without such an effort, kidney disease will continue to ravage this country.

ASN request for fiscal year 1999

The ASN is hopeful that a doubling of the NIH budget over the next 5 years, as called for in several pieces of legislation currently pending before Congress, can be achieved, and the ASN looks forward to working with each member of this Subcommittee and its Senate counterpart to accomplish this goal. For 1999, ASN feels strongly that this Subcommittee should approve a 15-percent increase above the 1998 level the NIH, as recommended by the Ad-hoc Coalition for Biomedical Research.

More specifically, for NIDDK and kidney research, ASN feels strongly that a 15-percent increase over the 1998 level is also appropriate if we are to be serious and move forward in eradicating kidney disease. Given the cost to human life and to the Federal Government caused by ESRD specifically, and of all the diseases for which research dollars are provided by the NIDDK, we urge this Subcommittee to provide a 15-percent increase.

Mr. Chairman, members of the Subcommittee, as President of ASN and as a representative to the Council of American Kidney Societies, I thank you for this oppor-

tunity and for your consideration of our request. That concludes my statement and I am prepared to answer any questions that you or other members of the Subcommittee may have.

PREPARED STATEMENT OF DR. JOHN F. NEYLAN, PRESIDENT-ELECT, AMERICAN SOCIETY OF TRANSPLANT PHYSICIANS

Mr. Chairman and Members of the Subcommittee, thank you for the opportunity to present testimony on behalf of the American Society of Transplant Physicians (ASTP).

I am John F. Neylan, M.D., Associate Professor of Medicine and Medical Director of the Renal Transplantation Program, at Emory University Hospital and I am President-Elect of the American Society of Transplant Physicians (ASTP). The ASTP, which has no governmental support, was established in 1982. Our membership, now over 1,000 members strong, is comprised of physicians and scientists actively engaged in the research and practice of transplantation medicine and immunobiology. Given that our membership spans the disciplines of cardiology, hepatology, nephrology, pulmonology, infectious disease, and histocompatability, and that 25 percent of our members are surgeons with an expertise in related surgical specialties of solid organ transplantation, the ASTP represents the largest and broadest number of professionals in the field of transplantation in the United States.

A principle goal of the ASTP is to serve as a forum for the exchange of scientific information related to transplantation and immunology and to promote and encourage research. One of the strategies for obtaining this goal is our annual scientific meeting. At the 1997 ASTP Annual Meeting in Chicago last May, we had over 1,000 abstracts submitted highlighting cutting edge science in transplantation medicine and immunobiology.

Today, my testimony will focus on fiscal year 1999 appropriations for the National Institutes of Health (NIH), particularly the National Institute for Allergy and Infectious Diseases (NIAID), National Institute for Diabetes, Digestive, and Kidney Diseases (NIDDK), National Heart, Lung, and Blood Institute (NHLBI). I will highlight those areas of research that need to receive additional emphasis and funding in fiscal year 1999.

During the next hour, four new names will join those 56,793 individuals in this country waiting for a solid organ transplant. And by the time I get home to Atlanta this evening, 10 individuals will have died because the wait for a transplant was just too long.

But, Mr. Chairman with increased funding for research there is hope.

Over the last 20 years, transplantation of solid organs has moved from experimental to accepted therapy, with nearly ——— performed in 1997 alone. The success of this procedure has improved greatly over the last few years with almost all solid organ recipients enjoying an 83 to 97 percent survival rate at one year. Much of this success can be attributed to research in immunosuppression that has been funded by previous NIH appropriations. However, this success has brought with it new challenges.

More and more individuals are agreeing to be placed on waiting lists for an organ transplant. As I mentioned before, 56,793 individuals are currently waiting for transplants, an increase of 255 percent in the last ten years. It is unfortunate and absolutely unnecessary for those in need of a transplant to go without the "Gift of Life." This happens because the supply of available donors is far less than the demand. Each year, the ASTP identifies the shortage of available donors as the number one problem in the field of transplantation.

In December 1997 the Administration launched a national organ and tissue donation initiative to encourage more families to discuss and understand there loved ones' wishes in regard to donation. This may help in reducing family refusal, which is the number one cause of loss of potential donors today. Therefore, the ASTP urges this Subcommittee to provide the Department of Transplantation located in the Health Resources and Services Administration with additional funds for fiscal year 1999. This funding will help to insure the success of the Administration's initiative and any other programs conduct by the Department of Transplantation that enhance donor awareness and improve the public trust in the process.

Research is central to all that occurs in the transplantation process. The ASTP believes that we are on the threshold of many important scientific breakthroughs in areas of transplantation research, such as rejection immunosuppression tolerance and xenografts. Because of this, the ASTP strongly urges this Subcommittee to continue its leadership in the area of biomedical research and provide a 15 percent in-

crease in funding for the NIH for fiscal year 1999. The ASTP supports this level of increase for the NIAID, the NIDDK, and the NHLBI, as well. By providing this increased level of funding, this Subcommittee will achieve the ultimate goal of doubling the NIH budget in 5 years. A concept supported by the ASTP and many of those societies who are members of the Ad hoc Coalition for Biomedical Research. With this level of increase, this Subcommittee and the Congress, as a whole, will have the personal satisfaction of knowing that they were responsible for expanding the general transplantation research authority at the NIH, as a whole.

With this expanded authority, clinical and basic transplantation funding at the NIH must be increased. In particular, we recommend that Congress and the NIH designate the following as high priority initiatives at the NIAID, the NIDDK, and the NHLBI.

The National Institute for Allergy and Infectious Diseases (NIAID)

(1) Basic and clinical immunology, stressing an understanding of immunologic mechanisms of tolerance and autoimmunity, evaluation of chronic transplant rejection, and immunosuppression in transplant patients.

(2) Basic immunology stressing the response to xenotransplants and methods to overcome the response.

(3) Further structures on identification and treatment of infectious disease risks associated with xenotransplantation.

The National Institute for Diabetes, Digestive, and Kidney Disease (NIDDK)

(1) Continuation of the liver transplant database.

(2) Studies to improve the survival of renal transplants, including improved mechanisms of donor and recipient matching.

(3) Clinical trials to compare the outcome of combined kidney-pancreas transplant to kidney alone for diabetic patients. Prioritize increased funding for pancreatic islet cell transplantation.

Great progress has been made in the field of pancreas transplantation and now simultaneous kidney/pancreas transplant offers greater survival at five years than kidney alone, and the majority of patients no longer need insulin. However, most insurance companies do not cover this combined transplant because definitive prospective studies have not been conducted. The NIDDK needs to sponsor a trial to document the superior benefit of combined kidney/pancreas transplant to convince third party payers and Medicare to cover this procedure, and further fund research to assess the comparative benefit of whole organ (pancreas) versus islet cell transplantation.

National Heart, Lung, and Blood Institute (NHLBI)

(1) Clinical trials in immunosuppression in heart transplantation.

(2) Research on chronic rejection, applying promising new technology such as intravascular ultrasound.

One new clinical advance is the development of an intravascular ultrasound imaging technique that allows measurement and detection of thickening of the vessel wall of the transplanted organ and follows these changes over time. This is currently being performed in heart transplant recipients, but the test is not reimbursed. This is the perfect opportunity to have NHLBI partner with industry to conduct a trial of new therapies to retard or prevent the development of this disease.

(3) Establish the creation of databases for each stage heart disease to understand the disease and plan future needs.

Heart failure is the number one admitting volume diagnosis in the Medicare system, the longest DRG, and it has the highest readmission rate. There are an estimated one million people with this diagnosis which has as much or more of an impact on the health care budget as any other disease. In addition, the increasing average age of the U.S. population indicates that this disease will only increase.

We talk quite a bit in the transplantation community about how receiving a transplant can be the "Gift of Life." You can't put a price tag in human terms of such a gift. Yes, a transplant procedure and follow-up care is expensive. But, relative to the lost productivity, the impact on quality of life, and the cost of living with end stage heart or renal disease, transplantation is cost effective. Also, it may be the only hope not just for improved survival, but for a full and healthy life for many individuals and their families. So, I end my remarks here today, by repeating ASTP's request that this Subcommittee and the Congress approve a 15 percent increase for the NIH for fiscal year 1999. Thus allowing the high priorities initiatives outlined above to be funded and commence.

PREPARED STATEMENT OF PETER E. SCHWARTZ, M.D., PRESIDENT, SOCIETY OF GYNECOLOGIC ONCOLOGISTS

Chairman Specter, Senator Harkin, and Members of the Subcommittee, I am Peter E. Schwartz, M.D. I am here today in my capacity as the President of the Society of Gynecologic Oncologists (SGO). The SGO is the only national medical specialty society devoted to the study and treatment of cancers of the female reproductive tract. These malignancies include cancers of the cervix, endometrium or uterus, and ovary. The SGO has more than 750 members who specialize in providing comprehensive care for women with gynecologic cancers, including prevention, diagnosis, surgery, and all subsequent therapy.

I am extremely grateful for the opportunity to provide public witness testimony on behalf of the SGO in support of increased funding for the National Institutes of Health, and particularly the National Cancer Institute.

My remarks today will focus on the three major types of gynecologic cancers, detailing their incidence and providing some examples of how additional research dollars are critically needed to improve prevention, diagnosis, treatment, and survival for the estimated 82,000 women who were diagnosed with a gynecologic cancer in 1997.

THE THREE MAJOR TYPES OF GYNECOLOGIC CANCERS

The three most common types of gynecologic cancers are cervical, endometrial or uterine, and ovarian cancer.

Cervical cancer

(1) Cervical cancer accounts for 6 percent of all cancers in women. In 1997, an estimated 14,500 women were diagnosed with invasive cervical cancer and an estimated 4,800 of those women died from cervical cancer. An estimated 65,000 women were diagnosed with pre-invasive cervical cancer.

Early detection greatly improves the chances of successful treatment. In fact, cancer of the cervix can be a preventable disease if women are regularly screened using the Pap test.

While the vast majority of cervical cancers can be prevented, there are usually no signs or symptoms associated with cervical pre-cancers and early cancer. The symptoms develop after the cancer has become invasive.

Survival rates of invasive cervical cancer patients are relatively high at eighty-seven percent one year after diagnosis and sixty-nine percent five years after diagnosis. However, we can and must do better.

Currently, there is some very exciting research being conducted to prevent and treat invasive cervical cancer. Some of the promising new developments include research in the following: (1) How certain genes called oncogenes and tumor suppressor genes control cell growth and how changes in these genes cause normal cervical cells to become cancerous; (2) New laboratory tests to detect the types of human papilloma viruses or HPV that appear to cause cervical cancer; and (3) Improvements in the Pap test. The most exciting research in this area is the work going on at the National Cancer Institute (NCI) in the area of vaccines for preventing and treating cervical cancer.

Increased funding for this research can speed new techniques for detection and treatment of cervical cancer to physicians and their patients.

Endometrial or uterine cancer

(2) Cancer of the endometrium is the most common cancer of the female reproductive organs. In 1997, an estimated 34,900 women were diagnosed with endometrial cancer and 6,000 of those women died from endometrial cancer.

While early detection improves the chances that endometrial cancer can be treated successfully, at this time, there are no recommended screening tests or examinations that can reliably detect most endometrial cancers in asymptomatic women.

In some cases, women experience symptoms of endometrial cancer, permitting diagnosis at an early stage. Unfortunately, endometrial cancers may reach an advanced stage before recognizable signs and symptoms are present.

The 1-year relative survival rate for endometrial cancer is 93 percent and the 5-year relative survival rate is 95 percent, if endometrial cancer is found at an early stage. The relative survival rate falls to 66 percent if the cancer is diagnosed at a regional stage.

To improve prevention, diagnosis, treatment, and survival of endometrial cancer patients, more research dollars are needed for projects such as the following: (1) determining the molecular pathology of endometrial cancer; (2) laparoscopic lymph

node sampling; (3) research regarding tumor markers; and (4) development of new chemotherapy drugs as well as angiogenesis inhibitors.

Ovarian cancer

(3) Ovarian cancer accounts for 4 percent of all cancers among women. Ovarian cancer ranks fifth as a cause of cancer deaths among women, and causes more deaths than any other cancer of the female reproductive system. In 1997, an estimated 26,800 new cases of ovarian cancer were diagnosed and an estimated 14,200 women died from ovarian cancer.

While early detection improves the chances that ovarian cancer can be treated successfully, early cancers of the ovaries rarely cause symptoms that women would notice, or the symptoms are mistaken for menopausal ailments or intestinal illnesses.

Early detection is complicated by the fact that the ovaries are deep inside the pelvis and cannot be seen directly without surgery. Small ovarian tumors are difficult for even the most skilled examiner to feel. In fact, there are no screening tests now available which are accurate enough to use in finding ovarian cancer early among women who have no symptoms.

Unfortunately, almost 70 percent of women with ovarian cancer are not diagnosed until the disease is advanced in stage. The 5-year survival rate for these women is only fifteen to twenty percent. More than ever, there is a need for a greater awareness and understanding of ovarian cancer. Educational efforts must be increased to ensure that women and their primary care physicians and gynecologists recognize the symptoms and understand the risk factors for ovarian cancer.

Additionally, now is the time to establish an agenda for more research into the areas of basic and translational research, genetic susceptibility and prevention, diagnostic imaging, screening and diagnosis, and therapy that could hold the most promise for future discoveries that will lead to improved prevention, detection, and treatment of ovarian cancer.

The PHS Office on Women's Health (OWH), the Society of Gynecologic Oncologists (SGO), and the National Cancer Institute (NCI), in an effort to put ovarian cancer at the forefront of our nation's cancer research agenda, sponsored a Strategic Planning Conference on New Directions in Ovarian Cancer Research on December 8–9, 1997, in Washington, D.C. The purpose of the Conference was to outline the priorities for ovarian cancer research over the next five years.

The Conference brought together a group of experts in gynecologic oncology, general oncology, diagnostic imaging, molecular endocrinology, and genetics, already armed with the knowledge of current procedures and techniques, in order to develop a strategic plan for ovarian cancer research.

The Conference participants identified the following eight critical components as the priorities for the strategy for attaining a greater understanding of the disease, and for which a commitment to increased funding and investment in biomedical research should be pursued:

EDUCATIONAL EFFORTS

The first critical component is to support greater educational efforts for both the physician and patient communities. Due to the fact that early detection of ovarian cancer is so difficult, and warning signs are often confused with symptoms of other types of abdominal ailments, it is essential that primary care physicians and gynecologists, as well as their patients, become aware of the potential early warning signs, the risk factors involved, and the importance of a complete medical history of both the patient and her family to assist in determining possible genetic risks.

INFRASTRUCTURE FOR THE STUDY OF OVARIAN CANCER

The second critical component is support for the development of a solid infrastructure for the study of ovarian cancer. Increased funding for ovarian cancer research is essential not only for Requests for Application (RFAs) and the creation of a Specialized Program of Research Excellence, otherwise known as a SPORE, but also for the recruitment and retention of young investigators as well as trained investigators from other fields. Innovative mechanisms to protect time for clinician scientists to conduct research are crucial, especially in the managed care environment that medical professionals now must practice in.

TISSUE PROCUREMENT AND BANKING

The third critical component is support for tissue procurement and banking. Tissue procurement and banking is an intrinsic part of clinical trials. By standardizing

tissue collection and storage, we can then gather epidemiological and follow-up data on ovarian cancer and correlate this data with molecular biological studies on the banked tissues.

IDENTIFICATION OF GENETIC CHANGES RELATED TO ALL STAGES OF OVARIAN CANCER

The fourth critical component is support for identification of all genes expressed in ovarian cancer tumors at all stages of the disease. This will facilitate the identification of molecular prognostic indicators, the identification of tools for early diagnosis, and the elucidation of the etiology of ovarian cancer.

TUMOR MAKERS AND DIAGNOSTIC IMAGING MODALITIES

The fifth critical component is support for the collection of data to evaluate the utility of current tumor makers such as CA125 and current diagnostic imaging modalities on mortality of ovarian cancer in a multinational randomized controlled trial. Such collection will also allow for the evaluation of additional markers to aid in detection of ovarian cancer.

COHORT STUDY OF PATIENTS AT A GENETICALLY HIGH RISK FOR OVARIAN CANCER

The sixth critical component is support for the development of a cohort study of patients at a genetically high risk for ovarian cancer. Such a study would provide a base for an assessment of ovarian cancer risk in relation to specific mutations, an evaluation of the benefits and risks of chemopreventive interventions, and an infrastructure for gathering tissue from prophylactic surgery in a uniform way for use in molecular studies.

EVALUATION OF CONVENTIONAL THERAPY APPROACHES TO OVARIAN CANCER

The seventh critical component is support for an ongoing, multinational evaluation of conventional therapy approaches to ovarian cancer. This would provide for an assessment of the role of cytotoxic chemotherapy and the role of surgical debulking, as well as an evaluation of the optimal time for surgical intervention.

DEVELOPMENT AND EVALUATION OF NOVEL INVESTIGATIONAL APPROACHES TO OVARIAN CANCER

And finally, the eighth critical component is support for the development and evaluation of novel investigational approaches to ovarian cancer. This includes research into anti-angiogenic agents, apoptosis targets, novel molecular targets, and gene therapy.

Chairman Specter, Senator Harkin, and Members of the Subcommittee, I greatly appreciate your time and attention to the need for additional resources for research being conducted for improved prevention, diagnosis, and treatment for gynecologic cancers. The SGO and I look forward to working with you in the years ahead on behalf of women and their reproductive health. I would be happy to answer your questions at this time.

PREPARED STATEMENT OF ROSALIE LEWIS, PRESIDENT, DYSTONIA MEDICAL RESEARCH FOUNDATION

I am Rosalie Lewis, President of the Dystonia Medical Research Foundation. It is my pleasure to have the opportunity to submit testimony to the Subcommittee on behalf of the Foundation.

First and foremost I would like to thank this subcommittee for its generous funding of the National Institutes of Health in its fiscal year 1998 appropriations bill. The Foundation is aware of the tremendous fiscal constraints under which you were working and we are extremely appreciative of your continued commitment and support of biomedical research.

I have been formally involved with the Foundation since 1989, but on a more personal level I have been dealing with dystonia since 1985 when the first of the three of our four children with dystonia was diagnosed. Dystonia has not only robbed my 20-year-old son Benjamin of the ability to walk unaided, or to use his hands for any fine motor coordination like writing, but now has made speaking most difficult. Like Benjy, my son Dan—now 17—also first exhibited symptoms of this disorder at age 7 and like Ben, dystonia has now made walking independently a challenge for Dan. The progression of early onset dystonia is relentless and uncontrollable. That is why, on behalf of the 300,000 other children and adults, I am asking for your help.

Dystonia is a neurological disorder characterized by severe involuntary muscle contractions and sustained postures. There are several different types of dystonia, such as: generalized dystonia which afflicts many parts of the body and usually begins in childhood (my sons Benjamin and Daniel have generalized dystonia); focal dystonias affecting one specific part of the body such as the eyelids, vocal cords, neck, arms, hands or feet (my son Aaron has a focal dystonia of the hand); and secondary dystonia which is secondary to injury or other brain illness.

There is no definitive test for dystonia (only now, with the identification of the genes responsible for childhood-onset and dopa-responsible dystonia is there a definite test for these two genetic forms). Many primary care doctors have never seen a case of dystonia. This fact coupled with its varied presentations make it difficult to correctly diagnose. It is estimated that 85 percent of those suffering from dystonia are not diagnosed or have been misdiagnosed.

In primary, uncomplicated dystonia, there is no alteration of consciousness, sensation, or intellectual function. Treatment for dystonia has met with limited and variable success with drug therapy, botulinum toxin injections, and several types of surgery. My children with generalized dystonia take huge doses of drugs which makes cognition difficult. But with a choice between walking and not walking, one may choose to tolerate drug side effects. Ben receives injections of botulinum toxin (botox) into the abductor muscles of his vocal cords, and he is experiencing moderate improvement.

I am proud to be involved with the Dystonia Medical Research Foundation, founded just 22 years ago and since 1993 a membership-driven organization.

The goals of the Foundation have remained the same: to advance research into the causes of and treatments for dystonia; to build awareness of dystonia in the medical and the lay communities; and to sponsor patient and family support groups and programs.

To advance research

Since 1977 the Foundation has awarded over 285 medical research grants totaling close to $15 million dollars. Among the more significant results of this research are the discovery this past year of the DYT1 gene, the gene for early-onset dystonia and in 1995 the identification of the gene for dopa-responsive dystonia. In addition, several drug therapies have been developed including the use of Botulinum Toxin, Baclofen, and Artane.

The discovery of the DYT1 gene for early-onset dystonia was made by Dr. Xandra O. Breakefield, geneticist at the Neuroscience Center of Massachusetts General Hospital in Boston, and her additional collaborators after two decades worth of research and over $1 million in contributions by the Foundation. With the discovery of the DYT1 gene came the identification of torsin A, the protein for which the DYT1 gene codes and which plays a crucial role in the chemistry of dystonia.

On November 13, 1997, Dr. Xandra O. Breakefield spoke at the National Institute of Neurological Disorders and Stroke on the hypotheses from her research, the significance of these discoveries and directions for future research. The following were presented based on Dr. Breakefield's research:

—It has been hypothesized that dystonia is caused by an imbalance in dopamine transmission to the basal ganglia, from the supporting data that: (*a*) drugs that block D2 receptors can cause dystonia symptoms; (*b*) dopa-responsive dystonia is due to a block in dopamine synthesis and treatable with dopa; and (*c*) dystonia symptoms occur in early-onset Parkinson disease and with low doses of dopa in Parkinson patients.

—It has been hypothesized the GAG deletion in torsin A disrupts (or decreases) the release of dopamine from the nerve terminal in a dominant-negative manner. Possible actions of this protein are as: (*a*) a heat-shock protein which protects dopa-minergic neurons from stress—such as high body temperature or overuse; (*b*) a component needed for vesicular release of dopamine at nerve terminals; and (*c*) a chaperone protein need for mitochondria integrity.

—Future research is necessary to determine the normal function of the torsin A protein through cellular localization, expression of the protein in the brain, animal models, interaction proteins, and functional assays in culture. Other members of the newly discovered torsin family of human proteins need to be mapped for and tested for involvement in other forms of dystonia; these proteins may be involved in other forms of dystonia or another neurological and psychiatric diseases, as our present knowledge of torsin A and childhood-onset dystonia suggests a new kind of pathogenic mechanism associated with a particular window of time of susceptibility combined with some kind of environmental or endogenous stress.

To build awareness

It is the goal of the Foundation to educate the lay and medical audiences about dystonia so that people afflicted with the confusing symptoms need not go undiagnosed or misdiagnosed as is so common.

The Foundation conducts medical workshops and regional symposiums during which comprehensive medical and research data on dystonia is presented, discussed, and then disseminated. In October 1996 the National Institutes of Health (NIH) was one of our co-sponsors for an international medical symposium with 60 papers on dystonia and 125 representatives from 24 countries.

Over 3,000 medical videos have been distributed since 1995 to hospitals and medical and nursing schools and at medical conventions. In addition, media awareness is conducted throughout the year but most especially during Dystonia Awareness Week, to be observed nationwide in 1998 from October 11th through the 18th.

To sponsor patient and family support groups

The Foundation has more than 200 chapters, support groups and area contacts across the United States and Canada. We have 15 international chairpersons representing awareness, children's advocacy, development, extension, the Internet, leadership, medical education, the on-line news group, and symposiums.

Patient symposiums are held regionally in order to provide the latest information to dystonia patients or others who are interested in the disease. Since 1995 we have held fifteen regional symposiums to attract, educate, and inform more people about dystonia. In 1998 we will have five more symposiums. Our most recent international patient symposium was held on May 24–26, 1996 in New York City, and was a tremendous success with 350 in attendance.

The National Institutes of Health and Dystonia

As mentioned, in October of 1996 we conducted a major medical symposium with support of the National Institute on Neurological Disorders and Stroke (NINDS). In February 1993 the Dystonia Foundation co-sponsored with the National Institute on Neurological Disorders and Stroke an international workshop to bring together basic and clinical investigators. We continue to need "a greater interaction among researchers from different scientific disciplines [and] carefully collected epidemiological information on the dystonia subtypes * * *. NINDS encourages these ongoing research efforts towards the elucidation, treatment and eventual prevention of the various subtypes within the clinical spectrum of dystonia."

As you probably are aware, it can be extremely difficult for young scientists to break into the NIH grant system. The Dystonia Medical Research Foundation recommends that the National Institutes of Health, the National Institute on Neurological Disorders and Stroke, and the National Institute on Deafness and other Communication Disorders be funded for fiscal year 1999 at a 15-percent increase over fiscal year 1998. This increase would be part of an overall request to double funding for the National Institutes of Health by fiscal year 2003. We would request that this increase does not come from funding sources which will require budgetary cuts in other public health service organizations. Because dystonia is the third most common movement disorder after Parkinsons and tremor and affects Americans six times more than most better known disorders such as Huntington's, Muscular Dystrophy, and ALS, we ask that NINDS fund dystonia-specific extramural research at the same level it supports research in those other neurological diseases.

With the proper dedication of resources, we believe that more treatments and a cure can be developed that will help my three boys—Aaron, Benjamin, and Daniel, and thousands of others.

Thank you for the opportunity to submit testimony to the Subcommittee on behalf of the Dystonia Medical Research Foundation.

Prepared Statement of Allison Rumery-Rhodes, Sudden Infant Death Syndrome Alliance

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to submit testimony to you regarding the federal government's response to and funding of Sudden Infant Death Syndrome (SIDS).

As the parent of a child who died from SIDS, I would like to remind you that SIDS is a frightening disease that knows no geographic, economic or cultural boundaries. It can strike any infant, even if the parents do everything "right." In the typical, but always tragic SIDS case, an apparently healthy child is put to bed without any indication that something is wrong. Sometime later, the infant is found dead.

The infant's prior medical history, a complete postmortem examination, and a thorough investigation of the death scene provide no explanation for the cause of death.

Although cases of the syndrome have been noted since biblical times, organized scientific research into the cause of SIDS is recent, dating to the mid-1970's. After decades of scientific study, we are just beginning to make real progress in reducing the number of babies dying of SIDS and are starting to unravel the mystery. The U.S. "Back to Sleep" campaign has heightened awareness about SIDS and offered parents an opportunity to reduce their infant's risk for SIDS. Initial results from this campaign indicate that SIDS rates have been reduced by 38 percent, the highest reduction in infant mortality rates in 20 years! We have also learned that some infants who die of SIDS have an abnormality in a region of the brain thought to play a role in heart and lung control. This defect may hamper normal respiratory activity, and though not the sole cause of SIDS, it may contribute to a larger respiratory impairment leading to the baby's death. Whereas healthy babies' nervous systems detect breathing difficulties and arouse them, it is believed that SIDS babies may not be able to detect reduced levels of oxygen or elevated levels of carbon dioxide. Therefore they do not respond by gasping for breath, crying, or turning their heads like a non-impaired infant, leaving them more vulnerable to SIDS.

These are important breakthroughs, expanding our understanding about SIDS and offering renewed hope that with further research we will be able to identify babies that are most vulnerable and ultimately prevent all SIDS deaths. However, our work is far from over. In this country more than 3,000 infants die each year as a result of SIDS. SIDS is the number one cause of death for infants one month to one year of age. It is a major component of the high rate of infant mortality in the United States, yet we still do not know what causes SIDS nor how to prevent it from claiming so many young lives.

The primary federal agency responsible for conducting research into SIDS is the National Institute of Child Health and Human Development (NICHD) at the National Institutes of Health (NIH). In addition to federal funding of SIDS research, there are other agencies involved in SIDS efforts. Since 1975, the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) has supported specific programs for SIDS family counseling and for public and professional education about SIDS. Currently, MCHB is implementing SIDS initiatives recommended by the federally funded "Nationwide Survey of Sudden Infant Death Syndrome Service," including a grant which was issued for a new SIDS Services Center in 1997. The Centers for Disease Control and Prevention (CDC) has established a standardized death scene investigation protocol for SIDS incidents. An Interagency Panel on SIDS, which includes the NIH, HRSA, CDC, Indian Health Services, Food and Drug Administration, Substance Abuse and Mental Health Service Administration, US Consumer Product Safety Commission, Department of Defense, Administration for Children and Families, and the Department of Justice help coordinate SIDS activities between government agencies.

National Institute of Child Health and Human Development.—Mr. Chairman, thanks to the funding which has been provided by this Subcommittee, researchers supported by the NICHD SIDS Program have been making real progress in the fight against SIDS. In 1988, at the request of Congress, the NICHD assembled a group of scientists to examine the current state of knowledge about SIDS and articulate future SIDS research needs. The result of this effort was the SIDS Five Year Research Plan. The Five Year Plan was so successful and productive that a second SIDS Five Year Plan was initiated in fiscal year 1995. Through research projects sponsored by NICHD, scientists have expanded our base knowledge of SIDS and our understanding of the causes and underlying mechanisms of the syndrome. Research objectives have focused on: identifying infants at risk for becoming victims of SIDS including developing markers to detect which babies are most vulnerable; clarifying the relationship between high-risk pregnancy, high-risk infancy, and SIDS; investigating factors which place babies at higher risk and stresses that may trigger a SIDS occurrence; and exploring mechanisms and interventions that may prevent SIDS deaths.

Provided below are a few examples of new or expanded initiatives that could be implemented with a funding level of $17,355,000 in fiscal year 1999 for the SIDS Five Year Research Plan.

—Establishment of a community child health research network in communities with substantial under-represented minority populations to develop and implement common biomedical research protocols targeted at reducing morbidity and sudden death in infancy and early childhood, and to train minority researchers.

—A study to validate potential predictive biologic tests for SIDS risk, such as computer analysis of heart rate variability and cry characteristics, in the general population.

—Issue a request for applications on the biology of arousal to inform the research community of NICHD's interest in grant proposals covering molecular, cellular, organ system and behavioral aspects of arousal in developing organisms.
—Extension of the prospective "Infant Care Practices Study" which is evaluating care-taking practices from birth through one year of age in two geographic areas. This project provides information to improve the efficacy of the "Back to Sleep" campaign.
—Expansion of the "Back to Sleep" campaign to improve the efficacy of the public health education effort. Additional resources are needed for the development and distribution of culturally relevant materials for minority groups, outreach to minority groups and day care centers, education of fathers and grandparents, exhibits and speaking engagements, and for evaluating the delivery of the strategies used to change the behavior of care givers.

The SIDS Alliance is grateful to the Subcommittee's past support. We urge you again to provide the additional funding necessary for the fifth year of the second Five Year SIDS Research Plan so that NICHD can complete critical initiatives. Further research is essential to find the reasons for, and means of preventing the tragedy of Sudden Infant Death Syndrome.

Centers for Disease Control.—Due to inconsistencies from state to state at the scene of an unexplained infant death, in 1993 Congress recommended that a standard death scene protocol be established. The hope was that the death scene protocol would be adopted by states to assist in developing a better statistical grasp on SIDS cases, and would help to avoid awkward and sometimes emotionally charged misunderstandings at the scene. In July 1993, the Centers for Disease Control and Prevention and the National Institute of Child Health and Human Development held a workshop on "Guidelines for Scene Investigation of Sudden Unexplained Infant Deaths". The proceedings of the workshop were published in the American Journal of Forensic Sciences in 1995. The actual protocol was published in the Mortality Morbidity Weekly Report in the summer of 1996. Since then it has also been republished by the Journal of SIDS Infant Mortality. 5,000 copies of the "Guidelines for Scene Investigation of Sudden Unexplained Infant Deaths" have been printed, and approximately 4,000 copies have been distributed to date. The long term goal of the SIDS Alliance is to work with and encourage each state's adoption of the guidelines. To help to realize this goal the SIDS Alliance would like to request that the CDC create a demonstration project to test the implementation of these guidelines in several communities nationwide.

Maternal and Child Health Bureau.—The MCHB supports a number of SIDS related services and issues, including the National SIDS Resource Center, a major source of current information about SIDS. The Center maintains a national database of approximately 5,000 books, reports, and articles on SIDS and bereavement, and publishes information for national distribution. The National SIDS Resource Center has played a significant role in the "Back to Sleep" campaign, staffing the 800 hotline number and processing the more than 4 million pieces of campaign materials.

MCH Service Block Grant funds are used by MCH State Directors, either alone or in combination with non-federal funds, to provide a range of services to SIDS families in each state. Block grant funds support activities such as contact with families immediately after death; discussion of the autopsy results with the family; and family support through the first year of bereavement. Unfortunately, in many jurisdictions across the country, funds for these services have decreased or even been eliminated because of budgetary difficulties.

At the direction of Congress, MCHB funded the "Nationwide Survey of Sudden Infant Death Syndrome Services" in 1992. In response to needs identified through the Survey, MCHB contracted the development and field testing of a curriculum to train health care providers in the case management of families who have experienced an infant death, as recommended by the Survey. To date, 100 health professionals have participated in the training program. MCHB is also supporting the development of model programs to meet the needs of families—particularly the under served and minorities—who experience an infant death, as recommended by the Survey. Four demonstration grants in California, Massachusetts, Missouri and New York have been initiated to target services for specific populations.

Recently, the MCHB established a national SIDS program support center to address SIDS service issues at the federal level on an ongoing basis. The SIDS Alliance has been chosen to run this center, which opened this year. The center was another recommendation of the SIDS Survey.

Fourth SIDS International Conference.—The SIDS Alliance, in conjunction with SIDS International and in cooperation with NICHD, MCHB and CDC hosted the Fourth SIDS International Conference on June 23–26, 1996 in Bethesda, Maryland.

Over 700 registrants and 300 guests participated in this unique event. The partnership of countries provided by the International Conference has resulted in a heightened awareness of SIDS throughout the world, as well as a vital link allowing the rapid exchange of high quality international research, prevention, and service data. The global focus of efforts facilitates scientific breakthroughs and enables the development of innovative public health strategies to combat SIDS and assist families. Collaborative efforts such as the Fourth SIDS International Conference are crucial in moving forward with all aspects of activities relating to SIDS including research, death scene protocol and local SIDS services.

We are all too painfully aware, Sudden Infant Death Syndrome has historically been a mystery, leaving in its wake devastated families and bewildered physicians. In the past there have been no answers to why a baby dies of SIDS. For new and expectant parents there have been no answers on how to prevent SIDS from claiming their child. But today, we are beginning to find some of the answers such as factors that increase the risk for SIDS and actions parents can take to reduce the risks. Recent research has provided us with an unprecedented opportunity to decrease the number of SIDS deaths by alerting new parents about a few simple steps that they can take. It is important to realize however, that while following the recommendations presented may help to prevent some SIDS deaths, it will not save all babies; we still do not know what causes SIDS nor do we know how to predict which babies are vulnerable.

There is still a great deal more that needs to be done in the fight against SIDS. It would truly be a tragedy if research efforts were halted or delayed at the point when so much progress is being made. Research capability and technology are available to conduct additional studies that will advance our abilities to eliminate SIDS. Now is the time for us to do something about SIDS and prevent babies from dying of SIDS in the future.

As a SIDS parent, I am active in private organizations such as the SIDS Alliance that provide support to newly bereaved families, educate the public about SIDS and reducing the risks for SIDS, and fund SIDS research; but these organizations cannot do it alone. We need your help, your commitment, and your support. Moving towards the 21st Century, the political and fiscal realities of the world require that the public and private sectors work together to solve societal problems.

I urge the subcommittee to support SIDS research and education by funding the NICHD at a level of $775,980,900. This is an increase of $10,121,490 or 15 percent over the fiscal year 1998 budget. This increase would be part of an overall request for doubling funding for the National Institute of Health by fiscal year 2003. We would request that this increase does not come from funding sources which will require cuts in other public health service agencies. As this subcommittee works toward doubling funding for the National Institutes of Health, we believe that it is reasonable to anticipate a doubling of the funding commitment to SIDS research through NICHD. We also request that Congress continue to encourage MCHB and CDC to move forward with their initiatives to help SIDS families by expanding the availability of services and promoting standardized, thorough and compassionate death scene investigations.

On behalf of the thousands of families who have been devastated by the loss of a baby to SIDS, and the millions of concerned and frightened new parents each year, we thank you for your past leadership and support, and for enabling the Sudden Infant Death Syndrome Alliance to provide this testimony. If you have any questions, please do not hesitate to contact us.

PREPARED STATEMENT OF SUSAN SCRIMSHAW, PH.D., DEAN, UNIVERSITY OF ILLINOIS SCHOOL OF PUBLIC HEALTH, ON BEHALF OF THE ASSOCIATION OF SCHOOLS OF PUBLIC HEALTH

Mr. Chairman, I am Susan Scrimshaw, dean of the School of Public Health at the University of Illinois at Chicago and a chair of the legislative committee of the Association of Schools of Public Health.

I would like to thank you, Mr. Chairman and members of the subcommittee, for the opportunity to present our statement on the ASPH fiscal year 1999 appropriations requests for PHS programs of primary concern to the academic public health community. You will find a chart at the end of my statement that outlines these recommendations. For now, I would like to highlight some of them.

Health professions education

Although we are pleased that the Administration recommended level funding for HRSA's health professions education and training programs (much better than last

year's proposal to cut them), we strongly recommend that Congress tackle a problem that has been left to fester for over a decade: the lack of adequately trained public health professionals to run this country's public health system. In 1988, the Institute of Medicine (IOM) found that the U.S. public health infrastructure was in a state of disarray and identified serious shortages of public health professionals. According to HHS, the U.S. public health system is still disorganized and experiencing shortfalls in the number of comprehensively-trained epidemiologists, biostatisticians, maternal and child health and environmental health specialists, public heath nurses, dentists and physicians, among others.

According to experts in the Public Health Service, less than 100,000 of the estimated 500,000 in the public health workforce have graduate education in the public health sciences. It is estimated that at least 40,000 environmental public health specialists require further training and education in order to function effectively on the job. Yet there is still a need for 120,000 more to staff unfilled vacancies.

There is a need for more public health physicians, dentists, and nurses. For example, there are only about 4,300 certified preventive medicine physicians in the U.S., yet the estimated need hovers around 10,000. Much the same can be said about dentists (there are 128 certified public health dentists as compared to the 5,000 that are required today) and public health nurses. Furthermore, federal, state and local public health officials report problems in recruiting epidemiologists, biostatisticians, maternal and child health, occupational health professionals, and public health nutritionists.

We are concerned that the large majority of practicing public health professionals currently lack the skills, knowledge and competencies to do their important jobs effectively. My school conducted a study recently and found that only about 25 percent of local public health departments have the staff to adequately address the three core areas of public health: assessment, policy development and assurance. Mr. Chairman, we need your help in seeking solutions to these inadequacies. We spend over $6 billion a year to ensure that physicians are well trained in the medical sciences to treat and cure diseases; yet we spend mere pittances to train professionals to prevent those diseases, promote health and diminish disability among U.S. citizens.

The rush toward controlling medical care costs has created the managed care movement. This development has increased the need for public health professionals, persons with the skills, knowledge, competencies and values to address the characteristics and challenges of this emerging health care system. According to the Pew Charitable Trusts, these are: greater orientation towards health; prevention of disease and disability; focus on the health status of populations/communities; expectations of accountability and cost control; knowledge of treatment outcomes; reconsideration of human values. Yet professionals with knowledge and skills to address them are in short supply.

To begin addressing these needs, Mr. Chairman, we respectfully request that Congress appropriate at least $50 million to support HRSA's public health training programs, including training of preventive medicine physicians, nurses and dentists, environmental health and maternal and child health specialists.

In addition, ASPH joins the more than 40 national organizational members of the Health Professions and Nursing Education Coalition (HPNEC) in recommending an fiscal year 1999 appropriation of at least $306 million for Titles VII and VIII of the Public Health Service Act. Along with these organizations I wish to thank the subcommittee members for supporting these important programs that are designed to meet the nation's need for primary care providers and public health professionals in short supply.

Prevention research

Congress authorized CDC to establish a national network of university-based centers to undertake research and demonstration projects in health promotion and disease prevention. Currently, 14 prevention research centers (PRCs), located mostly in schools of public health, form partnerships with state and local health agencies and community-based organizations to put into place innovative programs that prevent disease and promote health. PRCs serve to bridge the gap between public health science, research in academia and public health practice in communities.

In 1995, CDC asked the IOM to review the PRC program and determine the extent to which it was meeting its congressionally mandated goals: to provide a sound scientific basis for health promotion and disease prevention policies and practices; and to translate research findings into community-based interventions.

In short, CDC wanted the IOM to determine if the PRCs were: "applying research findings and making them work at the local level." Late in 1996, the IOM released its report on the CDC PRC program: Overall, the committee finds that the PRC has

made substantial progress and is to be commended for its accomplishments on advancing the scientific infrastructure in support of disease prevention and health promotion policy programs and practices.

In light of the IOM review, we respectfully request that you support an fiscal year 1999 appropriation of $24 million for the CDC prevention research centers program. The program was authorized in 1986 to provide $1 million per center; this goal has never been reached. An increase in fiscal year 1999, albeit minor in comparison to NIH appropriations for centers with similar missions, would contribute greatly to this nation's attempts to change behaviors that put Americans at risk for chronic health conditions; they claim a disproportionate number of lives, especially those Americans in vulnerable populations (the elderly, the underserved, the underrepresented), plus add fuel to the nation's excessive health care costs.

Mr. Chairman, we also go on record in support of the Administration's fiscal year 1999 request to fund CDC's extramural research program but at $100 million instead of $25 million. To effectively integrate health promotion and disease prevention strategies into our national health care system, promising interventions applicable at the community level need to be developed and evaluated. Prevention research enhances the nation's public health agenda by providing a scientific context for health promotion and disease prevention.

Speaking of prevention research at CDC, we respectfully recommend that the NIH be urged to focus more attention on population-based research strategies targeted at precluding the development of disease, or postponing its symptomatic onset, through changes in personal habits and factors in the social and physical environment. It is anticipated that greater resources across the NIH institutes would be put into extramural prevention research which includes the following types of activities: investigations into the epidemiology of disease including identification of social and behavioral determinants of illness; studies of means to ameliorate personal, social and environmental factors contributing to disease onset or exacerbation; studies on immunization strategies and of methods for and the cost-effectiveness of population screening programs; studies on immunization strategies and or methods for and the cost-effectiveness of population screening programs; and studies into the means by which further decline in physical or social functioning can be prevented in people already ill. In general, the focus would be upon research that employs retrospective and longitudinally prospective populations groups, such as high risk groups or communities.

In short, Mr. Chairman, we urge your subcommittee to support initiatives at NIH and CDC that adopt population-based approaches to the health status and needs of the American public: initiatives that work towards a better balance between caring for the sick and disabled and keeping people healthy. We should promote public health policies and programs that promote the postponement of morbidity opposed to the current practice of postponement of mortality (wellness instead of sickness).

There is another federal prevention initiative that, in our opinion, deserves the committee's support, Mr. Chairman: CDC's injury prevention and control program. Entitled "Safe America," this program is designed to ensure that Americans are safe in their homes, schools, while traveling and at work and play. This will be accomplished through a strong research program that provides the foundation for the delivery of effective intervention in states and communities, along with a national campaign and information system to inform Americans of what prevention measures work and how to access prevention resources.

Currently, the extramural research program at the National Center for Injury Prevention and Control consist of 10 injury control research centers located in major universities across the country and an investigator initiated research project grant program. Mr. Chairman, we request that you support a $40 million increase in the fiscal year 1999 appropriations for CDC's Safe America program. Of this $40 million , we are requesting that $20 million be directed to extramural research to expand the injury control research centers, increase the number of individual investigator awards and initiate a training grant program to attract new investigators to the field of injury control.

By the way, Mr. Chairman, ASPH strongly applauds your efforts to double the NIH budget and commends your vision and leadership in this quest. We support the Ad Hoc Group for Medical Research Funding and its recommendation of a 15 percent increase for NIH in fiscal year 1999. We see this as a "first step" in achieving your goal by 2003. We also urge that equal commitment be given to NIH partners in its mission to improve the nation's health: HRSA, CDC, AHCPR and OPHS.

As we prepare to celebrate the 200th anniversary of our nation's Public Health Service this July, we urge you and members of the subcommittee to renew the longstanding commitment and support of this stellar American institution by increasing funding for agencies that have contributed to making the U.S. health system the

best in the world. These public health partners, along with state and local public health agencies and community-based organizations, and this nation's 28 accredited schools of public health, have nurtured and harvested federal investments in improving the health status of the American public. As such, we support the fiscal year 1999 appropriations requests of the following coalitions that have or will testify before your subcommittee:

Ad Hoc Group for Medical Research Funding; CDC Coalition; Coalition for Health Funding; Friends of AHCPR; Friends of NIOSH; Friends of Title V (MCH block grant); and Health Professions and Nursing Education Coalition.

Mr. Chairman, the requests outlined by these coalitions represent the needs assessment that were derived from the views and expert opinions of this country's most respected administrators, scholars, scientists and leaders in the volunteer sector. I know you and the subcommittee members will take them into serious consideration when marking-up the fiscal year 1999 appropriations bill.

Mr. Chairman, I would like to end my testimony by once again commending you and the members of the subcommittee for supporting PHS programs, in general and academic public health programs, in particular. The latter contribute to our efforts to educate and train public health professionals in the population-based approaches to the prevention and control of disease and promotion of health among individuals and communities. These are:

—Assessment of the health status of communities to identify the most pressing health problems of each community, thus enabling effective and efficient deployment of health resources;

—Outreach, screening and personal health services to reduce the toll from vaccine-preventable diseases, tuberculosis, sexually transmitted diseases, AIDS, lead poisoning, infant mortality, violence and other preventable public health problems

—Community monitoring and health protection actions to assure clean air, safe water and nutritious, safe food supplies; and

—Education in health promotion and disease prevention by health care providers and public health professionals

Outlined below are the ASPH fiscal year 1999 funding recommendations for programs of primary concern to the academic public health community:

Centers for Disease Control and Prevention

Prevention centers	$24,000,000
Prevention research	100,000,000
NIOSH training	20,000,000
Injury control research	20,000,000
Total CDC	2,800,000,000

Health Resources and Services Administration

Public Health, Preventive Medicine and Dental Public Health	50,000,000
MCH training	20,000,000
Health professions	306,000,000
MCH block grant	705,000,000
Family planning	218,400,000
Total HRSA	4,200,000,000

National Institutes of Health

NIH	15,600,000

Agency for Health Care Policy and Research

AHCPR	175,000,000

The Association of Schools of Public Health (ASPH) is the only national organization representing the deans, faculty, and students of this nation's 28 accredited schools of public health in the United States and Puerto Rico. These schools have a combined faculty of over 2,500 and educate more than 15,000 students annually from every state in the U.S. and most countries throughout the world. The schools graduate approximately 5,000 professionals each year. The 28 schools of public health constitute a primary source of comprehensively trained public health professionals and specialists in short supply to serve the federal government, the 50 states

and private sector. According to the Pew health professions commission, managed care will increase the need for public health professionals.

PREPARED STATEMENT OF DR. J. ALFRED RIDER, PRESIDENT, BOARD OF TRUSTEES, CHILDREN'S BRAIN DISEASES FOUNDATION

I am Doctor J. Alfred Rider, President of the Board of Trustees of the Children's Brain Diseases Foundation. It is a pleasure to submit testimony on behalf of the Foundation for inclusion in the Senate Appropriations Committee, Labor-HHS Education Subcommittee hearing record for fiscal year 1998–99. I am submitting my testimony on behalf of the children's Brain Diseases Foundation and the thousands of children and their families who are affected with Batten disease.

Specifically, I would like to address the need for continued funding at the previous 1994 level plus an increase amounting to approximately an average yearly addition of 4.1 percent since then for Batten disease research or a total of $3,470,000. Batten disease is a neurological disorder affecting the brains of infants, children and young adults. It occurs once in every 12,500 births. There are approximately 440,000 carriers of this disorder in the United States. It is the most common neuro-genetic storage disease in children. There are four major types of Batten disease-the infantile, late infantile and juvenile in children and Kuf's disease in young adults. Motor and intellectual deterioration, visual loss, behavioral changes, and the onset of progressively severe seizures and termination in death in a vegetative state characterize the usual case. This irreversible severe illness constitutes an enormous nursing and financial burden to families with afflicted children. Patients may live in a deteriorating state from 10 to 43 years. The changes that occur in the brain in these children are quite similar to many changes that occur in the aging person. Thus, effective treatment for Batten disease may also allow us to alter the aging process and age associated senility in our senior citizens.

The Children's Brain Diseases Foundation, begun in 1968, has had a direct role in stimulating interest in Batten disease worldwide by granting money to various investigators. The Foundation has sponsored six worldwide symposiums; the most recent in Helsinki, Finland, June 1996. The next international symposium will be held in Dallas, Texas in June of this year. There are now over 100 investigators worldwide. Their work must continue to be encouraged and supported. Batten disease is now recognized worldwide.

A major impetus to these advances occurred as a direct result of your committee's perseverance and interest which began to achieve fruition in 1991 when for the first time, the committee recognized that not enough attention was being spent on Batten disease, and they directed the National Institute of Neurological Disease and Stroke (NINDS) to expand its research in this direction.

I am happy to say that the NINDS heeded your requests and suggestions and actively solicited research grants for Batten disease by sending out an official Request for Applications (RFA). A special committee was established to review Batten disease grants since it was felt that the usual committees did not have sufficient expertise to make proper evaluations. Numerous applications were received and a significant increase in money was spent on Batten disease research. In 1994, $3,272,699 was spent. As a direct result of this, monumental events have occurred.

In 1995, a group in Finland, in collaboration with the University of Texas, isolated the gene defect; mutations in the palmitoyl protein thioesterase gene localized on chromosome 1 p32, causing the infantile form of Batten disease. Also in 1995, the International Batten Disease Consortium isolated the genetic defect in the juvenile form of Batten disease and found it to be on chromosome 16 p12.1.

In 1996, a group in England, headed by Doctor Mark Gardiner, identified the region that contains the gene for the classical late infantile form of Batten disease. It lies on chromosome 11p15 and the gene for a variant form of the late infantile, which lies on chromosome 15q21–23. In 1997, a group led by Doctor Peter Lobel at the Center for Advanced Biotechnology and Medicine in new Jersey using a much faster novel approach of looking at lysosomal enzymes instead of concentrating on which of the 100,000 genes are defective, discovered the molecular basis for the late infantile form of Batten disease by identifying the single protein that is absent in late infantile Batten disease which sequence comparisons suggest is a pepstatin-insensitive lysosomal peptidase.

It is now possible to make an absolute definitive diagnosis and determine carriers in all three childhood forms by a simple blood test, and to prevent the disease by genetic counseling, including in vitro fertilization.

In spite of these unprecedented major significant breakthroughs, the NINDS in fiscal year 1997 has only spent $2,838,806 on research grants. This is 13 percent

less than in 1994. We are at a loss to understand this and are afraid that this trend may cast a damper on the whole research processes. Our scientists are there. They are like expensive finely tuned complicated scientific machines and like all machines, they need fuel. Instead of traditional fuels, these individuals need American dollars in sufficient amounts so that they may pay for their expensive new scientific equipment as well as being able to hire the technical help necessary to expedite the research.

Much needs to be done. The enzyme defects resulting from gene abnormalities in three of the four types must be determined. This should then lead to definitive therapy by gene replacement and/or specific enzyme therapy.

We are cognizant of the difficulty in getting funds for research. However, the amount requested is a small price to pay to solve a disease which wrecks havoc on the victims and families and is draining our national resources by approximately 712 million dollars per year based on approximately 300 children born with Batten disease each year and others living with this disease at an average treatment and maintenance cost of over $150,000 per year for each year of life. This lifetime, in a vegetative state, can last 10 to 43 years.

Specific recommendations

Although there have been four significant breakthroughs with regard to gene localization in Batten disease and the identification of the single protein that is absent in late infantile Batten disease, we were disappointed that the funding for fiscal year 1997 was approximately 13 percent less than in fiscal year 1994. Consequently, we would like to suggest that the following wording similar to that which we recommended last year, be used in this year's appropriation bill:

"The Committee continues to be concerned with the pace of research in Batten disease. The Committee believes that the Institute should actively solicit and encourage quality grant applications for Batten disease and that it continue to take the steps necessary to assure that a vigorous research program is sustained and expanded. The Committee has requested that $3,470,000 within the funds available to the NINDS be spent on Batten disease research. This represents an average yearly increase of 4.1 percent since 1994. This will allow for $2,838,806 for continuation and renewal grants and $631,194 for new grants."

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

The 85,000 member American Academy of Family Physicians would like to submit this statement for the record on three issues of critical importance to our organization: appropriations for Section 747 of the Public Health Service Act for family practice training; appropriations for the Center for Primary Care Research at the Agency for Health Care Policy and Research (AHCPR); and funding for rural health programs.

FAMILY PRACTICE TRAINING

The American Academy of Family Physicians strongly supports increased funding for Section 747 of the Public Health Service Act. Section 747 is the only federal program that provides targeted funding through grants for family practice residency training and funding for establishing and maintaining medical school departments of family medicine, predoctoral programs and faculty development. While Section 747 must be reauthorized this year, it is currently authorized at $54 million and received an appropriation of $49.4 million in fiscal year 1998.

The President's budget request is reported to contain level funding for Title VII (which includes Section 747) this year. Since this would be the first time in recent years that any President has begun the next year's budget discussion with a recommendation as high as level funding, we believe that value of this program is becoming more widely known and appreciated. While the Academy recommends a higher level, we are pleased with the Administration's request, as a starting point for our discussion.

Recommendation

Based on a review of future needs of the country for a more appropriate number of family physicians, the Academy supports a fiscal year 1999 funding level of $87 million for Section 747. This recommendation would provide funds for 20 new and developing residency training programs, 12 new and developing departments, 24 medical school clerkships, 700 new faculty and a number of innovative demonstration projects. The recommendation is the result of a strategic plan developed by the

Academic Family Medicine Organizations, which includes all five family medicine organizations.

Background

Any attempts to control costs and maintain quality in the American health care system will be frustrated by a structural problem in our country: the shortage of generalist physicians. While in most countries at least 50 percent of physicians are generalists (family physicians, general internists and general pediatricians), the US physician workforce is made up of more than 70 percent subspecialists and only 30 percent generalists. Family physicians make up only 13 percent of the total.

Most experts believe that a physician workforce of at least 50 percent generalists and 50 percent subspecialists would best meet America's health care needs. The Physician Payment Review Commission, Council on Graduate Medical Education, The PEW Commission, Institute of Medicine, American Medical Association and Association of American Medical Colleges all advocate increasing the supply of generalist physicians. A March, 1996, study by the Institute of Medicine encourages support for training of a primary care workforce.

At one time, the physician workforce in the US was comprised of 50 percent generalists, but after World War II, the nation's primary care workforce declined from a majority of the workforce to approximately one-third today. Public health service grants for medical education were a response to that decline, and the infrastructure they have helped establish is beginning to reverse the downward trend in primary care. During the 1990's, the number of medical students electing primary care residencies, and participating in family practice residencies, is increasing, however, the percentage is still only about one-third of graduating medical students. Much more progress is needed to begin to affect the national shortage. Section 747 support needs to be enhanced to provide a modest incentive for training more of the physicians America needs most.

Medicare payment policies have contributed significantly to the overspecialization of physicians. These policies have promoted training in the expensive inpatient specialties that involve numerous procedures rather than in family practice and other generalist specialties. NIH funding also contributes to the overspecialization of physicians. NIH grants, amounting to billions of dollars, go primarily to the subspecialist projects in the nation's medical education complexes, providing powerful incentives to promote subspecialization to develop the capacity to secure grants.

Moreover, a study conducted by KPMG Peat Marwick in September, 1995, indicated that Medicare spending could be reduced by at least $48.9 billion and as much as $271.5 billion over the next six years if primary care physicians were 50 percent of the total physician workforce. The analysis revealed a direct correlation between the availability of primary care physicians and the reduction of health care costs. The Role of Primary Care Physicians in Controlling Health Care Costs: Evidence and Effects is a comprehensive review of existing studies on the role of primary care physicians in controlling health care costs.

Section 747 is essential to provide at least a small incentive to offset the financial disadvantages that family medicine residencies and departments face. Until Medicare GME preferentially supports primary care training, and until primary care medical research is funded at more than a tiny fraction of subspecialist research, family practice residency programs and medical school departments will remain highly dependent on grants from Title VII.

Finally, let me emphasize that Title VII funding is still important, regardless of changes made to graduate medical education. Specifically, Title VII dollars go to medical schools and universities to develop a primary care infrastructure, while GME funds go primarily to hospitals to support residency training. Further, the cutbacks in indirect medical education may adversely affect graduate training of primary care physicians.

Family Practice Training Programs are Important to Meet the Nation's Health Care Needs

—Family physicians are distributed in urban and rural areas in the same proportion as the US population as a whole—unlike any other physician specialty. Even so, 149 counties representing 550,000 individuals have no physician at all. In addition, family practice residency training programs that receive Section 747 funding place greater numbers of graduates who locate in rural and underserved areas than programs that do not receive that funding.

—In community health centers, which rely heavily on primary care physicians, 52 percent report difficulty recruiting primary care physicians.

—The U.S. population 65 years of age and older will rise about 2 percent per year between now and the year 2020. Older people will require a wide range of

health care services, including preventive, primary, long-term, rehabilitative and hospice care—services that will require a substantial increase in the number of family physicians.

DATA AND OUTCOMES THAT PROVE SECTION 747 WORKS

Family practice residency programs

Over 90 percent of physicians who complete family practice residency programs work in direct primary patient care and are able to handle 85–90 percent of their patient's problems. (By contrast, over half of internal medicine residents subspecialize along with one-third of pediatric residents.) Section 747 grants to family practice residency programs have helped increase the number of training programs from 175 to 388 between 1975 and 1998. However, the nation needs 20–30 new programs and significant expansion of many existing programs to achieve a balanced workforce.

In contrast to other specialties, 80 percent of family practice residencies are located in community settings rather than in major tertiary care teaching hospitals. These residencies provide more ambulatory training than any other residencies. As a result, family practice programs do not have access to the considerable resources that flow to teaching hospitals. Further, 25 percent of family practice residencies are located in public hospitals. These hospitals receive low reimbursement for patient care services, and treat fewer Medicare patients. As a result, they do not receive substantial Medicare graduate medical education dollars. Section 747 is vital to the survival and expansion of these critical residency programs.

Family medicine departments in medical schools

Section 747 grants for establishing departments of family medicine have resulted in ten new departments in the past eight years. However, twelve of the nation's 124 medical schools still do not have departments of family medicine. An October, 1994 GAO report indicated that "students who attended schools with family practice departments were 57 percent more likely to pursue primary care." The same report indicated that "students attending medical schools with more highly funded family practice departments were 18 percent more likely to pursue primary care." Section 747 dollars are crucial to establishing these family practice departments and to graduating students into primary care careers, as well as to keep these important departments financially solvent.

Predoctoral programs

Section 747 funding for predoctoral under encourages medical schools to create required third-year clerkships in family medicine. However, 24 of the nation's 124 medical schools still do not have required third-year clerkships in family medicine. Requiring a third-year clerkship of more than four weeks duration results in 15.6 percent of a school's graduates choosing careers in family medicine, compared to 6.9 percent of the graduates of schools without required third-year clerkships. Moreover, the October, 1994 GAO report indicated that "students who attended schools requiring a third-year family practice clerkship were 18 percent more likely to pursue primary care." Section 747 funding has increased the number of medical schools with clerkships to 100, but continued funding is necessary to maintain and increase that number to all schools.

Faculty development

There is an acute shortage of faculty for family practice residency programs and family medicine departments as the discipline has been successful at placing its graduates in practice settings serving communities of need rather than in full-time faculty positions. Without adequate funding, there is a risk that even the progress that has been made so far will be compromised for lack of faculty.

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

While American medicine is praised worldwide for its excellence in biomedical research, it has often failed to translate these breakthroughs to practical treatment that will apply to the population at large. It is imperative that US research facilities complement their superb understanding of high-tech research with a similar dedication both to applying state of the art medicine to primary care settings and research to improve the delivery of primary care and preventive medicine so that there is less of a need for high-tech subspecialty care.

Recommendation

The Academy requests that additional appropriations be provided to the Agency for Health Care Policy and Research (AHCPR), and that dollars be targeted specifically to the Center for Primary Care Research. We believe that supplementary fund-

ing, coupled with direction from Congress, will permit AHCPR to address primary care issues. We recommend $50 million for this effort. In view of Administration recommendations for substantially increased funding for the National Institutes of Health, we ask that you consider additional dollars for the Agency for Health Care Policy and Research as a part of this initiative. It is equally important that we find ways to extend state of the art medicine to primary care physicians as it is to develop the state of the art of medicine further.

Background

The Academy strongly supports the Center for Primary Care Research within AHCPR. The Academy supported AHCPR's establishment and, in particular, the agency's statutory authority to support clinical practice research to include primary care and practice-oriented research. In fact, the 1992 Senate Report 102–426 accompanying Public Law 102–410, which reauthorized AHCPR most recently, states that the Agency should strengthen its commitment to family practice and primary care research. The report asserts that: "The committee believes that inadequate attention has been given to conditions that affect the(se) vast majority of Americans—that is, the undifferentiated problems individuals present to their generalist physicians. A focus on family practice/primary care research is essential if we are to redirect the US health care system that is currently skewed toward high technology medicine for catastrophic diseases."

Although over 95 percent of all medical conditions have been evaluated and treated outside of hospitals over the last 30 years, physicians are educated and trained using a knowledge base derived from hospitalized patients, or patients with complex conditions who were referred to specialists. This base of knowledge has frequently little relevance to the basic, entry-level concerns that affect most people. As a result, American health care is tilted toward institutions and systems that employ highly technological methods to treat catastrophic and end-stage disease. The consequences of this situation are serious; the US health care system has inadequate emphasis on cost-saving preventive care, scarce medical resources are delivered inefficiently, and costs continue to spiral upward.

Primary care research

As a result, a primary care research agenda is crucial. This agenda should be designed to provide new tools to family physicians and other generalist physicians as they serve the millions of patients they see each year. Such an agenda would include research to improve diagnostic accuracy because most people go to doctors with cluster of ill-defined symptoms. The job of the generalist physician is to make sense out of these symptoms; determining whether or not they constitute a short-term problem or one requiring ongoing or intensive treatment, and then initiating effective therapy. Primary care research would assist physicians in streamlining the diagnostic process and increasing accuracy while at the same time reducing their use of expensive, unnecessary or potentially dangerous medical tests.

Finally, generalists and subspecialists must learn to work together to provide a continuum of appropriate medical care. Familiar symptoms such as chest pain, headache, fatigue and insomnia bring millions of Americans to their physicians each year, symptoms that may or may not represent serious conditions. It is imperative that generalists and subspecialists work together to discern the causes, evolution and management of human suffering.

RURAL HEALTH PROGRAMS

Finally, the Academy supports continued funding for several rural health programs. In particular, we support the State Offices of Rural Health, the Federal Office of Rural Health, Area Health Education Centers and the National Health Services Corps (NHSC). We are pleased that the President's budget is reported to protect most of these important programs, including the NHSC and the Rural Community and Migrant Health Centers. In addition, adequate funding for the State Offices of Rural Health is necessary to permit states to implement the provisions of the Balanced Budget Act of 1997 expanding children's health insurance and to ensure that they are of the same value to rural residents as they are to urban dwellers. Continued funding for these rural programs is vital if we wish to provide adequate health care services to America's rural citizens.

Conclusion

Several key federal health programs focus on meeting the needs of the American people. At a time when policymakers are critically reviewing government programs for their cost-effectiveness and overall value, Section 747 is a program that scores high on both fronts; it works. On behalf of the American Academy of Family Physi-

cians, we ask you to appropriate funding for Section 747 of $87 million. In addition, scant research is available on basic patient care. The American Academy of Family Physicians recommends $50 million for the Center for Primary Care Research at the Agency for Health Care Policy and Research. Finally, we ask for continued funding for the rural health programs that help provide health care to rural Americans.

Thank you for your attention to these important requests.

PREPARED STATEMENT OF THE AMERICAN NURSES ASSOCIATION

The American Nurses Association (ANA) appreciates this opportunity to comment on fiscal year 1999 appropriations for nursing education, nursing research, and workforce programs.

ANA is the only full-service professional organization representing the Nation's 2.5 million registered nurses, including staff nurses, nurse practitioners, clinical nurse specialists, certified nurse midwives and certified registered nurse anesthetists through its 53 State and territorial nurses association.

We gratefully acknowledge this Subcommittee's support for nursing education and research. You have continued to recognize the importance of nurses in health care delivery and have funded programs for nursing education and innovative practice models. We believe that our shared goal of ensuring the nation of an adequate supply of well-educated nurses, to meet the increasing demands of our rapidly changing health care system, will reaffirm the need for continued funding of these programs. Today, we offer our professional recommendations for Federal funding of nursing education, nursing research and workforce programs.

DEPARTMENT OF HEALTH AND HUMAN SERVICES PROGRAMS NURSE EDUCATION ACT

More than 100,000 advanced practice nurses—registered nurses with education and clinical experience generally at a master's degree level—are providing primary care in the place of physicians or are providing an expanded type of primary care, either as nurse practitioners, certified nurse midwives or clinical nurse specialists. Due to unprecedented changes in our health care delivery system and the changing demographics and complexity of care, nurse practitioners will be in increasing demand and the nurse education system will be stretched to provide first-quality training for them. These changes call for the fullest utilization possible of the multidisciplinary providers who care for patients and families in an ever-increasing array of settings: hospitals, subacute care facilities, rehabilitation facilities, long term care facilities, schools and universities, workplaces and communities.

Federal support for nursing education in Title VIII of the Public Health Service Act (PHSA) is unduplicated and essential to achieve future goals for the public's health. Under current law, specific authorizations are made for nurse practitioners/nurse midwives; professional nurse traineeships; nursing special projects; advanced nurse education; nurse anesthetists; and disadvantaged assistance. Although the Nurse Education Act was not reauthorized during the 104th Congress, a proposal will soon be introduced that would give the Secretary of Health and Human Services broad discretion to determine which projects to fund, with priority given to projects which would substantially benefit rural or underserved populations, including public health departments. In this proposal, the Division of Nursing would have the needed flexibility to focus on curriculum development and other programs to help change the focus of nurse education from acute care settings to the preparation of more nurses who are able to function where there is a greater demand. It would also better address the need for increasing the numbers of minority nurses available to provide culturally competent, linguistically appropriate health care services to underserved communities. These nurses would be better prepared to assist these populations in changing the way they access our health care system, and in helping these patients understand the advantages of developing relationships with primary providers. By itself, the behavior change from accessing health care services through emergency departments to one in which the consumer routinely seeks care through a primary provider decreases health care costs exponentially.

As work on a reauthorization proposal progresses, it is crucial that the Division of Nursing be able to continue the administration of nursing education programs until the new programs can be implemented. For fiscal year 1998, the Nurse Education Act was funded at $65.6 million. For fiscal year 1999, we are requesting an increase in funding of 8 percent over fiscal year 1998 funding to fund the Nurse Education Act programs at $70.8 million. The following provides a brief description of these programs, along with the fiscal year 1999 individual funding recommendations.

Nursing special projects (section 820)

Title VIII of the PHSA is the only specific source of funds for innovation in nursing practice. Examples of innovation include nurse managed clinics, fifty percent of which have been developed or expanded with Title VIII support. The dramatic shift in health care delivery systems from inpatient to outpatient settings further emphasizes the need for workforce retraining and the development of new programs to address this educational need. We recommend funding at $11.4 million.

Nurse Practitioner and Certified Nurse-Midwife Program grants (section 822)

Advanced practice continues to hold the nation's greatest promise of providing primary care access in rural, inner-city and underserved areas of the country. Title VIII of the PHSA has provided support to more than 80 percent of the nurse midwifery programs in the U.S. and 60 percent of the nurse practitioner programs in the country. We recommend funding at $19 million.

Nursing education opportunities for individuals from disadvantaged backgrounds (section 827)

Over-utilization of costly emergency care, decreased access to primary care providers and a general lack of trust in the health care system has frequently been attributed to the lack of representation of minorities among health care providers. Funds from Title VIII of the PHSA have increased the number of minority nurses available to provide culturally competent, linguistically appropriate health care services to underserved communities. Evaluative studies have determined that this program has been the driving force behind many of the efforts nationwide to increase diversity in the nursing profession. We recommend funding at $4.1 million.

Traineeships for advanced education of professional nurses (section 830)

Nurse anesthetists (section 831)

Advanced Nurse Education Program (section 821)

Nursing education at the graduate (master's and doctoral) level provides the skilled clinicians for promoting excellence in practice and the faculty needed to maintain the nursing education pipeline. Professional nurse traineeships under Title VIII of the PHSA support over 93 percent of all full-time graduate students in nursing. Preference is given for traineeship programs which provide significant learning experiences at rural health facilities and those where students come from health professional shortage areas. We recommend funding for Professional Nurse Traineeships at $17.2 million, Nurse Anesthetists program at $2.9 million and Advanced Nurse Education Programs at $13.5 million.

Nurse loan repayment (section 836)

This program provides for up to 85 percent repayment of student loans for nurses who agree to a service payback in nursing shortage areas. We recommend funding at $2.3 million.

National Institute of Nursing Research (NINR)

The second funding priority for nursing is funding for the NINR, on the campus of the National Institutes of Health (NIH). We applaud this Subcommittee's commitment to advancing behavioral science research. Nursing research is an integral part of the effectiveness of nursing care. The NINR provides the knowledge base for practice of 2.5 million registered nurses. Advances in nursing care arising from nursing and other biomedical research improves the quality of patient care and has shown excellent progress in reducing health care costs and health care demands. The trend for earlier discharge from the hospital can potentially reduce hospital charges, but patients may and frequently require rehospitalization, increased acute care visits, and home care that families may be unable to provide. Research funded by NINR has shown that a model consisting of a carefully planned hospital early discharge program with follow-up care in the home by nurse specialists can result in improved recovery of patients at substantially reduced health care costs. The model was tested on three groups of women. Hospital costs were reduced by an average of 38 percent for diabetic mothers and their babies; 29 percent for mothers with cesarean births and their babies; and 6 percent for women undergoing hysterectomies. Moreover, the women had fewer rehospitalizations and expressed greater satisfaction with their care. This model needs further testing in different patient populations. However, if its initial promise holds true for other groups of hospital patients, then earlier discharge with qualified home follow-up care can improve recovery and save increasingly scarce health care dollars. While we support the Administration's proposed 8.4 percent increase above fiscal year 1998 funding of $63.5 million for this program, we recommend a 15 percent increase to fund NINR at $73 million.

Substance Abuse and Mental Health Services Administration (SAMHSA) Clinical Training Program

The SAMHSA Clinical Training Program has been a major source of the nation's mental health clinical training funds, and is a source of funding for ANA's Minority Fellowship Project (MFP). Since fiscal year 1994 the program had been funded at $2.5 million. The funding is allocated through SAMHSA to the minority mental health training programs in Nursing, Psychology, Social Work and Psychiatry. The MFP graduates have an outstanding record of public service to minority and indigent communities.

MFP graduates receive doctoral degrees and work as teachers in schools of nursing that serve minority students. They serve as role models and provide leadership to future nurses. As clinicians, graduates work in high risk urban and rural areas providing care to children and families who are victims of violence, HIV/AIDS, and substance abuse as well as the mentally ill. Nurses work in community based clinics and outreach programs and often are the primary care providers for indigent clients who might otherwise go without needed mental health services. In addition, these nurses generate research on minority mental health services, treatments and client outcomes. Culturally appropriate research helps us to identify ways to provide services faster and to more people, ultimately improving health care outcomes and reducing health care costs. This works to change the poor health outcomes and high risk health status that continues to plague minority communities. Unfortunately, last year this program was only funded at slightly above $1 million. We believe this program is a good investment in reducing mental health care costs and recommend funding of $1.5 million for fiscal year 1999 for the SAMHSA Clinical Training program.

AIDS Education and Training Centers (AETC)

The AETC program in the Bureau of Health Professions at the Health Resources and Services Administration provides specialized training for health care personnel who care for patients with AIDS. Emerging and evolving scientific information with profound impact on individual and public health requires a ready network for information dissemination and technology transfer. AETC's reduce care costs, promote private sector voluntarism and ease the suffering of families and communities. It is for this reason that we recommend a funding level of $25 million for fiscal year 1999 for the AETC's.

The National Institutes for Occupational Safety and Health (NIOSH)

NIOSH is the only federal agency with the mission to conduct research and develop practical solutions to prevent work injury and illness. NIOSH played a key scientific role in the development of the bloodborne pathogens standard. This standard provides significant protection to front-line health care providers from possible exposure to bloodborne pathogens, such as HIV, Hepatitis-B and Hepatitis-C. In addition, NIOSH funds Educational Resource Centers. These multi-disciplinary, university based occupational health and safety training and research centers as the primary vehicle for the development and training of a corps of trained occupational health nurses and other safety professionals. We recommend fiscal year 1999 funding of $153 million for NIOSH.

OTHER WORKFORCE FUNDING RECOMMENDATIONS

As an advocate for the economic and general welfare of registered nurses, the American Nurses Association also recommends appropriate funding for the Department of Labor and related agencies that serve to ensure a safe and fair workplace. ANA believes the work done by the Bureau of Labor Statistics, with respect to the ongoing collection and analysis of employment and economic data, is necessary for tracking changing economic conditions and essential to making workforce projections. We urge your support of the Bureau.

National Labor Relations Board (NLRB)

ANA is concerned about the ability of the NLRB to meet its statutory responsibility of enforcing and interpreting the National Labor Relations Act (NLRA). Current cutbacks have created delays in processing of complaints and holding representation elections thus jeopardizing the progress in employee and employer relations. ANA considers this a core independent agency function that must be preserved. We recommend fiscal year 1999 funding of $184 million for the NLRB.

Occupational Safety and Health Administration (OSHA)

The rapid restructuring of the health industry has increased and in some cases exacerbated the risk of exposure to illness and injury for nurses and other health

care workers. Hospitals and HMOs are downsizing both to cut costs and be competitive in the health care marketplace. These economic pressures have led to a reduction in the number of registered nurses providing care at the bedside. The remaining nurses in these acute care settings have to work harder and take care of more and sicker patients than ever before. The nurses themselves are sustaining more frequent incidences of injury and illness. According to the Bureau of Labor Statistics, in 1993, back and shoulder injuries accounted for 50 percent of the 31,422 injuries and illnesses that kept registered nurses away from work. Overall, lifting was specified as the cause of 26 percent of all registered nurse injuries. ANA is concerned about these increased incidences and adamantly opposes any proposal which would prevent OSHA from developing an ergonomic regulation.

Overall, there are an estimated 50,000 deaths per year that result from illnesses caused by workplace chemical exposures and 6 million nonfatal workplace injuries that occur annually. Budgetary reductions place OSHA at risk in meeting its statutory responsibility of establishing and enforcing national health and safety standards. ANA continues to be concerned about the strength of the Office of Occupational Health Nursing and its parity with similar offices. Occupational health nurses are the largest group of health care providers at the Nation's worksites. As such, they are uniquely qualified to assess the practical realities of work sites and related regulatory activities. This office must be fully staffed in order to accomplish its critical task of linking the ongoing work of occupational safety and health nurses to OSHA. We support the Administration's recommendation for fiscal year 1999 funding of $355 million for OSHA.

CONCLUSION

We appreciate the opportunity to comment on funding for nursing education, research and workforce programs. We thank you for your continued support and look forward to working with you as you proceed through the appropriations process.

PREPARED STATEMENT OF KAREN MURRAY, MEMBER, NATIONAL MARFAN FOUNDATION, ON BEHALF OF THE COALITION FOR HERITABLE DISORDERS OF CONNECTIVE TISSUE

Mr. Specter and members of the subcommittee, the members of the Coalition for Heritable Disorders of Connective Tissue (CHDCT) thank you for the opportunity to provide testimony regarding the budget of the National Institutes of Health.

I am Karen Murray, Member of the National Marfan Foundation which is a charter member organization of the Coalition for Heritable Disorders of Connective Tissue (CHDCT). The Coalition is an umbrella group, founded in 1988, which represents more than one half million Americans affected by heritable disorders of connective tissue. There are more than 200 such disorders which include names most of us have never heard of unless or until a family member is diagnosed with one—names such as Ectodermal Dysplasias, Ehlers-Danlos Syndrome, Epidermolysis Bullosa, Osteogenesis Imperfecta, Pseudoxanthoma Elasticum, the Chondrodystrophies, and Marfan Syndrome, to name some of the more common ones. They are genetic disorders that have existed for centuries, yet most people do not know their names; although many people will recognize the name of the sheep Dolly, cloned last year.

My son, Michael, was born August 13, 1991, 6 years ago, in one of the top hospitals in New York City. He was born with a dislocated hip, long fingers bent backward at the knuckle, and an indented chest. I overheard the physicians discussing among themselves, but not directly with me, the possibility of "Marfan syndrome." They sent Michael and me for echocardiograms, pronounced us fine, and released us from the hospital. The same doctors followed Michael for the next five years, during which time, Michael grew faster, longer, taller and more awkwardly than his peers and his indented chest became more severe. I went to all kinds of specialists: pediatrician, orthopedic surgeon, neurologist, occupation/physical therapist, pulmonist, all but cardiologist. I would constantly describe Michael's symptoms: "Why is my son so tall, thin, Awkward, loose-ligamented, indented chest, long fingers, arms, legs, narrow hands?" I was told to let it go, he's beautiful, he's fine.

I knew there was something wrong.

For Michael's 5th birthday, I bought him a computer which came with a free CD ROM called "The Family Doctor." Late one night, I clicked into it and recognized the words "Marfan syndrome" under the subject heading, "Rare Disorders." The first paragraph read "Children with Marfan syndrome grow taller than their peers, they have indented or protruding chest bones, fingers are disproportionately long, excessive joint mobility, muscle weakness * * *" and so on. The next morning, I brought

him back to the same prominent New York City hospital where he was born and five hours later, after an echocardiogram, the diagnosis of Marfan syndrome was confirmed.

Marfan syndrome is a genetic disorder that affects the connective tissue throughout the body—in almost all cases, it affects the heart and aorta. Approximately 200,000 Americans are affected by Marfan syndrome and related connective tissue disorders, but diagnosis requires an assessment of the three primary body systems: orthopdeic, ophthalmological and cardiovascular. Early diagnosis and careful daily management of someone with the Marfan syndrome is critical. At the time of Michael's diagnosis, his aorta was already very dilated. Severe dilation can lead to dissection which is what we know as an aneurysm. If medical personnel can't recognize the signs, the outcome is usually fatal.

My point is this: Doctors at the best hospital in New York City, extremely aware of Marfan syndrome—and whom suspected Marfan syndrome at Michael's birth—were not able to make the diagnosis. My son, Michael, in the hands of the best medical personnel in NYC, slipped away. Had I not heart the word "Marfan" or bought a computer, Michael could have been another statistic in his teens. But it doesn't have to be that way. Although Marfan syndrome is incurable, and a progressive disorder, it is diagnosable and treatable. Doctors and emergency room personnel need to be better educated in the recognition and treatment of Marfan syndrome. I am sure that if the best hospital in New York City didn't catch it, there are few other hospitals that will without considerable efforts to educate and increase awareness. As a parent of a Marfan child who is six years old—I'm nervous but optimistic Michael will be OK. I was lucky. I had the money to buy a computer and the persistence to keep looking because I always knew something wasn't quite right. I now know to have his heart monitored every three months. I'm having his orthopedic issues dealt with now. I have him on medication in the hope that his aorta will be less stressed. But there is still so much I don't know and I am told, "Sorry—we haven't research that yet—especially for children." As was almost the case with Michael, those children who go undiagnosed and untreated will, in most cases, die at a young age. Today, tens of thousands of people are undiagnosed. As a parent, I have questions that keep me awake at night. I wish I had enough money to fund research programs to answer some of my questions.

For example: I'm giving Michael calcium channel blockers daily—his aorta hasn't grown but what side effects will there be after years of calcium channel blockers?

Can and should Michael exercise? Take gym class?

—What's more effective—surgery or a brace to treat Marfan scoliosis in children?

—Do children with Marfan syndrome have weak tissue in their respiratory system and is that why Michael has asthma?

—Are spontaneous mutations more severely affected than those who have inherited Marfan?

—Since Michael has so many orthopedic issues, what can I do to help him live with less chronic pain?

—I'm scared to have another baby. Are there tests I can take to determine health of a fetus?

—Why do Marfans' lungs collapse?

—With such hefty medical bills, will a company employ him?

Undiagnosed Marfan patients end up in the emergency room. The emergency room staff does not know what to look for and thus many Marfan patients do not receive the tests that could save their lives. The key is to build awareness and educate the medical community from ObGyn's to pediatricians to emergency room doctors so that they can recognize and diagnose Marfan syndrome. Early diagnosis and careful management is critical in order to preserve and enhance the life of a Marfan patient.

The greatest challenges lie ahead of us. It is hoped that a firm understanding of Marfan syndrome and its cause, and the development of relevant animal models, will enable researchers to devise novel strategies for the prevention and cure of this and related disorders of connective tissue.

Similar challenges are faced by the other heritable disorders of connective tissue. Dystrophic Epidermolysis Bullosa mutations have been identified in several families, identifying the mutations of a specific collagen in Dominant Dystrophic EB. DNA-based prenatal diagnosis is looked to as a means of saving the lives of babies affected with EB. Much of the research that paved the way for these and other advances has been supported by the Committee.

Ehlers-Danlos (EDS) is a group of disorders caused by a defect in connective tissue. EDS is characterized by joint laxity, soft, hyperextensible skin, and tissue fragility. Manifestations are usually found in the joints, skin and vascular system. The degree of severity varies from type to type and even within each type. In some

types, researchers have detected the specific gene affected and there are biochemical tests available to diagnose those types. Researchers are able to use that knowledge to understand how the gene abnormality results in an abnormal protein which then results in EDS.

Osteogenesis Imperfecta (OI) is characterized by bones that break easily, often from little or no apparent cause. Most forms of OI are the result of imperfectly formed bone collagen, the consequence of a genetic defect. Research into treatments and a cure for OI shows great promise, thanks to individual donors, the Department of Defense, and public-private partnerships. Skin and DNA diagnostic tests are available, as well as a prenatal test. The OI Team at the DuPont Hospital for Children in Wilmington, DE, has developed a comprehensive database containing extensive information on a wide variety of clinical features of OI. Merck Research Laboratories and Shriners of North America are studying the efficacy of alendronate at 16 hospitals. At NIH, a clinical study is underway to assess the effects of braces on upright activity. A growth hormone study is starting up. Bone marrow transplants are being studied at St. Jude's Research Hospital in Memphis, TN. Like our growing database, each new piece of information is available for researchers to build on, to speed our progress toward a cure.

Pseudoxanthoma Elasticum (PXE) is a connective tissue disorder that affects skin, eyes, gastrointestinal and cardiac systems. It can lead to central vision loss, heart disease and life threatening complications. During the past year, the gene locus for PXE was discovered. This very significant discovery was elucidated at the International Centennial Meeting on Pseudoxanthoma Elasticum in November 1997 in Bethesda, MD. This meeting, attended by 50 scientists, was funded by the NIH. It has energized the research community and provides substantial direction for the coming years. Several labs, funded in part with NIH grants for PXE, are working on finding the gene, discovering the mutations, understanding the effect of these mutations and searching for applicable treatments. Funds from the NIH make a substantial difference in the recently accelerated pace of research on this devastating disease. We are particularly concerned that clinical research funding be supported, as this will become a major focus of PXE research in the coming years.

Ectodermal Dysplasias are a group of over 150 genetic disorders identified by abnormalities in two of more derivatives of the ectoderm. Researchers have localized the genetic abnormalities of X-linked hypohidrotic ectodermal dysplasia to a specific region on the X chromosome and can now predict the probability that a female is a carrier of the syndrome through DNA analysis.

Sticklers syndrome has gained increasing prominence and awareness in the medical profession. Every parent's hope is for a life without pain for their child. Stickler parents know that that hope lies in finding a cure. First steps are being taken by the National Human Genome Research Institute. A five year study has been undertaken to better understand this complex syndrome and other connective tissue disorders. Additional funding is needed to accelerate the study and cover a broader base. The immediate benefits in research on the Stickler syndrome are improved sites for knowledgeable diagnoses and improved therapies which provide hope. There is no more worthy place for our tax dollars.

Many exciting discoveries have been occurring in the Chondrodysplasias. After years, the gene has been identified for achondroplasia—one of the most common forms of dwarfism. This condition, caused by a gene mutation early in fetal development, occurs in one of every 20,000 births. Following upon this discovery was the identification of the gene mutation for diastrophic dwarfism, a recessive form. Additional positive research is being directed toward the goal of alleviating orthopaedic, neurological and respiratory/pulmonary conditions which can be lethal and have only partially effective surgical interventions.

The advances in genetic research to date bring hope to the many individuals and families affected by heritable disorders of connective tissue. Yet more dollars are needed to continue the momentum necessary to understand these complex disorders and to translate molecular findings into practical therapies.

In 1995 a workshop on Heritable Disorders of Connective Tissue was held at the National Institutes of Health at the recommendation of your committee. This workshop was a follow up of an earlier conference held in 1990. The workshop was critical in updating basic research findings, and translating these findings into practical clinical investigations. It served as a forum for scientists involved in connective tissue research and enabled the participants to focus on, and recommend, directions for future studies. It will soon be time to reconvene these collaborators in view of the rapidly changing technologies and genetic information.

A higher level of investment is needed to continue at an accelerated rate the science and the tools of the past decade. The CHDCT recognizes that the fundamental way science is conducted is changing at a revolutionary pace. It requires invest-

ment in new technologies, superspeed computer networks, new infrastructure and personnel with new sets of skills.

Research will lead to treatments and preventions that will stop this tragic economic and social drainage of money and spirit and will permit thousands of children and adults to realize their full potential as Americans. The American dream, for those with genetic disorders, can be attainable if we support the high quality of research that is currently underway.

Many of these disorders, although incurable at the present time, are treatable. We stand on the edge of an extraordinary time. The discoveries of science and technology of the past few years provide a promise that is breathtaking and provides hope to all suffering from these disorders.

We support the proposal of the Ad-Hoc Group for Medical Research Funding which calls for a 15-percent increase in funding for the NIH in fiscal year 1999 as the first step toward doubling the NIH budget over 5 years. We recognize the difficulty in achieving this goal under the current spending limits, and encourage the Congress to explore all possible options to identify the additional resources needed to support this increase.

Please help fund these important programs so that I can learn more about how to care for Michael, so we can make the medical community more aware of Marfan syndrome and Heritable Disorders of Connective Tissue so that a timely diagnosis can be made and a life can be saved. All the member organizations of the Coalition for Heritable Disorders of Connective Tissue and the patients and families they represent, join me in thanking this Committee and Congress for continuing support of research on Heritable Disorders of Connective Tissue.

PREPARED STATEMENT LEONARD H. FINKELSTEIN, D.O., CHAIRMAN, BOARD OF GOVERNORS, AMERICAN ASSOCIATION OF COLLEGES OF OSTEOPATHIC MEDICINE

Dear Mr. Chairman:As President of the Philadelphia College of Osteoapthic Medicine (PCOM) and Chairman of the Board of the American Association of Colleges of Osteopathic Medicine (AACOM), I am pleased to present the views of the 19 AACOM member schools on fiscal year 1999 funding for health professions educational assistance programs under Title VII and Title VIII of the Public Health Service Act. Specifically, we urge the Subcommittee to provide a funding level of $306 million for these programs, which is only about four percent over the fiscal year 1998 level approved by Congress last year.

AACOM is proud that the model of osteopathic medical education actively furthers the Federal objectives of addressing physician geographic maldistribution in the United States and increasing access to primary care services. I must point out that this model has not been developed recently in response to Federal funding requirements. Rather, it has been at the core of our osteopathic medical education for over one hundred years. AACOM member schools have a long history of dedication to training primary care physicians to work in America's smaller communities, rural areas, and underserved urban areas. Indeed, the mission statement of my institution, PCOM, states that we are "committed to educating community responsive, primary care-oriented physician prepared to practice medicine in the 21st century."

The health professions assistance programs under Title VII of the Public Health Service Act have been valuable in our efforts to ensure this commitment. Numerous programs are particularly important to enhancing osteopathic medical schools' ability to train the highest quality physicians. Among these programs are: General Internal Medicine Residencies; General Pediatric Residencies; Family Medicine Training; Preventive Medicine Residencies; Area Health Education Centers; Health Education and Training Centers; Health Careers Opportunities Programs; Centers of Excellence; and Geriatric Training Authority.

Title VII also authorizes student assistance programs that are important to osteopathic medical students. Forty-eight percent of our students come from families with annual incomes under $40,000. This Subcommittee must be concerned with minimizing the debt load of our graduates if they, in turn, can be expected to hold down medical costs, practice in primary care specialties, and locate in underserved areas. In addition, Exceptional Financial Need Scholarships, Financial Aid for Disadvantaged Health Professions Students, and Scholarships for Disadvantaged Students are all programs that must be maintained if we are to ensure access to medical education by underrepresented groups.

Mr. Chairman, AACOM strongly recommends full funding to restore the Health Education Assistance Loan (HEAL) Program. Effective October 1, 1995, a phase-out of the HEAL program began. Since that date no HEAL loans have been available to first-time borrowers. This action has created a special hardship for osteopathic

medical students who relied more heavily on HEAL than any other source of financial assistance. This is especially unfortunate in light of the fact that osteopathic medical students have had the lowest default rate among all health professions students who have HEAL loans.

It is our understanding that legislation to restore the HEAL program will be introduced soon. In anticipation of this reauthorization, we request that the Subcommittee restore full funding for the HEAL program.

Mr. Chairman, in conclusion, the efforts of the Subcommittee in support of health professions educational assistance programs have been most encouraging. We look forward to your continued support.

PREPARED STATEMENT OF GEORGE COLING, EXECUTIVE DIRECTOR, ON BEHALF OF THE NATIONAL FUEL FUNDS NETWORK

The National Fuel Funds Network (NFFN) thanks the Subcommittee for the opportunity to submit this testimony. NFFN supports funding for the Low Income Home Energy Assistance Program (LIHEAP) at no less than $1.3 billion for fiscal year 1999. NFFN also strongly supports the advance appropriations, enacted in November 1998, for fiscal year 2000 funding. Our nation must respond to needs of the growing number of low-income elderly and the needs of those in poverty. Those numbers are not decreasing. Therefore, we ask that the fiscal year 2000 appropriation be increased to $1.5 billion. This increase is reasonable compared to the current core and emergency funding of $1.4 billion.

The NFFN is a membership organization comprised of over 200 dues paying representatives of private fuel and energy assistance funds, community action agencies, social service organizations, utility companies, trade associations and private citizens. Our member organizations are located in 44 states and the District of Columbia. The NFFN is concerned with the ongoing energy crisis being experienced by the poor of America.

Since our first steering committee meeting in 1984, the NFFN and its member organizations have put into action a commitment to help, the poor of America meet their basic energy needs.

Our member fuel funds are organizations that raise private contributions in local communities in an effort to pay home energy bills. Fuel funds range from small church groups that distribute hundreds of dollars in a single neighborhood to large independent organizations that distribute millions of dollars across a state. Fuel funds may be a division of a large social service agency, or a local utility or energy company may operate them.

The value of LIHEAP in meeting basic human need is well documented. Without LIHEAP funding during periods of prolonged and extreme winter weather, approximately 2.8 million families with children would be left virtually "out in the cold." In 1994, of the 5.6 million households who received assistance from LIHEAP, fifty percent included a child under the age of eighteen. One in five have a disabled person. About 33 percent of households have elderly residents. For those states with extremely hot weather, the number of elderly households is more than 40 percent. The nation needs to turn the tide on these statistics and provide even more resources to prevent the health effects of hyperthermia and hypothermia that can be life threatening to our most vulnerable citizens.

Several examples from our member organizations illustrate the continuing need for energy assistance among America's poor and working poor now. In Charlotte, Crisis Assistance Ministry provides emergency energy assistance and several other basic needs in an effort to prevent homelessness among the community's low-income citizens. Every day during the cold weather season, more than 100 people come seeking assistance, while others are calling in for appointments. Over half of them have heat-related needs. Crisis Assistance Ministry has been administering emergency LIHEAP funds for the county since 1982. It also administers the local fuel fund of Duke Power Company and Piedmont Natural Gas, as well as its own funds, raised from the religious community and individuals. Despite having all these resources in place, Crisis Assistance Ministry estimates that the need is increasing about 20 percent per year. The Ministry is still not meeting all the need, and cannot begin to do so without the basic resource of a LIHEAP program with increased funding. Thanks to the President's release of emergency funds in the last two fiscal years, the Ministry has been better able to address some cooling needs, an essential thing in the South.

Last year was one of the warmest years that the Midwest has recorded. Nevertheless, at EnergyCare in St. Louis, the number of families calling for energy related

help, grew by about 2,500. In the hot July of 1997, 2,100 families called EnergyCare for assistance in using energy to cool their homes.

New Jersey offers the final example. In that state in 1997, 146,000 households lost their energy services due to past-due bills. A coalition of New Jersey's top energy companies and nonprofit agencies has created NJ SHARES, a new nonprofit, statewide fuel fund to address this situation. However, this effort, funded principally by a $1 million start up grant from the New Jersey Board of Public Utilities, will not meet all the need. Increased LIHEAP appropriations are essential for even more New Jersey families to stay warm and healthy.

Whatever their form, all fuel funds raise and distribute private sector monies, and they all, inevitably, discover that the resources they manage and the resources provided by LIHEAP, are inadequate. Consequently, fuel funds become involved in attempting to increase the resources available to help the poor meet their energy needs.

NFFN has identified nearly 300 fuel and energy assistance funds which have developed since the late 1970's to raise private energy assistance dollars at the local level to provide a safety net for households who have exhausted all avenues of public energy assistance. The families served by fuel funds rank among the "poorest of the poor" in America; the majority of them have annual household incomes of less than $10,000. Nationally, fuel funds make heating and cooling bill assistance payments of over $72 million each year on behalf of over 500,000 families. That totals $14.40 per family, and a little over $5 per person. These payments, while vitally needed, are quite small in comparison to the $1.1 billion in fiscal year 1999 LIHEAP funding.

As a result of the decline in LIHEAP funding over the years, other sources of payment assistance, such as private fuel and energy assistance funds, have taken on increased importance. When state programs close before winter's end because of inadequate federal funding, many needy families must look to other sources of energy assistance. On February 4, 1998, Caroline Myers, Chair of the NFFN Board of Directors and Executive Director of Crisis Assistance Ministry in Charlotte, described typical needy clients of her energy assistance program to the House of Representatives Subcommittee with jurisdiction over LIHEAP: "The primary common denominator that I can define is that they are poor. Here is a profile of that poverty in Charlotte:

—In our program, 70 percent of clients are below the federal poverty guidelines, at least in the thirty days before coming to Crisis Assistance Ministry. On average, they pay as much as 20 to 25 percent of their already inadequate income to heat and light their homes, almost as much as the federal recommendation for all shelter costs. For low-income families, less discretionary money means less food or less medicine. Their dilemma is, regrettably, which necessities to do without.

—Almost 70 percent of the people that we help have earned income, but it is so inadequate that there is no reserve and also no benefits to provide pay while single parents tend sick children, etc.

—Often applicants are temporarily unemployed. The loss of a job, even a low wage job, throws a family already struggling to make ends meet into immediate crisis. Savings, if any, pay the rent; and nothing is left for utility bills. The efforts of our clients are often heroic, with many working more than one job, as they struggle to keep a roof over their heads and their children warm.

—Other recipients are disabled and struggling to pay monthly expenses. In some winters, gas and fuel prices increase as much as 30 percent. Then, these families are simply unable to keep up with utility bills and must seek fuel fund help. From 1980 to 1992, for example, the national average increase in energy prices was 65.41 percent. In North Carolina, energy prices increased 97 percent."

From NFFN's experience, this profile of needy families reflects the situation in other communities, and—as shown above—families' needs for energy assistance is growing. In the face of this growing need, two things have been happening over the past few years. First, fuel funds have not been able to fill the gap between the need for assistance and available federal funds. Indeed, many fuel funds, themselves, are under greater pressure and struggling to maintain current funding and levels of service. Second, as LIHEAP payments became smaller, the states have had difficulty in providing a meaningful level of aid to the many citizens who qualified. Clearly, more federal funds are needed.

Several other factors support the case for increased LIHEAP appropriations. For example, in areas without local fuel funds, people continue to heat with unsafe methods. Some must do without heat for extended periods of time—something most of us do only when the power lines are down. The receipt of assistance to pay utility

bills can mean the difference between someone remaining safe and warm in her or his home, or suffering deadly consequences. According to a LIHEAP report, when asked what they did for heat when they had a heat interruption, 54 percent of the households who had experienced a heat interruption said that they were not able to heat their homes. Thirty-nine percent reported that they heated one or two rooms with another heat source such as a fireplace or a cooking stove to keep warm—clearly a fire hazard.

There have been a number of tragic events from using dangerous alternatives. House fires disproportionately take the lives of children and the elderly. In 1991, inappropriate heating was the third cause of civilian fire deaths. Recognizing the relationship between loss of utility service and the risk of injury and death from fires, the NFFN has formed a relationship with fire marshals in Philadelphia, Washington DC, Detroit and other communities, to educate families about the risk of fire and to put in place prevention measures.

Another factor is that the need for energy assistance is just as important in the South as it is in the North. Nationwide, median income families spend an average of 3.8 percent of their monthly as in the household income on energy. In North Carolina, the average is 4.4 percent. Low-income households across the country spent and average of 12.1 percent of their monthly income on energy, compared to North Carolina's low-income population's spending 14 percent

NFFN suggests that when we talk about "the poor", we are generalizing. Families and individuals move in and out of that category due to the circumstances of their lives. A death in the family, divorce, a plant closing, loss of a job, extended illness or any number of situations can create a crisis. These are the people that fuel funds and emergency assistance programs seek to help.

A third factor concerns our children. The receipt of assistance to pay utility bills can make a significant difference in the quality of life for low-income children. In recent years, increasing national attention has been focused on education, yet low-income children are still less likely to receive a good education. A study entitled "A Road Often Taken: Unaffordable Home Energy Bills, Forced Mobility and Childhood Education in Missouri" explored the interconnection between two seemingly unrelated problems in rural Missouri households: unaffordable home energy bills and poor educational attainment. Findings conclude that a substantial portion of the low-income population is "frequently mobile" over a five year period; that one primary cause of this frequent mobility is the unaffordability of home energy bills, including home heating and electricity; and that the frequent mobility creates problems for both the students in these mobile households and for the teachers and schools who seek to educate those transient students.

Another study done in Philadelphia reports that a utility shut-off notice is the clearest indicator of potential homelessness. When families are unable to maintain essential services, they may be forced to move. The result is abandoned properties, and the economic decline of neighborhoods. Intervention, in the form of energy assistance, helps stabilize those families.

Reductions in LIHEAP—thankfully reversed by Congress last year—brought more and more families to the doors of fuel funds around the country. As skilled as we are in raising charitable contributions from private donors, we are not able to compensate for the loss of federal support. Most fuel funds do not distribute LIHEAP funds. Most are last resort programs that require that applicants have sought all other resources, including LIHEAP, before receiving help. When that assistance is inadequate or insufficient, they turn to private resources.

The impact of welfare reform on energy assistance is just beginning to be felt. People who are leaving public assistance enter low paying jobs and will still be confronted with energy bills that they cannot pay. These families are at risk and must have support systems like LIHEAP and emergency assistance if welfare reform is to meet its goals. LIHEAP appears play an increasing role in the welfare reform transition. Former public assistance recipients, for the most part, make only slightly more than minimum wage, nowhere near the living wage that a family needs. In Charlotte, for example, a living wage has been calculated at almost $13 per hour.

Some may suggest that private fuel funds and other charitable contributions will make up the deficit resulting from further cuts in LIHEAP funding. Others will point to fuel funds as an example of the kinds of help that could potentially take the place of LIHEAP. Fuel funds raise only about 5 percent of what is available through LIHEAP As thankful as we are for the continued generous response from private donors across the country, we are painfully aware that our efforts still fall far short of the need. Privately raised energy assistance dollars can only supplement LIHEAP dollars to a small degree, and can never take the place of Federal energy assistance funds. In addition, in an era of deregulation and restructuring of the elec-

tric utility industry, can we realistically expect utility companies to step up the pace in growing their fuel funds?

While we who daily serve the energy needs of low-income families understand the difficult task of setting national priorities that is before Congress, we respectfully, but urgently request you, as you consider funding for fiscal year 1999, to keep in mind the important role that LIHEAP plays as a safety net for millions of our Nation's most vulnerable citizens. It is a broad based, effective and efficient program. The need is very real. We trust that your deliberations will significantly assist those who struggle daily to protect themselves and their families from extremes of weather.

Thank you for your consideration of this testimony.

PREPARED STATEMENT OF DR. HARRY S. JACOB, ON BEHALF OF THE AMERICAN SOCIETY OF HEMATOLOGY

Senator Specter and members of the Subcommittee, thank you for the opportunity to testify on behalf of the American Society of Hematology (ASH). My name is Dr. Harry Jacob and I am President-Elect of ASH. I have been a recipient of grant funds from the National Institutes of Health for many years. The Society has over 8,000 physicians and research scientists who are united by our interest in the workings of the blood and blood-forming organs and by a commitment to understanding and curing blood disorders. On behalf of the Society and the biomedical research community as a whole, we wish to thank the Subcommittee for their strong and unwavering support of the National Institutes of Health and of biomedical research. Along with many others in the biomedical research community, we support the development of a long-range plan for funding biomedical research as well as the largest possible increase in the next fiscal year to allow scientists in this country maximal opportunity to make new discoveries. In this regard, we are quite pleased to learn that the Administration's fiscal year 1999 budget proposes a significant increase in NIH funding.

I would like to use this opportunity to explain how NIH-sponsored basic research in the field of hematology has led to important discoveries and generated new treatments and pharmaceutical products of broad general interest. I would also like to focus on the synergy and cross-fertilization that is intrinsic to scientific work and show you how basic hematologic research has aided scientists and physicians who treat patients with illnesses as varied as heart disease, strokes, venous thrombosis, end stage renal disease, cancer, and AIDS.

Arterial thromboembolism

The leading cause of death in this country is cardiovascular disease, primarily heart attacks and strokes. In the next year, over 600,000 Americans will have their first heart attack and nearly half of them will die before reaching the hospital. Hematologists have made several important discoveries that promise to reduce the incidence and the number of deaths from heart attacks and strokes. They helped document that coronary occlusion by platelets and coagulation proteins is the cause of virtually all heart attacks and demonstrated that aspirin, an inhibitor of platelet function, could be used to prevent heart attacks. Basic work by hematologists led to the development of therapeutic agents to dissolve blood clots that had formed in coronary arteries and to the development of potent agents which completely block platelet aggregation. The clot dissolving or fibrinolytic agents and this new generation of antiplatelet drugs, both marketed by American biotechnology companies, are saving the lives of patients who suffer heart attacks and strokes. In addition to helping patients, these discoveries have created important new business opportunities along with thousands of jobs and will generate at least a billion dollars of revenue in the next year.

Hematopoietic hormones

Basic research on the growth and development of the bone marrow has led to the discovery of several important regulatory hormones which have revolutionized the treatment of patients with cancer and renal disease. NIH-sponsored research enabled American biotechnology companies to develop and market erythropoietin, the hormone which regulates red blood cell production. It is being used to treat patients with renal failure who become severely anemic. This treatment, along with dialysis, has improved the well being and life span of kidney failure patients and eliminated the need for blood transfusions. Granulocyte colony-stimulating factor or G-CSF, another product of NIH sponsored research, was developed and marketed by an American biotechnology corporation. It is being given to cancer patients undergoing chemotherapy. It raises their white blood cell count and protects them from infection. A

similar hormone, called thrombopoietin, which regulates platelet production, is undergoing clinical trials and may be used in a similar way to prevent bleeding due a low platelet count. These remarkable new drugs have been developed because the biotechnology industry has been able to rapidly translate the observations of NIH-sponsored scientists and produce useful products. The reduced need for blood transfusions in patients with kidney failure and the reduced incidence of infections in cancer patients will lower medical costs and improve the quality of life for thousands of patients each year.

Venous thrombosis and embolism

Venous thrombosis is a disorder in which blood clots form in the legs and pelvic veins. The most feared and sometimes lethal complication is pulmonary embolism, a condition in which the clots travel and block the circulation through the lungs. This condition can affect several hundred thousand people in this country each year. Until recently, there was little information available on the underlying cause of this disorder. Work by hematologists studying blood coagulation has identified a common mutation in one of the blood clotting proteins, which is present in 2 percent of the general population and may account for 25–30 percent of the cases of venous thrombosis. The identification of this mutation will allow screening to determine which individuals are at risk to develop venous thrombosis and allow early treatment. This should be particularly beneficial to women who can be warned to avoid drugs like the oral contraceptives or high doses of estrogens that may cause them to develop venous thrombosis. This information could improve the treatment of older Americans who have the highest incidence of venous thrombosis. Susceptible individuals may develop blood clotting after undergoing surgery, sustaining a fracture, or being confined to bed or a wheelchair. In addition to improving the quality of life and preventing additional complications like pulmonary embolism, the prevention of venous thrombosis could result in substantial savings by avoiding a large number of unnecessary hospitalizations.

New anticoagulants

I would also like to mention a new anticoagulant that may revolutionize our treatment of patients who develop venous thrombosis. Heparin has been used for over 50 years to treat patients with venous blood clots. It is an impure substance derived from the tissues of beef cattle and pigs and is a byproduct of the meat industry. At present, heparin is given intravenously and requires daily laboratory testing to adjust its dose. Despite careful laboratory monitoring, heparin still causes serious bleeding and lowers the platelet count in many recipients. Hematologists studying its mechanism of action were able to isolate and characterize the active fraction of commercial heparin. Several pharmaceutical companies developed techniques to purify large quantities of this heparin fraction and have completed clinical trials showing that it is a superior anticoagulant. Patients who receive these new heparins have a lower incidence of bleeding and do not require daily laboratory testing. This means that many patients with blood clots who required hospitalization for heparin therapy can now be treated as outpatients. The savings to the health care industry will run into the billions of dollars as this new drug replaces conventional heparin therapy.

Therapy for AIDS

Over two decades ago, hematologists interested in understanding the immune system began to characterize the cell surface proteins of lymphocytes. They carried out much of this work on cells derived from patients with various types of lymphoma. This work led to the classification of two major classes of lymphocytes: those that contain a protein called CD4 that help to produce antibodies and another that contains the protein CD8 which kills tumors. Years later, scientists studying AIDS were able to build on these fundamental observations. First, they showed that the number of CD4-containing cells decreased following infection with the virus causing AIDS and that this could be used as a way to follow the effects of the virus. Second, they were able to show that the CD4 protein was one of the receptors that the virus used to gain entry into lymphocytes. Within the past year, AIDS researchers were able to show that another class of receptors discovered by hematologists studying inflammation, called chemokine receptors, were also needed for the AIDS virus to infect cells. These studies demonstrate nicely how basic research in one area can provide information of great benefit to scientists working in other fields.

Treatment of sickle cell anemia

Another example of this important interrelationship can be seen in research on sickle cell disease. This is an important and debilitating disease which afflicts 1 percent of African Americans and causes recurrent painful crises, frequent hospitaliza-

tions, and serious damage to the brain, kidneys and lungs. Until very recently, there were no effective treatments for this disorder. Scientists studying drugs of use in treating cancer made the interesting observation that some agents which interfered with DNA synthesis in cells could stimulate the cells to make a form of hemoglobin which prevented sickle hemoglobin from precipitating with red blood cells. One of these agents, called hydroxyurea, had minimal toxicity and was shown to have a similar effect when given to patients with sickle cell anemia. An NIH-sponsored multi-institutional clinical trial confirmed hydroxyurea could reduce the incidence of painful crises in sickle cell patients and has provided the first effective treatment for this disorder. Patients who were frequent visitors to emergency rooms and often required hospitalization now have long periods of time free of pain.

Conclusion

I have tried to summarize a number of important discoveries by basic researchers in the area of hematology that have led to new methods of treating patients with many common diseases. As hematologists, we are quite proud that hematologic research has resulted in so many useful new drugs that have helped to spawn the American biotechnology industry. There are numerous other examples that could also be discussed. Hematologists were one of the first groups to study the amyloid proteins which are pivotal in the development of Alzheimer's disease. An American hematologist, E. Donnall Thomas, received the Nobel Prize for the development and implementation of bone marrow transplantation. This important technique has revolutionized our treatment of many disorders including various forms of leukemia, immunodeficiency states, bone marrow failure, and a number of genetic disorders that affect the brain and other organs. Hematologists are now working on methods to use bone marrow stem cells for gene therapy and expanding transplantation to treat a wide variety of malignant disorders. We remain confident that basic and applied biomedical research, when coupled with a vigorous pharmaceutical and biotechnology industry, will lead to better and more cost effective ways to treat medical disorders.

While much has been accomplished, there is clearly much more to be done. We thank the members of the Subcommittee for your past support of the work that has led to the discoveries just discussed and hope that you will find a way to increase funding for biomedical research. In this regard, the American Society of Hematology endorses the Ad Hoc Group for Medical Research Funding's recommendation of a 15 percent increase in NIH funding for fiscal year 1999.

PREPARED STATEMENT OF DR. DAVID R. BICKERS, SECRETARY-TREASURER, ON BEHALF OF THE SOCIETY FOR INVESTIGATIVE DERMATOLOGY

Mr. Chairman and subcommittee members: I am very grateful for this opportunity to testify today on behalf of the Society for Investigative Dermatology. I am Dr. David Bickers, Secretary-Treasurer of the Society for Investigative Dermatology and Chairman of the Department of Dermatology at Columbia/Presbyterian Medical Center in New York City.

The Society for Investigative Dermatology has as its mission the support of research in skin disease. Our 2,000 members include scientists and physician researchers from universities, hospitals, and industry committed to the science of dermatology. Each of our members firmly believes that research is critical to improved prevention, diagnosis, and treatment for the 60 million Americans afflicted with skin disease. My purpose in being here today is to personally emphasize the need for increased funding of the programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

We support the proposal of the Ad Hoc Group for Medical Research Funding, which calls for a 15 percent increase in funding for the NIH in fiscal year 1999 as the first step toward doubling the NIH budget over five years. We recognize the difficulty in achieving this goal under the current spending limits, and encourage the Congress to explore all possible options to identify the additional resources needed to support this increase. We support an increase of 15 percent specifically for NIAMS as well.

It is my understanding that all other members of the NIAMS Coalition will be seeking a similar amount.

My testimony is drawn from the booklet, Skin Disease Research: Successes, Opportunities, Support (you have a copy before you). If any of the members of the Subcommittee would like to receive extra copies for your staff or for persons in your district, please indicate that to me and I will see that you receive them in the mail quickly.

Background

Good health depends on healthy skin. Much of what we see on the outside of the body is a reflection of a person's health inside. From the yellow of hepatitis, to the purple lesions of Kaposi's sarcoma—a sometime feature of AIDS, from the skin lesions of lupus erythematosus, to the painful deformed nails which may occur in patients with arthritis and psoriasis, internal health disorders often show up first as problems on the skin's surface. Skin conditions have profound effects on our ability to interact with other people. Common skin conditions such as acne compromise our self-confidence. Loss of hair sometimes says "I am old." Studies in the United Kingdom reveal a higher rate of unemployment among acne patients than among unaffected people of comparable ages and abilities. Ancient prejudices and ignorance often lead people to shun those they deem unhealthy on the basis of appearances.

The ongoing revolution in molecular and cell biology, genetics, immunology, information processing and laser technology provides unprecedented opportunities for achieving advances in basic research and medical treatment. The accessibility of the skin makes it an ideal organ to study, both at the basic cellular level and as a tissue. It permits us to assess the effects of new therapies both for skin diseases and, in some instances, internal diseases. Skin samples are often used to make genetic diagnosis of internal disorders and in the future the skin may be a very convenient target for gene replacement.

Advances in cell biology allow us to understand the life cycle of skin and hair-producing cells and to explain how a malfunctioning immune system undermines the health of the body in general and the skin, in particular. We are also becoming more adept at growing skin cells in the laboratory and at producing artificial skin. Increasingly, laser surgery is replacing more invasive and traumatic traditional surgical methods.

These and other advantages are towering monuments to the tenacity and creativity of our scientists and hold out tremendous promise for improvements in health care. But as spectacular as these achievements are, we are far from realizing their full potential. We must still do more to understand and treat the problems at hand rationally and effectively to prepare for the challenges of the next century.

As the population ages and we live longer, dermatologists will be asked increasingly to treat cancers and other skin disorders that appear more often in older individuals. Dermatologists will need to find new and better ways to help prevent and heal common conditions of the elderly such as bed sores. Ulcers of the skin cost $8 billion per year. Much remains to be done—to improve diagnosis and treatment, both for current and future problems—and clearly more research is needed across the entire spectrum of the more than 3,000 dermatological diseases.

Research discoveries have already reduced the costs of treating and curing some diseases. Expanding our research program will allow us to build on recent findings, to learn more about the mechanisms of diseases that are still poorly understood and to improve the economic and physical health of the nation.

There are more than 3,000 different diseases of the skin, hair and nails, which in an average year affect about 60 million Americans. The combined annual cost to society of medical care and lost wages from these conditions is estimated to be $7 billion. The potential cost to individuals suffering from these conditions includes: discomfort and pain, disfigurement, disability, dependency, and death.

Research Advances

The past two decades have witnessed an explosive growth in technology and an increased sophistication in our understanding of the genetic and cellular mechanisms underlying many of these disorders. One consequence of these findings is a radical new paradigm shift in which the skin is now viewed as a complex organ that is intimately responsive to the body's immune system. Several distinct cell types in the skin actively generate, regulate and perpetuate immune responses. Other important new research findings include the following:

—A gene responsible for the inherited form of basal cell carcinoma has been identified. This may lead to important new information about the origins of skin cancer.

—A gene for an inherited form of hair loss has been discovered.

—A new protein has been discovered that links collagen and vascular defects in scleroderma.

—Advances in the design of drug-delivery systems allow for sustained release of drugs through the skin, probably leading to more effective treatments using this pathway.

—Methods to grow real and artificial skin in the laboratory are currently used to prepare skin grafts for burns and wounds.

Paralleling these technological advances of the past two decades, there has been a comprehensive focus on evaluation. Technologics beyond the laboratory such as

clinical epidemiology, biostatistics, economics, and the quantitative social sciences are being used to determine the effectiveness of certain procedures and whether they contribute to the quality of life and health of both patients and society. The public deserves value in return for research support and health care expenditures, and it is incumbent upon the research community to address such important issues.

As you know, medical research organizations such as the Society for Investigative Dermatology work closely with patient support and advocacy groups. We are pleased to say that for many years we have worked with the Coalition of Patient Advocates for Skin Disease Research. The many organizations that participate in the Coalition have been the best possible advocates for increased funding, as they understand that unless major research efforts are undertaken, advances in understanding and improvements in the health of patients will not occur. Every year, we participate with these organizations in advocating increased funding. Recently, working together, we have created a comprehensive analysis and a research plan for further progress, detailed in the document before you. May we suggest that bill report language be inserted in the bill report noting this document and its use, and urging the support of NIAMS in its publicizing? We suggest language such as the following:

The Committee has learned of the efforts by the skin diseases researchers and patient advocate organizations to develop a comprehensive analysis of research opportunities and a research plan for further progress in finding cures and improving care for patients with these diseases. The Committee applauds this initiative and requests NIAMS to publicize and support widespread use of this material.

Thank you, Mr. Chairman and subcommittee Members, for this opportunity to discuss with you the science of dermatology.

I will be pleased to answer any questions you may have.

PREPARED STATEMENT OF STEVEN R. BERG, DIRECTOR OF PROGRAM, NATIONAL ALLIANCE TO END HOMELESSNESS, INC.

The fight against homelessness in 1998

The national fight against homelessness is at a critical juncture. Despite low unemployment, all indicators are that the number of homeless people continues to rise. A recent study by Second Harvest, a nationwide nonprofit that provides food for shelters, soup kitchens and food pantries, showed that approximately 3.4 million people were homeless at some point in 1997, up from 1.3 million in 1988. The latest 29-city survey by the U.S. Conference of Mayors, A Status Report on Hunger and Homelessness in America's Cities: 1997, reported continued increases in requests for emergency shelter. Only two of the 29 cities reported that all need was being met; all but three of those reporting indicated that homeless families with children were turned away from shelter.

While this continued increase in homelessness may come as a surprise given the low rates of unemployment prevalent in much of the country, it should not. Many homeless people either can not work due to disabilities, or face barriers that make them likely to have the lowest paying jobs. The trends that brought about the sharp increase in homelessness since the early 1980s continue unabated:

—Wages for the lowest-paid workers have continued to fall in real terms.

—Public assistance has become less available. State after state has eliminated "general relief" programs for childless adults. Many people with disabilities related to substance abuse have been dropped from the SSI program, some as a result of conscious policy changes, others who should remain eligible but have been unable to negotiate the process for documenting their continued disability. States' TANF programs have terminated benefits to many families, and studies by the GAO and the states of New York and Maryland indicate half or more of those leaving welfare are not working steadily.

—States have continued to reduce the number of inpatient beds for people with mental disabilities.

Combined with these long-term trends, new factors have pushed the number of homeless people up. For the past three years there has been a net decline in the number of federally subsidized housing units available at affordable rents for low-income people. At the same time, the good economy has brought about skyrocketing rents in many locations, making it all the more difficult for people living on low-wage work or disability benefits to remain housed.

Even while this grim situation persists, certain opportunities make it possible, with effective leadership from the federal government, to make serious inroads against the problem of homelessness. The good economy means that jobs are plentiful. One outcome of welfare reform is a new commitment on the part of human serv-

ice providers, government and business to do the work necessary to make those jobs feasible for low- income Americans.

Perhaps more important, a result of ten years of experience implementing programs under the Stewart B. McKinney Homeless Assistance Act is a growing body of know-how. It is largely with the membership of the National Alliance to End Homelessness that this know-how resides. The Alliance has approximately 2,000 members, in every state, nonprofit organizations, government agencies and private businesses that are actively engaged in moving people out of homelessness. They are the best source of information about how federal programs work, and what is needed to make the fight against homelessness more effective.

Our members' experience with fighting against homelessness indicates the primary importance of a coordinated network of services and opportunities, working at the local level to ensure that there is affordable housing, adequate income through employment or government benefits for those who are unable to work, and human services for those who need them. This is not solely a task of the federal government, or indeed of government at all, but requires active participation by private business (providing jobs and knowledge about what kinds of workers are needed) and nonprofit agencies (providing commitment to serving individuals, plus the entrepreneurial energy to put programs together), as well as government (providing funding, coordination of programs, expertise, and networking on a local, state and national level).

Federal programs funded by the departments of Labor, Health and Human Services, and Education provide important pieces to the puzzle that homeless service providers must put together at the local level. These efforts will become even more important in the near future, due to initiatives of the Congressional committees that oversee the Department of Housing and Urban Development. HUD, of course, runs the largest of the federal government's homeless-specific programs, the Homeless Assistance Grants Programs. In the past, local recipients of Homeless Assistance Grants have used that money not only to provide shelter and housing, but also to provide human services. In fact, in the most recent year for which analysis is available, more than half of the money from the HUD Homeless Assistance Grants went to pay for non-housing services. Recent Congressional initiatives, however, have sought to focus the HUD resources more on permanent housing, where HUD has a formidable expertise. This creates a challenge to other federal agencies, to use their expertise to fill in service gaps.

Homeless-specific programs

The departments under this subcommittee's jurisdiction already have important programs targeted specifically to homeless people. The Department of Education's Education for Homeless Children and Youth program provides money to states to ensure that homeless children are able to have access to school. Health Care for the Homeless, part of HHS's Consolidated Health Centers, funds clinics to do outreach and provide medical care to homeless people. The Runaway and Homeless Youth program, also within HHS, pays for outreach, transitional housing and other services to this particularly vulnerable segment of the homeless population. HHS domestic violence programs address one of the major contributing factors to homelessness among women. The Homeless Veterans' Reintegration Project, run by the Department of Labor, funds local agencies to move homeless veterans into the job market through a range of services. Each of these provides funding and a centralized locus of expertise to deal with a particularly difficult aspect of the problem of homelessness. For each of these programs, the National Alliance to End Homelessness supports a level of funding that will adequately address critical need.

The PATH Program

Perhaps the most difficult aspect of homelessness is the subject of the PATH program (Projects for Assistance in Transition from Homelessness), administered by the Substance Abuse and Mental Health Services Administration within HHS. PATH provides formula grants to each state for community-based outreach, case management and treatment for homeless people with severe mental illnesses, including those with a dual diagnosis of mental illness and drug or alcohol addiction. PATH grantees often search out homeless people in streets and abandoned buildings, and respond to calls from concerned business owners and others about homeless people with obvious mental illnesses who have no connection to local networks of services.

In fiscal year 1996, when PATH funding was cut to $20 million, its grantees served 76,000 people, approximately $263 per person per year. This is in sharp contrast to the cost of involuntary hospitalization in a psychiatric facility, often hundreds of dollars per day.

Although PATH is extremely effective, its resources are overextended. Those with mental illnesses constitute up to one-third of homeless adults. By all accounts, this group is expanding. Homeless service providers often identify specialized mental health outreach and treatment as a service that is in too-short supply. PATH's fiscal year 1998 appropriation is $23 million, still well below its $33.1 million appropriation for fiscal year 1991. Even at its high point in 1994, PATH served 127,000 people. The most recent available count of homeless people with disabilities, from 1987, showed that even that long ago there were at least 180,000 adults with severe mental illnesses who were homeless. The actual number by now is almost certainly much higher.

Because homeless people with severe mental disabilities are so difficult to move into permanent housing, and because the PATH program has worked so well, the National Alliance to End Homelessness believes that a major increase in PATH funding is necessary in order to complement HUD and other homeless programs and ensure that the drive to move homeless people into permanent housing includes those with mental illnesses. The Alliance recommends an appropriation of $34 million for fiscal year 1999.

Other programs

A number of programs, not specifically targeted toward homeless people, provide funds for the kinds of services most needed by homeless people. These "mainstream" programs have not had a sufficient impact on the problems of homeless people. Job Training Partnership Act programs are an example. For several years, the Department of Labor ran a Job Training for the Homeless Demonstration Project. The results of this demonstration showed that, for employment-related activities to work for homeless people, they must be at least coordinated with housing services, so that residence is stabilized before homeless people attempt to take advantage of job-related programs. With the demonstration over, there needs to be a concerted attempt to encourage JTPA grantees to coordinate their services with local homeless providers, so that homeless people can gain from JTPA-funded activities.

The Substance Abuse and Treatment Performance Partnership Block Grant, administered by the Substance Abuse and Mental Health Services Administration, funds services that are desperately needed by up to half of homeless adults. The Administration has proposed an increase of $200 million in this block grant. Demonstration projects from the late 1980s show that substance abuse treatment for homeless people can be effective if coordinated with other services. Nevertheless, there is little indication that homeless people are benefiting from programs funded by the Substance Abuse Block Grant.

The National Alliance to End Homelessness urges the subcommittee to take measures to focus HHS and the Department of Labor on making their "mainstream" programs address the needs of homeless people.

Conclusion

The National Alliance to End Homelessness, for its members, thanks the Subcommittee for its attention to these issues. There is no reason that we need to tolerate homelessness. The know-how exists to solve the problem. All sectors of society are engaged. The federal government has programs that allow it to do its part, exercising leadership and filling gaps in services, efficiently and effectively. These programs need only to be brought to a more realistic scale, through strong funding for homeless-specific programs, and attention to the needs of homeless people when administering "mainstream" block grants.

PREPARED STATEMENT OF ROBERT M. TOBIAS, NATIONAL PRESIDENT, NATIONAL TREASURY EMPLOYEES UNION

Chairman Porter, Members of the Subcommittee: My name is Robert M. Tobias, and I am the National President of the National Treasury Employees Union (NTEU). NTEU is the exclusive representative of more than 160,000 federal employees across the government. Thank you very much for the opportunity to come before your Subcommittee today.

NTEU appears today on behalf of the employees we represent in the various divisions of the Department of Health and Human Services (HHS) and the Social Security Administration (SSA). This includes employees in the Office of the Secretary, Office for Civil Rights, Administration on Aging, Administration for Children and Families, Agency for Health Care Policy and Research and the Health Resources and Services Administration. In addition, NTEU represents employees within SSA's Office of Hearings and Appeals.

While we are unable to comment on specific proposals included in the President's fiscal year 1999 budget for the Department of Health and Human Services, the message I want to deliver today is this. Federal employees represented by this Union—not just in HHS and SSA—but government-wide, are working smarter and accomplishing more even while the resources available to them have continued to decline. There is an essential need for stable and steady funding levels, for improved and expanded training programs and for continuity in direction if our public servants are to continue delivering top quality service to the American taxpayer.

The federal government has undergone unprecedented downsizing. Over 300,000 federal jobs have been eliminated since President Clinton took office. As the President pronounced in his State of the Union Address just one week ago, "We have the smallest government in 35 years * * * a government that is leaner, more flexible, a catalyst for new ideas * * *"

And I hope the President was right that we have "moved past the sterile debate between those who say government is the enemy and those who say government is the answer". The federal employees represented by this Union who continue to serve the public are competent, hardworking and motivated individuals who want to deliver a high quality product to the American taxpayer.

The political reality is that the federal government is likely to continue to shrink. Many, if not most agencies have imposed restrictions on hiring, promotions and reassignments. Morale, in the wake of government bashing, budget cuts, reductions in force, efforts to contract out federal jobs, federal government shutdowns and the Oklahoma City bombing is at an all time low. We must recognize that only when we value the work our public servants perform can we expect the best and the brightest to continue to seek out careers in public service. The federal government operates as a business and like any successful business, it must recognize that its most important resource is its dedicated and committed workforce.

The uncertainty surrounding both the amount of annual appropriations agencies can expect and the date each year when new spending might be enacted into law has taken its toll. When annual funding hangs in the balance and rumors circulate that agency salary and expense accounts may be slashed, even the best employees become consumed by threats of losing their jobs. For several years now, employees across government have lived under a cloud of potential reductions in force. As you may know, Mr. Chairman, one important tool federal agencies have had has been the ability to offer buy-outs to employees whose jobs are being eliminated. That authority expired December 31, 1998. If further staffing reductions are envisioned at agencies funded under this appropriations measure, I urge this Subcommittee to carefully consider the need for new buyout authority for these agencies.

It is our hope, however, that agencies will be fully funded to enable them to continue the important work they perform. As the Chairman knows, the many programs administered by HHS and SSA have a wide impact on our Nation's citizens.

In fiscal year 1998, HHS's Administration for Children and Families (ACF) received $140.7 million for program direction. This represented a reduction of $2.3 million from the fiscal year 1997 appropriation for ACF. The ACF oversees an array of important federal initiatives including the successful Head Start program, child abuse prevention and treatment programs and a host of other critical child, youth and family programs. Cuts in this agency's funding have hampered employees' abilities to fulfill the agency's mission and I urge this Subcommittee to be mindful of these concerns as it debates fiscal year 1999 spending decisions.

Program support funding for the Agency for Health Care Policy and Research (AHCPR) was set at $2.2 million in both fiscal year 1997 and 1998. Clearly, this agency will require increased funding just to continue its important work.

Similarly, the Office of the Secretary should be carefully reviewed for its departmental management funding. In fiscal year 1998 the Office received $177.4 million—a decrease from its fiscal year 1997 funding level.

For the Administration on Aging (AOA), program administration funding increased by $37,000 from fiscal year 1997 to the 1998 level of $14.7 million. This modest increase enacted by Congress recognized the important services AOA delivers with the funding it is provided and NTEU hopes AOA will continue to be fully funded.

Program management funds for the Health Resources and Services Administration (HRSA) increased by $1.1 million from fiscal year 1997 to an fiscal year 1998 level of $114 million. HRSA plays a central role in ensuring that quality health care is available to millions of Americans and I hope this Subcommittee will carefully review this agency's continuing needs.

The mission of HHS's Office of Civil Rights (OCR) is to ensure that recipients of federal funding through HHS do not discriminate against program beneficiaries. OCR has an enormous responsibility, yet, historically, appropriation levels have not

kept pace with its workload and staffing requirements. Funding for OCR in fiscal year 1998 was set at $19.6 million, a modest $169,000 increase over the funding received by OCR in fiscal year 1997. The work performed by this division will continue to be in the spotlight in the coming fiscal year and I hope this Subcommittee will fund that work to the greatest extent possible.

NTEU is also critically concerned about funding for the Food and Drug Administration (FDA). Although the FDA is not funded under the Chairman's appropriation measure, I bring this need to your attention because FDA employees work in HHS facilities and alongside HHS employees. Underfunding compromises the important, as well as lifesaving, work of the FDA. Personnel levels must be brought to the point where timely approval can be given to medicines and other products without compromising accuracy, meticulousness or quality. The increase from fiscal year 1997's appropriation of $820 million to the $857.5 million FDA received in fiscal year 1998 was mostly to cover the costs of the new food safety initiative.

In the five years since passage of the Prescription Drug User Fee Act (PDUFA) of 1992, FDA has greatly improved the speed with which it can approve drugs for marketing—down from 30 months to 15 months. At the same time, however, the number of new submissions has increased by 50 percent. Staffing levels have not kept pace. Frontline employees are being asked to accept ever increasing workloads while striving to uphold FDA's policy of reducing approval times. While we applaud PDUFA and its recent reauthorization (PDUFA II) for creating a dependable revenue stream for the Agency through user fees and for its commitment to review times that will bring important drugs to consumers with greater speed, we caution any action that could sacrifice quality for speed.

There are several areas of concern regarding the Social Security Administration (SSA) that I would like to bring to your attention. SSA continues to have two major problems with its disability system, Continuing Disability Reviews (CDR) and the backlog at the Office of Hearings and Appeals (OHA). NTEU believes that the current level of funding for the CDR program will permit significant progress to be made in that area. However, the OHA backlog problem continues because substantial funds are being expended in the Disability Process Redesign (DPR) apparently toward the goal of decreasing the backlog, but without appreciable results. NTEU believes that SSA could make a significant reduction of that backlog with a much smaller expenditure by suspending or terminating the Adjudication Officer Initiative of the DPR and continuing the highly successful and relatively inexpensive Senior Attorney Program (also known as the Short Term Disability Program Action No. 7).

The massive increase in the disability backlog that OHA experienced from 1992 to 1996 has been contained and finally reversed. The case backlog has fallen from a high of approximately 570,000 in 1995 to 518,862 in December 1996 and to 458,142 by December 1997. While no one at OHA is satisfied with the current level of cases pending, we have demonstrated that we can, and will continue to significantly reduce the backlog without significantly changing agency operations. This substantial reduction of the backlog is due in great part to the Senior Attorney Program (approximately 120,000 decisions since its inception), which in continued, will facilitate an even greater reduction in the case backlog and in processing times, and a reduction in the reversal rate thereby providing greatly improved service to the public.

Senior Attorney Program

The Senior Attorney Program is a sharply focused plan with a well defined target, the disability backlog at SSA's Office of Hearings and Appeals, which for the most part uses existing agency assets. This program did not require restructuring the Agency, a massive infusion of expensive technology, revising the decisional methodology, extensive employee dislocations, comprehensive, lengthy and expensive training of substantial numbers of employees and nearly four years of planning without tangible results. In short, the Senior Attorney Program, which produced nearly 100,000 decisions in fiscal year 1996 and fiscal year 1997, has been relatively inexpensive and very effective and provides greatly improved service to the public primarily through redirecting current assets.

Senior Attorneys spend approximately 30–50 percent of their time performing work related to the short-term disability project and most of the remaining 50–70 percent of their time drafting ALJ decisions. The ability of Senior Attorneys to perform both tasks significantly increases managerial flexibility, allowing human assets to be directed to the highest priority tasks, thereby maximizing OHA productivity. Agency statistics reveal the overall productivity of Senior Attorneys to be approximately 25–30 percent more productive that "non-senior attorney" decision writers. Unfortunately, the potential effectiveness of this program has been somewhat decreased by the continued fierce opposition of many of the Agency's ALJs, some hear-

ing office managers, and many senior SSA officials, all of whom have their own agendas. Despite this persistent opposition, the Senior Attorney Program produced nearly 100,000 decisions in 1996 and 1997. With less organized opposition, NTEU is confident that the Senior Attorney Program can produce at least 75,000 decisions in fiscal year 1999 and over 100,000 decisions in fiscal year 2000 without significantly impacting upon ALJ case production. Quality Assurance studies conducted by the Appeals Council have demonstrated that the accuracy rate of Senior Attorney decisions significantly exceeds that of Disability Process Redesign's Adjudication Officers and is somewhat higher than that of on-the-record ALJ decisions. The accuracy of the Senior Attorney decisions combined with the significantly lower payment rate of Senior Attorneys (approximately 25 percent) again demonstrates that the Senior Attorney Program can reduce the time deserving claimants must wait for a decision by as much as a year in many hearing offices. During the course of the Senior Attorney Program, the overall payment rate at OHA has significantly declined thereby incurring a substantial savings in program costs. Additionally, the implementation of the Senior Attorney Program has not resulted in an unacceptable increase in the number of ALJ decisions awaiting drafting.

OHA has a long history of cyclical fluctuations in the cases awaiting drafting which can make comparisons in workload status somewhat misleading. OHA has established a goal that cases awaiting decision drafting not exceed a 10 day limit. NTEU believes that claimants are entitled to decisions on their applications as quickly as possible, and that cases decided by ALJs should be drafted as expeditiously as possible. However, too much emphasis has been placed upon the goal of maintaining the decision drafting pending level at 10 days at the expense of claimants who deserve, but will be deprived of a timely award of benefits. The average processing time of a disability case adjudicated in OHA hearing offices was 381.54 days at the end of December 1997. If the OHA goal of 10 days is met, the time the case has spent awaiting decision drafting constitutes approximately 2.5 percent of the time OHA currently requires to process a case; if the awaiting decision drafting time were to increase to 20 days, it would still be only 5 percent of the total processing time. The problem at OHA is not the time a case awaits decision drafting, but the months and months it awaits a hearing and/or it awaits a decision by an ALJ. The Senior Attorney Program has resulted in deserving claimants receiving a favorable decision with an average processing time of approximately 120 days as compared to the over 1 year for a case requiring an ALJ hearing. In other words, approximately 120,000 deserving claimants received their favorable decision only four months after filing because of the Senior Attorney Program. Service to the public demands that the Senior Attorney Program be vigorously supported.

While the number of cases awaiting decision drafting has risen since September 1996, the single biggest factor in that increase is the marked reduction of decisions drafted by ALJs. Interestingly enough, despite the decline in ALJ decision drafting, SSA has purchased an expensive notebook computer for each ALJ. Given the fact that few ALJs draft decisions, and virtually none draft the much more difficult denial decisions, the Agency's willingness to spend such a substantial sum on notebook computers for ALJs while requiring its "decision writers" to use obsolete machines and software, is an insight to the Agency's priorities.

The Adjudication Officer (AO) initiative of the disability process redesign

The primary Long-Term Initiative purporting to improve the OHA workload is the Redesigned Disability Process (DPR). However, at the outset of DPR, SSA admitted that is was not intended to deal with the two largest problems plaguing the Social Security disability system, the lack of an effective Continuing Disability Review (CDR) and the backlog at OHA. SSA subsequently claimed that one goal of the Adjudication Officer Initiative was to reduce the OHA backlog. The DPR consists of 83 separate initiatives of which GAO noted over a year ago that none have been completed. That situation has not changed. It is interesting to note that the United States won World War II in less time than it has taken SSA to attempt to implement the AO Program.

The initiative that SSA believes will provide relief to the OHA is the Adjudication Officer Initiative which began testing in November 1995. Despite the highest level of priority, carefully selected personnel, a priority on data processing equipment, and the establishment of closely controlled, ideal test conditions, AO productivity remains one half the level predicted by the DPR model. SSA has admitted that the DPR model upon which implementation of DPR is predicated is flawed. Yet, at the outset of the AO test, SSA was so confident in the reliability of the model that it questioned the need for testing at all, and publicly stated that the test was not a test of the concept, only a test to fine tune implementation of the AO Program, The AO concept has undergone extensive and rigorous testing since it was implemented

in November 1995. In February 1997, significant changes in the AO process were implemented and subjected to the on-going testing procedures. The results have not significantly changed; productivity remains approximately 50 percent of the projected levels and severe quality problems persist. Recently the Office of Workforce Analysis (OWA) issued a harshly critical assessment of the AO Program. OWA found that the AO Program was not cost neutral, and that it did, in fact, increase program costs.

Currently, OHA has approximately 7,500 employees including central office and regional office support staff and the Office of Appellate Operations (the Appeals Council) who are not directly involved in hearing office productivity. The DPR originally estimated that AO productivity would be two (2) "clearances" a day requiring approximately 1,500 Adjudication Officers. Additionally, DPR contemplated that 3 support staff persons would be needed to support 5 Adjudication Officers. After nearly two years of testing, productivity is still only slightly above 1 case a day in the best of circumstances. Such a level of productivity demonstrated in a carefully controlled test, is unlikely to be matched in a "real world" full scale implementation. Nonetheless, even accepting a productivity of 1 per day, 3,000 Adjudication Officers will be needed and nearly 2,000 additional support staff. SSA has avoided providing documentation regarding the number of support persons involved in the AO test, but NTEU believes that the level of support required has been significantly greater than anticipated. Full implementation of the AO Program will require nearly as many people as OHA currently employs in its hearing offices and yet these people are performing only a relatively small portion of the work currently performed at OHA hearing offices. Of course, if the DPR blueprint is accurate, the work of these 5,000 people will reduce the number of claimants requiring ALJ hearings by 25 percent, approximately the same amount already accomplished by the approximately 500 Senior Attorneys in the hearing offices.

By any objective measure the AO test has been a nearly complete failure. Yet SSA has continued to pursue this failed program to the detriment of other programs which do significantly improve the disability adjudication process. The DPR, particularly the AO test, has had no measurable effect upon the workload of OHA except consuming resources, both human and material, that could have been put to much better use.

Recommendations

1. The Senior Attorney program has significantly reduced the delay in granting deserving disabled people their disability benefits, stabilized the OHA workload, and reduced the overall payment rate at OHA, thereby contributing to a savings in program costs with a relatively small outlay in funds. NTEU recommends that funding for this program be continued to ensure 75,000 Senior Attorney decisions are rendered in fiscal year 1999 and 100,000 Senior Attorney decisions are rendered in fiscal year 2000.

2. Modern computer hardware (including notebook computers) and software to facilitate the decision process should be provided to those individuals responsible for drafting the vast majority of OHA (ALJ and Senior Attorney) decisions.

3. The Adjudication Officer Initiative of the Disability Process Redesign should be immediately suspended or terminated and at least some of the funds scheduled for that project should be redirected to effective efforts at reducing the OHA backlog.

Thank you again for the opportunity to appear. I would be happy to answer any questions.

PREPARED STATEMENT OF EMILY S. DEROCCO, EXECUTIVE DIRECTOR, INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES

Overview

The Interstate Conference of Employment Security Agencies (ICESA) is the national organization of state officials who administer the nation's public Employment Service, unemployment insurance laws, labor market information programs and, in 41 states, job training programs. In most states, these officials are also responsible for coordinating workforce development one-stop centers, and they play an important role in welfare-to-work services.

As you know, appropriations for administration of unemployment insurance programs, employment services, labor market statistics, and certain veterans employment programs come from the Unemployment Trust Fund (UTF). The UTF, like the Social Security Trust Fund, is made up of dedicated revenues from state and federal employer-paid payroll taxes. While the trust fund revenues are sufficient to fully fund the operation of those programs, the focus on elimination of the federal budget

deficit and the inclusion of unemployment trust funds in budget deficit calculations have undermined the funding arrangements set up by the system's founders. Less than 60 percent of estimated fiscal year 1998 FUTA revenues were appropriated for employment security administration. A survey by ICESA a year ago showed that 43 states were using over $200 million in state funds to supplement federal appropriations for employment security administration.

Frustration with the federal budget and appropriations process has convinced many states that a fundamental change in the administrative funding arrangements of the employment security system is needed. A coalition of states and business interests has developed a proposal to shift responsibility for collection of federal unemployment taxes to the states which would retain most of the funds. Twenty-six states currently support this proposal, and the House Ways and Means Committee, Subcommittee on Human Resources, intends to consider the legislation this session.

One-Stop Employment Service

For the last several years, Congress has been considering bills to consolidate job-training programs and develop an integrated workforce development system. Even though no legislation has yet been enacted, the public policy discussions have yielded substantial support at all levels of government for a one stop service delivery system, i.e., ensuring that customers—jobseekers and employers—can access the full array of employment, unemployment, training, and labor market information services easily and through a single source. As a result, beginning in fiscal year 1994, the Department of Labor requested and the Congress began appropriating resources to be used as one stop grants for states to design and implement one stop career center systems.

The Department of Labor and virtually all of the states view the state Employment Services as the essential "glue" that holds together the one-stop systems. While one stop grants—available to states for three years—have been used to build linked information systems, in some cases to integrate services in shared physical facilities, and to develop and implement new customer-friendly technologies and service delivery approaches, continued high quality, customer friendly service in communities across the nation will depend upon the strength of the foundation or infrastructure of the one stop system. As states complete their third year one stop grants—the first one stop implementation states' third year grants will expire in fiscal year 1999—the continued vitality and success of their one stop systems will be dependent upon their basic employment and training program funding. This means the state Employment Service state allotments must be shored up or the success of one-stop career center systems will be short-lived.

As implementation of one stop systems is accomplished and one stop funding trends downward, we ask you to commit additional funds to ES state allotments-the foundation of the one stop center systems and the assurance of universal services for both jobseekers and employers—rather than funding new initiatives. The states are requesting $811 million to support state ES allotments.

In addition to their importance to the continued operation and success of state one stop systems, the state Employment Services ensure the only linkage between employment and training programs and the unemployment insurance system. The Employment Services are the vehicle to provide job search assistance to individuals who have been "profiled" and identified as likely to exhaust their UI benefits and still be unemployed. Research conducted by the U. S. Department of Labor and evaluated by Mathematica Policy Research, Inc., has shown that intensive job search assistance to unemployment insurance beneficiaries reduced receipt of benefits by an average of three-quarters of a week.

This may not sound significant until you translate it into dollars and impact on the federal budget. Using economic assumptions in the President's Budget, there are estimated to be about 8.1 million unemployment insurance beneficiaries in fiscal year 1999. The average weekly benefit amount is estimated at $198.50. A reduction of three-quarters of a week of benefits would save the unemployment trust funds $148.88 per beneficiary. If funds were available to state Employment Services to provide job search assistance to just 30 percent of the total number of beneficiaries—2.4 million UI beneficiaries—the savings to the unemployment trust fund would be $357,312,000. The cost of providing the services would be approximately $137,856,000 (based on estimated average state time spent per beneficiary and staff salaries). This yields net savings to the trust fund of $219,445,000 in one year. Thus, each dollar invested in the Employment Service and directed to serving UI claimants saves the unemployment trust fund and the federal budget about $2.59. The importance of the linkage between the unemployment insurance system and a strong Employment Service cannot and should not be ignored.

Again, an $811 million investment in the state Employment Services is critical to the one stop systems in the states, to providing effective job search assistance to unemployed workers and saving trust fund dollars, and to maintaining and enhancing new electronic tools to efficiently and effectively match jobseekers to available jobs.

National Activities—Employment Service

In addition to state Employment Service allotments, there are three programs/initiatives funded under ES national activities that are critical:

The Electronic Labor Exchange—The state Employment Services are the source of the job vacancies currently listed in the highly acclaimed and often cited America's Job Bank. The success of this electronic labor exchange tool is well known. To illustrate its growing popularity, in July 1996, 7.2 million customer transactions were recorded, and in June 1997, over 29 million transactions were recorded, making AJB one of the most visited websites on the Internet. This tool is only valuable to jobseekers as it continues to contain active job vacancies, provided through the state Employment Services and their outreach to employers across the nation. In the coming year, America's Talent Bank, the resume side of the electronic labor exchange, will be available to job seekers and employers. We urge you to continue supporting these exciting tools of the state Employment Services.

Alien Labor Certification—Federal alien labor certification laws ensure that admission of foreign workers on a permanent or temporary basis does not affect adversely the job opportunities, wages and working conditions of U.S. workers. State employment security agencies (SESAs) must oversee and evaluate the recruitment efforts of employers for U.S. workers and assure that "prevailing wages" are being offered for particular positions before a certification can be issued that the employers can hire foreign workers.

Federal funding for administration of the Alien Labor Certification program by SESAs has been cut dramatically in recent years. In fiscal year 1997, state allocations were cut by an average of 50 percent from fiscal year 1996; a number of states were cut by more than 60 percent. In fiscal year 1998, the President's budget requested the same level of appropriations as fiscal year 1997, but it also stated that the Administration would seek legislation—which was never submitted—to authorize fees to support this program. These fees were estimated to bring in approximately $19.2 million in fiscal year 1998. The combination of this severe cut in funding and a significant increase in cases brought about by changes to federal immigration laws has resulted in huge backlogs-more than a year in some states. The frustration of parties to the pending cases has resulted in bomb threats and other threats of violence to state agencies. Several states are considering whether to refuse to continue to operate the program under these untenable conditions.

In order to address this critical problem, it is essential that this committee restore funding to at least $50.5 million—which is the total of fiscal year 1998 appropriations, $31.3 million, plus the estimated, but non-existent, fees of $19.2 million. We also ask that the committee direct the Department of Labor to work with the state employment security agencies to streamline procedures and eliminate unnecessary and bureaucratic red tape that chokes the certification process.

The Work Opportunity Tax Credit (WOTC) and Welfare to Work (W2W) Tax Credit are federal tax credits administered by state employment security agencies that encourage employers to hire certain jobseekers. Both programs enjoy broad bipartisan support from Congress and the Administration. WOTC was recently extended through June 30, 1998, and will likely be extended at least through fiscal year 1999. The Welfare-to-Work (W2W) Tax Credit program, which provides tax credits to businesses that hire the hardest to employ welfare recipients, is in effect through April 30, 1999.

In order for state agencies to make timely certifications of eligibility so businesses can claim the tax credit, administrative funds are essential. ICESA requests $20 million for state administration of these two programs.

Unemployment Insurance

We would like to thank the subcommittee for its support for a special appropriation of $200 million in the fiscal year 1998 appropriations bill to bring state employment security agency computer systems into compliance with the Year 2000. These funds have been allocated, and ICESA's members are working diligently to revise millions of lines of program code to ensure that payment of unemployment benefits is not disrupted due to the "millennium problem." Although the timetable is still very tight, Year 2000 compliance would have been an impossible task for many states without these funds.

Even during this time when our economy is healthy and dynamic, the unemployment insurance system plays a larger economic role than might be imagined. A dynamic economy means that skilled workers may be laid off from jobs in one sector of the economy and may find new ones in another sector. During the time they look for new jobs, unemployment benefits provide temporary wage replacement. State unemployment insurance programs are expected to pay $23.2 billion in benefits to 8.4 million unemployed workers and collect $22.4 billion in state unemployment taxes during fiscal year 1998. Estimates for fiscal year 1999 project 8.1 million beneficiaries, benefit payments totaling $24.2 billion, and state unemployment tax collections of $24.2 billion.

The federal-state partnership in the unemployment insurance program has worked well during most of the 62-year history of the program. The federal partner's responsibility for providing adequate funds for proper and efficient administration of state laws resulted in establishment of a system of administrative funding based on hard data: workloads (e.g., claims filed, payments made, employers subject to the state law) accomplished; staff productivity factors; and the salaries of state merit system staff. In recent years the gap between the funding needed based on these data and the amount actually provided has become so wide that it is not clear to states that a connection exists between these "need factors" and the funding provided.

For fiscal year 1999, we urge you to provide $2.369 billion—the President's request—for state unemployment insurance activities.

In addition, we urge you to appropriate $91 million authorized for unemployment insurance integrity activities in fiscal year 1999 by the Balanced Budget Act of 1997. These funds are needed to support intensified tax collection/audit and claims monitoring activities. These funds will be used to: reduce accounts receivable; register and tax all new employers immediately; improve collection of delinquent taxes; implement/improve fraud cross match programs; train staff in claims adjudication; and improve detection and collection of benefit overpayments. This $91 million appropriation will be more than offset in the federal budget by increased taxes collected and overpayments prevented or recovered.

Labor market information

In the debate surrounding workforce development reform, there is clear consensus that accurate and timely labor market information is an essential part of our economic infrastructure, providing information about employment, jobs, and workers. Such information is an invaluable resource for jobseekers, businesses, educators, and young persons who are planning careers—answering their questions of: Where are the jobs of the future? What changes are occurring in the skill requirements for today's and tomorrow's jobs? Which industries are growing rapidly? Where are layoffs occurring?

State employment security agencies in cooperation with the Bureau of Labor Statistics and other federal agencies produce most labor market information. This cooperative system provides a sound basis upon which to build an expanded and readily accessible nationwide system of labor market information envisioned by workforce development reform legislation currently under consideration by the Congress. Today's information technology presents a dazzling array of opportunities to integrate labor market information with education/training and job matching data into exciting and powerful new systems. ICESA supports an appropriation of $55 million for BLS Cooperative Programs.

Veterans' employment and training

Congress has made it clear that providing employment services for veterans is a national responsibility. Title 38 of the U.S. Code includes provisions for special employment services for veterans, with priority given to disabled and Vietnam era veterans, through the Disabled Veterans Outreach (DVOP) and Local Veterans Employment Representative (LVER) programs. DVOPs and LVERs serve our veterans population by helping to ensure a smooth transition of separating military personnel into the civilian workforce.

Title 38 also provides formulas to determine DVOP and LVER staffing levels. Since 1990, appropriations for DVOPs and LVERs have not supported the number of positions authorized by the statutory formulas. In fiscal year 1997, the appropriation funded 440 fewer DVOP specialists and 260 fewer LVER staff than authorized by the statutory formulas. Many local offices and one stops no longer have any veterans' staff. ICESA encourages the committee to explore funding above last year's level that would allow at least one DVOP and LVER in every full-service office. Specialized veterans' employment representatives working in state employment service

offices and one-stop career centers nationwide will help ensure that our nation does not abandon the fine men and women separating from the military.

Job training

While economic growth in the United States is the envy of the rest of the world, one of the problems of our current economy is a lack of qualified workers for many job openings. The economic sectors where there are labor shortages include entry level jobs, where potential workers need basic skills, as well as information technology jobs where workers with highly specialized skills are needed. Federal job training programs for disadvantaged adults and youth help to prepare welfare recipients, students, and others to enter the labor force; programs for dislocated workers help them to develop new skills needed to participate in the "new economy." We urge your continued support for federal job training programs authorized by the Job Training Partnership Act.

Conclusion

In summary, our message is one of encouraging efficient and effective investment of public resources in a strong workforce development system built on the infrastructure that exists today. With your help and targeted investment, we have the ability to link unemployment, employment, labor market information, and training programs together to provide seamless, high quality customer service to America's employers and jobseekers.

PREPARED STATEMENT OF GLENN A. GRANT, ESQ., BUSINESS ADMINISTRATOR, CITY OF NEWARK

Dear Mr. Chairman, thank you for the opportunity to submit written testimony on behalf of a proposed pilot project in Newark, New Jersey designed to identify and address the needs of a most vulnerable part of our population—children affected by domestic violence. The City of Newark is seeking $1 million for the Newark Kids Initiative, which is an effort to identify members of this at-risk group, diagnose their needs, and improve the system that provides services to them.

Newark is home to over 275,000 residents, and is the most densely populated city in the state of New Jersey. Newark suffers from other concurrent difficulties, including a high unemployment rate, low per capita income, and poor literacy rates. The children of Newark suffer from a range of poverty-related ills: a high infant mortality rate, low birth weights, low immunization rates, and a low rate of routine "well child" care. When a child suffering from these and other problems, is also exposed to domestic violence, they have a broad range of physical, psychological and emotional needs.

The City of Newark Police Department has taken an aggressive stand in response to calls to domestic violence situations. In 1997, officers received approximately 10,000 calls, with nearly 4,000 of those reported as Uniform Crime Report recognized cases. Most of these calls involve a combination of abusive behaviors, physical, sexual or emotional assault, and drug or alcohol abuse in the home. Through a US Department of Justice grant, Newark officers are being trained in techniques to respond to domestic violence. The Police Department, though, is just a first step in getting help to these families in crisis. The mission of the Police Department does not, and cannot, address the needs of the youngest victims of abusive family situations—the children. In the most severe cases, referrals are made to the New Jersey Division of Youth and Family Services, and a child may removed from the home. However, more often, the abusive parent and the children remain in the home, with a loose and uncoordinated "safety net" in place to aid the family.

At the same time, the City Department of Health and Human Services and community service organizations see a broad range of health and social problems presented in their clientele under the age of 12, most of which stem from, or are exacerbated, by substance abuse. This substance abuse may be by parents or others in the home itself, in the neighborhood, or by the children themselves. The drug treatment facilities in the City are not able to handle the volume of cases presented, and do not provide the kind of extensive counseling and follow-up the entire family may need.

The City of Newark proposes to establish a pilot project to identify children affected by domestic violence, research the problems specific to their situations in partnership with a local university, assess their needs, and provide referrals to the appropriate service providers. The program will explore possible linkages to court-ordered sanctions, and will work to ensure that treatment and staff training are sensitive to cultural norms while working enhance family cohesiveness.

It is estimate that the pilot program will include 100 families, who will be the subjects of intensive evaluation, research, and coordinated service referrals. Trained civilian staff will be hired to assist the Police Department in identifying at-risk families and their children under the age of twelve from the pool of reported domestic violence cases. The university partner will perform in-depth research on the problems involved, and develop training, treatment, and referral protocols to address the needs of children. This may include substance abuse treatment for parents, medical assistance to family members, family and individual counseling, or other modalities discovered or recommended through the research. The Newark Department of Health and Human Services will serve as a case coordination entity for the children, and support and train community agencies as needed to provide necessary services.

Federal assistance is requested to support the dedicated staff of both the Police Department and Health and Human Services Department, contract with a local university to perform the study and provide treatment recommendations, and support training for pertinent community service agencies to deal with the full range of problems presented by the children of domestic violence. The Newark Kids Initiative could indeed serve as a model for the nation's most vulnerable residents, thereby breaking the cycle of family violence.

PREPARED STATEMENT OF JOSEPHINE NIEVES, MSW, PH.D., EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF SOCIAL WORKERS

On behalf of the 155,000 members of the National Association of Social Workers (NASW), I respectfully request that you consider NASW's funding requests, as well as the attached recommended report language to accompany the fiscal year 1999 Labor/HHS/Education Appropriations bill.

NASW's requests focus on two important areas: the maintenance of fiscal year 1998 discretionary funding ($6 million) for Child Welfare Training, Title IV–B, Section 426 of the Social Security Act, and an increase in fiscal year 1999 funding for the health professions training programs administered by the Health Resources and Services Administration (HRSA) to $306 million.

Maintain funding for the Child Welfare Training Program, Title IV–B, Section 426, of the Social Security Act, at the $6 million level

NASW requests that Child Welfare Training, Title IV-B, Section 426 continue to be funded at the fiscal year 1998 level of $6 million. This program is administered by the Administration for Children and Families in the Department of Health and Human Services (HHS). Child abuse and neglect has reached staggering levels. The need for skilled and highly qualified workers in our child welfare system is greater than ever. The enclosed recommended report language ensures the availability of professionally trained social workers within the child welfare system. The increased funding would help expand the pool of much-needed professional child welfare workers.

Increase funding for health professions training programs administered by HRSA in HHS to $306 million

NASW requests that the Subcommittee increase funding for Title VII and VIII (Public Health Service Act) programs to $306 million. It is important to provide adequate funding for the health professions programs, which are crucial to ensuring an appropriate supply of health and mental health professionals, including social workers. These programs have been instrumental in increasing the number of health providers from minority backgrounds, fostering community-based education, and enhancing service to underserved communities.

Enclosed is recommended report language, which is similar to language included in the fiscal year 1998 House and/or Senate Appropriations Committee Reports for the Departments of Labor, Health and Human Services, and Education. This includes report language that addresses the need for standards and guidelines on training mental health professionals, including social workers, for practice in primary care and managed care settings targeted to underservedand rural communities. The language encourages collaboration between HRSA and the Substance Abuse and Mental Health Services Administration (SAMHSA) in preparing health professionals to work in public health settings and managed care organizations.

Additionally, the National Institutes of Health (Nod) has effectively implemented fiscal year 1997 and fiscal year 1998 report language encouraging them to form a working group of appropriate institutes on child abuse and neglect research. The working group, led by the National Institutes of Mental Health (NIMH), is addressing the need to coordinate child abuse and neglect research within NIH, developing a consensus on a research agenda, and providing some leadership with other federal

agencies involved with child abuse and neglect research. NIH Director Dr. Harold Varmus issued a report in April 1997 that outlined NIH current research efforts in this critical area and made recommendations for future action. We feel it is critical to recognize what NIH has done and to encourage them to continue by including fiscal year 1999 report language, which is enclosed.

Also included is recommended report language supporting additional social work research and training programs in NIH, SAMHSA, and Centers for Disease Control and Prevention. We hope that you will give our requests for funding and our suggestions for report language serious consideration throughout the appropriations process.

We appreciate the support you have given on appropriations issues important to social workers and the clients we serve. If you have any further questions or need any information, please contact Madeleine Golde, Government Relations Staff Associate, at 202-336-8237.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PEDIATRICS

On behalf of the American Academy of Pediatrics and the endorsing organizations, the Society for Adolescent Medicine and the Ambulatory Pediatric Association, we would like to submit this statement for the record.

Fortunately, most infants are born healthy and continue to grow and develop normally if they have access to and receive basic health care services. Unfortunately, there are still far too many that suffer needlessly from disease, injury, abuse, and a host of societal problems. Our task as pediatricians is to promote preventive interventions and to diagnose, treat and manage acute and chronic problems of children and adolescents. Your task is to provide the funds to sustain vital federal programs that underpin and complement these efforts. As pediatricians we recognize the integral tie between basic research and the care we provide; we see the impact of poverty and violence on the health of our children and adolescents; and we know that the future of our workforce depends on the decisions we make today. We ask that you continue to recognize the importance of preventive and chronic health services, research, and the education and training of pediatricians and other health professionals and to appropriate the necessary funds to the extent possible.

A chart at the end of this statement will offer funding recommendations for many programs, but we would like to focus on a few.

Prevention and early intervention

Childhood Immunization Program.—The CDC's childhood immunization program is the cornerstone of preventive health care for children served in the public sector and for uninsured children. Tremendous strides in establishing effective immunization programs have been made over the past few years. In addition to the cost-effectiveness of vaccines, the number of reported cases of vaccine preventable diseases are at or near all time lows. Immunization levels of two-year old children are the highest ever recorded. We attribute this, in part, to the Vaccines for Children (VFC) Program and encourage Congress to maintain its commitment to ensuring its viability. The VFC program combines the efforts of public and private pediatricians and other health care professionals to accomplish and sustain vaccine coverage goals for both today's and tomorrow's vaccines. It removes vaccine cost as a barrier to immunization for some and reinforces the concept of a "medical home." To date, its successful implementation has resulted in the enrollment of more than 40,000 public and private provider sites. Yet, despite this good news, the most recent National Immunization Survey reports that nearly 1 million two-year-olds still are under-immunized. Furthermore, adolescents continue to be adversely affected by vaccine preventable diseases (e.g., varicella, hepatitis B, measles and rubella). Comprehensive adolescent immunization activities at the national, state and local level are needed to achieve national disease elimination goals. In addition, continued investment in CDC efforts to assist states in developing immunization information systems will serve to maintain high immunization levels by reminding parents when immunizations are due/overdue. It also helps pediatricians and other health care professionals know the immunization status of the children they serve. Obviously, the ultimate goal of immunizations is eradication of disease; the immediate goal is prevention of disease in individuals or groups. Until other remedies are firmly in place, the continued investment in CDC efforts must be sustained. In fiscal year 1999 the Academy and the endorsing organizations recommend at least $539 million for CDC's Childhood Immunization program.

Maternal and Child Health Service Block Grant.—The MCH Block Grant is a "block grant" that works. It provides preventive and primary care services to 17 mil-

lion women and children, including 11.3 million infants, children and adolescents, 900,000 children with special health care needs as well as preventive services to approximately 4.8 million women—including one-third of all pregnant women in the U.S. The MCH Block Grant includes an important set-aside of 15 percent percent to support the Special Projects of Regional and National Significance (SPRANS) to improve maternal and child health and promote more effective delivery systems. One example is the Healthy Tomorrows Partnership for Children Program, a collaborative venture between the MCH Bureau and the Academy. The Healthy Tomorrows Partnership projects represent a new initiative in a community or an innovative component that builds upon existing community resources. These projects have provided: primary care for uninsured children and children insured through the Medicaid program; intervention and care coordination for children with special health needs; interventions for health promotion through risk reduction in families; adolescent health promotion; expanded perinatal care and parent education services and services for special child and family populations. Projects have been funded in a variety of communities including: Washington, DC; Chicago; New Haven; Dallas; Anchorage; and Milwaukee. Another important component of the MCH Block grant is that it addresses interdisciplinary adolescent health training and services and research for both the physical and mental health needs of adolescents. The Office of Adolescent Health supports initiatives such as health care programs for incarcerated youth, health care services for minority group adolescents, and violence and suicide prevention. We support the funding of the MCH Block Grant program at its full authorization of $705 million—a modest 3.5 percent increase which will help to preserve and improve crucial public health services for children and mothers including outreach to the most vulnerable and at-risk families under the new State Child Health Insurance Program (SCHIP).

Tobacco.—The Academy and all of the pediatric community have strived for decades to curb children's and adolescents' access to and use of tobacco. This is a silent and deadly plague. Each day 3,000 children nationally begin to use tobacco. Of those people who will ever smoke, 90 percent begin before age 19. Young smokers suffer from respiratory problems and asthma, and among teens who are regular smokers, one in three will die prematurely from smoking. Overall, tobacco-related illnesses claim the lives of over 400,000 Americans each year. Tobacco prevention and cessation efforts must involve pediatricians, parents, schools and communities. Not only do we counsel our patients about the addictiveness of nicotine and its detrimental health effects; we also discuss with parents the impact of secondhand smoke on their children. Additionally, we hope to work with you to make sure that federal, state and local programs are effective at preventing tobacco use. Tobacco use truly is a "pediatric disease" that is completely preventable. We recommend at least $61 million for CDC's Office on Smoking and Health in fiscal year 1999, this includes funds for the transfer of the tobacco prevention and cessation program (ASSIST) currently housed at the National Cancer Institute. These programs have proven records of success at reducing smoking rates. The 105th Congress has the historic opportunity to more fully address tobacco control issues now and save lives. We urge you to support well-funded and comprehensive tobacco control legislation.

CDC injury prevention.—Injury is the leading cause of death and disability among children and young adults (ages 1–44). Unintentional injury and intentional injury are the leading causes of death for children and adolescents. Countless others are injured and disabled. Injury is costly on multiple levels—in the emotional toll it takes on its victims and on their families; in direct medical expenses (acute and chronic); and in long-term economic costs due to the years of potential life and productivity lost (especially with respect to children). In direct medical costs alone, injury costs the federal government $12.6 billion annually, and an additional $18.4 billion each year in disability and death benefits. Therefore, measures to prevent injury or reduce its severity are extremely cost-effective. The National Center for Injury Prevention and Control (NCIPC) fulfills a unique function in this undertaking. It works closely with other federal agencies; national, state, and local organizations and community groups; state, tribal,[1] and local health departments; and research institutions to monitor injury and to develop, evaluate, and disseminate effective interventions to prevent injury or reduce its impact. The Center's work addresses many types of injuries, both intentional (homicide, suicide, physical and sexual assault against children and women, youth-perpetrated violence) and unintentional (motor vehicle, bicycle and pedestrian injury and home and recreational injury, including fires, poisonings, and falls). The Center also administers special programs to reduce violence against women, and traumatic brain injury. Additional resources

[1] Deaths due to unintentional injuries are twice the rate for Native American children than for children of all other races.

would enable the Center to continue its important leadership in the "Safe America" program, through which NCIPC has brought together diverse public and private-sector entities to develop and disseminate injury prevention information and interventions. The initial focus of the effort is to reduce injury among children and adolescents. Further support would also enable the Center to expand efforts to reduce physical and sexual violence against children, develop a comprehensive youth violence prevention program, and ensure that every U.S. resident has access to the life-saving and cost-effective services of a poison center through national or state specific toll-free numbers. To carry out continuing and expanded activities, we recommend that the CDC injury prevention program be funded at $70 million.

Emergency medical services for children.—In 1993, an Institute of Medicine report described serious deficiencies in emergency medical services for children (EMSC); for example, many ambulance services and hospital emergency departments lack child-sized equipment (e.g., oxygen masks, IV-tubes, neck braces) and many emergency medical personnel need additional training to adequately treat children, whose medical needs are very different than those of adults (e.g., children have more serious breathing problems, are less tolerant of blood loss, are more vulnerable to head injuries, and respond differently to medications). The federal EMSC grant program has helped states and localities make significant strides in improving EMSC through, for example, the development of model training programs, ambulance equipment lists, treatment protocols, and triage and transport systems. Grantees' work has been widely disseminated so that others can build upon it, thus enhancing the cost-effectiveness of the federal investment and the opportunity to improve EMSC. We know that the federal EMSC program has saved lives. For example, in Kentucky this year, paramedics were able to resuscitate a 14-year old girl in cardiac arrest, using skills recently acquired through training instituted with EMSC funds. Paramedic training and other system components, are necessary but not sufficient, however. Localities, states, and inter-state regions must get together to designate facilities based on their degree of pediatric emergency expertise (similar to the "Level I, II, II" trauma care designations), and to establish emergency transport protocols and inter-facility transfer agreements. Only when such regional systems are in place will a critically ill or injured child be sure to get the best possible emergency care. Unfortunately, there are few geographic areas where such arrangements have been established. The federal EMSC grant program is working to spur the development of such systems, an especially challenging task in the face of a continuous lack of understanding of the unique needs of children. To continue to stimulate life-saving EMSC system improvements, we recommend funding this program at $15 million.

Head Start, Early Head Start, child care, after-school care.—The Academy strongly supports efforts to improve the accessibility, affordability and quality of early child care/education in this country. Recently published research on early brain development underscores what pediatricians have known for years—that a child's care in the earliest years of life are critical in developing his or her potential to be a healthy and productive citizen. For older children and teens, after-school programs can direct their energies to positive activities, and away from juvenile crime, gangs, tobacco, alcohol, drugs, and premature sexual activity. Therefore, we recommend, at a minimum, funding Head Start and Early Head Start at levels necessary to achieve the goals recently proposed by the President—to serve one million children in Head Start and 80,000 infants and toddlers in Early Head Start by the year 2002. Additionally, we urge funding the Department of Education's "21st Century Community Learning Center Program" at $200 million for fiscal year 1999 in order to expand school-based after-school care. We also urge the Committee to fully fund any additional spending that might be authorized this year to assist families rearing children, whether or not they use out-of-home child care.

Pediatric research

Agency for Health Care Policy and Research.—The AHCPR is the primary federal agency charged with developing clinically-based, policy relevant information for use in improving the health care system, providing leadership in health services research and providing training for new health services researchers, such as pediatricians. It uniquely serves the interest of both health care consumers and health care professionals. Important outcomes research supported by AHCPR have shown that improving quality of care can save taxpayers hundreds of millions of dollars per year. For example, universal implementation of guidelines on the treatment of otitis media with effusion, a common condition of the middle ear in young children, could cut the total cost of care in half and annually save over $700 million. Funding from AHCPR has supported several important studies of asthma, including a study of the management of acute asthma in pediatric practices and the ASTHMA PORT study, currently in process, that is focused on improving quality of care and cost savings

in the treatment of asthma. In an AHCPR-funded study of the assessment of fevers in very young infants, the Academy is collecting data on how pediatricians assess febrile infants less than 3 months of age. One product of the study will be a revised guideline for diagnostic work-up for infants with fever. It is anticipated that such a guideline will make it possible to eliminate at least 10 percent of the hospitalizations for observation and diagnosis of these infants that currently occur. Such a result would save $36 million in current hospital costs. Another recent AHCPR study on pediatric referrals identified factors related to pediatric referrals for specialty care. Implications from this study are being discussed in terms of interventions that can improve physician referral making in ways that impact both the quality and cost of care. To enable the Agency to continue its critical research that provides policymakers, health care providers, and patients with the information on what works and how to best implement what is most effective in health care we recommend funding of $175 million for AHCPR in fiscal year 1999. We commend this Committee's recognition of and recommend continued emphasis on children and adolescent health services issues as an AHCPR priority.

National Institutes of Health.—Research funded by NIH has made great strides in improving the health status of children and youth in all aspects of life, from issues of child care and obesity to reduction of infant mortality and maternal-to-infant transmission of HIV. These research projects and many more improve the quality of life for many children and adolescents everyday. For example, research conducted at NIH on Sudden Infant Death Syndrome (SIDS) has clearly shown a relationship between infant sleep position and SIDS. In fact, as a result of the "Back to Sleep" public health campaign, the incidence of SIDS has been reduced by 38 percent. The development of surfactant, which can be administered into the lungs of premature infants, has resulted in fewer deaths of infants from Respiratory Distress Syndrome (RDS) and has saved an estimated $90 million a year in hospital costs. Thus, an investment in children's medical research not only saves lives and alleviates suffering, but also reduces future health care expenditures. In addition, we endorse the testimony of our pediatric colleagues, the Public Policy Council, that outlines in greater detail the importance of a strong national pediatric research agenda. We join with the Ad Hoc Group for Medical Research Funding in recommending a 15 percent increase for NIH in fiscal year 1999 and also join the Friends of NICHD in supporting $776 million for the National Institute of Child Health and Human Development. In order to increase pediatric biomedical and behavioral research within NIH, we recommend $50 million for the Pediatric Research Initiative.We believe that these requests represent the best and most reliable estimate of the level of funding needed to sustain the high standard of scientific achievement embodied by the NIH. However, we strongly encourage Congress to explore all possible options to identify additional sources of funding needed to support these increases if we are to reach this goal under the current spending limitations.

Education/Training

Health professions training.—Title VII of the Public Health Service Act, Primary Care Training Grants for General Internal Medicine and General Pediatrics, remains a small but vital incentive program for generalist education and training as well as increasing the pool of under-represented minority group pediatricians and other health care professionals . These grants provide support for faculty development and a large number of residents to receive intensive primary care training in diverse ambulatory settings—this is the only federal support targeted to training primary care health care professionals. Faced with increases in the incidence of AIDS, substance abuse, adolescent pregnancy and other health concerns, pediatricians of the future will be expected to manage both acute and chronic health problems, care for children and adolescents with disabling conditions, and effectively screen and counsel for problems that are psychosocial or behavioral in nature. Given the complex needs of their patients, pediatricians will also be called upon to utilize community resources and to collaborate with other health care providers. Title VII grants in pediatrics have supported education and training in a variety of community and non-hospital based settings such as juvenile detention centers, homeless shelters, child nutrition programs, child care centers and community health centers. We recommend fiscal year 1999 funding of at least $25 million for General Internal Medicine/General Pediatrics and join with the Health Professions and Nursing Education Coalition in supporting, a modest increase of $306 million in total funding for Title VII and Title VIII, which is last year's level plus medical inflation. We further recommend funding of $125 million for the National Health Service Corps a key component of any effort to remove barriers to health care and to ensure an adequate distribution of health care providers across the country.

Conclusion

Thank you for this opportunity to provide you with our recommendations for the coming fiscal year. In summary, the following list highlights programs, along with funding recommendations, of importance to children. The Academy joins with its many friends in other organizations and coalitions in presenting these recommendations.

Recommendations for fiscal year 1999

Department of Health and Human Services:	
Centers for Disease Control and Prevention	$2,800,000,000
Childhood Immunization Funding	539,000,000
Injury Control	70,000,000
Lead Poisoning	50,000,000
Office on Smoking and Health	61,000,000
Folic Acid Supplement Program	20,000,000
Health Resources and Services Administration	3,734,000,000
Ryan White Pediatric Demos	61,000,000
EMSC	15,000,000
Family Planning (Title X)	218,452,000
MCH Block Grant	705,000,000
National Health Service Corps	125,000,000
Health Professions Training (Total)	306,000,000
General I.M/Pediatrics (Title VII)	25,000,000
Agency for Health Care Policy and Research	175,000,000
National Institutes of Health	15,694,000,000
NICHD (Child Health)	776,000,000
NIEHS (Environmental Health)	379,624,000
Pediatric Research Initiative	50,000,000
Administration for Children and Families:	
Child Abuse and Treatment and Prevention:	
Title I Grants to states	100,000,000
Title II Community Based Family Resource and Support Grants	66,000,000
Child Care and Development Block Grant	1,000,000,000
Indian Health Service	2,537,456,000
Department of Education:	
IDEA part B	4,607,500,000
IDEA part c (formerly part H)	400,000,000
IDEA section 619	500,000,000

PREPARED STATEMENT OF THE PUBLIC POLICY COUNCIL

This statement is submitted on behalf of the Public Policy Council which represents the Society for Pediatric Research, the American Pediatric Society and the Association of Medical School Pediatric Department Chairmen. These organizations represent thousands of pediatric researchers involved in basic, clinical and health services research. Our collective goal is to improve the quality of life for all of America's children. The scientists represented by our organizations come from medical schools, children's hospitals and other research facilities. They are the driving force behind the biomedical advances that benefit children and they also are the mentors for training our next generation of pediatric investigators.

On behalf of the pediatric academic research community, our statement speaks about the importance of increasing funding for pediatric biomedical, behavioral and clinical research, and for the training of future pediatric bench and clinical investigators.

Our statement addresses three issues: first, why do we need to fund pediatric research; second, why fund pediatric investigators; and third, how do we preserve pediatric research and sustain its investigators.

What is the Justification for Funding Pediatric Research?

Infants and children are leading healthier lives. Research funded by the National Institutes of Health (NIH) has had a significant impact on the well-being of children. As a result of NIH funded research, deaths from sudden infant death syndrome (SIDS) have been reduced by 38 percent, the development of surfactant for infants with respiratory distress syndrome (RDS) has saved the lives of premature babies, and infants now receive a vaccine to prevent Hemophilus influenza type b (HIB) meningitis, one of the leading causes of mental retardation.

However, there are still many pediatric diseases that are not preventable or for which treatment may not exist, may only be palliative or is simply inadequate. Even relatively common pediatric diseases, such as, cystic fibrosis and juvenile onset diabetes—diseases that we do know a great deal about—do not currently have a cure. Modern therapy for such diseases is cumbersome, costly and stressful for children and their families.

Whereas it is obvious that we want to improve the health of children for their own sake, it may be less obvious that improvements in pediatric medicine will have far-reaching implications on the societal and economic costs of disease in adults. Many diseases usually associated with adulthood begin in childhood. A strengthened investment in pediatric research will benefit adults as well as children. Why? Let's mention just two examples: osteoporosis and diabetes mellitus. In both examples, the enormous societal and economic costs of these diseases are not incurred during childhood. Nonetheless, both disorders have their origins in pediatrics and might be less severe or preventable if we focus on these conditions in our children. We know that osteoporosis is a disease that causes crippling bone deformities, most commonly in post-menopausal women. But to quote a famous expert on osteoporosis, "senile osteoporosis is a pediatric disorder." This is because all of us deposit bone minerals throughout childhood, adolescence, and early adulthood. In fact, by the age of 30, we have each achieved our peak bone density. After that, bone mass declines throughout the rest of adult life. Deficiencies in bone mass in childhood and adolescence thus predispose individuals to lower bone mass in adulthood. If we could improve acquisition of bone mineral during childhood and adolescence, we might prevent adult osteoporosis.

Another example is diabetes, which causes tremendous morbidity, pain and suffering. There are two types of diabetes that affect adults and both types have their origins in childhood. Recent results of a large, multi-center NIH-funded study known as the DCCT (Diabetes Control and Complications Trial) demonstrate that by tightening blood sugar control, long term complication rates are reduced. The study did not include prepubertal children and thus, we do not know how tightly young children with diabetes should be controlled. Since there are also risks associated with tight control, this type of study in children must be done. The other type of diabetes known as adult onset diabetes is associated with environmental factors such as obesity, high fat diets and inadequate exercise. We are now seeing this disease in younger and younger children. Is the increased incidence of obesity and the sedentary lifestyle of our children predisposing us to an adult disease? The only way to answer these questions is with further research in pediatrics.

The importance of the linkage of pediatric research to adult health can also be seen in the fact that some families have a genetic tendency to develop heart disease. Research indicates that this could be associated with a high level of cholesterol in their blood or with high levels of triglycerides. Although many children in these families do not yet suffer from heart disease the way that adults do, at what point does cholesterol begin obstructing blood flow injuring blood vessels and subsequently injuring the heart? Should children be treated with one of the new cholesterol lowering drugs? If so, which one and when? What are the side effects of these drugs in children? Are they the same as in adults, or are they more serious? Clearly more research is needed and necessary.

Moreover, as we continue with the human genome project and learn more about genes associated with disease, more windows of opportunity between early detection and overt symptoms of disease will open for intervention. This aspect of that project makes research involving children imperative. The ability to precisely determine what disease will affect a person will be available before gene therapy can provide a cure. Moreover, as we explore this very important opportunity to develop preventive strategies through genetic testing of children, we must recognize that this is still an evolving area of medical science that has social, ethical and psychological implications that will need further study. For instance, recently it was discovered that ibuprofen (Advil and Nuprin) delays the onset of symptoms in some people who have genes that convey the susceptibility for Alzheimers disease. Would screening for carriers and treating them in childhood make a difference? Do benefits in sixty years outweigh side effects now? Once again, we see that to adequately answer these questions, more pediatric research is needed and necessary.

Why fund pediatric investigators?

We are in an age of great technological innovation that has allowed for a better understanding of the pathogenesis of disease, enhancing diagnostic capabilities and improving the treatment of patients. However, the actual practice of medicine is too often based on empiricism rather than evidence derived from well-controlled clinical trials. Clinical trials when done well can establish the usefulness of a particular test

or treatment and examine their cost effectiveness compared to current practice. Unfortunately, according to a report issued by the Government Accounting Office, only 10–20 percent of medical practices are based on data from well-controlled studies. Thus, when your child or grandchild is being treated for an illness today there is only about a one in five chance that the therapy is based on solid evidence that it will be helpful.

There is a growing concern among our academic colleagues that there is a looming crisis for the future of pediatric research. Most pediatric research is performed at the nation's medical schools, children's hospitals and the intramural programs at NIH. As the focus of academic health centers shifts away from the traditional roles of research, teaching and patient care, to one focused predominately on patient care, we are concerned that the quality of training of future generations of pediatric medical scientists will be impaired. This will in turn jeopardize the future health of our children. There are many reasons for this trend, as recently outlined in the NIH Director's Panel on Clinical Research 1997 Report, including the specialized, complex training and role of teacher-clinician-scientists, student debt after leaving medical school, and the changes to the health care system brought about by managed care.

How do we promote pediatric research and preserve the training of pediatric investigators?

The pediatric community applauds the ongoing commitment of Congress, through the leadership of this Committee, to increase NIH funding. We support the fiscal year 1999 recommendation presented by the Ad Hoc Group for Medical Research Funding, that calls for a 15 percent increase in funding for the NIH as the first step toward doubling the NIH budget over five years. This recommendation includes support for increased funding for the general clinical research centers (GCRCs) which the Public Policy Council also supports. The pediatric academic societies endorse the Friends of NICHD Coalition's recommendation for the National Institute of Child Health and Human Development (NICHD) of $776 million and the overall fiscal year 1999 Public Health Service funding recommendations of the Coalition for Health Funding. In particular, your Committee has helped make pediatric research a priority at the highest level of the NIH by establishing a new pediatric research initiative that was funded at $38.5 million in fiscal year 1998. This is a reasonable starting point. Today, we encourage you to increase funding for this initiative to $50 million in fiscal year 1999. We recognize the difficulty in achieving these goal under the current spending limits. However, we encourage you to explore all possible options to identify the additional resources needed to support this recommendation.

Furthermore, we urge increased funding for training programs that will attract minority group students into the medical profession, encourage medical students to pursue clinical research, support young investigators, provide opportunities for mentoring by experienced clinical investigators as well as enhance the quality of our mentors. We must not short change our children from receiving care from well-trained and qualified pediatric investigators.

Inclusion of children in clinical trials

We commend this Committee's recognition and strong encouragement to the NIH in fiscal year 1996 "to establish guidelines to include children in clinical research trials conducted and supported by the NIH." The NIH is developing these guidelines and we foresee the implementation later this year. We anticipate that significant advances will be gained in understanding the mechanism and improving the treatment of pediatric diseases. This new policy is an excellent initial step. Moreover, it reflects an important partnership and the commitment of the research community to work with the NIH in the development of proposals that will increase clinical research participation for children without mandating it. However, we believe that it should only be viewed as a first step. In order for this policy to be effective, it must be followed by other measures. For example, detailed and specific mechanisms must be outlined and established that will ensure implementation of the policy and a process should be established to assess the efficacy (or lack thereof) of the policy in generating both data about and therapeutic advances for children. We welcome and look forward to working with the NIH on these and other implementation issues of the new guidelines.

Conclusion

As pediatricians and researchers, we know first hand that there are many important opportunities for additional pediatric research which promise significant return on investment—not only improved health for our children today but also economic productivity tomorrow—as these children grow into adulthood. We support the in-

creased investment in research in general and the new pediatric initiative in particular.

In summary, the following list highlights programs, along with funding recommendations, of importance to children. The Public Policy Council joins with its many friends in other organizations and coalitions in presenting these recommendations.

Recommendations for fiscal year 1999

National Institutes of Health	$15,694,000,000
NICHD (Child Health)	776,000,000
Pediatric Research Initiative	50,000,000
Agency for Health Care Policy and Research	175,000,000
Centers for Disease Control and Prevention	2,800,000,000
Folic Acid Supplement Program	20,000,000
Health Resources and Services Administration	3,734,000,000
MCH Block Grant	705,000,000
Health Professions Training (total)	306,000,000
General I.M./Pediatrics (Title VII)	25,000,000

Prepared Statement of the Association for Health Services Research

Thank you, Mr. Chairman and Members of this Subcommittee, for the opportunity to submit this written statement on the role of health services research in improving our nation's health care. The Association for Health Services Research (AHSR) is a non-profit organization and the only national professional association devoted to improving the health status of Americans through health services research. AHSR represents more than 2,800 individuals who use and produce health services research and approximately 140 organizational members, including universities, insurers, providers, major employers, and health plans.

Just as federal funding of biomedical research is essential to developing new treatments for disease, a continued strong federal commitment to health services research is needed to ensure that these discoveries are appropriately translated into the delivery of quality health care. By evaluating the effectiveness of health care and the ability of the health care system to deliver these services efficiently, health services research aids in the transfer of science from the laboratory into practical use by physicians and hospitals—essentially speeding the integration of biomedical research into patient care and disease prevention.

Health services research also plays a critical role in educating consumers and purchasers about the care they receive, serving as a resource not just for disease treatment and prevention information, but also providing information, such as quality data for health plans, that enables consumers to better choose their health care. Furthermore, by examining the impact of the delivery and financing of health care on access and quality, health services research provides the evidence needed by policymakers to better determine health care priorities, particularly among vulnerable populations and within the Federal health Medicare and Medicaid programs.

Demand for health services research among consumers, employers, providers, health plans, and policymakers has never been greater. As our nation's health care marketplace continues to become more sophisticated and more complex, health services research has become an essential resource for making informed decisions about how to deliver needed care efficiently. The goal is to identify which treatments work best for which patients and to assess the relative cost of those treatments so that health care providers and patients can make informed decisions about what regimens to choose.

ADVANCING THE ROLE OF HEALTH SERVICES RESEARCH

Our country is the world's leader in making some of the most remarkable and life-enhancing medical discoveries ever known. Integrating these discoveries into health care delivery requires a collaborative effort, particularly among the federal government's health research agencies. Health services research is not an activity about which one can say that if the federal government does not do it, the private sector and perhaps a state and local government will step in. Lack of federal support will mean a chronic under investment in health services research to improve the quality of health care. Each of the agencies plays an important role in influencing the delivery of health care in America and bring its own contributions or tools to the health care quality equation.

Agency for Health Care Policy and Research

The Agency for Health Care Policy and Research (AHCPR) serves as the focal point within the federal government for determining what works best in health care. The President has recommended an increase of $25 million for AHCPR, or a total fiscal year 1999 budget of $171 million. These new funds will allow AHCPR to carry out several new directives recently mandated by Congress, including:

—Continued research on improving the quality of care for Medicare and Medicaid beneficiaries, the uninsured, and children, focusing particularly on improving the management of chronic conditions such as congestive heart failure and osteoporosis;

—Support for the Congressional initiative, the Children's Health Insurance Program, by providing scientific evidence on how to improve quality care for uninsured children;

—The establishment of centers for education and research, as authorized in the Food and Drug Administration Modernization Act, to increase the awareness of new uses and the risks of drugs and other medical products;

—Full implementation of the agency's private sector initiatives, including the Evidence-based Practice Centers, which provide a forum for physicians, health plans, employers, and researchers to work together in addressing prevalent and costly health conditions in American society; and

—Increased awareness of the preventive care recommendations of the U.S. Preventive Services Task Force to encourage screening and immunizations.

Recommendation.—Recognizing Congress' interest in improving health care quality, AHSR strongly believes that the health services research activities of AHCPR must be even further strengthened with additional funding. AHSR urges the Subcommittee to support an additional $4 million for AHCPR for a total fiscal year 1999 budget of $175 million.

Health Care Financing Administration

The Health Care Financing Administration's research arm, the Office of Research and Demonstrations (ORD), guides the development and implementation of new health care financing policies and evaluates their impact on Medicare and Medicaid beneficiaries, participating providers, and states. ORD plays a critical role in creating a better understanding of how well the Medicare and Medicaid programs are performing in terms of access, quality, efficiency, costs, and beneficiary satisfaction and in how to further improve program performance.

Recommendation.—AHSR supports the President's fiscal year 1999 funding request of $50 million for the Health Care Financing Administration's Office of Research and Demonstrations.

National Institutes of Health

As the foremost biomedical and behavioral research institution in the world, the National Institutes of Health (NIH) also provides significant funding for health services research. While many Institutes fund health services research, NIH primarily supports health services research through:

—Prevention and treatment programs of the National Institute of Alcohol Abuse and Alcoholism (NIAAA) and the National Institute on Drug Abuse (NIDA),

—Studies on risk factors and cost-effective mental health care of the National Institute on Mental Health (NIMH), and

—Information dissemination activities of the National Library of Medicine (NLM).

Recommendation.—AHSR supports the President's fiscal year 1999 budget request for a $1.1 billion increase for the National Institutes of Health and, specifically supports the increases proposed for NIAAA, NIDA, NIMH, and NLM.

Centers for Disease Control and Prevention

CDC's National Center for Health Statistics (NCHS) is the nation's principal vital and health statistics agency, conducting ongoing studies to meet the nation's health information needs. These tools provide the basis for research at AHCPR and NIH on specific diseases or within certain populations.

Recommendation.—AHSR supports the President's request of $86 million for NCHS.

Conclusion

The Congressional promise to the American people to improve the quality of health care will be difficult to keep unless it is coupled with increased health services research funding. We can not improve quality without a body of evidence-based science to guide clinicians and public and private policymakers about what works best and how to create systems to deliver good quality care at acceptable cost. The degree to which that body of evidence is available and the extent to which we suc-

ceed in achieving quality improvement in health care will depend directly on the level of funding support that is made available for health services research.

PREPARED STATEMENT OF ALAN H. RICHARDSON, EXECUTIVE DIRECTOR, AMERICAN PUBLIC POWER ASSOCIATION

The American Public Power Association (APPA) is the service organization representing the interests of the more than 2,000 municipal and other state and locally owned utilities throughout the United States. Collectively, public power utilities deliver electric energy to one of every seven U.S. electric consumers (about 35 million people) serving some of the nation's largest cities. The majority of APPA's member systems are located in small and medium-sized communities in every state except Hawaii. APPA member systems appreciate the opportunity to submit this statement in support of fiscal year 1999 appropriations for the Low Income Home Energy Assistance Program (LIHEAP).

We fully support the Administration's fiscal year 1999 budget request of $1.1 billion for LIHEAP. APPA also supports the request for $300 million in emergency funds in fiscal year 1999 and $1.1 billion in advanced funding for fiscal year 2000. Because the majority of LIHEAP monies are needed during a short period of time in the winter months, advanced funding for LIHEAP is critical in enabling states to effectively plan for and administer the program.

Funding cuts since LIHEAP's last reauthorization have forced a tightening of eligibility standards and, in some cases, significant reductions in benefit levels. According to the National Energy Assistance Directors' Association (NEADA), the primary educational and policy organization for state LIHEAP directors, the number of recipients has been cut by over one million households during the recent past and average benefits have declined by about 10 percent. Prior to the dramatic reduction in LIHEAP funding in fiscal year 1995, the program was serving 20 percent of the eligible population, with one-half of the recipients being elderly or disabled Americans living on fixed incomes. Without the assistance provided by LIHEAP, many would be forced to choose between paying their home energy bill or purchasing other necessities of life, such as food.

As the debate over restructuring of the electric utility industry and the issue of providing and funding "public benefits" programs continues, some in Congress have stated their belief that electric utilities should assume the entire burden of energy assistance for low income customers as a cost of doing business. As these restructuring efforts take place at both the federal and state levels, the risks become greater that bills for residential customers, especially those with low incomes, will increase if retail markets are opened to competition. The need for full funding of LIHEAP remains critical in ensuring that all those in need of energy assistance receive help. APPA believes that any public benefits programs should not replace or supersede existing programs, such as LIHEAP, that are funded by federal appropriations.

As evidence of commitment to low income assistance, public power systems across the country support a variety of programs providing help to low and fixed income customers. A survey conducted by the National Fuel Funds Network (NFFN) shows that publicly-owned utilities raised 14 to 26 cents more per customer than other utilities in their efforts to assist low income and needy customers in paying their bills. Many public power systems provide special rates for low income households and some have residential conservation and demand side management programs designed to reduce energy consumption.

In addition, the impact of welfare reform on energy assistance is just beginning to be felt and LIHEAP is likely to play an important role in the transition. Persons who will be leaving the public assistance rolls likely will be entering lower paying jobs and still will be confronted with large energy bills. These families remain at risk.

LIHEAP is one of the outstanding examples of a successful state-operated program. The requirements imposed by the federal government are minimal and most important decisions are left to grantees.

APPA urges this Subcommittee's favorable consideration of the Administration's fiscal year 1999 budget request for LIHEAP. Again, thank you for this opportunity to present our views.

PREPARED STATEMENT OF DEB BECK, PRESIDENT, DRUG AND ALCOHOL SERVICE PROVIDERS ORGANIZATION OF PENNSYLVANIA

My name is Deb Beck and I serve as the President of the Drug and Alcohol Service Providers Organization of Pennsylvania (DASPOP). DASPOP is a coalition of

drug and alcohol prevention and treatment practitioners, programs, and drug and alcohol associations organized for advocacy on behalf of individuals and families in need of drug and alcohol prevention, education, intervention and treatment. DASPOP represents more than 365 organizations, programs and clinics, 1,900 certified addictions professionals, 1,200 student assistance professionals, and others throughout Pennsylvania.

I am submitting this testimony on behalf of DASPOP, the National Coalition of State Alcohol and Drug Treatment and Prevention Associations, which is composed of 33 state-based associations of treatment and prevention providers in 29 states and the Legal Action Center, a non-profit law and policy firm that represents individuals in recovery from and struggling with alcohol and drug problems and AIDS. Through federal and other funds, the programs I represent provide services to addicted parents and pregnant women who want a better future for their children, addicted individuals in the criminal justice system who can move to a sober and crime free life, and millions of children and adults at risk for developing alcohol and drug problems.

We appreciate last year's increases for alcohol and drug prevention and research programs and the Committee's refusal to cut funding for alcohol and drug treatment programs. Providing strong support for alcohol and drug treatment, prevention, and research is imperative to maintain and improve the health and well being of our Nation. These programs effectively decrease alcohol and drug use, crime, health care costs, AIDS, and welfare dependence.

Treatment and prevention needs in Pennsylvania and around the Nation

Pennsylvania programs, such as Gaudenzia Inc. and the Diagnostic and Rehabilitation Center have been leaders in developing effective programs for women, youth, homeless individuals and other under served populations. However, according to a recent survey conducted by the National Association of State Alcohol and Drug Abuse Directors (NASADAD), on any given day in Pennsylvania there is a waiting list of 1,400 individuals and families in need of treatment for alcoholism and drug dependence.

Because of changes to welfare laws on both the state and federal levels, we are seeing increased demand for all levels of alcohol and drug prevention and treatment services supported by the Substance Abuse Prevention and Treatment Block Grant and we expect this trend to accelerate. Studies have demonstrated that 16–20 percent of the individuals on welfare have alcohol or drug problems. In Pennsylvania, an estimated 41,872 TANF (Temporary Assistance for Needy Families) recipients will be in need of addiction treatment. However, because of treatment capacity limitations due to public funding limits and obstacles created by some forms of managed care, many individuals will be unable to receive treatment during their period of welfare eligibility. It is imperative that sufficient treatment and prevention programs be available to help individuals and families move from welfare to work.

Far too often, treatment is unavailable until the person is in need of intensive treatment or has entered the criminal justice system. In particular, residential treatment for women and children and for addicted adolescents is getting increasingly difficult to obtain. Lack of parity in private insurance coverage for alcohol and drug treatment and prevention services coupled with often ineffective and inaccessible consumer grievance procedures limit the ability of individuals and families to get help through private insurance and HMO coverage. This problem shifts individuals onto the public treatment system funded by the Substance Abuse Prevention and Treatment Block Grant.

Recommendations

For providers to supply these essential services in Pennsylvania and throughout the nation, we need your support. We urge Congress to adopt the following increases in fiscal year 1999 funding for alcohol and drug treatment, prevention, and research programs in the Substance Abuse and Mental Health Services Administration (SAMHSA), Department of Education, and National Institutes of Health. These are wise investments that will provide desperately needed services in communities across the country:

—$1.51 billion for the Substance Abuse Prevention and Treatment Block Grant (an 11 percent increase over fiscal year 1998 appropriations, including the $50 million appropriated in the "Contract with America Advancement Act" (Public Law 104–121)).

—$180 million for the Center for Substance Abuse Treatment (CSAT) (a 15-percent increase over fiscal year 1998) and $180 million for the Center for Substance Abuse Prevention (CSAP) (a 15-percent increase over fiscal year 1998), which includes $10 million for the High Risk Youth Grants program (a 66-per-

cent increase over fiscal year 1998). These allocations would fund Knowledge Development and Application (KDA) activities and targeted capacity expansion programs that increase treatment and prevention services for high risk youth, ex-offenders, and women and children on welfare.

—$606 million for the Safe and Drug Free Schools and Communities Act program (a 10-percent increase over fiscal year 1998).

—$262.2 million for research at the National Institute on Alcohol Abuse and Alcoholism (NIAAA) (a 15-percent increase over fiscal year 1998) and $658.9 for research at the National Institute on Drug Abuse (NIDA) (a 25-percent increase over fiscal year 1998).

Treatment and Prevention Reduce Alcohol and Drug Use, Have Public Support

Numerous studies have demonstrated the effectiveness of treatment and prevention in reducing alcohol and drug use. The most recent, the National Treatment Improvement Evaluation Study (NTIES), evaluated CSAT's demonstration programs and found sustained reductions in drug use. Drug use declined by 50.7 percent for crack, 55 percent for cocaine, 46.5 percent for heroin, and 50 percent for marijuana for the 5,700 clients studied one year after completing treatment. NTIES also found a 77.6 percent decrease in violent crime, 18.7 percent increase in employment, and 10.7 percent decrease in welfare dependence. I have attached a copy of this study so that it may be included in the record.

Prevention also has been shown to be effective in reducing use. A 1997 NIDA study found that research-based prevention programs significantly reduce youth alcohol and drug use. A 1995 Cornell University study of 6,000 junior high students in New York State found that students who participate in school-based prevention programs are 40 percent less likely to use alcohol and drugs than those who did not participate.

Treatment has been repeatedly shown to be cost-effective. A 1994 California study found that each $1 invested in substance abuse treatment and prevention saves taxpayers $7; a 1996 Oregon study determined the return to be $5.60 for every $1 invested.

The public recognizes the value of treatment and prevention services. A 1995 Gallup poll found that 77 percent of Americans favored increased spending for alcohol and drug treatment services. Police have echoed the public's support for treatment. In a March, 1996 poll, 300 police chiefs from around the country ranked drug abuse as the most serious problem in their communities—more serious than domestic violence, burglary and theft, or violent crime. Large-city police chiefs have repeatedly identified the shortage of treatment programs as the most serious limitation in their ability to address drug problems successfully.

The treatment gap in our communities is growing

Access to alcohol and drug treatment does not meet the current need for services. Only 50 percent of the individuals who need treatment receive it.[1] Waiting lists for alcohol and drug treatment are six months long in some regions.

Recent entitlement reforms will shrink existing alcohol and drug treatment and prevention services significantly at a time when more services will be required.

Welfare reform has reduced treatment availability by making individuals convicted of drug felonies after August 22, 1996 ineligible for cash assistance or food stamps in many states. Residential treatment programs, particularly programs serving low-income women and children, have relied on the these funds to help support room and board costs of care. Without these funds, treatment availability will decrease. Welfare reform also requires states to move individuals from welfare to work within a given time period, or a state's federal welfare funding will be decreased. Several national studies have concluded that 16–20 percent of welfare recipients have alcohol and drug problems. This could translate into an additional 400,000–800,000 adult welfare recipients needing treatment to move into recovery, off welfare, and into jobs.

Loss of Supplemental Security Income (SSI) support for individuals with alcohol and drug problems also will increase the need for public treatment services. On January 1, 1997, an estimated 200,000 individuals with alcohol and drug disabilities lost their SSI and Medicaid coverage. Less than 60,000 of these individuals have requalified for SSI and Medicaid under another disability. Methadone maintenance, residential, and outpatient programs have relied on Medicaid to provide treatment. These programs now face budget gaps which reduce treatment availability.

---

[1] Woodward, A., Epstein, J., Gfroerer, J., Melnick, D., Thoreson, R., and Willson, D. "The Drug Abuse Treatment Gap: Recent Estimates." Health Care Financing Review, Vol. 18, Number 3. Spring, 1997.

In addition to the shortfalls created by these changes to SSI eligibility, the $50 million per year that Public Law 104–121[2] appropriated to the Substance Abuse Block Grant for alcohol and drug treatment services was only appropriated for fiscal years 97 and 98 and will not be available in fiscal year 1999. Therefore, in fiscal year 1999 there is an additional $50 million shortfall in treatment funding.

Investment in prevention programs pays off: Further investment required

The "1997 Monitoring the Future Survey" reported an encouraging result this year—after years of dramatic increases in illicit drug use among eighth graders, drug use remained stable for most drugs, and decreased slightly for marijuana and certain other substances among eighth graders from 1996–1997. Even more significant was the fact that for the first time since 1991, the 1997 survey indicated an increase in the percentage of eighth graders disapproving of occasional and regular use of various drugs, including marijuana, powder cocaine, and alcohol. Such shifts in attitudes among adolescents demonstrate the success of expanding prevention programs.

In order to reduce the remaining high levels of alcohol and drug use among youth, further expansion of prevention programs must occur. Every adolescent should have access to alcohol and drug prevention services. Increased funding in fiscal year 1999 is needed to provide such necessary access to prevention services.

Drug and alcohol treatment, prevention, and research funding must be expanded

Substance Abuse Prevention and Treatment Block Grant—SAMHSA/CSAT.—The majority of SAMHSA's funding for drug and alcohol treatment and prevention is sent directly to states through the Substance Abuse Block Grant. The Block Grant is the primary source of federal funding for alcohol and drug treatment and prevention services, accounting for more than one-third of public funding for these services nationwide.

Programmatic changes in SAMHSA's categorical grant program, described below, have left the Block Grant as virtually the only source of federal funding for community-based treatment and prevention services in SAMHSA. In tandem with dramatic decreases in demonstration funding, these changes will translate into a significant loss of direct services funding over the next several years.

To help meet the pressing and increasing need for alcohol and drug treatment and prevention services, we urge Congress to fund the Block Grant at $1.51 billion for an overall increase of $200 million over fiscal year 1998 funding.

SAMHSA/CSAT and CSAP—balancing the knowledge development and application (KDA) program with the need to target services to under served populations

In fiscal year 1997, the Administration restructured CSAP and CSAT demonstrations into "knowledge development and application" (KDA) programs targeted at testing models of care in the community instead of increasing service capacity. Historically, these programs directly funded community-based services filling critical service gaps for, among others, pregnant women, women with children, people involved in the criminal justice system, the homeless, youth in high-risk environments, and community-based prevention partnerships. We are very concerned that these changes have translated into the loss of direct, community-based treatment and prevention services at a time of increasing need.

We believe that funding at the Centers should be directed toward two major activities: the continuation of existing grants under the Knowledge Development and Application (KDA) Program and services capacity expansion for populations at high risk or which have increased need for treatment and prevention services. Targeting service funding to specific populations, such as high risk youth, offenders, and women and children on welfare, allows CSAP and CSAT to determine the most efficient and effective way to serve these populations at a time when treatment and prevention resources are at a premium. Indeed, the demonstration programs have been absolutely essential to our ability to test the effectiveness of services. Without them, for example, we would not have the outcome data I related earlier from NTIES about the effectiveness of federally funded treatment programs. Investment in the application of research findings is also a key Federal responsibility, and CSAP and CSAT, as the lead Federal agencies in prevention and treatment, are singularly equipped to translate research findings into innovative application programs.

Despite studies demonstrating the efficacy of treatment and prevention services, funding for the Centers was dramatically reduced in fiscal year 1996. Currently

---

[2] The "Contract with America Advancement Act," which ended eligibility for Supplemental Security Income (SSI) for individuals with alcohol and drug disabilities alone.

CSAP is $87.5 million and CSAT is $52.4 million below their fiscal year 1995 funding levels.

For fiscal year 1999 we urge Congress to appropriate $180 million for CSAT and $180 million for CSAP, a $24 million increase for CSAT and a $29 million increase for CSAP over fiscal year 1998 funding. (CSAP's funding recommendation includes the recommendation of $10 million for the High Risk Youth Grant program).

Safe and Drug Free Schools and Communities Act—Department of Education

Research has demonstrated that school-based prevention programs that focus on personal and refusal skills development can significantly reduce alcohol and drug use. This program also supports student assistance programs that intervene with students who are beginning to use alcohol and drugs and refer them to appropriate services. These early intervention programs, which have no other source of federal funding, are critical to reaching youth at high risk early.

For fiscal year 1999 we urge Congress to appropriate $606 million for the Safe and Drug Free Schools and Communities Act program, a $50 increase over fiscal year 1998.

Basic Research—NIH/NIAAA and NIDA

Research into the causes, costs, and "cures" of alcoholism and drug dependence is an important component of our field's continuum. This past year NIDA scientists have observed biochemical changes in the brain stimulated by drug use with Positron Emission Topography (PET) and scientists at NIAAA have been making great strides in genetic research relative to alcoholism. These breakthroughs have demonstrated that alcoholism and drug dependence research hones our knowledge about addiction and improves our ability to treat and prevent it.

We believe more resources are needed to ensure adequate research attention. We urge Congress to appropriate $262.2 million for NIAAA (a $35 million increase) and $658.9 million for NIDA (a $131.7 million increase).

Conclusion

Alcoholism and drug dependence continue to be among our Nation's most serious and costly health problems. The programs I have discussed are the first line of defense to protect our children from developing drug and alcohol problems, as well as the funding source of last resort to treat Americans who have already developed these problems. As a society, we must keep these programs strong. Thank you.

PREPARED STATEMENT OF THE NATIONAL KIDNEY FOUNDATION

The National Kidney Foundation (NKF) is the nation's largest voluntary health organization devoted to the care of patients with kidney disease, as well as the prevention and cure of diseases of the kidney and urinary tract. The NKF consists of more than 30,000 lay and professional volunteer constituents. The NKF is a member of the Council of American Kidney Societies (CAKS), and we support the testimony that has or will be presented by the other members of that Council: the American Society of Nephrology, the American Society of Pediatric Nephrology, the American Society of Transplant Physicians and the Renal Physicians Association.

The NKF is most appreciative of the significant support that the Committee has provided to the National Institutes of Health (NIH) during the last few years. We know that the members of the Committee have been faced with difficult funding decisions for many worthy programs, and we thank you for making the NIH a priority. We are particularly appreciative of the 7.5 percent increase that the Committee provided to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for fiscal year 1998.

We also wish to thank Congress for its expressed interest and past support of the problem of kidney disease caused by pain killers. The NIDDK has launched a new initiative to identify the prevalence of analgesic nephropathy in the United States, as recommended in the House Committee Report to the fiscal year 1998 appropriations bill. Similarly, the Committee's concern about the kidney complications of diabetes has resulted in an NIDDK Request for Applications concerning diabetic nephropathy. These are important initiatives which have been made possible by your support, and we are grateful for it.

Resolutions have been introduced in the House and Senate in support of doubling the funding for NIH over five years. We are encouraged by this broad and growing support throughout Congress. We urge the appropriate Committees, including the House and Senate Budget Committees, to support this effort through the identification of additional resources beginning in fiscal year 1999. This additional funding is needed to maintain our country's lead in scientific investigation at a time when

traditional sources for funding fundamental investigation and clinical research are diminishing and threatened to disappear. We would like to request a 15 percent increase in the appropriation for NIDDK. This commitment of additional resources is essential to continue the support of new opportunities for improving the health of Americans which biomedical research has provided and continues to offer today. To that end we would like to recommend to you some new research opportunities and challenges in the area of kidney disease and to solicit your support for them.

Proteinuria.—There are 300,000 Americans with irreversible kidney failure or End-Stage Renal Disease (ESRD) who require dialysis or a transplant to survive. We estimate that there are ten times as many individuals who have detectable protein in the urine, which is an early indication of progressive kidney disease, well before the presence of any other clinical or laboratory evidence of the problem. These Americans should become the focus of new attention for intervention and prevention. It is these individuals, with early kidney disease manifested by proteinuria, who are more likely to progress to ESRD. More importantly, there is a much larger number of individuals who have proteinuria whose kidney disease will not progress to ESRD, but who are still at greater risk of heart attack and stroke than Americans without evidence of protein in the urine. How many? No one knows for sure right now because not enough work has been done in this important public health area. We estimate the number to be in the millions. Nevertheless, very few of these individuals are identified or receive the care and attention that could prevent their morbidity and premature mortality. We need to know more about the incidence and prevalence of proteinuria, as well as the efficacy of interventions which could address this public health problem. The NKF is strongly committed to that goal. We recommend that the Kidney Program of the NIDDK be encouraged and provided support to gather basic epidemiologic information on this high risk segment of the population and to explore the appropriate strategies for the early identification and treatment of those at risk.

Nutrition.—Malnutrition is a common complication of chronic dialysis patients, occurring in about 40 percent of such individuals. Other than age, nutritional status is the most potent predictor of mortality in patients with ESRD. These poorly nourished patients are more susceptible to infection and are more likely to be hospitalized than other patients. Some of these patients are compromised nutritionally because of the poor appetite which often accompanies ESRD and because of the dietary constraints which they must follow. These factors are complicated by metabolic problems associated with kidney failure which are not fully understood. Without that understanding, we cannot comprehensively address the problem of malnutrition in ESRD patients. As a first step, we recommend that the NIDDK sponsor a demonstration project, in conjunction with the Health Care Financing Administration (HCFA), which would document the efficacy of the various interventions that are currently available in improving the nutritional status of ESRD patients, including that of intradialytic parenteral nutrition. We ask Congress at this point to endorse such an initiative by providing language directing HCFA and NIDDK to work with the health industry to develop a clinical trial that will investigate whether nutritional therapy of malnourished chronic dialysis patients will improve their health and survival.

Transplantation.—According to the United Network for Organ Sharing (UNOS) 19,817 Americans received kidney transplants between April 1991 and March 1993. As of April 1997, 2,588, or 13 percent, of these individuals experienced a rejection of their transplant and had to return to dialysis to await retransplantation. We need to find better ways to prevent kidney transplant rejection. The National Institute of Allergy and Infectious Diseases (NIAID) has taken the lead in this search. These efforts must be redoubled. There is a second, and perhaps greater, opportunity for transplant research. As of January 21, 1998, there were 38,387 Americans waiting for a kidney transplant. Unfortunately only 11,000 kidney transplants were performed last year. The gap between those who need a kidney transplant and the availability of human organs donated for transplantation continues to grow every day. The greatest challenge facing the transplant community is the scarcity of organs for transplantation. Currently, xenotransplantation (animal to human transplants) is the only process on the horizon which could meet the need for additional transplants. As we approach the millennium, it is time to foster efforts which could answer the question of whether xenotransplantation is a viable option to solve the problem of supply and demand in kidney transplantation. With additional funding, NIAID would be able to support investigation and seek solutions to this problem.

Cardiovascular Disease.—Heart Disease and Arteriosclerosis are the leading causes of morbidity and mortality of patients with kidney disease during its progressive stage to ESRD, after the onset of ESRD while on dialysis, and after successful kidney transplantation. Without careful study of the accelerated course of cardio-

vascular complications in kidney disease, we cannot address this issue comprehensively or provide solutions to the leading cause of death of the hundreds of thousands of patients with kidney disease, those on dialysis and those who are transplanted. As a first step, the NIDDK and the National Heart, Lung, and Blood Institute (NHLBI) should be encouraged to support basic and clinical research in this high risk group to determine the role of the interventional measures that have been shown to be promising in the general population.

Vascular access.—Access to the vasculature is necessary to provide hemodialysis to patients with ESRD. It is vital to maintain the functioning of grafts and fistulas as long as possible. Yet, occlusion and complications of vascular access, including infection, constitute the single largest cause of hospitalization of dialysis patients, and are a major contributor to the increase in the cost of the Medicare ESRD Program. Support is needed for research to develop new techniques for the early identification of access problems and of new ways to resolve them.

We hope that our testimony has demonstrated the importance of research and its potential for preventing kidney disease and improving the lives of kidney patients. We would be pleased to provide any additional information that the Committee may wish.

PREPARED STATEMENT OF KATHERINE N. CLAPP, PRESIDENT, FRAXA RESEARCH FOUNDATION

My name is Katherine N. Clapp. I am from West Newbury, Massachusetts. My husband, Dr. Michael Tranfaglia, and I have two children with Fragile X, the most common inherited cause of mental retardation. Most Fragile X children are limited to an I.Q. of 20 to 60 and require a lifetime of special care, at an average cost of over two million dollars per person. The emotional cost to affected families is incalculable. Like cystic fibrosis and muscular dystrophy, Fragile X is caused by a single gene and will someday be curable. Yet public funding for Fragile X research is strikingly low, in spite of its high prevalence and cost.

In 1994, my husband and I joined with other Fragile X parents to form FRAXA Research Foundation, to fund research in universities around the country. The first year we raised $39,000, enough to partially fund two postdoctoral fellowships. Four years later FRAXA has 20 chapters, 2000 contributors, and, in 1997, raised over $500,000 for research. We are currently funding 9 grants—all without a single government dollar. This growth was possible only because of the ground swell of support we received from families around the country affected by Fragile X.

I am here to make two suggestions about what the Congress can and should do to help over 90,000 Americans with Fragile X:

—Fragile X research is vastly underfunded (see Attachment No. 1). Present funding levels by the National Institute of Child Health and Human Development (NICHD) are woefully inadequate in light of this disease's prevalence in the population, the potential for the development of a cure, and the significance that Fragile X research has for related disorders such as autism. Congress should move quickly to correct this deficit. A modest investment made now will pay off handsomely, in terms of dollars saved and reduced human suffering (see Attachment No. 2).

—Newborns can be given a simple, inexpensive, and accurate DNA test for Fragile X (along with, and using the same blood spot as, the now-routine PKU test). This permits early diagnosis and intervention. Congress should provide funding to The Centers For Disease Control (CDC) and the Health Resources and Services Administration (HRSA) to develop and implement a nationwide newborn testing program (see Attachment No. 3).

Prevalence

Fragile X—sometimes called Fragile X "Syndrome" although its occurrence is now clearly definable by DNA testing—affects one in every 2,000 males and one in every 4,000 females. One in 400 women carries this disease—even though most of these carriers have never heard of it.

Most studies estimate that 80 to 90 percent of affected individuals remain undiagnosed. In part, this is because:

—It is relatively newly-discovered.

—DNA testing is even more recently discovered.

—Diagnosis is often difficult during the first few years of life.

Potential for Treatment

Researchers discovered the Fragile X gene on the X chromosome in 1991. In individuals with Fragile X, this gene fails to produce a single protein needed in the

brain, which often leads to mental retardation, behavior challenges such as aggression and anxiety, and seizures. Current research is unveiling the function of this protein and how it is involved in learning and memory. Other ongoing research is exploring ways to replace or compensate for the protein or to find medications that can ameliorate symptoms. Fragile X research is of critical importance for several reasons:

—It will lead to an effective treatment or cure for Fragile X.

—It is likely to lead to understanding and treatment of many cases of autism, since about 10 percent of autistic individuals have Fragile X. Fragile X is unique among the autism-spectrum and developmental disorders because its cause is known, which makes it an excellent research model for these disorders.

—It will shed light on human intelligence and learning in general since Fragile X is the only single-gene disease known to directly impact human intelligence.

Last year NICHD spent about 2 million dollars on Fragile X research, just 4 times the amount our tiny foundation raised for research. Only when the Congress and the NICHD expand and accelerate this research will the exciting projects on the drawing board reach the laboratories. Your Committee should help the NICHD to expand its Fragile X research.

Newborn Screening

Newborn screening of all children can be carried out by means of a simple blood test. Presently, every newborn donates a drop of blood for PKU and other tests. Each state has its own program, generally assisted by the Health Resources and Services Administration of the Department of Health and Human Services under Title V of the Social Security Act. Testing for Fragile X should be offered to new parents, along with current tests and using the same drop of blood. Dr. Roger Stevenson of the Greenville Genetic Center of Greenville, South Carolina—the Mayo Clinic of Genetics—estimates that adding this test would cost only about $5 per child. This small price would spare Fragile X families the torments of uncertainty and mistaken diagnoses that commonly mark the early childhood years. It would provide families the information they need for future family planning, and it would enable them to seek early interventions—educational and medical—that have been shown to improve lives dramatically. The Centers for Disease Control in cooperation with the Health Resources and Services Administration will need funds to develop and implement this program for the states. Please fund such testing.

Conclusion

Given its prevalence, I am sure you agree that research on Fragile X is underfunded. No one ever dies of Fragile X; life span is normal. But the hopes and dreams of Fragile X parents do die. These children lose the chance to lead normal, productive lives, and their basic needs and sustenance often become the responsibility of American taxpayers. Children born with Fragile X lack only one vital protein. We need your help to support the research that will show us how to replace or compensate for this protein and enable people with Fragile X to live normal, productive lives. Only major research can make this happen. My children, Andy and Laura, and thousands of other precious children deserve the chance this research will provide, and I hope you will make it happen as a priority by funding NICHD, CDC, and HRSA Fragile X programs.

Thank you.

I enclose "Brain Briefings", a 1998 Society for Neuroscience publication on Fragile X.

ATTACHMENT NO. 1

Genetic disease	Incidence	U.S. population [1]	NIH research	Amount [2]	Per person
Down Syndrome	1/1,000	275,000	1996	16.7	61
			1997	17.0	62
			1998 (est.)	18.0	65
			1999 (est.) [3]	19.0	69
Batten's disease	1/100,000	2,750	1996	3.0	1,090
			1997	3.0	1,090
			1998 (est.)	3.0	1,090
			1999 (est.)	4.0	1,455

ATTACHMENT NO. 1—Continued

Genetic disease	Incidence	U.S. population [1]	NIH research	Amount [2]	Per person
Duchenne's Muscular Dystrophy ...	1/1,000 males	275,000	1996	10.8	39
			1997	14.0	51
			1998 (est.)	14.0	51
			1999 (est.)	16.0	58
Fragile X	[4] 1/3,000	91,666	1996	1.8	20
			1997	2.0	22
			1998NA		NA
			1999NA		NA

[1] Based on a U.S. population of 275 million.

[2] Millions of dollars. Figures obtained from NIH Budget Office for Down syndrome, cystic fibrosis, Batten's disease, and Duchenne's muscular dystrophy. The Office did not have figures for Fragile X, because the amounts were too small.

[3] Based on President's projected budget.

[4] 1 in 2,000 males; 1 in 4,000 females.

ATTACHMENT NO. 2

RECOMMENDATIONS FOR NICHD FRAGILE X RESEARCH FUNDING PRIORITIES

We urge the Committee to incorporate the following language in its report:

Fragile X.—The Committee commends the NICHD for its continuing support for Fragile X research, and includes funds necessary for the Institute to further expand and strengthen its research activities on this disorder. Fragile X is the most common inherited cause of mental retardation. It is unique among autism-spectrum and developmental disorders because NICHD-funded research has identified the cause: the failure of a single gene to produce a specific protein. Although the protein can be produced synthetically, no cure or effective specific treatment has been found. The Committee urges the Institute to increase its efforts to find a cure for Fragile X, and to expand our understanding of the role of the Fragile X protein in brain function. The Committee is pleased that the NICHD is co-sponsoring with the FRAXA Foundation an international Fragile X conference planned for December of this year. The Committee looks forward to receiving a report on the recommendations and goals set at the conference. An important portion of the conference will address increased research efforts to develop effective treatments for individuals with Fragile X, including testing of existing medications and development of new psychopharmacologic medications that are safe and effective. The Committee also is pleased that NICHD has added Fragile X patients to its expanded program of autism research, and urges the Institute to include Fragile X patients in the pediatric psychopharmacology clinical trials being conducted by autism investigators as another effort to develop safe and effective medications for individuals with Fragile X.

ATTACHMENT NO. 3

RECOMMENDATIONS FOR FRAGILE X NEWBORN TESTING

Public Health Needs

Newborn screening to identify at birth underlying conditions which can cause or contribute to disease, disabilities, and death represents a tremendous unmet opportunity for preventing morbidity, disability and mortality. Currently, newborn screening programs for phenylketonuria (PKU), sickle cell anemia, and hypothyroidism have demonstrated the benefits of early intervention in preventing the consequences of these diseases. Nutritional intervention early in life prevents mental retardation in children with PKU, the use of penicillin prophylaxis prevents severe bacterial infections in children with sickle cell disease, and hormone replacement prevents mental retardation in children with hypothyroidism.

In light of advances resulting from the Human Genome Project and related research, it is now possible to extend newborn screening programs to a wide range of conditions, including Fragile X. As more and more disease genes are identified, the need for a systematic approach to newborn testing becomes increasingly apparent. Public health policy leadership is needed to meet these new challenges. This will require a concerted effort among national and state public health agencies.

We urge Congress to provide $20 million for the Centers for Disease Control (CDC) and the Health Resources and Services Agency (HRSA), in order to develop and implement a strategy for evaluating and expanding newborn screening programs, including Fragile X. Together, CDC and HRSA can evaluate scientific and programmatic developments, translate this knowledge into public health program guidance, and develop recommendations to states for strengthening newborn screening programs.

In particular, CDC would:

—Hold public and professional discussions on the needs, strategies and benefits of newborn testing, early intervention, and treatment

—Evaluate public health policy and strategies for newborn testing programs, and perform public health research to develop recommendations for strengthening and expanding effective approaches

—Assess and develop methods for applying and evaluating new laboratory tests in newborn public health testing programs

—Establish and evaluate the effectiveness and safety of pilot demonstration projects

—Provide technical, laboratory, and evaluation assistance to states for implementation of newborn screening recommendations.

HRSA would:

—Provide technical assistance and evaluation to states to develop systems coordination for access to a "medical home" for families identified

—Facilitate the development of systems of retrieval of those identified by the newborn testing for genetic counseling, follow-up and medical treatment

—Establish a system to evaluation patient satisfaction of the pilot programs.

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF RHEUMATOLOGY

The American College of Rheumatology (ACR) is an organization of physicians, health professionals, and scientists that serves its members through programs of education, research and advocacy that foster excellence in the care of people with arthritis and rheumatic and musculoskeletal diseases. The ACR is pleased to provide written testimony to the Senate Appropriations Subcommittee on Labor, Health, and Human Services regarding the Medicare Physician Practice Expense Regulations. The College's testimony will refer to the findings and recommendations of a report on physician practice expense by the General Accounting Office (GAO), and to recommendations that the Medicare Payment Advisory Commission (MEDPAC) made in its March 1 report to Congress.

GAO Report on HCFA's RBPE Implementation Methodology

ACR has had the opportunity to review the final GAO report on HCFA's methods for revising physician practice expense payments, and we commend the GAO for accomplishing this significant task within a relatively tight timeline. Furthermore, we concur with the vast majority of the report's findings. The College's testimony will focus on the following aspects of the GAO report: (1) HCFA's methodology for developing direct cost estimates; (2) Linking; and (3) Use of physician nurses in the hospital setting.

HCFA's Methodology for Developing Direct Cost Estimates.—The GAO report states that "HCFA used an acceptable method to develop direct cost estimates." The ACR fully concurs with this assessment. ACR believes that the Clinical Practice Expert Panel (CPEP) methodology utilized to generate data on direct practice costs was an open and inclusive process that resulted in values that will serve as an effective starting point for developing appropriate practice expense RVUs. We reject the opinion of many stakeholders that the data is fundamentally "flawed". The intent of the CPEP process itself was to develop a body of data using a multidisciplinary, representative sample of physicians and other experts (nominated by specialty societies) with expertise regarding the practice expenses under their review. Every opportunity was provided for all affected parties to provide input. By the time the official transition to resource-based practice expenses begins in May, 1998 with the release of the proposed rule on the 1999 Medicare Fee Schedule, physicians and other interested parties will have been given over ten formally promulgated opportunities to provide input into this process. In fact, physicians themselves will have actively participated in the actual development of RBPEs through every stage of the process, including participation in the original CPEPs, in the validation panels conducted in October, 1997, and the multispecialty panel meeting convened in December. HCFA has also provided a variety of other forums for physician groups to convey their opinions to the agency. For these reasons, we believe that the agency's actions to

date—and the plans for future opportunities to submit views—already fully meets Congressionally mandated requirements in the Balanced Budget Act of 1997 that HCFA "consult with organizations representing physicians regarding data and methodology to be used."

We also fully concur with the passage in the report indicating that "Other methods for estimating direct expenses have limitations." The College agrees that the expense of alternative approaches such as mail or on-site surveys (both in time and actual cost) makes them, by definition, prohibitive. Additionally, these types of data gathering efforts are invariably plagued by low response rates, as noted in GAO's report, and are often hampered by design bias and potentially even by gaming. The report's stated concerns that activity-based or cost-based accounting do not provide the specificity needed to adjust the Medicare fee schedule, are also shared by ACR.

It has come to the attention of the College that the coalition of procedurally-oriented groups has suggested that HCFA's current approach be replaced by a cost-accounting based methodology generated by a "public-private partnership" of HCFA and the medical specialty society community. The ACR finds such a proposal problematic in several ways. First, we believe that such an approach would result in a top-down RVS that would mirror the inequities in the current charge-based system—i.e., those services that are now reimbursed more for their practice expenses because of Medicare's charge-based system would still get more; those services that are reimbursed less would still get less. This is because the American Medical Association's Socioeconomic Monitoring Survey (SMS) data, on which the proposal would be based, itself is distorted by the current charge-based RVUs. HCFA's approach is a bottom up approach—figure out the resources that are required to perform each service, and then convert them into a relative value system (RVS), resulting in the Congressionally mandated resource-based relative value system.

The College also believes that HCFA has been engaging the professional medical community in a "public-private partnership" on RBPEs all along, as evidenced by the preponderance of opportunities for input afforded to the specialty societies. Finally, it is our opinion that use of a cost-accounting approach would merely maintain the status quo where procedurally-oriented services are over-reimbursed at the expense of evaluation and management services.

Linking.—ACR believes that the issue of whether to utilize the redundant CPT codes reviewed by the CPEPs to link the direct cost estimates generated by the separate CPEPs remains fundamental to the development of accurate resource-based practice expenses. The College concurs with HCFA's assertion in last June's proposed rule that the relative relationships within CPEPs are correct, but the relationships between CPEPs need to be normalized to bring the relative estimates to a single scale. Accordingly, ACR agrees with the GAO report that the CPEP estimates need adjustment and that linking is desirable. In the absence of such linking, the proposed RBPE RVU system would not truly contain "relative" values.

GAO's report does raise questions regarding the specific linking formula utilized by HCFA, primarily regarding anomalies caused by the formula and the redundant CPT codes used to develop the links. While we believe that HCFA should remain open to the possibility of revising its linking methodology if credible alternate approaches are identified that can develop appropriate practice expense values, we reject the notion that the proposed linking methodology must be overhauled, reconstructed or abandoned. We therefore concur with the opinion of the Physician Payment Review Commission (PPRC) staff cited in the report that it is not necessary for HCFA to select new redundant codes, assemble new CPEPs, and estimate the linking regression on new data. It is our firm belief that the overall validity of the practice expense RVUs is dependent on HCFA adopting policies and rules to establish an appropriate relativity between the staff time estimates by the varying CPEPs. Therefore, while the College is not wedded to the specific linking model currently outlined by HCFA, we agree with the GAO report in the strongest possible terms that the CPEP estimates need some type of adjustment, and we believe a linking methodology is an appropriate approach.

Use of Physician Nurses in the Hospital Setting.—The GAO report concluded that "HCFA appropriately disallowed nearly all expenses related to staff that accompany physicians to the hospital since there is no available evidence that these expenses are not already being reimbursed or are a common practice." Some surgical groups have argued that surgeons often bring their nurses into the hospital and that these costs should be reimbursed by HCFA. GAO staff has been told by surgical groups that new evidence had been given to HCFA in response to the October rule-making notice that supports the claim that this is a widespread practice. GAO staff has said that it planned to examine the evidence and determine if it should modify its conclusion. ACR recommends that the GAO ask HCFA to independently validate any such

evidence, to determine if it is the usual practice for a typical Medicare patient, before agreeing that such expenses should be allowed.

MEDPAC Report on Medicare Payment Policies

MEDPAC has recommended that HCFA not adopt its proposal to reduce payments for procedures provided in conjunction with an office visit or other E/M service without further study. The ACR strongly agrees with this recommendation. It is the opinion of the ACR that extending the 50 percent discount for multiple procedures to non-surgical services would be highly inappropriate, at best. We believe that using reductions for multiple surgical procedures performed through a single incision as a template for reducing multiple diagnostic procedures performed during an office visit or other E/M services is simply illogical. In these situations, the only savings in physician work or practice expenses that could be realized is a minor reduction in the administrative time associated with scheduling another appointment or pulling a chart, which is to say the savings in practice costs would be neglible. In light of the lack of data provided to support making such a dramatic change in reimbursement for services rendered during an E/M visit, we strongly urge HCFA to at least pilot-test the effects of such a proposal before implementation.

We also concur with the MEDPAC recommendation that a volume and intensity adjustment, or behavioral offset, should not be used. In its June 18, 1997 propose rule, HCFA stated that it intended to assume that 50 percent of the reductions in payments for specific procedures will be offset by an increase in volume and intensity. The effect of this assumption is to increase the amount of reductions for some procedures, and reduce the expected gain from others. The College agrees with MEDPAC's view that HCFA's experience with implementation of the RBRVS does not support the need for such a volume and intensity adjustment. Further, MEDPAC correctly that the sustainable growth rate for physician services, also mandated by the BBA, already corrects for any increase in the volume and intensity of physician services. ACR strongly urges Congress to advise HCFA that application of a volume and intensity offset to the PE-RVUs is inconsistent with requirement that resource-based practice expenses be implemented in a budget neutral manner.

Conclusion

The ACR concurs with virtually all of the findings outlined in the GAO report. We believe that HCFA did utilize an acceptable method to develop direct cost estimates, and that while the specific proposed formula for linking the estimates is not perfect, some sort of linking or normalization is desirable. As was indicated by PPRC staff in the GAO report, drastic overhaul of the process, or implementation of an alternative approach, is not necessary. ACR agrees with the GAO that HCFA was correct in disallowing the costs associated with nurses who accompany a surgeon into the hospital, without independently verifiable data that this is a typical practice. The College also concurs with the recommendations relating to practice expense made by MEDPAC. We believe that it would be highly premature for HCFA to proceed with its recommendation to reduce payments for procedures provided in conjunction with an office visit or other E/M service without further study. We also agree that history does not support the need for a volume and intensity adjustment, and that the institution of the sustainable growth rate system makes this adjustment unnecessary.

Prepared Statement of the National Association for State Community Services Programs

The National Association for State Community Services Programs (NASCSP) thanks this committee for its continued support of the CSBG and seeks an appropriation of $505 million for the state grant portion of the Community Services Block Grant (CSBG). The amount appropriated for the state grant portion in fiscal year 1998 is $491 million. NASCSP's request includes an increase only for inflation. Funding for the CSBG block grant to the states and other programs funded under the CSBG for fiscal year 1998 was $542 million. The President's budget request for fiscal year 1999 is $491 million. This amount is for the block grant to the states and does not include the discretionary programs generally included in the full block grant.

For the past two years language has been added to the Labor HHS Appropriations bill that addresses the use of carry-over funds at the local level. The language restricts the ability of the states to administer the CSBG and NASCSP therefore asks that it not be included in the fiscal year 1999 appropriations bill.

NASCSP is the national association that represents state administrators of the Community Services Block Grant (CSBG), and state directors of the Department of Energy's low-income Weatherization Assistance Program.

Background

The Community Service Block Grant was created as part of the Omnibus Budget and Reconciliation Act of 1981, during the Reagan Administration. The CSBG is a unique block grant that has successfully devolved decision making to the local level. Federally funded with oversight at the state level, the CSBG has maintained a local network of over 1,100 agencies with $5 billion in federal, state, local and private resources. Operating in almost every county in this country and serving over 11 million low-income persons, local agencies, known as Community Action Agencies (CAAs), provide services based on the characteristics of poverty in their communities. For one town this might mean securing jobs, for another developing affordable housing and in rural areas it might mean providing access to health services or developing a rural transportation system.

Since its inception, the CSBG has shown how a partnership between states and local agencies can work to the greater benefit of citizens in each state. We believe it should be looked to as a model of how the federal government can best support self-sufficiency for low-income persons in a decentralized, non-bureaucratic and accountable way.

Long before the creation of the Temporary Assistance for Needy Families (TANF) block grant, the CSBG was setting the standard for private-public partnerships that could work to the betterment of local communities and low-income residents. Family oriented while promoting economic development and individual self-sufficiency, the CSBG relies on an existing and experienced community-based service delivery system of CAAs and other non-profit organizations to produce results for its clients.

Major Characteristics of the Community Services Network

Adaptability.—CAAs provide a flexible local presence that governors have mobilized to deal with emerging poverty issues, i.e., CAAs have demonstrated success in moving persons from welfare to work and in developing self-sufficiency among low-income persons.

Leveraging Capacity.—For every CSBG dollar they receive, CAAs leverage over $4 in non-federal resources (state, local, and private) to coordinate efforts that improve the self-sufficiency of low-income persons and lead to the development of thriving communities. In some states that number is even higher. For instance in 1997 in New Hampshire, the CAAs leveraged $11 in non-federal resources for every CSBG dollar they received.

Volunteer Mobilization.—CAAs mobilize volunteers in large numbers. In fiscal year 1995, the most recent year for which national data are available, the CAAs elicited nearly 25 million hours of volunteer efforts, the equivalent of 12,250 full-time employees. Using the minimum wage, these volunteer hours are valued at more than $100 million.

Emergency Response.—CAAs are utilized by federal and state emergency personnel as a front line resource to deal with emergency situations such as floods, hurricanes and economic downturns. They are relied on by families in their community to deal with local hardships, such as a house fire.

Locally Directed.—CAAs are guided by tri-partite boards of directors. These boards consist of one third-elected officials, one-third low-income persons and one-third representatives from the private sector. The boards are responsible for establishing policy and approving business plans of the local agencies. Since these boards represent a cross section of the local community, they guarantee that CAAs will be responsive to the needs of the community.

The statutory goal of the CSBG is to ameliorate the effects of poverty while at the same time working within the community to eliminate the causes of poverty. The primary goal of every CAA is self-sufficiency for its clients. This is a long-term activity that requires multiple resources. This is why the partnership of federal, state, local and private enterprise has been so vital to the successes of the CAAs.

What do Local CSBG Agencies Provide?

Since Community Action Agencies operate in rural areas as well as in urban areas, it is difficult to describe a typical Community Action Agency. But, one thing that is common to all is the goal of self-sufficiency for all of their clients. This may mean providing daycare for a struggling single mother as she completes her General Equivalency Diploma (GED), moves through a community college course and finally is on her own supporting her family without federal assistance. It may mean assisting a substance abuser as he seeks employment. Many of the Community Action Agencies' clients are persons who are experiencing a one-time emergency, others

have lives of chaos engendered by many overlapping forces—a divorce, sudden death of a wage earner, illness, lack of a high school education, closing of a local factory or (as was the case in the Midwest in the eighties) the loss of family farms.

CAAs provide access to a variety of opportunities for their clients. Although they are not identical, most will provide some if not all of the services listed below; employment and training programs; micro business development help for low-income entrepreneurs; a variety of crisis and emergency safety net services; local community and economic development projects; housing and weatherization services; Head Start; nutrition programs; family development programs.

CSBG funds many of these services directly. Even more importantly, CSBG is the core funding which holds together a local delivery system able to respond effectively and efficiently, without a lot of red tape, to the needs of individual low-income households as well as to broader community needs. Without the CSBG, local agencies would not have the capacity to work in their communities developing local funding, private donations and volunteer services and running programs of far greater size and value than the actual CSBG dollars they receive.

CAAs manage a host of federal, state and local programs which provide a one-stop location for persons whose problems are usually multi-faceted. CAAs manage the Head Start program. Using their unique position in the community, CAAs recruit additional volunteers, bring in local school department personnel, tap into religious groups for additional help, coordinate child care and bring needed health care services to Head Start Centers. They also manage the Low Income Home Energy Assistance Program (LIHEAP), raising additional funds from utilities for this vital program. They administer the Weatherization Assistance Program (WAP) and are able to mobilize funds for repair work on residences that keeps a number of elderly low-income owners in their homes. CAAs coordinate the WAP with the Community Development Block Grant program. This stretches federal dollars thus providing a greater return for individual tax dollars. They also administer the Women, Infants and Children (WIC) program as well as job training programs, substance abuse programs, transportation programs, domestic violence and homeless shelters, food pantries and gardening and canning programs.

Whom does the CSBG Serve?

National data compiled by NASCSP show that the CSBG serves a broad segment of low-income persons, particularly those that are not being reached by other programs and are not being served by welfare programs.

—74 percent have incomes at or below the poverty level; 48 percent have incomes below 75 percent of the poverty guidelines. In 1995 the poverty level for a family of three was $12,590.

—33 percent of adults served have not finished high school.

—34 percent of all client families were "working poor" and have wages or unemployment benefits as income.

—18 percent depend on pensions and Social Security and are therefore poor, former workers.

—25 percent receive welfare benefits.

—61 percent of households served have children.

During the past two years, many states have been scrambling to deal with the new Temporary Assistance for Needy Families (TANF). The CAAs and their state offices have been working to assist in an easy transition from Aid to Families with Dependent Children (AFDC) to TANF.

In Washington state, all of the Community Action Agencies (31) have established or are about to establish agreements with regional state public assistance agencies to work with TANF clients who have been referred to community action for services. The agencies programs are being designed to fill gaps in the community such as transportation, small business development and the creation of job training sites. In Missouri, the Community Action Agencies have three representatives on the Governor's Welfare Reform Committee. This committee is an advisory group for the Department of Social Services. In Iowa, the Community Action Agencies provide intensive family development and self-sufficiency services to families referred to them from Welfare-to-Work offices. The families most often referred are those who require comprehensive assistance.

In New Hampshire CSBG funds are being used for alcohol and drug rehabilitation programs for welfare recipients to assist them in staying drug free and in securing and keeping jobs.

In New York, CSBG funds are being used for family and community development specialists for TANF.

In Wisconsin, 25 percent of the local agencies have applied for designation as the administering agency in their services area for the Wisconsin Works program. The

other agencies will continue to provide supportive services such as child care, transportation and training. To recapitulate: The CSBG provides a community-based service delivery system. Each local organization, through its local board of directors, establishes priorities and serves its community and low-income residents through programs designed and delivered locally in partnership with state and local governments, businesses, civic and religious groups and others. The CSBG leverages resources that are far in excess of the appropriations it receives. As noted above, the CSBG generates $4 in non-federal funds for every CSBG dollar that is appropriated. Additionally, nearly 25 million hours of volunteer services were contributed to CAAs in 1995. CSBG agencies have used the increased funds they received for the last two years to continue their activities that lead to self-sufficiency and have become integrally involved in the implementation of TANF in most states across the nation.

NASCSP therefore urges this committee to provide an increase that factors in inflation and to fund the CSBG grant to the states at $505 million.

Prepared Statement of the American Association of Health Plans

I. Introduction

The American Association of Health Plans (AAHP) appreciates this opportunity to comment on the Health Care Financing Administration's fiscal year 1999 budget request. The Balanced Budget Act of 1997 (BBA) authorizes the Health Care Financing Administration (HCFA) to charge each Medicare+Choice organization and Medicare risk contractor a fee equal to the organization's pro rata share of HCFA's estimated costs of enrollment and information dissemination activities. Congress appropriated $95 million for these activities in 1998 and suggested that HCFA focus first on developing and publishing the comparative information booklet. On December 2, 1997, HCFA announced its intent to assess all Medicare risk contractors a fee equal to 0.428 percent of their monthly Medicare payments beginning in January and continuing through September 1998 until it collects the fiscal year 1998 assessment of $95 million. The BBA authorizes HCFA to collect up to $150 million in fiscal year 1999 for its beneficiary education campaign subject to the appropriations process.

In addition, the President's budget calls for a series of new user fees to generate an additional $660 million. According to budget documents, funds collected through the user fees would enable HCFA to meet the new workload demands imposed by the Health Insurance Portability and Accountability Act and the BBA. Included in these additional user fees is $37 million from Medicare+Choice organizations for costs associated with reviewing initial applications and contract renewals.

The information fee and the new user fees proposed in its fiscal year 1999 budget will jeopardize some of the additional benefits enjoyed by beneficiaries enrolled in the Medicare HMO program—benefits which for many enrollees have made the Medicare HMO program more attractive than the traditional Medicare fee-for-service program. AAHP believes that health plans and their enrollees should bear a share of the cost of HCFA's education and information dissemination campaign that is consistent with the proportion of total beneficiaries enrolled in the Medicare HMO program, as opposed to the current user fee structure which requires health plans to bear the entire cost.

II. Importance of Beneficiary Education Activities

AAHP supports efforts to ensure that beneficiaries receive information that will enable them to make informed decisions about coverage options. AAHP and its member plans are looking forward to working with the Health Care Financing Administration, beneficiary groups and others as the beneficiary education and information dissemination campaign moves forward. The central goal of this initiative, to provide more and better information to beneficiaries about all of the options available to them, is critical to permitting beneficiaries to take advantage of the expanded range of choices envisioned under the new Medicare+Choice program. As health plans participating in the Medicare program today know well, there are significant challenges in reaching out to Medicare beneficiaries and ensuring that the information they receive is useful and understandable. AAHP's member plans have a great deal of experience in communicating with beneficiaries and are constantly working to refine and improve our outreach and communications efforts.

The most important aspect of our efforts is to listen to Medicare beneficiaries and be responsive to the information needs they identify. Information must be provided when, where and in a form in which it will be most accessible and useful to beneficiaries as they consider the differing options available to them under the Medicare+Choice program. Only an active and intensive dialogue between all parties in-

volved in the beneficiary education and information campaign will allow HCFA to meet this challenge. HCFA has already initiated this dialogue and we appreciate their efforts. We are committed to playing an active part in this process and urge heavy reliance on beneficiary focus groups and other mechanisms for ensuring at each step of the campaign's development that it will produce information that beneficiaries can readily use.

III. User Fees Are a Tax on Health Plans and Will Hurt Beneficiaries

AAHP is concerned that the fiscal year 1998 user fee represents more than 20 percent of the 2 percent minimum payment update received in the vast majority of counties in 1998. HCFA's additional proposed user fees were not anticipated when Congress developed the payment methodology under the BBA. In addition, growth in spending for the Medicare+Choice program is lower than had been anticipated when Congress enacted the Balanced Budget Act. The table below shows some examples of the impact of the user fee on high and moderate payment counties as well as on floor counties.

MEDICARE INFORMATION FEE AS PERCENTAGE OF 1998 PAYMENT UPDATE

MEDICARE INFORMATION FEE AS PERCENTAGE OF 1998 PAYMENT UPDATE

County	Enrollees	User fee per month	Payment update (per enrollee per month)	Fee as percentage of 1998 payment update
High payment counties:				
Los Angeles, CA	372,149	$2.72	$12.45	22
Philadelphia, PA	75,730	3.07	14.08	22
Moderate payment counties:				
Denver, CO	29,086	2.20	10.08	22
Hillsborough, FL	40,819	2.12	9.73	22
Kern, CA	28,377	2.24	10.24	22
King, WA	62,513	1.87	8.57	22
Harrison, MS	64	2.45	11.24	22
Hennepin, MN	52,100	1.77	8.11	22
Payment floor counties:				
Bonner, ID	317	1.57	33.12	4.7
Dubuque, IA	4,586	1.57	31.65	5.0

[1] Assuming a 0.428-percent assessment on the 1998 Medicare+Choice payment.

While it is reasonable for health plans and their enrollees to contribute to funding HCFA's enrollment and information dissemination initiatives, the 14.3 percent of the beneficiaries enrolled in health plans should not have to bear 100 percent of the cost. Rather, they should pay their share of the cost, as related to their proportion of all Medicare beneficiaries.

In fiscal year 1998, the user fee was applied only to Medicare HMOs, effectively the only type of organization participating in the Medicare+Choice program at that time. In fiscal year 1999, Medicare+Choice organizations could again be in the position of shouldering a disproportionate share of HCFA's beneficiary information user fees. Furthermore, the campaign is designed to educate beneficiaries regarding all their options, including providers in the traditional fee-for-service program. Beneficiaries in Medicare+Choice organizations should not have to bear the burden of the full cost of HCFA's education and information activities.

Partly as a result of constrained payment growth rates under the new Medicare+Choice program and the imposition of a $95 million user fee in fiscal year 1998, a number of Medicare HMOs have announced reductions in the additional benefits they offer seniors. Several plans have ended coverage of outpatient prescription drugs, a benefit not covered under the traditional fee-for-service Medicare program. Other plans have eliminated vision and dental care benefits. Still others have retained these benefits but increased the cost sharing associated with them or raised premiums. Because the traditional fee-for-service Medicare program does not cover benefits like outpatient prescription drugs, dental, and vision, many seniors have been attracted to Medicare HMOs because of the more comprehensive coverage they offer. The $150 million in beneficiary information fees authorized by the BBA and the $37 million in application fees requested by HCFA in its proposed fiscal

year 1999 budget have the potential to further erode health plans' ability to offer these attractive benefits with little or no additional premium.

IV. A Closer Look at HCFA's Planned Education Activities

In conducting the beneficiary education and information dissemination activities, AAHP urges HCFA to examine its existing infrastructure for disseminating information to beneficiaries. Although HCFA currently conducts numerous beneficiary education and information dissemination activities, it is unclear whether HCFA will use its existing capabilities or create a new infrastructure to meet the BBA requirements. HCFA already maintains two toll-free numbers for its Medicare program. HCFA also needs to explore the capacity of some of its sister agencies that work with Medicare beneficiaries, such as the Social Security Administration, in conducting education activities. The Social Security Administration maintains a toll-free number that could also assist in providing information to Medicare beneficiaries.

In addition, almost every state has a separate toll-free line operated by the state's Department on Aging and Department of Insurance under HCFA's Health Insurance Information, Counseling, and Assistance program. It is possible that this capacity could be tapped for the Medicare beneficiary education and information dissemination activities. States' health insurance counseling programs distribute comparative health plan information and it would appear that at least some of HCFA's efforts may be duplicative of these local activities.

Moreover, HCFA's cost estimates for certain activities far exceed actual costs incurred by health plans operating similar services. Several health plans that operate toll-free lines to field pre- and post-enrollment questions reported a $5.50 or less per call estimate including phone calls, training, staffing, and other overhead. HCFA's initial per-call estimate of $7.50, which does not include training and other overhead, is 36 percent more than the $5.50 (or less) per call reported by several health plans.

Plans' experiences in educating beneficiaries clearly show that certain activities are more effective than others and that the effectiveness of a strategy can vary geographically. As HCFA proceeds with its campaign, we recommend that HCFA continue to create forums so that health plans and others with experience in beneficiary education have an opportunity to share their lessons learned. For example, many plans no longer consider health fairs an effective communications strategy yet HCFA initially requested $65 million for health fairs and other public relations activities.

A majority of health plans surveyed by AAHP reported an average health fair attendance of 100 or fewer Medicare beneficiaries. In many cases, average attendance was much lower than 100. Health plans have had as few as four, eight, and fifteen beneficiaries attend health fairs, even though the events are designed to accommodate a larger audience. Weather conditions, timing, and location of the health fair, along with the availability of refreshments and token souvenirs, are crucial factors that influence beneficiaries' attendance.

HCFA has limited experience with program-wide information dissemination initiatives, and must develop the expertise to plan, administer and carry out the programs necessitated by the BBA. A massive initial effort does not allow sufficient opportunity to learn from experience. In addition, state experience with enrollment brokers has demonstrated that contracting out these activities presents substantial challenges to define contractor accountability and to monitor their performance. Consequently, even if HCFA contracts out significant portions of the new programs, a broad first-year effort would be unwise.

When Congress appropriated $95 million for these activities in 1998 it suggested that HCFA focus first on developing and publishing the comparative information booklet. The prioritization recommended by Congress represents a good first step to focus HCFA's efforts. AAHP strongly urges that steps following publication of comparative information consist of pilot testing of carefully designed projects during the initial years of the Medicare+Choice program. Pilot testing education and information dissemination activities will build a better foundation for effective education and information activities during future coordinated open enrollment periods than would conducting a range of untested activities.

Finally, it is unclear whether HCFA has done any additional research or budgetary analysis to determine more accurately how much funding is needed for the various beneficiary education activities required under the BBA. Furthermore, HCFA has not indicated whether it intends to supplement funds authorized for its fiscal year 1998 or fiscal year 1999 beneficiary education and information dissemination campaign with other funds, such as those funds dedicated to administrative or program management activities.

V. Additional User Fees Pose Additional Hardships on Beneficiaries and Plan

In addition to the $150 million authorized by the BBA for beneficiary education activities in fiscal year 1999, HCFA has requested $37 million in user fees from Medicare+Choice organizations for reviewing initial applications and contract renewals. Such a user fee was not anticipated by Congress when it enacted the Medicare+Choice payment methodology. In addition, new user fees such as this one and the others included in HCFA's budget raise the question of whether it is appropriate to fund government activities through user fees.

The $37 million in user fees for reviewing initial applications and for contract renewals represents a significant burden on the 322 health plans already participating in the Medicare HMO program. These user fees could also potentially dampen interest among new entrants to the Medicare+Choice program. Health plans invest considerable resources in becoming Medicare HMOs. It is not unusual for a plan to spend $100,000 to $150,000 just to prepare and submit an application to become a Medicare risk HMO. An additional user fee of $115,000 per plan presents an unreasonable barrier to entry for new plans that are considering serving seniors through the Medicare+Choice program. Furthermore, a fee of this level raises the question of the actual cost for HCFA to conduct reviews of application and renewals and what specific resources the fee would finance.

Currently HCFA does not charge an application or contract renewal fee. In addition, HCFA has indicated that it intends to make the initial application process for existing Medicare health plans to convert to Medicare+Choice plans fairly simple and streamlined. It is unclear therefore, why HCFA needs to collect what would amount to a $115,000 tax per health plan to conduct these limited activities. In addition, if this fee is approved by Congress and it subsequently generates more funds than HCFA spends on reviewing application and renewal, AAHP believes that excess funds should be returned to Medicare+Choice organizations so they can dedicate these resources to patient care.

VI. Conclusion

AAHP looks forward to working with HCFA as it implements its beneficiary education and information dissemination campaign. Health plans have valuable experience to share with HCFA in how to best communicate with seniors and how to be responsive to their information needs. An effective education campaign will be critical to informing beneficiaries about their new options under the Medicare+Choice program. At the same time, HCFA needs to finance this campaign in a manner that does not disproportionately burden Medicare HMOs. Such a burden has the potential to limit rather than expand consumers' choices, and thus to undermine the key objectives of BBA. We urge the Subcommittee to review the assessment of the beneficiary information fee and whether it is equitable. In addition, we ask the Subcommittee to consider carefully the appropriateness of additional user fees such as the $37 million in user fees for reviewing initial applications and for contract renewals.

PREPARED STATEMENT OF DANIEL PAUL PEREZ, PRESIDENT, FACIOSCAPULOHUMERAL SOCIETY

Mr. Chairman, it is a great pleasure to submit this testimony to you today.

My name is Daniel Paul Perez, of Lexington, Massachusetts, and I am testifying today as President of the Facioscapulohumeral Society and as an individual who has this rare disorder.

As a chief patient activist for the tens of thousands of individuals living with Facioscapulohumeral Disease (FSHD) in the United States I will continue to argue the case of wanting to live life free from disease.

The FSH Society

Eight years ago, several of us with FSHD began the task of organizing a society of patients. The purposes of our organization, which represents over 1000 families that have been diagnosed with FSHD are: to encourage and promote scientific and clinical research and development through education of the general public, governmental bodies and the medical profession; to support such research and development; to accumulate and disseminate information about FSHD; to actively cooperate with related organizations; and to represent individuals and families with FSHD.

The Clinical Picture of FSH Muscular Dystrophy

The FSH Disorder, otherwise known as Facioscapulohumeral Muscular Dystrophy or FSHD, is a neuromuscular disorder that is inherited in an autosomal dominant fashion and has an estimated frequency of one in twenty thousand (1/20,000).

Autosomal dominant means that there is a fifty-percent chance that a child will inherit the disease from an affected parent. The prevalence could be as much as three times greater than the estimated frequency stated in the literature due to an undetermined number of sub-clinical cases.

The major consequence of inheriting this disease is that of a progressive and severe loss of skeletal muscle, with the usual pattern of initial noticeable weakness of facial, scapular and upper arm muscles and subsequent developing weaknesses of other skeletal muscles.

The age of onset is variable and noticeable muscle weaknesses are usually present by the age of twenty. The penetrance of FSHD is high and is estimated to be near ninety-five percent. A 95 percent penetrance implies that the expression of the FSH disorder will be outwardly noticeable in 95 out of 100 patients with the FSHD genetic defect by the age of twenty. The age of onset and the severity of clinical symptoms are variable within and between families. Recent research has shown that in some families there will be anticipation of the disease. Anticipation implies that FSHD will become more and more severe with each successive generation affected with the disorder.

The progression of FSHD usually begins between the first and second decades of life for men and between the second and third decades of life for women. Life expectancy is normal in many, but many if not most patients become significantly incapacitated in the prime of life. Approximately twenty percent (20 percent) of individuals with FSHD are wheelchair-bound by the fourth decade of life. FSHD affects both males and females and appears to show no racial bias.

There are families where the parents are asymptomatic, clinically normal, but they have children, one or more, with FSHD. Sporadic cases of FSHD are common and can be caused by mutations and germline mosaicism.

Lastly, an early onset, infantile form of FSHD exists where the symptoms are more severe than that of the typical FSHD. Children with infantile FSHD are wheelchair bound at a very early age. Additionally, the infantile form FSHD is extremely severe and may result in an early death. Thus, infantile FSHD resembles Duchenne muscular dystrophy in its clinical course and prognosis.

Stated clearly, FSHD can be extremely severe and in some forms can lead to an early death. FSHD can happen to anyone of us.

The Need For NIH Funding For FSHD

My testimony is about the profound and devastating effects of a disease known as Facioscapulohumeral Disease which is also known as FSH Muscular Dystrophy or FSHD and the urgent need for NIH funding for research on this disorder. In past years and earlier this year (1994, 1995, 1997, 1998) we submitted testimony before both House and Senate Appropriations Committees' subcommittees on Labor, Health and Human Services and Education and Related Agencies which stated that NIH and Congress could help bring about a significant research and scientific opportunity which would benefit hundreds of thousands of people worldwide with modest investments.

The FSH Society has previously informed the members of this committee of the United States Congress on the need and rationale for research on FSHD. We have updated you on the most recent developments in clinical medicine with respect to FSHD, kept you abreast of the latest breakthroughs in the molecular genetics of the disease and given you insight into the difficulty of living a lifetime with this disease.

Largely, thanks to your efforts, Mr. Specter, NIH research funding continues to grow. However, I regret to say that not all areas of promising research are benefiting. It saddens me to inform you that the American research effort on FSHD has suffered a tremendous setback in the past two years with loss of momentum on the only NIH project working on FSHD molecular genetics. At risk are invaluable and irreplaceable cell lines and pedigrees, which currently have no permanent repository. We need to create a core center for FSHD research to be run within the auspices of the NIH. We need intramural NIH programs enacted immediately. We need extramural contracts and grant programs enacted immediately.

We have met at NIH with regard to the current crisis in FSHD research. The National Institute of Neurological Disorders and Stroke (NINDS), the National Institute of Arthritis, Musculoskelatal and Skin Diseases (NIAMS) and the Office of Rare Disorders (ORD) and the FSH Society recently held, for the first time ever in the United States of America, an International Conference on the Cause and Treatment of Facioscapulohumeral Muscular Dystrophy (FSHD) in Boston, Massachusetts on April 12, 1997. We all realize the profound loss of dedicated and talented professionals working on FSHD from coast to coast and the continuing need to attract, retain and maintain programs solely focused on FSHD. The purpose of the Inter-

national conference on FSHD was to promote research in this area and to encourage scientists and researchers to submit the research grants on FSHD.

In the past year the communication between the research community, the FSH Society, NIH (NIAMS, NINDS and ORD) and Congress has been unprecedented. We are indebted to the members of this subcommittee and to your colleague Representative Edward J. Markey from Massachusetts for his continued support and for the report language submitted to you last year and co-signers Representatives Barney Frank, John M. McHugh, Martin T. Meehan, Charles E. Schumer and Robert Wexler.

In late February, 1998, after giving testimony before the House of Representatives on Appropriations for FSHD, we received a formal response to last year's report language from Congress to the Director of NIH with respect to research on FSHD. In the third or fourth week of February, 1998, the National Institutes of Health (NIH) responded to Congress as follows: "The NIAMS and the National Institute of Neurological Disorders and Stroke (NINDS) support research on the many forms of muscular dystrophy including Facioscapulohumeral disease {FSHD). In 1990 scientists discovered the general location of the defective gene for FSHD on chromosome 4. However, much remains to be learned about the functional changes that accompany the disease and treatments. In April 1997, the NIAMS, NINDS and the NIH office of Rare Diseases, along with the Facioscapulohumeral Society, held a FSHD conference designed to identity medical problems associated with the disease and to help focus research efforts by identifying new research opportunities. As the next step in an effort to increase research interest on FSHD, NIAMS and NINDS are developing a program announcement to follow-up on recommendations from the April meeting. NIAMS, NNDS and the NIH Office of Rare Diseases will continue to work closely on encouraging FSHD research and to share relevant scientific advances."

On March 20, 1998, shortly after the response to Congress regarding the report language, the National Institutes of Health issued Program Announcement 98–044 (PA–98–044) jointly sponsored by the National Institute of Neurological Disorders and Stroke (NINDS) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) titled "Pathogenesis and Therapy of the Muscular Dystrophies."

The purpose of the PA–98–044 is as follows: "The National Institute of Neurological Disorders and Stroke (NINDS) and the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) encourage investigator-initiated research grant applications to study the pathogenesis and therapy of the various forms of muscular dystrophy in children and adults. Responses to this program announcement may include studies in appropriate animal models or preclinical or clinical studies in patients with Facioscapuilohumeral dystrophy (FSH), limb-girdle muscular dystrophy (LGMD), myotonic dystrophy, congenital muscular dystrophy (CMD), Emery-Dreifuss muscular dystrophy (EMD), Duchenne muscular dystrophy (DMD), Becker muscular dystrophy (BMD), or other forms of muscular dystrophy."

The FSH Society appreciates NIH's response to last year's Committee Report which encouraged NIH take steps to stimulate research in the area of Facioscapuilohumeral disease (FSHD) which it has done through a program announcement covering FSHD as well as other muscular dystrophies. However, the FSH Society notes that NIH has not responded in developing a plan for enhancing FSHD research including the question whether an intramural program in this area would be beneficial. Therefore, the FSH Society urges NIH to conduct a research planning conference in the near future in order explore scientific opportunities in FSHD research both intramurally and extramurally.

Report Language from Congress to the NIH for Research on FSHD

"The Committee appreciates NIH's response to last year's Committee Report which encouraged NIH take steps to stimulate research in the area of Facioscapulohumeral disease (FSHD) which it has done through a program announcement covering FSHD as well as other muscular dystrophies. However, the Committee notes that NIH has not responded in developing a plan for enhancing FSHD research including the question whether an intramural program in this area would be beneficial. Therefore, the Committee urges NIH to conduct a research planning conference in the near future in order explore scientific opportunities in FSHD research both intramurally and extramurally."

Conclusion

The men, women and children who live with the daily consequences of this devastating disease are your friends, neighbors, fellow taxpayers and contributors to the American way of life. With an historical 88 percent employment rate and an average educational achievement level of 14 years (source: Impairment and Disability

Profiles on Neuromuscular Diseases: Facioscapulohumeral Muscular Dystrophy, Research and Training Center on Neuromuscular Disease, Department of Physical Medicine & Rehabilitation, University of California, Davis and The National Institute on Disability & Rehabilitation Research, 1994), we personally bear our burden of the health care costs and training expenses to prepare for and maintain financial and personal independence.

We appeal to you today to take our hard earned tax dollars commensurate with our numbers and valuable contributions to American Society. We urge the United Sates government to allocate a proportion of our tax burden towards research on FSHD. The current amount per person per year living with FSHD is unacceptable. We ask for an overall research budget that will cover the creation of a core center for research at NIH and the expansion of extramural and intramural research programs.

Time is of the essence here. Lives are in the balance and the race against this disease is ongoing. The FSHD community believes that now is the time to move to action and it demands persistent and innovative research programs and the willingness to take risks in previously uncharted territory. We who are gradually losing strength physically daily are gaining it rapidly in collective numbers. We who are least able to do the simplest physical tasks daily have undertaken the most complex task of FSHD. We who have the most severe limitations imposed on us have mobilized. We stand ready, we have moved to action, and we are prepared to act cooperatively with the NIH and with Congress.

This is the United States of America, and in a country as great as ours with all of its technical means and ability it should be absolutely clear, if not completely black and white, that the number one priority for individuals with FSHD and the one absolutely commanding imperative for the Federal Government is to initiate and accelerate in any way possible, research on FSHD. With modest funding and a clear direction from Congress to the NIH to support research on FSHD significant progress can be made in conquering and eliminating this and other devastating diseases.

Mr. Chairman, again, thank you for providing this opportunity to testify before your subcommittee.

PREPARED STATEMENT OF PAUL L. KAUFMAN, M.D., PRESIDENT, ASSOCIATION FOR RESEARCH IN VISION AND OPHTHALMOLOGY

On behalf of the Association for Research in Vision and Ophthalmology (ARVO), the world's largest organization of clinicians and scientists dedicated to the field of eye and vision research, I am grateful for the opportunity to provide input to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies concerning the fiscal year 1999 budget request for the National Institutes of Health. A more detailed statement of our position is outlined in the testimony which will be submitted to the Subcommittee on behalf of the National Alliance for Eye and Vision Research.

We are beginning to reap the health care benefits of our investment, via the NIH/NEI, in basic and clinical vision science, but more and more we are forced to prioritize between important and promising opportunities because of insufficient funding.

It is only through further advances in research that we will gain a better understanding of vision disorders, and thereby develop cost-effective advances in disease prevention and treatment. This will be ever more important as our population ages, since the most common blinding disorders are strongly age-related.

We now have the scientific and technological capability to make substantial progress in all areas of eye and vision research, if an expanded research effort is supported. Such progress will only be possible if we insure that the NEI has sufficient resources to pursue initiatives in the key areas outlined in the soon-to-be-released Vision Research Plan of the NEI.

Tremendous advances have been made in understanding the epidemiology, cell, molecular-, and neuro-biology, and molecular genetics of age-related macular degeneration, diabetic and inflammatory eye disease, glaucoma, cataract, and developmental disorders of the visual system, and in developing pharmacologic and surgical therapies to redress the altered pathophysiology of these diseases. Despite remarkable progress, our current diagnostic, therapeutic and preventive measures are far from ideal in terms of efficacy, safety, tolerability and cost-effectiveness. The opportunities to advance our basic scientific knowledge of ocular and visual system pathophysiology, and translate it into improved therapy and prevention of disease,

are unprecedented. However, this will require a quantum leap in funding to the NEI, which we hope that the Committee will allocate.

We thank you for your continuing support for medical research funding, and urge you to provide a 15 percent increase in fiscal year 1999 for the NIH as the first step toward doubling the budget over the next five years. Furthermore, we urge you to provide $408.6 million, a 15 percent increase, for NEI in fiscal year 1999 as requested by the National Advisory Eye Council in its "Citizens Budget Proposal".

Thank you for the opportunity to participate in the process.

PREPARED STATEMENT OF THE AMERICAN COLLEGE OF PREVENTIVE MEDICINE AND THE ASSOCIATION OF TEACHERS OF PREVENTIVE MEDICINE

The American College of Preventive Medicine (ACPM) and the Association of Teachers of Preventive Medicine (ATPM) are pleased to submit jointly this statement concerning appropriations for federal activities in disease prevention and health promotion.

ACPM is the national medical specialty society of physicians whose primary interest and expertise are in preventive medicine. ATPM is the professional organization of academic departments, faculty and others concerned with undergraduate and postgraduate medical education in preventive medicine. Together, these organizations are proud to offer the public a high degree of knowledge and skill in disease prevention and health promotion.

ACPM and ATPM urge the Subcommittee to maintain federal support for prevention. In particular, we urge a minimal increase in the level of funding for preventive medicine residency training and for training other public health professionals included in Title VII of the Public Health Service Act. We also urge an increase for the activities of the Centers for Disease Control and Prevention and an earmark for the invaluable work of the Office of Disease Prevention and Health Promotion in the Office of the HHS Secretary.

We are well aware of the fiscal constraints that this Subcommittee faces and we do not make these recommendations lightly. However, we are deeply concerned that weakening our nation's efforts in disease prevention and health promotion will become an unintended consequence of necessary reductions in discretionary appropriations. At a time when the private sector is struggling mightily to contain medical care costs, the nation can ill afford a diminution in public health efforts to prevent disease that only the government can conduct. Compared to the vast sums of public funds that are spent on curative medicine, the amounts that we recommend be targeted to prevention are small indeed.

Training in Preventive Medicine and Public Health—$9 million

Prevention, in its broadest sense, is practiced by all physicians and other health professionals who help their patients stay healthy. It also is the principal goal of our nation's state and local health departments, who perform core functions in health protection and promotion that no single private institution or health provider can fulfill. The specialty of preventive medicine bridges the gap between the perspectives of clinical medicine and public health.

The tools of preventive medicine are the population-based health sciences, including epidemiology, biostatistics, environmental and occupational health, planning, management and evaluation of health services, and the social and behavioral aspects of health and disease. These are the classic tools of practice in public health agencies, but they have grown in importance in other health care settings where there is increasing recognition that improving the health of a patient population and reducing the costs of medical care also require application of the population-based health sciences.

Departments of preventive medicine, community medicine, or social medicine in medical schools, schools of public health, and preventive medicine residency programs (which are located in medical schools, schools of public health, and a few health departments), are the loci of expertise in the population-based health sciences. Federal support for preventive medicine training and public health training is essential to help meet the workforce needs not only of public health departments, but also of a rapidly-evolving health care system that must be cost-effective and accountable.

The small sums appropriated for preventive medicine residency training under Section 763 in Title VII of the Public Health Service Act have been the exclusive federal support for programs training physicians in general preventive medicine and public health (other than the residency programs conducted by the Centers for Disease Control and Prevention and the military). Medicare graduate medical edu-

cation funds have been largely unavailable to these programs because they are based not in hospitals but in community outpatient and public health settings. Because preventive medicine programs derive little or no revenue from one-on-one patient care, this common source of funds for physician training also is unavailable.

Currently, residency programs scramble to patch together funding packages for their residents. Funding from any source is available for only 60 percent of preventive medicine residency positions. The remainder of the openings go unfilled due to lack of funds, and potential applicants must be turned away.

A 1991 survey of all 1,070 graduates of general preventive medicine/public health residency programs from 1979 to 1989 conducted by Battelle, an independent consultant under contract to the Centers for Disease Control and Prevention and the Health Resources and Services Administration provided a clear picture of the accomplishments of the training programs and the impact of these federal funds. A majority of the graduates have initiated or managed major programs in prevention and control of infectious disease, chronic disease, sexually transmitted diseases, or maternal and child health. In addition to creating and running community health programs such as these, 60 percent of the graduates engage in research in disease prevention and health promotion, and 70 percent also take care of individual patients.

This survey also documented that funds invested in training these physicians have a lasting impact. Ninety percent of preventive medicine graduates remain involved in public health or preventive medicine. Moreover, Title VII funds were shown to be directly related to the viability of preventive medicine residency programs. In programs that have received federal grants, the number of graduates has more than doubled since 1983. Conversely, the number of graduates of programs that no longer receive federal funds has decreased significantly.

The training of public health professionals is closely linked to preventive medicine. The nation's 28 schools of public health provide training for physician specialists in preventive medicine as well as for many other health professionals who comprise our public health workforce. In addition to the shortage of physicians trained in preventive medicine, there are shortages of epidemiologists, biostatisticians, environmental and occupational health specialists, public health nutritionists and public health nurses. In addition to Section 763, Sections 761 and 762 of Title VII (Public Health Traineeships and Public Health Special Projects) support public health training in these areas. An appropriation of $9 million for Sections 761, 762, and 763 in fiscal year 1998 will allow for the continuation of efforts to build the nation's cadre of prevention professionals. Finally, ACPM and ATPM support the Health Professions and Nursing Education Coalition's (HPNEC) recommendation of $306 million for all of the health professions education programs funded under Titles VII and VII of the Public Health Service Act.

Centers for Disease Control and Prevention—$3 billion

Physicians working in preventive medicine and public health rely heavily on the expertise and activities of the Centers for Disease Control and Prevention, the nation's premier agency for disease prevention and health promotion. Therefore, we support, alongside many other organizations and coalitions with a concern for prevention, including the Coalition for Health Funding and the CDC Coalition, a total CDC appropriation of $3 billion.

Through funding of state and local prevention programs, research, training and surveillance, CDC has a major impact on every important issue in prevention. Compared to the billions that are spent on acute health care, our national investment in prevention continues to lag. The increases in health care costs we have witnessed are not a reason to cut back on funds appropriated for prevention. They are a reason to make a large investment now. Given the resources, CDC can play a critical role in revitalizing programs and services of proven effectiveness in reducing death and disability in this country. Reducing CDC funds would be an act of extraordinary short-sightedness. Time and again we have seen, as in the cases of tuberculosis and measles, when public health efforts falter, the nation pays a high price later in the costs of preventable disease.

Office of Disease Prevention and Health Promotion—$4.6 million

The Office of Disease Prevention and Health Promotion (ODPHP) stands out among federal agencies for its ability to leverage small amounts of funding into large accomplishments in highly innovative ways. ODPHP manages the Healthy People 2000 initiative, the national prevention strategy used by health agencies across the nation to set measurable objectives for health improvement. ODPHP provides guidance and prototype materials to health practitioners through the Put Prevention Into Practice (PPIP) project. It is conducting ground-breaking research concerning the cost-effectiveness of preventive services, and has long served as the focal

point for coordinating departmental activities in prevention as well as innovative public-private partnerships. Explicit support for ODPHP is vital in signaling a continued federal commitment at the Secretary's level to leadership in prevention. We urge the Subcommittee to earmark $4.6 million for this office, an amount equivalent to fiscal year 1995 funding, before the budget for this office was incorporated into the amounts appropriated for the Office of the Secretary.

Prepared Statement of the American Society of Clinical Oncology

The American Society of Clinical Oncology (ASCO) is pleased to submit comments to the Subcommittee regarding the cancer research program supported by the National Cancer Institute (NCI). ASCO is a national medical specialty society representing more than 11,000 cancer specialists involved in patient care and clinical research.

The nation recently received the good news, reported by NCI, the Centers for Disease Control and Prevention (CDC) and the American Cancer Society, that both the incidence of cancer and death from the disease have declined. This announcement represents tangible evidence of returns from the federal government's investment in cancer research. More subtle but possibly more important, we are enjoying an unparalleled era of discovery in genetics and molecular biology that will likely lead to even greater declines in cancer incidence and mortality in the not-too-distant future.

However, in order to enjoy the full potential of these biomedical research discoveries, they must be translated into clinical applications. The process by which basic science is harnessed for patient benefit is through translational and clinical research. The NCI budget must fully support translational and clinical research if results in terms of cancer incidence and mortality are to be maximized.

To ensure the healthiest possible environment for clinical research, ASCO recommends: significant increases in funding for all cancer research, from basic to translational to clinical; reforms in the peer review of patient-oriented research proposals; improvements in the training of clinical researchers; and Medicare coverage for the patient care costs of those enrolled in high-quality clinical trials. Although the last recommendation is not strictly in the jurisdiction of the Subcommittee, recognition by all third-party payors that they should cover patient care costs for those enrolled in such trials is an essential element of support for clinical research.

INCREASES IN NIH FUNDING

ASCO applauds the proposal of the Clinton Administration to increase National Institutes of Health (NIH) funding by approximately 8.5 percent in fiscal year 1999 and boost funding for cancer research by 10 percent in fiscal year 1999 and by 65 percent over five years. This action is a significant departure for the Administration, which has previously proposed very modest increases in NIH funding, and was apparently a response to the tremendous research opportunities that greet investigators today. Although we are pleased that the Administration has proposed to increase funding for NIH, we also support the more ambitious recommendation of the Ad Hoc Group for Medical Research Funding that the NIH budget be increased by 15 percent in fiscal year 1999.

Our support for the Ad Hoc Group recommendation is not intended to undermine the NCI Bypass Budget. In past years, the cancer community has made reference to the NCI Bypass Budget, without a real expectation that it would be adopted. This year, in contrast, we believe the Bypass Budget must be seriously considered. The Bypass Budget is a concise document which presents the professional judgment of NCI regarding the funding necessary to support current cancer research opportunities. Because this is an era of impressive discovery in several areas of cancer research, the Bypass Budget makes a persuasive case for a substantial increase in NCI funding to take advantage of these critical research opportunities. Some Members of Congress have asked if NCI can absorb such a significant increase in funding. ASCO believes that increases of the magnitude proposed in the Bypass Budget—35 percent in fiscal year 1999—could be used productively to advance our knowledge of the underlying mechanisms of cancer and improve treatment of the disease.

PEER REVIEW OF PATIENT-ORIENTED RESEARCH APPLICATIONS

Basic research findings must be evaluated in clinical trials that include actual patients before new therapies are accepted as standard medical practice. ASCO has long believed that the current process of peer review at NIH is not adequate to evaluate clinical research proposals. Study sections, which are the groups that re-

view all investigator-initiated research proposals, are dominated by basic scientists who may not be familiar with the methodologies used in clinical research. Moreover, basic research involving relatively straightforward laboratory measures usually scores higher in the review process than that which includes patient-oriented outcomes.

In order to correct these imbalances, ASCO has advocated since 1991 establishment of a separate study section specifically dedicated to clinical research. Support for significant reform of the review system has now reached a critical mass: various Members of Congress have urged appointment of a special clinical research review panel; an NIH-appointed clinical research study group concluded that patient-oriented research is not treated equitably and recommended significant reforms of the peer review system; an Institute of Medicine study documented the hurdles to funding clinical research; and the National Cancer Advisory Board has endorsed a specific study section for clinical cancer research.

Although NIH has instituted some welcome improvements in the peer review process, it has not established a study section for the review of cancer clinical research applications. The Center for Scientific Review, formerly called the Division of Research Grants, indicated several months ago that it would establish, on a pilot basis, a special study section for the review of cancer clinical research applications. Despite that announcement, no such review panel has been formed.

Unless a more suitable review mechanism for investigator-initiated research applications is promptly established, a whole generation of potential researchers will be discouraged and major advances in patient care may be at risk. ASCO believes there should be no further delay in appointing a cancer clinical research study section, a modest step that will bring equity to the review of patient-oriented research applications. We urge the Subcommittee to require NIH to report, by May 31, 1998, on its progress in forming the cancer clinical research study section.

TRAINING OF CLINICAL RESEARCHERS

Careers in clinical research are becoming exceedingly unattractive to young investigators. In addition to facing uncertainties about funding for their research, clinical investigators are also under great pressure to maximize patient care revenues, leaving little time for clinical research. It is difficult for physicians in this environment to pursue careers in clinical research. Fundamental changes in the health care system will be necessary to ensure a cohort of clinical researchers in the next generation, and NIH should be charged with developing recommendations to address the practical barriers to clinical research in a health care system increasingly dominated by managed care and for-profit medicine.

In the shorter term, as NIH considers these difficult issues, ASCO advocates that NIH increase funding that allows experienced senior clinical researchers to serve as mentors for young clinical researchers. ASCO uses its own funds to support a training program for clinical researchers that includes mentoring as one of its features. We believe this mentoring program provides significant encouragement to those who are beginning their clinical research careers and should be replicated in NIH grants. We applaud the recent announcement by NIH of a Mentored Patient-Oriented Research Career Development Award that will provide mentored research experience for clinical investigators and look forward to enhanced efforts in this area, where the federal cost is modest and the benefits substantial.

MEDICARE COVERAGE FOR PATIENT CARE COSTS FOR PATIENTS PARTICIPATING IN CLINICAL TRIALS

For the cancer community, one of the most important features of the President's budget is the proposal to establish a Medicare demonstration project that would provide reimbursement for the routine patient care costs for patients enrolled in cancer clinical trials. The best care for cancer patients is often in a clinical trial. Furthermore, clinical trials advance our knowledge about the best possible treatment for cancer. Unfortunately, the Medicare policy on coverage of clinical trials is unclear, and Medicare beneficiaries are often discouraged from enrolling in trials, even when those trials represent their best treatment option.

The Clinton initiative would address this problem by guaranteeing payment for patient care costs for those beneficiaries who enroll in certain ''approved'' trials. Purely research costs associated with the conduct of clinical trials—including supplying the investigational agent and collecting and analyzing data—would continue to be borne by the research sponsor, whether NIH or industry. However, patients enrolled in approved clinical trials would be assured that the Medicare program would not deny payment for routine patient care costs like physician or hospital charges. ASCO has worked for many years to secure Medicare patients this guaran-

tee of access to quality clinical trials. Assured Medicare coverage would not only improve treatment for the individual patient but also integrate clinical trials into the standard of care for Medicare beneficiaries with cancer. For this Subcommittee, the proposal is important because it creates a positive environment for clinical research without requiring the expenditure of discretionary funds.

The Clinton-Gore clinical trials proposal is modeled after legislation introduced in the 105th Congress by Senators Rockefeller and Mack and Representatives Johnson and Cardin, except it would limit Medicare coverage to those trials that are sponsored by NIH and give the Secretary the option to expand coverage to other high-quality clinical trials. The Rockefeller-Mack legislation, in contrast, would have authorized coverage of trials that are approved by NIH, the Food and Drug Administration, the Department of Defense, the Veterans Administration, and private entities with adequate peer review systems. These are the criteria for coverage that were developed by ASCO and broadly adopted by the cancer community. The Clinton-Gore proposal should be expanded to meet the standards of clinical trials coverage outlined by ASCO, because those criteria would ensure that patients have access to all high-quality trials that might offer them therapeutic benefit. ASCO will work for the enactment of legislation to implement Medicare coverage for cancer clinical trials and for a broadening of the definition of a covered cancer clinical trial.

We appreciate the opportunity to present ASCO's recommendations to enhance the climate for cancer clinical research. An NIH program that supports all aspects of the research continuum—from basic to translational and clinical research—is essential if recent reductions in cancer incidence and mortality are to be only the first of many successes in our progress toward prevention and reliable cure of cancer.

PREPARED STATEMENT OF DR. LEE W. SAPERSTEIN, DEAN, SCHOOL OF MINES AND METALLURGY, UNIVERSITY OF MISSOURI-ROLLA

Introduction

Mr. Chairman, I want to thank you for this opportunity to present testimony to the Subcommittee on the appropriations for fiscal year 1999 on MSHA and NIOSH programs related to mine safety and research. I want to commend you for your outstanding leadership and for your continuing efforts to ensure that the scientific and research capability of this nation remains second to none.

I am Lee W. Saperstein, Professor of Mining Engineering and Dean, School of Mines and Metallurgy, University of Missouri-Rolla (UMR). The School is one of the largest academic units in the United States devoted to natural resources, minerals, materials, energy, the environment, and the safe, productive, and environmentally sound use of crustal resources. It is the oldest of the three component parts of UMR. Founded in 1870 in response to the economic needs of Missouri, we are part of the great Land-Grant University movement. It is axiomatic, but still worth repeating, that this movement put together the States and the federal government in a partnership that stimulates economic development through education and research at our leading universities. This is a partnership that is as timely today as it was in 1862 when it was first formulated.

NASULGC Mission

Founded in 1887, NASULGC is the nation's oldest higher education association. Currently the association has over 190 member institutions—including 17 historically black institutions—located in all fifty states, with a total of 3 million students. The Association's overriding mission is to support high quality public education through efforts that enhance the capacity of member institutions to perform their traditional teaching, research, and public service roles—roles which reflect a strong social commitment to investing in the development of America's greatest resource, its people. NASULGC does not receive any Federal grants. The Section on Mineral and Energy Resources brings together leading educators and research scholars in the Association's universities to promote university-based programs in mineral and mineral-fuel resources, and to demonstrate the importance to the Nation of maintaining a strong capability in research and education in mineral-resource engineering and science to promote public understanding of mineral-resource issues.

Importance of Extramural Research

The Government Performance and Results Act presents extraordinary opportunities for creative partnerships between the Federal government and universities. These partnerships can contribute significantly to the national goal of a more efficient and productive Federal government by providing policy makers higher quality research at lower cost to address society's most compelling issues. The country's in-

vestment in higher education continues to provide not only the incalculable dividends associated with a better educated workforce, but also the very tangible benefits that meet daily human and economic needs. Competitive, peer-reviewed extramural research is fundamental to developing the technologies which ensure safe food and water supplies, a healthy environment, sufficient energy sources, better medical care, improved communications and transportation systems, a stronger national defense and strategies and tools to mitigate natural hazards. Information from such research leads to improved management of natural resources and maintenance of conditions that contribute to a desired quality of life.

Miner Safety and Health

It is a long-term goal of all us who have worked on projects for miner health and safety that no mine worker should have his or her life shortened or health compromised in pursuit of a livelihood. Mining has historically ranked high among all industries in fatality and injury incidences and has unacceptably high prevalence rates in pneumoconiosis, silicosis, and noise-induced hearing loss. Efforts to date allow me to say that the more than 250,000 people who work today in the United States's mining and mineral industries enjoy an unprecedented record for safety. Accidents, both fatal and non-fatal disabling, are close to an all-time low as are their incidence rates (number of accidents normalized by the working hours of exposure). This enviable record is in itself no accident but is the result of both vigilance and research applied toward miners' health and safety. Inasmuch as a mine is not inherently a safe place, this record is a tremendous testimonial to our successes in promoting mine safety.

The avoidance of work-place losses, in particular those that can lead to harm to workers, is achieved by three main thrusts: engineering design, worker training, and enforcement and inspection. Engineering design for safe mines includes, amongst many topics, roof and slope control, ventilation for removal of explosive and deleterious gases and dusts, safe and encompassing control cabins for equipment, and removal, by selective use of advanced mechanization and automation, of the worker from the active mining faces. These are topics that are researched in the national laboratories of NIOSH and the mining universities alike. Worker training may be either task (job skills) or safety training or both. The design of classes and training modules should reflect considerations of effectiveness, often called "outcomes." Measures of desirable outcomes could include reduced accident rates, increased productivity, and reduced losses. Of particular concern to mine safety is continuing improvement in accident rates among those workers who benefitted from the training. Universities have participated actively with MSHA in creating effective training materials and in designing outcome assessment programs for when this material is presented to miners.

Without question, the federal presence, found in enforcement activities of the Department of Labor's Mine Safety and Health Administration (MSHA) and research activities of the Department of Health and Human Services' National Institute for Occupational Safety and Health (NIOSH), has a direct influence on this outstanding record. The role of the States is equally as important and often performed collaboratively with institutions of higher education, in furthering the work of the federal agencies. MSHA's State Grants program and NIOSH's Mine Safety and Health program of extramural grants are relatively modest in scope but they are key to the maintenance of the State-federal partnership for mine safety. I will elaborate on each.

Mine Safety and Health Administration

NASULGC urges full funding of the fiscal year 1999 budget request of $211.2 million for MSHA. However, we would like to draw your attention to that part of MSHA that works with the States and with institutions of higher education, namely the State Grants program found within the Technical Support line of the MSHA budget. The 1999 request for State Grants is $6.013 million; we urge full funding of this line. Indeed, we urge that, where possible, MSHA consider expansion of that request and further involvement of universities in the achievement of their mission.

The Mine Safety and Health Administration is a component part of the Department of Labor and is charged with fostering the health and safety of American miners. The State Grants program has participants from 44 States and the Navajo Nation. Monies are distributed by a formula that is reflective of a State's mining activity. The money is often spent on safety-related items that are specific to the geographic region; often the money is spent on training-program development and delivery. Universities, with their particular experience in course development, have cooperated on much of this course development. This cooperation can be seen with eight of the 44 State programs being centered in colleges or universities. Further

numbers of States have contracted with colleges and universities to provide training or training materials. For example, both Pennsylvania and West Virginia contract with their respective State Universities for these materials. Penn State, West Virginia U., and the University of Kentucky cooperate to present a series of TRAM (Training Resources Applied to Mining) conferences to showcase new developments in mine training.

MSHA, through its Educational Policy and Technical Support Divisions, provides training support that ensures that the nation's mines are able to deliver safety and task training required within the federal mine safety law. MSHA hopes to expand its Technical Support functions to provide mines and miners with an understanding of currently available technologies that will assist with the safety mission. Our universities are willing partners in this push for safety through training and better use of technology. As we train, we are providing one of the three requisites described above for safe mines. Of course, MSHA's main business, which we acknowledge but in which we do not participate, is enforcement of the nation's mine safety laws. As can be seen in the next section, universities look for scientific and technological solutions to on-going problems with the expectation that these solutions will make for easier compliance with the safety laws.

Office of Mine Safety and Health Research, NIOSH

Recently, the National Institute of Occupational Safety and Health (NIOSH), which reports to the Centers for Disease Control and Prevention, Department of Health and Human Services, was given responsibility for research into problems of miner health and safety. This area of research had been part of the mission of the Bureau of Mines but was transferred upon the closure of the Bureau. NIOSH has established an Office of Mine Safety and Health Research and oversees the work of two national laboratories: Pittsburgh and Spokane Mine Safety and Health Research Centers. This research domain is one in which there used to be strong links between the federal laboratories and the universities. There are still strong emotional ties and a very clear parallelism of purpose. NASULGC urges the restoration of formal links between the laboratories and the universities. We believe that these links return a value in research accomplished that is far greater than the dollar investment in them.

The Office of Mine Safety and Health Research was funded in fiscal year 1998 at $32 million. During that fiscal year a recurring amount of $4 million has been added to bring their total annual budget to $36 million. The budget includes $0.5 million in extramural funding for research. We urge two modest but important moves: first is to increase the extramural research share of the budget to one million and the second is to consider restoration of cuts that were made when the function was transferred from Interior to HHS. These requests would expand the fiscal year 1999 budget to $42 million.

The last requisite for safe and healthy mines is to have inherently safe technology and mine design. This need drives the research conducted by the Office. Research is needed to develop technology that removes or mitigates the hazards to workers at active mine locations. For all the advances that we have achieved, we are still uncertain over the reliable provision of breathable environments that rarely if never exceed thresholds for dust and other contaminants. Although equipment is more reliable than in the past, we cannot predict breakdowns and failures nor can we guarantee freedom from fires. We construct our mines within the earth and though we know a lot about its geology and its mechanical behavior, we still cannot predict exactly where or when it might fail disastrously. These problems, however, and others are amenable to research and may given the right combinations of talent yield their secrets. When they do, we will progress to another level of mine safety. We will also be able to share our technology with workers in other but related fields where vigilance is today's only insurance from accidents.

Again, Mr. Chairman, thank you for the opportunity to be here today and I look forward to working with you and answering any questions you may have.

Prepared Statement of Ron Kramis, Ph.D., Fibromyalgia Network

FIBROMYALGIA SYNDROME (FMS)

Mr. Chairman and Members of the Committee, people with fibromyalgia syndrome (FMS) battle diffuse pain from head-to-toe, severe fatigue, unrestful sleep, concentration difficulties, and a myriad of symptoms. Studies have shown that FMS afflicts at least 2 percent of the general population (mostly women in the prime of their life), the symptoms don't go away, and prescribed therapies are ineffective. Last year a multi-center study published in the June issue of Journal of

Rheumatology revealed that 26 percent of the FMS patients surveyed were receiving some form of disability payment. Then in September, two more articles from the multi-center study appeared in Arthritis & Rheumatism. The first stated that the average cost of treating an FMS patient was $2,274 per year. The second article indicated that despite the variety of treatments employed, patients showed no significant improvement over the seven-year follow up period. The high disabling rate, coupled with the lack of effective therapies, should have triggered NIH to fund more research on this condition (four years of Congressional language have failed to accomplish this). Instead, the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS) opted last year to fund a cost-containment study on FMS to help out the HMOs, not the patients who suffer so miserably.

Could FMS be a Product of Stress or Mental Status?

The answer to this question was provided by neurophysiologist Ronald Kramis, Ph.D., of Portland, OR, during his public witness testimony to the House Appropriations Subcommittee on Labor-HHS in January of this year:

"In any chronically painful condition you are going to develop some psychologically associated conditions. But, it is very clear that there are physiological mechanisms here which are known from the basic sciences to be related to the persistent pain that is occurring in these individuals. There is an unfortunate tendency right now, because the medical community does not have the means to treat this disease and they do not understand it, that there is a push to do cost-containment studies and get rid of these people rather than try to treat them. Individuals with FMS have a real disease, it's not going away, they will continue to tax the socioeconomic system, and cost-containment is not the answer."

Fibromyalgia: Pain Without Injury

There is a major problem of faulty logic in the way this highly disabling condition is being perceived. The pain of fibromyalgia is not usually fazed by modern therapies and when you look at the tissues that hurt, you won't see any evidence of injury or disease. It's pain without tissue pathology. Just because you can't see the pain, some might say that the pain is not real, the usual assumption being that it is "psychological." That's the faulty logic often employed. Pain does not require obvious tissue disease to be real and excruciating.

You can understand this phenomenon quickly with a simple test. With your thumb and all four fingers, reach across your chest and firmly squeeze the back top of your shoulder muscle near the base of your neck. Squeeze modestly, but until it hurts—and then squeeze a bit more. Maintain that pressure. Now, consider living with that sensation, not just in your shoulder, but throughout your entire body, day after day, year after year. If you are able to do that, you will have some understanding of the quality of life of people who must endure the symptoms of FMS.

Most people who do this test will experience a deep, diffuse, distressing pain—all in the absence of tissue pathology. This test doesn't produce any injury to the shoulder, but the pain felt was real. Some people may be surprised at how little pressure was necessary.

The occurrence of body-wide pain in the absence of tissue damage, as in fibromyalgia, interferes with all aspects of a person's life and undermines their credibility. The problem is that normal activities can be exhausting, sleep is disturbed, the ability to concentrate is impaired, gastrointestinal function is often abnormal, persistent headaches are common, and the unrelenting pain that no one can see is often detrimental to their personal and professional lives—as it creates a "credibility gap."

Pain is Determined by the Central Nervous System

Pain is most often perceived as if it were occurring in some peripheral tissue when an injury or disease is present, but the actual sensation of pain clearly does not occur there. The initial information (signal) about damage to tissues comes from the periphery. Yet, the perception of that signal as painful occurs in the central nervous system, or CNS (brain and spinal cord), not in the tissues—even though it feels as if the pain is in those tissues.

If one thinks that the cause of pain must be in the tissue felt to be painful, one can jump to the wrong conclusion that diffuse pain syndromes such as fibromyalgia fall into the category of musculoskeletal diseases. Then when research fails to show signs of injury or disease in the painful tissues, false assumptions are often made that the pain is not real but of psychological origin.

To further advance the science of fibromyalgia syndrome (FMS) and related chronic pain disorders, it is imperative to look beyond the tissues that hurt—the musculoskeletal structure—and examine the role of the central nervous system. Distortions in the way the central nervous system operates can lead to chronic pain without

tissue injury. This usually results in disturbed sleep, severe fatigue, concentration problems, and GI upset—basically all of the symptoms of FMS.

Relevant Research Findings in FMS

People with FMS have a threefold increase of substance P in their spinal fluid, which among other things, functions as a pain messenger. This finding is not new; it has been confirmed in three different laboratories. Based on the substantial body of literature from neuroscientists, people with such a high level of substance P would be expected to have their entire central nervous system functioning off kilter in a hypersensitized state. Substance P is also known to regulate a multitude of body systems and it is no surprise that individuals with FMS have numerous symptoms. More recently, elevations in nerve growth factor have been found in the spinal fluid of people with FMS and there is compelling scientific evidence to link this abnormality to the high production of substance P and disordered sleep.

Another finding that points to the central nervous system as the source of problems in FMS includes lower than normal blood flow levels to two major pain processing areas in the brain (the thalamus and caudate nuclei). The principal investigator in this study, Laurence Bradley, Ph.D., says that this pattern of reduced blood flow in the brain resembles that of other chronic pain conditions involving nerve injury and metastatic cancer.

The groundwork for understanding the neurological processes involved in pain (in the absence of tissue injury) has already been done for other chronic pain conditions. This science needs to be applied to the study of FMS. There are a large number of pain researchers who would be eager to apply their knowledge to the study of FMS if only NIH would provide sufficient opportunity to do so.

Economic Responsibility

A recent multi-center study showed that 26 percent of the patients surveyed were receiving some form of disability compensation. The average annual health care cost for a fibromyalgia patient is $2,274. Over 20 billion dollars per year are being spent on fibromyalgia patients because physicians are unable to provide them with therapies that work. Despite this huge financial drain and frustrating attempts by clinicians to treat the pain, the quality of life for a person with fibromyalgia is poor.

Ordinarily, when a medical condition produces a high degree of work-disability and treatments are not effective, rational thinking would lead to more research on the condition. For FMS, fears over the costs that may be required to help people with this medical problem have overshadowed rational thinking. Last year, NIAMS added a cost-containment study to its list of funded projects. This study is designed to trim $1,200 per year off of the HMO health care costs of tending to each person with FMS. The needs of patients with FMS are being forced into second place, behind the needs of cost-cutting HMOs to make a profit.

The cost issue is real, but disregarding individuals with FMS is not an effective approach. People racked with the unyielding pain and draining fatigue of FMS will continue to seek medical attention, and in the absence of effective therapies, many will be forced to apply for disability compensation.

Economic responsibility to ensure that adequate research is being done on FMS rests on the shoulders of this Appropriations Committee and NIH. This Committee has passed language for the past 4 years, urging NIAMS to step up its research program on FMS. NIAMS has refused and, instead, has stepped into the cost-containment funding arena—an action that will only escalate patient suffering. Regardless of all of the mishaps that have been occurring at NIH, it is still up to this Committee to enforce economic responsibility in research matters pertaining to health conditions such as FMS.

Recommendations

NIAMS has traditionally been the home of FMS research and should step up its efforts in this area (NIAMS-funded research has been stagnant for three years). However, with modern advances in our understanding of chronic pain syndromes, it is appropriate for the neurological Institute (NINDS) to also be a significant sponsor of research on FMS. Here are our recommendations:

NIAMS, in cooperation with NINDS, the Office of Alternative Medicine (OAM), the Office of Behavioral and Social Sciences Research (OBSSR), and the National Institute of Dental Research (NIDR), published an RFA on March 26 of this year. The estimated funds available adds up to only $1.85 million after years of NIH doing precious little. This RFA was not a surprise; it was recommended last year by both the House and Senate Appropriations Committees. Although one of the areas of interest includes pain-related research, many of the other items being solicited have to do with psychiatrizing FMS. Pharmacological treatments are not even listed, but proposals for behavioral and alternative therapies are being solicited in

place of testing traditional medicines used for other painful conditions. We ask this committee to urge NIH to place stronger emphasis on pain mechanism research, investigation of disease markers, and pharmacological interventions—the three areas that will help FMS patients the most.

NIAMS and NINDS should routinely publish a 2-year PA on FMS to generate grant proposals from scientists of all different specialties. The PA will also work to lower the pay-line for FMS grants, which is a necessary step because only a few investigators have sufficient preliminary data on FMS to compete with applications for researching other medical conditions that have been studied for years.

A Special Emphasis Panel (SEP) was set up 2 years ago to grade research grant proposals submitted to NIH on FMS and the related condition, chronic fatigue syndrome. This SEP needs to be recognized by NINDS and other Institutes at NIH.

Prepared Statement of the Population Association of America (PAA) and the Association of Population Centers (APC)

Thank you, Mr. Chairman for this opportunity to present the position of the Population Association of America (PAA) and the Association of Population Centers (APC) to the Subcommittee on Labor, Health and Human Services and Education on fiscal year 1999 funding for the National Institutes of Health (NIH), specifically the National Institute on Aging (NIA), and the National Institute of Child and Maternal Health (NICHD). You are a long-standing friend of both organizations and we want to emphasize how grateful we are for your appreciation and support of demographic research.

As you know, PAA is a scientific and educational society of professionals working in demographic research. APC is a consortium of 27 leading American population research centers. In addition to their academic roles, members of both organizations provide federal, state and local government agencies, as well as private sector institutions, with data and research to guide decision-making.

In this testimony, we wish to express our support for the National Institutes of Health (NIH), specifically NIH support for demographic, social and behavioral research, and share recent demographic trends and research findings of interest with Congress.

Demographic research covers many issues important to our nation, such as retirement, minority health, disability and long term care, child care, immigration, labor force participation, worker retraining, family formation and dissolution and population forecasting. The United States is undergoing far-reaching shifts in its demographic composition and distribution. Such changes often are not recognized or understood until they confront society with new and immediate needs—often requiring federal and state expenditures. Incorporating demographic, social and behavioral research into long term policy discussions allow such changes to be tracked and anticipated in a manner that promotes more coherent and efficient planning and policy implementation.

NIH, specifically the National Institute of Child Health and Human Development (NICHD) and the National Institute on Aging (NIA) provide primary support for demographic research. We would like to take this opportunity to share with you information concerning aging, trends in adolescent health, the incidence of teenage pregnancy and abortion prevalence and changes in fatherhood.

The National Institute of Child Health and Human Development (NICHD)

NICHD has a well-established, successful population research program. NICHD is currently funded at $674 million with $39.6 million of the budget for research funded through the Demographic and Behavioral Sciences. Among the many areas of demographic research supported by NICHD are families and households; marriage and family change; fertility and family planning; teen pregnancy; mortality; HIV prevention; and population movement, distribution and composition. NICHD also funds a highly regarded population research centers program. Population research centers provide a critical core of professionals who conduct research in a cost-effective manner. Further, the centers' training programs are an essential source of population scientists who bring fresh perspectives, ideas and improved methodologies to demographic research.

As you can see from the wide range of research topics listed above, NICHD-supported demographic research provides important, ongoing information critical to policymakers. Last year's committee report for the fiscal year 1998 NICHD appropriation specifically mentioned the National Longitudinal Study of Adolescent Health, also known as the Add Health Survey, and this committee's interest in continued reporting on this study. We are pleased to provide some information in this testi-

mony that focuses on Add Health, your interest in the decreasing rates in teen pregnancy and abortion, the Fatherhood Initiative, and the Family and Child Well-Being Research Network.

Add Health

The Add Health survey is the first comprehensive national study of the social, psychological and environmental determinants of adolescent health. This study provides information that is valuable to parents, educators, researchers and policymakers. Although teens are generally a very healthy sub-group in the population, one in five has a serious health problem which are often costly and affect adult health. Each year, in the mid-1980's, the lifetime cost of injuries to young people 15–24 years of age were estimated at $39.4 billion; public support for families headed by adolescents cost $16.7 billion per year; treatment costs for adolescents with mental health problems were estimated at $3.5 billion annually; and $2.0 billion or more per year was spent on facilities for delinquent adolescents.

One of the key findings from the Add Health study was that "family connectedness" played a central role in protecting adolescent health: adolescents who felt loved and cared for by their parents and were satisfied with their family relationships were least likely to smoke, drink or use illegal drugs; least likely to become sexually active at a young age; least likely to be emotionally distressed or contemplate or attempt suicide, and least likely to engage in violence.

Determining how to prevent and treat adolescent health problems will contribute to a stronger and healthier society. PAA and APC hope this committee will continue to support research, such as the Add Health study, that adds to our understanding of changes in the teenage and adult population.

Teen Pregnancy and Teen Abortion

There are encouraging trends in teen pregnancy and the prevalence of abortion. The teen birth rate has been steadily decreasing in recent years. Since 1991 the rate has declined 12 percent to 54.7 per 1,000 in 1996. Between 1991 and 1995, the teen birth rate dropped 17 percent among non-Hispanic blacks and by more than 9 percent among non-Hispanic whites. The teenage Hispanic population did not show a comparable decline in birth rates between 1991 and 1995. Another encouraging note is that there was a decline in the teen abortion rate in the early 1990's. These data suggest that the decrease in the teen pregnancy rate is not being driven by an increase in abortion.

Although rates of teen pregnancy are decreasing, the United States still has one of the highest teen pregnancy rates among industrialized countries. NICHD is currently supporting a study to identify key groups of young women who are at a higher risk of becoming a teen parent. One such group, younger sisters of pregnant and parenting teens, have more permissive childbearing attitudes than do their age and socio-economic status-matched peers who do not have an older sister who is a teen parent. Realization of this type of information will prove very important when creating intervention programs targeted at further decreasing the teenage pregnancy rate.

Fatherhood

The declining significance of marriage has the particular effect of weakening the ties of men to women and children, with a resulting burden to the welfare system and to women and children themselves. Thus, it is important to understand the conditions which help to sustain men's obligations to family members. NICHD, in conjunction with the Federal interagency Forum on Child and Family Statistics and the National Center on Fathers and Families, launched a Fatherhood Initiative to review the capacity of the federal statistical system to conceptualize, measure and gather information from men about their fertility and role as fathers. This same study identified ways to improve data collection and research in this area.

Family and Child Well-Being Research Network

Finally, we wanted to bring you up-to-date on NICHD's Family and Child Well-Being Research Network—an interdisciplinary data system focusing on child- and family-related research that relies on cross-agency cooperation. The network is comprised of scientists from seven universities collaboratively working with federal officials from NICHD, the Office of the Assistant Secretary for Health, of the Department of Health and Human Services (DHHS), the Administration of Children and Families, of DHHS, the Census Bureau and the Department of Education. This network currently addresses a variety of questions about the interrelations between parent characteristics, family structure and organization, neighborhood attributes and different forms of social support. The network is committed to increasing the visibility of basic research findings to those involved in formulating public policy.

Projects such as the Family and Child Well-Being Research Network perform the important task of helping synthesize research into sensible policy solutions.

NICHD's Family and Child Well-Being Research Network, in cooperation with federal statistical agencies and the research community developed a comprehensive set of indicators of child well-being. Information from these indices are published annually by executive order. The first report titled, America's Children: Key National Indicators of Well-Being, was released in 1997. This report provides a much improved information base that summarizes the changes in the overall well-being of American children and families on an annual basis.

PAA and APC enthusiastically support initiatives such as NICHD's Family and Child Well-Being Research Network that provide quick access to data and are efficient and effective resources for policy-related research in cross-disciplinary fields.

The National Institute on Aging (NIA)

The NIA also has a well established and widely respected demographic research program which provides crucial information on the implications of an aging of the American Population for our country. Currently, the NIA is funded at $519 million, with $38 million of that budget dedicated to demographic research—training, career development, and demographic, economic and epidemiologic research. As the US population ages and Congress contemplates changes in Medicare and Social Security, the demography of the elderly steadily become more important. The NIA has a strong history of supporting the collection of data which allows demographers to study questions of concern to policymakers. Chief among these are the NIA-supported studies, the Health and Retirement Study (HRS) and its auxiliary survey, the Asset and Health Dynamics of the Oldest-Old (AHEAD) study. You have been a solid supporter of these two studies over the years, Mr. Chairman, and we would like to express our gratitude for your support.

Health and Retirement Study (HRS)

As you know, the HRS focuses on retirement decisions and includes data on disability, work history, health and health insurance, pensions and retirement plans and obligations to family that may bear on retirement decisions. Using HRS data, researchers are able to explore issues related to health, disability and labor force participation; prospects for economic security; cognitive changes, health insurance coverage in the decade before Medicare eligibility.

HRS research conducted by economists at the University of Pennsylvania, for example, indicated that while pre-retirement savings appears to be substantial ($340,000 for the median household), the present value of Social security wealth accounts for a large share of average total wealth (about $145,000). To meet a post-retirement income target of 70–80 percent, an average couple in their mid-50's would have to save $10,700 each year until age 65. This would translate into a savings rate of 23 percent, far greater than typical savings rates in the U.S. Persons in poor health are even less well prepared for retirement, with only $5,000 in pension wealth and $80,000 in Social Security wealth.

Asset and Health Dynamics of the Oldest-Old (AHEAD)

The companion survey of HRS, AHEAD, provides unique information on the dynamics of health, economic resources and health care services. The study provides badly needed data on the costs and burdens of chronic disease and the consequences for the extended family. Over time, AHEAD will provide data on how families redistribute their resources across generations, and how these flows interact with public sector transfers. Such a study is needed to make informed policy decisions on initiatives such as Medicare/Medicaid coverage for community long term care and health care reform.

AHEAD data and research are also providing insights into the complex family support system which sustains persons of all ages in times of need. Despite the stereotype of the "greedy geezer", analyses of AHEAD indicate that financial transfers overwhelmingly flow from parents to children, even when the parents are very old. These transfers disproportionately target adult children in the family who are relatively less well off than their siblings. Adult children who benefit from such transfers, however, are far more likely to provide personal care as their parents become disabled in later life.

HRS and AHEAD data also provide opportunities to track the cognitive performance of older persons as they age. In the total non-institutionalized population age 70 and over, about 5 percent have severe cognitive impairment and another 48 percent score below average. As expected, persons of low education and limited financial resources are more likely to evidence cognitive deficits in middle and late life.

Finally, PAA and APC are interested in and support the current efforts to strengthen the Federal Forum on Aging Related Statistics that coordinates data

across federal agencies. The forum is an example of NIA's interest in supporting NIH's innovative endeavor of streamlining federal databases and making data accessible to researchers from varied fields.

PAA and APC would like to thank you for the opportunity to present this information. Demographic data and research are important tools for policymakers that can both save public funds and promote more informed decision-making. If this vital research is to continue producing relevant and timely information, adequate funding and Congressional support are needed. The Population Association of America and the Association Population Centers support a 15 percent increase in funding to sustain the momentum of demographic research in the National Institutes of Health as part of the broadly based support to double the the funding for the NIH over the next 5 years.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR CANCER RESEARCH

The American Association for Cancer Research (AACR) is the premier professional association of basic, clinical, and translational cancer researchers. Its membership of 14,000 scientists is committed to the understanding, diagnosis, treatment, and prevention of cancer. The AACR's international headquarters is located in Philadelphia, Pennsylvania. We appreciate the opportunity to present a statement to the Committee Record on behalf of increased funding for cancer research.

Cancer is a disease which devastates its victims. Based upon today's incidence rates, 42 percent of Americans alive today will develop cancer, and over 20 percent will die from this disease. Cancer's daily death toll is 1,550 people, one person every 57 seconds. To fully grasp the concept of cancer's death rate, imagine five Boeing 747 jumbo jets crashing EVERY DAY for a year, and that will equal the number of Americans who die annually from cancer—over 565,000. In fact, the number of Americans who die of cancer each year exceeds all U.S. combat deaths in all of the wars in this century. This should shock the public into action; it should be our wake-up call. The ravages of cancer are not acceptable to those of us on the front lines of the fight against cancer, and especially not to its victims and their family members. Indeed, the human toll of this disease is painful to quantify.

The AACR fully supports the priorities and programs articulated in the fiscal year 1999 ByPass Budget of the National Cancer Institute (NCI). We call on Congress to consider seriously the priorities outlined in this important document and to provide a funding level for the NCI of $3.1 billion in fiscal year 1999 in order to fully fund these opportunities for accelerated progress against cancer. The 1999 ByPass Budget specifically outlines the following:

—Extraordinary Opportunities in cancer genetics; preclinical models of cancer; imaging technologies; developmental diagnostics; and,

—NCI Challenges which are to dramatically increase access to and participate in clinical trials; enhance investigator-initiated research; support and encourage clinical investigators; restructure and expand NCI Cancer Centers; develop state of the art informatics systems; study emerging trends; and increase training and education.

These priorities are vitally important to our national effort to conquer cancer. We need your support for the fiscal year 1999 ByPass Budget to fully pursue them.

The importance of investments in scientific research has recently gained momentum in Washington. The AACR is encouraged by the Clinton Administration's proposal to increase cancer research spending at the National Institutes of Health (NIH) by 65 percent over the next 5 years. The increase requested for the NCI is part of an unprecedented $1.5 billion increase requested by the Administration for NIH in fiscal year 1999. The AACR also supports Senator Specter's Resolution to increase the funds provided to the NIH this fiscal year by $2 billion—in increase of 14.65 percent—and the AACR asks that you support the spirit of this Resolution as the Budget Committee develops its priorities, and when the Subcommittee marks up its fiscal year 1999 bill. We recognize that, in order for you to support our request for increasing the appropriations to the NCI, it is important for you to understand what has been accomplished and what needs to be done now. The research community is committed to working with your colleagues in the leadership and on the Budget Committee to realize the potential advances outlined in the ByPass Budget.

Twenty-five years ago the nation enacted legislation to wage a war against cancer, funding a program of research, establishing a network of cancer centers, and developing national programs to improve diagnosis and treatment. The progress made to date has been extraordinary. We have established a research infrastructure that is the envy of the world. We have attracted the best and brightest minds to the prob-

lem of cancer, and we have made research discoveries that we did not even think were possible when the National Cancer Act was passed.

Our investment in basic research has produced unprecedented opportunities for advances on all fronts in our national war to eradicate cancer. These victories in basic research have often been difficult. Cancer has proven to be an extraordinarily complex disease that presents an ongoing challenge beyond what cancer researchers imagined 25 years ago. Significant progress has been made that has allowed us to cure certain types of cancer and has led to the development of new diagnostic, therapeutic, and prevention strategies for several other cancers. Researchers are beginning to understand the causes of cancer and also to make inroads into cancer control through new methods of screening high-risk individuals and advances in diagnosis. The battle against cancer is now turning in our favor, as demonstrated by the recent announcement of a decline in mortality of several cancers.

Regrettably, at this, our moment of greatest potential, we are losing momentum. Just when the possibility of eliminating cancer has never been greater, we are facing a critical loss of national will. We are also faced by the grim reality that we have not fought the "war" that the public believes has been waged against cancer. In fact, there has only been a skirmish.

A crisis of unprecedented proportions has developed and continues to threaten continued progress in research. The AACR believes that this crisis will block further progress and could even reverse past advances. While we recognize the extraordinary support that Congress has provided to cancer research in the past, our resources to combat this disease remain inadequate. The legacy of years of inadequate investment in basic, translational, and clinical cancer research—combined with the devastating limitations that managed care has recently placed on clinical research and the declining support for young investigators is strangling the pace of discovery in basic research findings into effective treatments for people diagnosed with cancer.

The cost of care for persons with cancer exceeds $107 billion annually, yet the research budget proposed for cancer is $2.7 billion. No company in America would stay in business with an investment in research and development that is less than 3 percent. No general would ever go to war with such limited resources. What a terrible irony that $61 billion was spent on the Gulf War and that a sizable proportion of that money was invested to ensure that no more than 10,000 Americans lost their lives, yet America tolerates 560,000 deaths from cancer every year. One person dies of cancer every 57 seconds. That is why the following points are so important.

Research grants.—When the National Cancer Act was signed into law, 40 percent of approved research grants were funded. This year, less than 23 percent of approved research grants will be funded. We reject far more approved research than we fund. As a result we can only afford to fund research that is a sure thing. We are unable to fund the innovative, high risk science which may have the greatest potential to significantly advance the frontiers of science or to fund the plodding, methodical, and costly translational studies needed to bring exciting advances out of the lab and to the cancer patient.

Clinical research.—We believe that current levels of NCI funding remain an impediment to a fulsome clinical research enterprise. Certainly Congress has provided tremendous support for the NCI in the context of significant fiscal pressures over the past several years. However, we are gravely concerned about the shortage of physician-scientists dedicated to clinical and translational research as well as those who are unable to obtain research funding and are leaving careers in academic medicine to pursue careers in clinical practice. Further, a predictable, sustainable budget that reflects a level of funding adequate to pursue the existing tremendous research opportunities is vital if we are to achieve the appropriate balance of basic and clinical research.

Clinical trials offer the most promising therapy for cancers which have not been cured through standard therapies (commonly referred to by patients as "slash, burn, and poison"). Yet, we accept the fact that our nation's programs of clinical research, which have led in the development of curative treatments for a few cancers, are stagnant or declining. It is unacceptable that only 2 percent of adults with cancer are actually treated on clinical trials that test the best available therapies.

Translational research.—Translational research is less an entity unto itself than part of a process that may lead ultimately to general human applications. It is the bridge between progress in the laboratory and new methods of prevention, diagnosis, and treatment, and it is thus essential to progress against cancer. Translational research has been responsible for some of the most stunning clinical successes of this century, including the description of molecular mechanisms of colon cancer, the engineering of effective AIDS treatments, and the development of new treatments to reduce the side effects of chemotherapy, to name just a few. Unfortunately, however, as scientific complexity increases and, conversely, the complexity

and often the toxicity of modern treatments escalate, the valley between those discovering molecular relationships in the laboratory and those who translate those discoveries into meaningful treatments has widened and deepened. The path to discovery is multifaceted, dependent on continuous productive interactions between basic and clinical scientists both in the laboratory and at the patient's bedside. Yet this highly innovative approach to research does not compete well in the current environment due to funding constraints.

Tobacco.—For decades, the tobacco industry has denied that smoking is the major causative factor in lung and numerous other cancers. Researchers have now demonstrated that active tobacco smokers have a greater than 15-fold increase in their risk for lung cancer as compared with nonsmokers. Tobacco use is the cause of more than 160,000 cancer deaths each year in the United States and is responsible for about 30 percent of all cancer deaths annually. In addition, smoking and other tobacco use have been determined to be a major cause of many other serious illnesses and deaths each year, most notably from cancers of the pharynx, larynx, esophagus, oral cavity, pancreas, bladder, and other organs.

What has not been known until very recently is that former smokers continue to be at high risk for lung cancer for many years after smoking cessation because they carry long-term DNA damage in their lungs. It has been found that these DNA changes are associated with the development of cancer, that the changes persist for many years after smoking cessation, and that the lung tissue may never return to its normal state. Since DNA damage is absent from the lungs of lifetime nonsmokers, this leads to the conclusion that the changes observed in former smokers are directly related to their previous smoking. Those who have stopped smoking can remain from 1.5 to 4 times more likely than nonsmokers to develop lung cancer. In fact, over half of all lung cancers in the United States occur in former smokers.

Therefore, the AACR urges Congress to ensure that public health funds obtained from the tobacco settlement are provided to the National Institutes of Health (NIH) and the NCI for additional peer-reviewed, national cancer research programs of the highest quality. It is highly appropriate that funds be provided from the tobacco settlement for research, and it is essential that the amount be consistent with the scope and gravity of this epidemic.

Specifically, these new resources should be directed to the NCI in support of important priorities in basic, clinical, and translational cancer research. We ask Congress to ensure that the resources provided through the tobacco settlement will: markedly increase the cancer research budget of the NCI; underwrite the cost of participation in clinical research trials ontobacco-related cancers that will contribute to curative or preventive new therapies; and supplement, not supplant, current resources provided to the NIH and NCI.

To exploit the research opportunities that exist and to build on the promising developments of just the last few years alone, the AACR believes that a real War on Cancer is now warranted. Congressional support of cancer research has been considerable over the past 25 years but far too much work remains to be done and our casualty rate is far too high. Without your leadership in support of our National Cancer Program, we will not be able to do our job at both laboratories and hospitals across the country.

Thank you for the opportunity to present this statement.

PREPARED STATEMENT OF THE COLLEGE ON PROBLEMS OF DRUG DEPENDENCE

The College on Problems of Drug Dependence (CPDD) is the nation's longest standing organization that addresses the problems of drug dependence and drug abuse and the leading scientific society in the field of drug dependence research. CPDD urges the Committee's continued support of the National Institutes of Health (NIH), the National Institute on Drug Abuse (NIDA), and the Substance Abuse and Mental Health Services Administration (SAMHSA).

National Institute on Drug Abuse

CPDD sincerely appreciates the almost unparalleled 7.6 percent increase provided to NIDA in this fiscal year 1998, and urges that the Committee increase this base in fiscal year 1999 to continue the ongoing peer-reviewed research funded by NIDA. Such research is essential for continuing to further our understanding of the etiology, prevention, and effective treatment of substance abuse problems.

Despite these recent increased appropriations and encouraging decreases in certain categories of drug use, drug use trends remain mixed and more research is necessary to provide effective interventions to reduce overall illicit drug use and achieve the goals of the National Drug Control Strategy to reduce the prevalence

by 50 percent by 2007. The 1997 Monitoring the Future Study found that illicit drug use among younger adolescents appears to be slowing. However, there were again increases in the fraction of twelfth graders using drugs such as marijuana, cocaine, LSD and cigarettes, and this population's increased use of drugs is particularly alarming as they are poised at the brink of exiting our school system, a means to monitoring youth drug use. As the Institute of Medicine recommended in their 1996 Report on Opportunities in Drug Abuse Research, there is a need for additional monitoring to provide more information about escalation to abuse and dependence. The inconsistencies in drug use patterns command our attention and demand that we continue to expand our efforts to identify and disseminate science-based information on the perils of drug use and the most effective practices for prevention and treatment. We must remember that drug abuse in fact is a preventable behavior.

It is important for Congress to recognize that research is essential to produce significant and long lasting changes in drug use. We have learned a lot about the causes of drug abuse, and our latest treatment advances reflect some of that knowledge. Some of what leads people to abuse drugs is inherited from their parents. Availability of drugs is also an important determinant of initial use, but much less important to addicts, though even they turn out to be somewhat sensitive to the price. We are also learning about the increased risk for drug abuse which children with certain types of psychiatric and behavioral problems have and the need to treat these disorders if we are going to prevent substance abuse problems. Something happens to the brains of people who use drugs regularly. We are learning a tremendous amount about this, taking advantage of some of the latest techniques from the neuroscience. Indeed, drug abuse research is coming of age. NIDA was established just over two decades ago. It funds virtually all drug abuse research in the United States and more than 85 percent of all drug abuse research worldwide, few other governments support this research. There is little pharmaceutical industry research in this area and few foundations support any basic research, since the market potential for medications in this area is fairly modest. As the Institute of Medicine Reported in 1996, "The field is on the threshold of significant advances and a sustained research effort will strengthen society's capacity to reduce drug abuse and ameliorate its adverse consequences."

Great strides are being made in understanding the causes of drug abuse, and the scientific community relies upon NIDA's support. Researchers now have the ability to show in detail what drugs are actually doing to and in the brain—we can actually visualize as it happens where drugs are binding in the brain. We have discovered the specific brain circuits involved in drug use and we are beginning to unveil the changes in activity patterns in these circuits during the processes of addiction and withdrawal. Researchers have identified the genes for the receptor sites for practically every illegal substance. The next step is to develop new addiction medications. NIDA devotes about $80 million of its budget to drug development. We rely upon this investment which is not complemented by industry sponsored research; NIDA's support in this arena is unparalleled and therefore all the more vital.

To build upon these and other past breakthroughs and to exploit the opportunities that exist, CPDD recommends additional research in the following broad areas:

Increase basic drug abuse research.—The explosion of new information in neuropharmacology and other neuroscience has the potential to provide major breakthroughs in drug abuse treatment and prevention. We need to better understand the role of heredity and other sources of individual differences as risk factors for drug abuse. We also need additional information on the harmful effects of acute and chronic exposure to drugs of abuse.

Maintain and expand our knowledge of trends in drug abuse practices.—Continued support is needed for large scale surveys that provide an informed public policy. We need better access to existing data, which would facilitate our understanding of drug abuse and its consequences; we need improved methods for obtaining scientific data on newly emerging drug abuse problems; and we need to support more long-term prospective studies on risk factors that co-vary with the development of drug abuse problems. Large scare ethnographic studies funded by NIDA play a vital role here. These should lead to the development of more comprehensive and systematic surveillance of young adult populations.

Increase research on the effectiveness of drug abuse prevention and public policy initiatives aimed at reducing demand for drugs among our youth.—The DARE program has been widely implemented despite adverse evaluations in part because there is a dearth of alternative programs that have moved beyond the initial pilot evaluation stage. Effective prevention programs must be based upon an understanding of the causes of drug experimentation and even more critically on the escalation from drug experimentation to drug abuse and dependence. Additional research is

also needed on prevention programs for high risk youth and on the general patterns of termination and escalation.

Increase research on the development of new drug abuse treatments and on the evaluation of existing treatments.—Improved treatment strategies that combine the use of medications and behavioral treatments are needed, as are new treatments that reduce relapse. We also need additional evaluations of treatment effectiveness for special populations. For example, what are the best ways to link drug abuse treatment to the criminal justice system, in order to take maximal advantage of the leverage of criminal sanctions?

Increase research on the relationship between drug abuse and the transmission of AIDS.—We need a better understanding of how drugs alter the likelihood of risk-taking behaviors that increase HIV transmission since an estimated one-third of HIV cases result from drug use, and we need improved treatments targeted to the abuse of drugs by persons who are infected with the HIV virus. Further, we need a better understanding of the effects of drug abuse on the immune system in order to better prevent and treat AIDS and its associated opportunistic infections.

The College on Problems of Drug Dependence also recognizes the public interest in reducing tobacco use, particularly youth tobacco use, as evidenced by the June 1997 draft global tobacco settlement. Despite Congressional attention to this issue as articulated by the profusion of tobacco related bills pending action by the 105th Congress, we recognize the political roadblocks to codification of a tobacco settlement. If the public health goals of both the June 20, 1997 proposal and the pending legislation are to be attained, a vast amount of research must be done, and should be funded as soon as is possible. Your support for NIDA is vital as current prevention and treatment programs are not powerful enough to assure that, even with adequate program funding, the goal of reducing adolescent cigarette use rates by 60 percent within ten years can be achieved or that most current smokers will quit within the next decade. Modern research has provided a much better understanding of the etiology and health consequences of tobacco consumption, and the basic biological effects of nicotine and other tobacco ingredients. The combination of large scale epidemiological studies and laboratory research have been critical in creating a public awareness of the dangers of smoking and have indeed forced the tobacco companies to accept their responsibility for a public health disaster of the first order. Health scientists have established that tobacco use can become addictive; this is the cornerstone to the proposed regulation of nicotine by the FDA and an aspect of the settlement strongly supported by the College. NIDA funding provided the initial research leading to the development of nicotine replacement medication and NIDA and other NIH institutes have supported research that has improved the efficacy of gums and patches. These advances have enabled large numbers of Americans to give up tobacco smoking.

Whatever else emerges from the settlement discussions, two scientific aims are important:

We need to develop better tools for monitoring use patterns so we have adequate and reliable performance measures for compliance with or achievement of the goals of any settlement. The Monitoring the Future and Youth Risk Behavior surveys are not sufficient on their own. This matter needs to be studied carefully.

FDA and NIDA should work together to help develop the scientific foundation, now lacking, for even thinking about regulating nicotine in tobacco products.

Substance Abuse and Mental Health Services Administration

The research dissemination and training programs of the Substance Abuse and Mental Health Services Administration (SAMHSA) are also an essential part of our national drug abuse treatment and prevention strategy. We are especially supportive of the training and demonstration grant functions of the Center for Substance Abuse Treatment (CSAT) and the Center for Substance Abuse Prevention (CSAP).

Much more needs to be done to determine the feasibility of implementing NIDA-supported research advances in community prevention and treatment programs. There is a tremendous gap between what is known about prevention and treatment effectiveness and what is actually being done in many communities. We need more research on the barriers to the implementation of effective new treatment and prevention programs. The treatments and the prevention strategies that emerge from NIDA-supported research require community-based programs to evaluate their effectiveness. CSAT and CSAP demonstration grants provide a critical link between research and its implementation. Furthermore, SAMHSA training programs are needed to insure that counselors, educators, and other professionals have the necessary knowledge of new advances in the field. The large cut that these programs experienced in fiscal year 1996 have severely curtailed their effectiveness.

Funding request

CPDD urges the committee to provide the highest possible increase for NIDA in fiscal year 1999. Further, the College on Problems of Drug Dependence supports the Ad Hoc Group for Medical Research Funding's proposal to increase funding for the NIH overall by 15 percent this fiscal year, as the first step toward doubling the budget over five years. Similarly, we encourage continued support for SAMHSA, and request that adequate support be provided for the demonstration and training programs supported by CSAT and CSAP.

Thank you for the opportunity to submit the views of the College on Drug Dependence.

PREPARED STATEMENT OF THE RESEARCH SOCIETY ON ALCOHOLISM

FISCAL YEAR 1999 RECOMMENDATION

The Research Society on Alcoholism (RSA) is a professional research society whose 1,200 members conduct basic, clinical research and psychosocial research on alcoholism and alcohol abuse.

Alcoholism is a tragedy that touches all Americans. One in ten Americans will suffer from alcoholism or alcohol abuse, but their drinking will impact on the family, the community, and society as a whole. Alcohol is a factor in 50 percent of all homicides, 40 percent of motor vehicle fatalities, 30 percent of all suicides, and 30 percent of all accidental deaths. Every American is affected and all Americans bear the cost. Children exposed to alcohol during pregnancy are afflicted with birth defects and mental retardation. Nearly 7 million children live with an alcoholic parent, often in chaotic homes where they suffer physical and emotional abuse.

Alcoholism and alcohol abuse cost the nation nearly $100 billion annually. One tenth of this pays for treatment; the rest is the cost of lost productivity, accidents, violence, and premature death. Prohibition did not solve the problem of alcoholism, and current therapy is simply not good enough. Only research holds the promise of effective prevention and treatment of alcoholism; however, alcohol research is woefully underfunded. The National Institute on Alcohol Abuse and Alcoholism (NIAAA) funds over 90 percent of all alcohol research conducted in the United States. For 1998, the budget of the National Institute on Alcohol Abuse and Alcoholism (NIAAA) is $227 million. We are committing to alcohol research only $2 for every $1,000 lost from alcohol abuse and alcoholism and only $12 for every affected individual. In 1997, NIAAA could fund just 25 percent of all grant applications; the comparable figure for NIH is 29 percent.

The inability to fund outstanding grant applications comes at a time of unprecedented opportunities in alcohol research. In the next few months you will learn of important new findings on the genetics of alcoholism. For the first time scientists, funded by the NIAAA Collaborative Study on the Genetics of Alcoholism (COGA), have identified discrete regions of the human genome that contribute to the heritability of alcoholism. This first success in the genetic mapping of a complex biological and behavioral disorder must be followed by an expensive, labor intensive effort to pinpoint and identify the genes of interest. Armed with this knowledge, health providers may one day be able to identify individuals at risk and target these individuals for prevention programs. Genetic research will accelerate the rational design of drugs to treat alcoholism and may improve our understanding of the interaction between heredity and environment in the development of alcoholism.

One of the most promising areas of alcohol research is in the field of neuroscience. The development of effective drug therapies for alcoholism requires an improved understanding of how alcohol changes brain function to produce craving, loss of control, tolerance, and the alcohol withdrawal syndrome. Naltrexone, a drug that blocks the brain's natural opiates, reduces craving for alcohol and helps maintain abstinence. Ongoing clinical trials will help determine which patients benefit most from naltrexone and how the drug can best be used. Another promising drug, acomprosate, has proven effective in European trials and is undergoing evaluation in the United States.

One of the most tragic consequences of alcoholism is Fetal Alcohol Syndrome (FAS). FAS is a permanent condition characterized by mental retardation, small size, behavioral problems, and specific facial abnormalities. Fetal alcohol syndrome is the most common, preventable cause of mental retardation in the United States. If pregnant women did not drink, there would be no fetal alcohol syndrome; however, as we know too well, many individuals cannot stop drinking, even when the consequences are well known.

From animal studies we have learned that alcohol's effects during pregnancy depend on the timing, pattern, and amount of alcohol intake. Magnetic resonance imaging, brain wave recordings, and behavioral assessments of affected children have identified specific changes in brain structure and function that result from heavy prenatal alcohol exposure. A better understanding of alcohol's effects on the developing brain will allow us to better target the treatment of exposed people. This research will allow those with FAS to maximize their potential and circumvent some of their deficits. An improved understanding of risk factors will help us target and prevent FAS.

Recent research has shown that even light drinking during pregnancy can interrupt normal development. Consequently, most researchers recommend that pregnant women abstain totally from drinking. In the laboratory, it has been shown that low doses of alcohol can interfere with normal processes of development. We are optimistic that understanding the mechanism by which alcohol disrupts fetal development will lead to effective strategies for reducing deficiencies associated with FAS.

Alcohol abuse and alcoholism are devastating problems of national importance. Alcohol research has now reached a critical juncture, and the scientific opportunities are numerous. With the continued support of this Committee and the Congress, we are optimistic that the next few years will bring significant advances in alcohol research.

Recommendation.—The Research Society on Alcoholism requests that funding for NIAAA in fiscal year 1999 be increased by $34 million (15 percent) to $261 million. This request balances the impact of the disease and the abundance of research opportunities.

PREPARED STATEMENT OF HEATHER R. FRASER, CYSTIC FIBROSIS FOUNDATION

On behalf of the 30,000 children and young adults with cystic fibrosis (CF) in this country, the Cystic Fibrosis Foundation (CFF) is pleased to submit public witness testimony to support fiscal year 1999 appropriations for the National Institutes of Health (NIH). The Foundation applauds this Subcommittee for the CF-specific language included in the Appropriations Bill last year. Your collective vote of confidence in the NIH served to make the future for me, and many other individuals with this disease, much brighter.

Four years ago, my health status was in a radical state of decline. On average, I was hospitalized every four months to receive IV antibiotic therapy to treat recurrent respiratory tract infections. Then Pulmozyme®, the first new drug in 30 years designed specifically to CF patients, was made available in January of 1994. I felt as though I had been given a new lease on life. Suddenly, I had more energy to do what I was used to doing, and even some "reserve" to do things I had previously been unable to accomplish. And yet, for all its merit, Pulmozyme® could only do so much to protect my lungs from the nemesis of chronic infection. Over time, my respiratory status resumed its downward course. Oral antibiotics continued to become less and less effective. And just when it seemed as though I was losing my battle against this insidious disease, the aerosolized antibiotic TOBI—was approved.

Over dramatization? No way—over exuberance, coupled with the utmost gratitude for the scientists and clinicians that helped bring this drug to fruition. They gave me and many others with this disease the greatest gift in the world—time. I know TOBI—is not a "forever fix" and am sobered by the reality that my pulmonary status will again one day require stronger therapeutic intervention. What will my armament be then? This year, you will hear testimony punctuating the need for increased federal funding for many entities, including medical research. It is my hope that one day there is not going to be the need for extensive deliberation—not because an infinite pool of resources has suddenly become available, but because a portion of that need has been eliminated. For individuals with CF, this will occur the day researchers correct CF cells permanently. The Foundation is counting on your continued investment to write the final chapter of our success story.

The CFF urges the House of Representatives to concur with the President's recommendation to double the funding for the NIH over the next five years and, as a down payment on this commitment, provide an increase of at least 15 percent in fiscal year 1999. We request your continued support of the full spectrum of research—basic, clinical, and translational—sponsored by the National Institute on Diabetes, Digestive, and Kidney Disorders (NIDDK) and the National Heart, Lung, and Blood Institute (NHLBI). The resource capacity of these two Institutes is of paramount importance to propel the frontiers of CF research into the new millennium. The CFF believes this funding level is justifiable and an appropriate allocation, given the clear and pressing research opportunities which exist.

Current success rates enable funding of a little more than two out of every 10 approved research grants.—In essence, this biomedical research policy allows us to open only two out of every ten "doors of opportunity." This is unconscionable, and one cannot help to wonder what progress could emerge and how many lives would be saved if all these meritorious projects were funded. At a minimum, 50 percent of the approved research projects must be funded by the NIH in fiscal year 1999.

Support to General Clinical Research Centers (GCRC) to translate research progress from test tube to bedside must be increased.—These 74 centers are specifically equipped to provide support to clinically trained investigators to examine disease conditions and to access new therapies. With the advent of managed care and the increasing constraints that academic medical centers are operating under, more and more ancillary costs for clinical trials are being passed on to GCRCs. GCRCs are pivotal to the identification of new therapies to treat and eventually cure CF and other life-threatening diseases. For viability to be sustained, there needs to be an increase of at least 15 percent provided to these centers.

The NIH has a clear and important role in translational and clinical research. The Foundation recently completed a study looking at the therapeutic benefits of high-dose levels of ibuprofen to reduce airway inflammation in the prophylactic management of CF. This is a study that the private sector would not have undertaken due to the modest rate of return, but nonetheless was an important clinical research initiative to the CF population. The NIH must have the resources to explore these types of clinical research opportunities.

Further, we ask this Subcommittee to direct the NIDDK, NHLBI, and the National Center for Research Resources to develop key mechanisms to assure rapid translation of basic research into new therapeutic interventions. While we applaud the acquisition of new knowledge through current programs at the NIH, a mechanism must be created to nurture clinical research. Creative development of an institutional infrastructure, similar to that already in existence to support basic research in teaching institutions, should be created to support and monitor ongoing clinical trial investigations.

The NIH has an incredible track record in developing basic research and understanding of cellular processes. However, it is naive to think that the pharmaceutical and biotechnology industries are prepared to lead the effort to take this newly acquired knowledge and follow it through to clinical evaluation. Unless there is a permanent mechanism in place, drug development opportunities, along with many lives, will be lost.

Clinical research training opportunities must be expanded.—A cadre of well-trained clinical investigators is vital to further progress made in the research laboratory, and to translate that progress to patients. Never before has the need been more urgent and the number of candidates so small. Additional initiatives in post-doctoral training, support for new and young investigators, and programs to facilitate the mentoring of these individuals are pressing priorities. Simply, we stand to lose the next generation of clinical scientists. There must be opportunities present to allow clinical scientists to obtain support for their research endeavors. This must occur at both the program level, with funding provided for clinical research, and the review level, to ensure that individuals familiar with clinical research will review and evaluate clinical research proposals.

The current research infrastructure must also be updated to maximize the progress of an expanded national research enterprise.—Research management costs must be adjusted proportionately to support intramural program operations and provide training for scientific program officers. Institutional research capacity is critical and thus, enhanced resources must also be directed toward extramural facilities, state-of-the-art equipment and instrumentation, and computer technologies.

The NIH and Cystic Fibrosis Foundation continue to work together to provide a base for leadership in this country that is unparalleled. As a Foundation, we understand current funding constraints and that federal programs—regardless of their merit—have been placed in competitive positions. However at the end of a day, when I retreat home exhausted, in part due to work but more worn out as a result of dealing with the daily rigors that are the unwelcome hallmark of this disease, that cavalier acceptance is just not justified.

Sadly, there will be casualties at the close of this debate. Nevertheless, we must work together to ensure that the human cost is kept to a minimum. This can clearly be accomplished by a guaranteed investment in biomedical research. On behalf of the Cystic Fibrosis Foundation, I close by urging this Congress to seriously consider the President's recommendation to double NIH appropriations over five years, and provide a 15 percent increase in funding for fiscal year 1999.

Thank you.

PREPARED STATEMENT OF THE JOINT COUNCIL OF ALLERGY, ASTHMA, AND IMMUNOLOGY

The Joint Council of Allergy, Asthma, and Immunology (JCAAI) is pleased to submit public witness testimony in support of fiscal year 1999 appropriations for allergy, asthma and immunology programs supported by the National Institutes of Health (NIH). These programs are supported primarily in two of the NIH Institutes: the National Institute of Allergy and Infectious Diseases (NIAID) and the National Heart, Lung and Blood Institute (NHLBI). The JCAAI is a professional, nonprofit organization comprised of the American Academy of Allergy, Asthma and Immunology and the American College of Allergy, Asthma and Immunology, and it consists of more than 4,000 researchers and clinicians who are dedicated to providing care for the 50 million Americans who suffer from allergic or immune disorders.

First, we would like to express our appreciation for the tremendous support this Committee has provided to the NIH during the past two years. We know that you have been faced with tremendous budget constraints and we sincerely appreciate your making the NIH a priority for funding increases. We urge your continued leadership for NIH and for the allergy, asthma, and immunology programs supported by the NIAID and the NHLBI. Further, we are supportive of the legislative proposals that have been proffered to double the budget of the NIH, such as Sen. Res. 170. We have encouraged our members to educate their elected officials to obtain the broadest base of support in Congress to achieve this important objective.

The JCAAI supports the Ad Hoc Group for Medical Research Funding proposal to double the budget for the National Institutes of Health over the next five years. Our national research enterprise is poised to make significant strides if the necessary funds are available to pursue the scientific opportunities, preserve the integrity of the research infrastructure, and adequately support and mentor physician investigators as the health care marketplace dramatically alters.

Asthma and allergic diseases

Allergic diseases, including asthma, afflict twenty percent of Americans. The term allergic diseases describes a myriad of medical conditions such as asthma, allergic rhinitis, atopic dermatitis, food allergies and anaphylaxis. Asthma alone afflicts 14 million Americans, the prevalence is on the increase and the associated economic costs of this disease are quite significant.

In 1999, the NIAID will renew the Asthma, Allergic and Immunologic Diseases Cooperative Research Centers. These centers provide an infrastructure and collaborative environment to study the complex problems associated with asthma, allergic and immunologic diseases. An important object of these research centers is to integrate basic and clinical research initiatives to improve the diagnosis, prevention, and treatment of these diseases.

Allergic diseases.—Allergic rhinitis (hay fever) alone affects as many as 35 million Americans and is the most common chronic disease. Food allergies and food intolerances are also a major problem. Eight percent of children under six years of age experience food intolerances.

Allergic reactions can be minor, such as reactions to pollen, mold, or dust, or they can be severe and potentially fatal, such as reactions to penicillin, insect venom, or allergic reactions to food. As many as 2 million people experience severe reactions to insect stings every year, and many experts believe life-threatening allergic reactions to food may occur just as frequently.

Research.—A variety of therapies have been developed to treat allergies, but researchers still do not fully understand certain critical aspects of allergies. When an allergic individual comes in contact with an allergen (the allergy-provoking substance), immune system cells produce an unusual type of antibody known as immunoglobulin E, or IgE, which starts the allergic reaction. Researchers are attempting how to comprehend how the immune system recognizes an allergen, why some people have a more severe reaction to an allergen, and what factors, including environmental and genetic, might be responsible for allergic diseases.

NIAID-supported researchers are among the leaders in the study of allergies. For example, they identified the IgE antibody and they have identified the structure of the IgE receptor. By blocking the activity of the receptor, researchers may be able to provide a new therapy for allergies. NIAID-supported research has also demonstrated that DNA vaccines are capable of stimulating an immune response that may diminish allergy symptoms. Such vaccines could provide a more potent, consistent, and convenient treatment than the current therapy of allergy shots.

Asthma.—Asthma is a major health problem. As many as 15 million people in the U.S. have asthma, and the number of people with self-reported asthma increased from 10.4 million in 1990 to 14.6 million in 1994. The actual number of asthmatics

may be higher—asthma is sometimes difficult to diagnose because it often resembles other respiratory problems such as emphysema. Children have a 41 percent higher prevalence of asthma than that of the general population and an estimated 4.8 million children under age 18 have asthma. It is the most common chronic disease in children, and it is one of the most common reasons for missed days of school (parents are also forced to miss work to care for their asthmatic child). Recent research has identified that very early exposure to asthma-causing agents, in infancy or prior to birth, may determine a child's chance of developing asthma. Further, clinical and epidemiological data suggest that viral respiratory infections and exposure to allergens are the most important risk factor early in life that may lead to wheezing, prolonged alterations in airway function and chronic asthma.

Asthma is approximately 25 percent more prevalent in African-American children than in Caucasian children, and asthmatic African-American children experience more severe disability and have more frequent hospitalizations than their Caucasian counterparts. In 1993, African-Americans aged 5 to 14 were four times more likely to die from asthma than Caucasians, and those aged 0 to 4 were six times more likely to die from asthma. Asthma is also more prevalent in African-American adults than in Caucasians. Their hospitalization rate in 1992 was 400 percent higher than for Caucasians and their age-adjusted mortality rate was 300 percent higher. The reason for the higher incidence is uncertain; however, lack of access to proper medical care is related to the poor outcomes.

Direct and indirect costs for asthma were an estimated $6.2 billion in 1990, 43 percent of which was associated with emergency room use, hospitalization, and death. Inpatient hospital costs represented the largest single direct expenditure, totalling $1.6 billion, and emergency room use cost another $295 million. In 1993, asthma was the first-listed diagnosis in 468,000 hospital admissions and asthmatic children under age 15 experienced 159,000 hospitalizations (asthma is the leading cause of hospitalization of children).

Research.—Asthma varies from person to person—symptoms range from mild to severe. While there is not a cure for asthma, it can be controlled with proper measures, including medications, learning to manage episodes, and learning to identify and avoid what triggers an episode. Triggers include controlling irritants in the air—90 percent of children with asthma and half of adult asthmatics have allergies; avoiding excess physical exertion; and managing emotions. Medications consist of anti-allergy drugs, corticosteroids, and bronchodilators.

In August 1996, researchers (Weinstein, et. al.) published a report that summarized the results of a study to examine the economic impact of a short-term inpatient hospitalization program for children with severe asthma. The program, based in part on programs developed by NHLBI, significantly reduced inpatient and emergency care days for the subsequent 4 years of follow-up. In a study of 59 children, the median of 7 inpatient days the year prior to rehabilitation was reduced to zero (0) days during each of the following 4 years. Emergency care visits were reduced from 4 in the year prior to rehabilitation to zero. The year before rehabilitation, medication charges as a percentage of medical charges was 9 percent; by the third and fourth years of follow-up they were 45 percent of total medical charges.

The NIAID National Cooperative Inner-City Asthma Study has designed new strategies to reduce asthma morbidity and mortality. The first phase of the study looked at over 1,500 children and discovered factors including high levels of indoor allergen, especially cockroach allergen (the leading asthma-producing material that children were exposed to), high levels of smoking among family members; and exposure to high levels of nitrogen dioxide. In the second phase, 1,000 high risk children and their families were assisted by a nurse practitioner in managing the child's condition and instituting environmental controls. This resulted in significant reduction in asthma symptoms, improved school attendance, and a 30 percent decrease in asthma-related hospitalizations and unscheduled physician and emergency room visits. The NIAID has continued the study to disseminate the results.

Research enterprise

The JCAAI is gravely concerned about the integrity of our research environment. In July, the Journal of the American Medical Association published an article entitled "Preventing the Extinction of the Clinical Research Ecosystem." The authors made recommendations regarding the appropriate steps that must be undertaken if we are to preserve our national capacity to translate research findings from the laboratory to the patient. A strong cadre of highly trained, expert clinical scientists are key to achieving that objective, and this cadre of experts is presently threatened. It is imperative that we move forward in addressing the following: establishing a process for setting broad goals in clinical research; provide additional resources for clinical research; restructure the approach to clinical research training to maximize

the entry of talent into the field of clinical research; and, provide resources for clinical investigators to maintain clinical, laboratory and patient care responsibilities.

We recommend that Congress consider these priorities as you develop your funding recommendations for fiscal year 1999.

Summary

Allergies and asthma are serious health problems, affecting millions of Americans in both acute and chronic forms. Through research supported by the NHLBI and NIAID, researchers and clinicians have learned much about how to diagnose and treat these diseases, but much more remains to be done. The JCAAI requests a 9 percent increase for the NIH in fiscal year 1998 to explore some of the exciting research opportunities that exist in these areas.

Thank you for your consideration of our request.

PREPARED STATEMENT OF THE NATIONAL COALITION FOR CANCER RESEARCH

On behalf of the 22 organizations of the NCCR, a coalition of organizations dedicated to cancer research, please accept this testimony to the Committee record. The NCCR is comprised of 22 not-for-profit lay and professional organizations devoted to the pursuit of cancer research. These organizations which consist of 55,000 cancer researchers, nurses, physicians, and health care workers; tens of thousands of cancer survivors and their families; 40,000 children with cancer and their families; 82 cancer hospitals and cancer centers across the country; and more than 2 million volunteers, and on their behalf I appear before you today in support of the National Institutes of Health and the National Cancer Institute.

Let me say at the outset, that the NCCR recognizes the commitment this Subcommittee has demonstrated in the past to cancer research. We understand the real funding constraints you are under and have already written to the House and Senate Budget and Appropriations Committee Chairmen asking that they enable you to provide the NCI with an increase by first increasing the health function of the Congressional Budget and subsequently by providing your Subcommittee with the increased allocation necessary to achieve this goal.

The indispensable and long-term value of investing in scientific research today has recently gained momentum here in Washington. The NCCR is encouraged by the Clinton administration's initiative to increase cancer research spending at the National Institutes of Health by 65 percent over the next five years. The increase requested for the NCI is part of an unprecedented $1.5 billion increase requested by the Administration for NIH in fiscal year 1999. The NCCR commends Senator Specter's Resolution to increase the funds provided to the NIH this fiscal year by $2 billion, an increase of 14.65 percent, and asks that you support the spirit of this Resolution when the Subcommittee marks up its fiscal year 1999 bill. But for you to consider our request for increasing the appropriation to the National Cancer Institute, it is important that you understand what has been accomplished, and what needs to be done now, and that we as a community are committed to working with your colleagues in the leadership and on the Budget Committee to realize these gains.

In 1972, we conceptualized a great endeavor—a War on Cancer. President Nixon pledged the full resources of our government to conquer this dreaded disease. Unfortunately, only limited research funding trickled out and we supported only a small skirmish. This was not an American-style effort to go to the moon, to crack the atom, or to fight a Gulf War. This effort could only support a few thousand investigators to fight only a limited engagement. Still, six cancers were essentially cured, including those that primarily affect young people, such as leukemia and testicular cancer. However, today the big six cancer killers (lung, breast, colon, prostate, bladder, and brain cancer) continue to ravage the bodies of their victims. Now, 25 years after this country pledged to go to war against cancer, one half of all American men and one third of all American women will be struck by the horror of being diagnosed with cancer during their lifetimes. One fourth of all Americans will one day die from this most unpleasant and painful disease. During the approximately 2½ hour period that this hearing will be in session, 161 Americans will die from cancer, compared with 11 who will die from AIDS and 7 who will be murdered. It would take 5 Boeing 747 jumbo jets crashing EVERY DAY for a year to equal the half million Americans who die each year from cancer. This number of cancer deaths per year exceeds all U.S. combat deaths in all of the wars in this century. This carnage on our people from cancer must stop, and it can, with research funded by this Congress. In the past, medical research has conquered the pain of amputation, surgery, and dental procedures, as well as infectious diseases such as typhoid fever and pneumonia; one

day, medical research will conquer AIDS and cancer. We have already proved that we can cure six cancers through medical research; now it is time to eradicate the other major cancers. However, this will be slow to be realized at the current funding levels, when only one penny out of every ten tax dollars is spent to research this tremendously costly disease. If we doubled our effort on cancer today, it would still cost less than one-third of our space effort and only one-twentieth of the cost of the Gulf War. Taxpayers are far more endangered by a "berserk" cancer cell than by a bullet from an enemy, and they want to be protected against cancer.

No one can predict when or where cures or successful prevention strategies will originate, but all agree that they will only come from funding a large base of investigations. At present the cancer research cup is three-fourths empty. Of every 100 grants approved for funding after critical peer review, less than 25 will receive funding. The other 75 unfunded projects represent lost opportunity, valuable time in the fight against cancer, and more lives lost.

Health care costs for cancer exceed $107 billion annually and over half of the medical costs of cancer are due to the treatment of breast, lung and prostate cancers. However, we only invest about 2 percent of cancer's health care costs in research to find effective prevention measures, treatments and cures for cancer. The federal research budget for cancer is only $2.5 billion. Even the National Cancer Institute's Bypass Budget request of $3.191 billion, which the NCCR supports, is a conservative investment when contrasted with the $100 billion that will be expended in care.

It is the NCCR's central conviction that the solution to the complex problems surrounding cancer—the reduction in morbidity, mortality, and the high costs of medical care—will come in a stepwise manner from the generation of new knowledge through research. The NCCR entreats you to exert your leadership and provided an unparalleled increase to the NCI, full funding of the NCI's Bypass Budget request of $3.191 billion, a 25 percent increase over the current fiscal year. At a minimum, the NCCR supports the Ad Hoc Group for Medical Research Funding's proposal that you increase funding for the NIH overall by 15 percent this fiscal year, as the first step toward doubling the budget over five years. As stated, the NCCR supports the Congressional leadership demonstrated in Senate Resolution 170 to increase by 14.65 percent the budget of the National Institutes of Health, including the National Cancer Institute, and we appreciate the President's request to increase funding for cancer research across the Institutes by 10 percent and the NCI by 9 percent. But to equitably fund science, we must rely upon the expert recommendations of scientists, and the Bypass Budget request of the NCI is just that—an estimate by experts in the field of research of how much is needed to "sustain current successful efforts—and increase our capacity to reduce suffering due to cancer." We urge your leadership in eradicating cancer by appropriating a 25 percent increase to the NCI which will enable the following:

—fund a greater proportion of fully approved investigator initiated research applications;
—support of the priorities identified in the By Pass Budget, including cancer genetics; preclinical models of cancer; detection technologies; developmental diagnostics;
—strengthened efforts in translational research to more rapidly translate research progress from the bench to the bedside;
—initiatives to incentivize the research collaboration and establish a strong partnership between the government, academia and industry to maximize our research investment;
—expand cancer prevention and detection research programs;
—strengthen our current efforts in cancer survivorship research to ensure the highest quality of life after cancer; and
—added support, such as the NCI scholars program, to enable outstanding new investigators in basic, clinical or population-based biomedical research to establish independent research careers.

In order to be most effective, funding must be provided in a manner that enhances creativity—encourages the risk taking inherent in innovation. Research funding must be sustained, also, in order to prevent the detrimental interruptions to investigators and research institutions that have long lasting effects.

Progress depends in no small extent on insuring the continued and sustained renewal of the intellectual resources at the heart of the creative process—the dedicated, highly educated, creative scientists that determine the success of these endeavors. Regrettably, there is a trend of the "brightest and best minds" in our country away from the biomedical sciences into careers that appear more challenging and a more important part of our nation's future. This trend must be reversed.

Maintaining the integrity of a group of top-notch academic health centers and strengthening a related group of research universities is also of vital importance. Clearly, these institutions provide the "environment" and many of the resources necessary to a full spectrum of investigational and educational programs. The preservation and enhancement of these centers of excellence is an urgent matter of public concern. The chaotic conditions of the "health care marketplace" and the increasingly severe financial constraints that result, are forcing academic health centers devoted to research and education toward the "endangered species" designation. A strong and vital national research program is one of the cornerstones of preservation for these centers.

Patient-centered research merits careful attention because it is the link between laboratory discoveries and the advances in prevention, diagnosis and treatment that improve medical practice and the quality of life of patients and their families. This transition is currently threatened by the practices of various health care management companies and by the payment practices of insurers. Further, the nominal support provided by the NCI to this endeavor—less than 10 percent of NCI's total budget—is causing many talented clinical researchers to go the way of the dinosaur as they are forced away from research and into clinical practice.

Experimental therapy administered under the aegis of a fully approved clinical trial is often the best therapy available to many patients. It is important that patients not be denied access to clinical trials. The knowledge gained through these studies is important to progress, and the treatment offered may represent the best alternative available to the patient participants. Yet insuring participation in clinical trials due to charges in the health care marketplace is compromising our capacity to translate research from the laboratory bench to the bedside. The NCCR supports the spirit of the Administration's proposed demonstration to provide medical coverage for Medicare beneficiaries who participate in federally-approved cancer clinical research trials, but urges this Subcommittee to fund this demonstration in this fiscal year, rather than rely upon funding this program with receipts garnered through tobacco legislation which has not, and which may not, be enacted.

Public support for medical research has never been articulated as clearly than over the past year. Since the June 20, 1997 global tobacco settlement, there has been a groundswell of public support to enhance our medical research enterprise to combat the effects of tobacco use. Congressional efforts to attend to this issue are evidenced by the profusion of tobacco related bills pending action by the 105th Congress. However, the NCCR recognizes the political roadblocks to Congressional codification of a tobacco settlement and urges this Subcommittee to meet the public health goals of both the June 20, 1997 global tobacco proposal and the pending legislation to fund research as soon as is possible by providing a substantial increase to the National Cancer Institute this year. Your support for the NIH is vital as current prevention and treatment programs are not powerful enough nor swift enough to protect the 160,000 people who will die this year in the United States from cancers caused by smoking. Prevention and cessation programs alone cannot stop the threat of cancer, for recent studies have found that even former smokers continue to be at high risk for lung cancer for many years after smoking cessation because they carry long-term DNA damage in their lungs. Scientists have recently learned that these DNA changes are associated with the development of cancer, that the changes persist for many years after smoking cessation, and the lung tissue may never return to its normal state. Since DNA damage is absent from the lungs of lifetime nonsmokers, this confirms that the changes observed in former smokers are directly related to their previous smoking. Those who have stopped smoking can remain from 1.5 to 4 times more likely than nonsmokers to develop lung cancer. In fact, over half of all lung cancers in the United States today occur in former smokers. These new findings have alarming public health consequences for both current and former smokers. Bolstering the budget of the NCI will enable scientists to conduct important studies into the long-term adverse effects of tobacco carcinogens in proportion to the devastation caused by tobacco-induced cancers on our public health. Specifically, additional funding would support research to identify the specific DNA alterations associated with smoking and their role in lung cancer. Further investigations must be conducted to unravel the pathways and the timing of events leading to cancer. It is important to increase our understanding of the carcinogenic effects of tobacco, of how these malignant lesions can be treated most effectively after diagnosis, and of how these cancers can be prevented. Epidemiological studies are also required to increase our knowledge base of statistical trends in cancer to guide early detection efforts and facilitate the control of cancer. We cannot wait for broad Congressional codification of last summer's tobacco settlement, the time is now to stop the effects of tobacco use and this Subcommittee can do so by increasing the budget of the National Cancer Institute.

We hope that you will find the rationale on which we base our recommendations to focus on cancer research compelling, and that you will be able to direct funds to cancer research to open the doors for researchers to find new methods for the prevention and treatment of cancer. Thank you for the Subcommittee for this opportunity to present this statement.

PREPARED STATEMENT OF THE FDA-NIH COUNCIL

Mr. Chairman, Members of the Committee, thank you for the opportunity to present a statement to the Committee as you deliberate funding priorities for fiscal year 1998. The FDA-NIH Council appreciates the opportunity to submit testimony concerning the importance of a sustainable, predictable funding base for the National Institutes of Health (NIH). In past years, this Committee has been vitally important in addressing the funding needs of the NIH, and the research community is grateful for your support of the crown jewel of the Public Health Service.

The FDA-NIH Council is a coalition of 24 organizations comprised of patient advocates, academic scientists, health professionals, and medical research-based corporations. These partners in the process of medical discovery and innovation have come together to seek common ground in addressing the complex challenges the Food and Drug Administration (FDA) and the National Institutes of Health face.

There is an intricate process of medical discovery and innovation that relies on the relationship of inter-dependent partners—government, academia, biomedical research industries, foundations, health professionals and consumers. Medical research and innovation seek to improve health and the quality of life by finding ways to cure and prevent disease. Breakthroughs come from a process of innovation, each advance building upon the one that preceded it. From research in academic, government and industry laboratories, and from the accumulation of clinical experience in managing disease, our information about the mechanisms of disease and innovation in medicine are continually developed. As a representative of industry, I welcome the opportunity to address the unique contributions of the government in this regard as it is the national commitment to the NIH which lays the foundation of our ability to bring research discoveries from the laboratory to the consumer.

All of the partners in the process of medical discovery are interdependent, each contributes a piece to the puzzle. The success of our national enterprise is not possible without each piece being vibrant and strong. A healthy partnership between government, industry, academia and non-profit foundations is critical to maintain the U.S. position as the world leader in medical research and innovation. Most importantly, the millions of Americans afflicted with catastrophic, acute and chronic diseases are the REAL beneficiaries of this partnership.

The NIH is the primary funding source for basic research through universities and independent research institutions throughout the country. The NIH also plays a critical role in support of clinical and translational research. NIH-supported research has led to major advances in the understanding and treatment of various diseases and disabilities. NIH-funded researchers are now at the forefront of the global effort to build upon these findings and develop new, more effective treatment regimens. Success against disease will only be possible with a strengthened national research effort. Therefore, continued support of the NIH is critical to the vitality of our medical research enterprise.

At the present time, our national support of the NIH is less than 3 percent of our national health care costs. In essence the NIH is investing less than 3 percent of the national costs of illness in research efforts to find effective treatments and preventatives. From a business standpoint, it is logical that this investment paradigm should change as there is no health-care or science-based corporation in America who could sustain an effective operation with a 3 percent investment in innovation. To that end, the FDA-NIH Council is pleased to support proposals put forward in the House and the Senate in the last Session of the 105th Congress to double the NIH budget over the next five years. We commit to this Committee that FDA-NIH Council will work to support to realize these proposals.

Industry presently devotes approximately 20 percent of its U.S. sales to research and development. This investment, which is greater than that of the NIH, is directed toward efforts quite different from the NIH but complimentary and equally essential. Our basic research efforts are more targeted and our clinical research initiatives are more expansive and directed toward the end product. Industry does not, and cannot, devote resources to the discovery of new knowledge at the basic, fundamental level that the NIH supports. Industry's responsibility in this partnership is the maturation of scientific knowledge and the translation of research discoveries from the bench to the bedside through targeted basic and applied research efforts.

In addition, industry is closely aligned with academic medicine in centers throughout the country. Through the collaborations with universities and independent research institutes industry is involved in developing new technologies, setting standards for adopting and disseminating technologies, and supporting cutting-edge applied research to bring innovation to the marketplace.

Throughout modern history, there have been revolutions in medicine that have saved millions of lives. The development of antibiotics, vaccines, and proven surgical techniques have constituted the revolutions of the past. We are now on the threshold of the next great revolution in modern medicine, gene therapy. Each time researchers discover a gene, they open the door to a new therapy or cure. Today, when we talk about our medical research enterprise, we speak from the standpoint of great success and even greater opportunities.

Treatments for people with chronic diseases have stemmed from medical research and innovation.—medications control a variety of chronic diseases such as hypertension, high cholesterol and diabetes; asthmatics regularly participate in competitive sports where prior to innovative therapies they were subject to frightening breathing attacks; angina and shortness of breath associated with cardiac disease are now effectively managed through the use of medication; and the hope of gene therapy offers great potential to help persons with genetic diseases as well as for others suffering with a variety of chronic conditions.

People with life threatening and chronic diseases look to medical research and innovation for the promise and hope of a cure.—Today, we have drugs to cure testicular cancer, childhood leukemia, and Hodgkin's disease, and to prevent strokes or permanent heart damage from heart attacks. Research efforts are starting the long process to develop and validate diagnostic markers and other tests to diagnose disease or determine the state of a chronic disease before it is evidenced (or worsens) in order to offer treatments prior to prevent disease progression.

Medical research and innovation have prevailed to improve the quality of life for millions of us, but the challenge remains to find answers for millions more who face disease and disability.—Our current armament of therapeutic options consist of many half-way technologies and it is imperative that we push forward to develop effective cures and treatment for may of the hardest diseases that continue to confront us—cancer, heart disease, strokes, Alzheimer's disease, Parkinson's disease, multiple sclerosis, cystic fibrosis and others.

The health of our nation is dependent upon a strong national commitment to medical research. The research opportunities have never been greater, or more exciting. Further, our leadership in the international arena in medical research and innovation is at a critical juncture, due to our international competitors' expansion of their research investment over the past two decades. Today, Japan and Germany devote a greater percent of their GNP to research and development than the U.S. does. This is a warning sign which should be taken seriously as we contemplate national priorities.

As we enter the new millennium, we have attracted some of the best scientific minds to our national enterprise, and initiated ground-breaking programs that have already yielded critical knowledge, and improved patient care and quality of life. However, we are confronted with the extraordinary challenge of how to maintain the integrity of our research efforts, and rapidly and cost-effectively translate that research and development into use by health professionals and consumers, in both the public and private sectors.

Budget Request

We must position our national research efforts by providing a sustainable, predictable funding base for the National Institutes of Health augmented by new resources in order to pursue the extraordinary research opportunities which await. In that regard, the FDA-NIH Council urges Congress to enact a plan that will provide for a doubling of the NIH budget over the next five years. The FDA-NIH Council supports the vision articulated in H.R. 83, S.R. 15 and S. 124 which call for a doubling of the budget for the NIH in response to our declining commitment to research, based on the proportion of GNP invested in research, over the past 30 years. As a starting point, the FDA-NIH Council recommends an increase of at least 15 percent for fiscal year 1999 as the first step in achieving this goal.

While many other witnesses, representing a broad cross section of disease and research organizations will draw very compelling cases to devote these additional resources to specific disease research, members of the FDA-NIH Council would like to draw your attention to the capacity of our national research enterprise and its long term health as it undergoes the transformation required to meet the challenges of the next millennium. These needs will be critical to effectively undertake the many important research priorities that my colleagues will bring to your attention.

Translation of new knowledge into clinical practice.—A balance in our federally-funded research program requires that we adequately support the translation of research from the test tube to the patient. As new knowledge is discovered, it is vitally important for the NIH to support early patient-oriented research to determine the application of laboratory advances to persons with disease. This early research must validate test tube observations prior to the maturation and full exploitation of advances in the marketplace. Further, training and educational programs require adequate resources to ensure that the next generation of clinical scientists is in place to continue the rapid translation of research from the bench to the bedside.

Integrity of the peer review system.—As mentioned earlier in this statement, the United States has a national research capacity and track record that is unparalleled throughout the world. One of the core components of this research capacity is the integrity of our peer review system. Unlike many other agencies of the government, such as the Department of Defense, the peer review system of the NIH is critically important to the allocation of resources by the NIH. In fact, peer review is the cornerstone to insure that stewardship of the American taxpayer's contribution to this important initiative and direct our investment to the areas of greatest scientific opportunity.

Resources for Research Support.—As the research capacity of the NIH expands, the expertise and staffing necessary to appropriately oversee that enterprise must be available. Management support budgets of the NIH must be carefully evaluated to ensure scientific program staff are in place to effectively guide an expanding research effort.

Research Infrastructure.—The sophistication of our research initiatives requires an ever-increasing sophistication in our physical plants support our national research efforts. Research facilities, equipment and instrumentation, and animal facilities must be state-of-the-art in order to fully exploit our research potential.

The FDA-NIH Council recognizes that the Members of this great body have a very tough job in terms of weighing the available resources and numerous worthy federal programs. We recognize the tough choices that you have ahead of you. And, we recognize and are extremely grateful for the support that this Committee has provided to the NIH in the past. However, we also believe that the functions of the NIH are vital to our economy and the health and welfare of our citizens. Health must be one of our nation's top priorities, for a wealthy and economically sound country is predicated on the health and well being of its citizens.

Thank you for the opportunity to present a statement before the Committee today. We appreciate your support of this agency and look forward to working with you in the coming months.

The members of the FDA/NIH Council are: the A-T's Children Project, Candlelighters Childhood Cancer Foundation, Allergy and Asthma Network—Mothers of Asthmatics, Inc., Alliance for Aging Research, Schering-Plough Corporation, Albert B. Sabin Vaccine Foundation, American Medical Association, Merck & Co., Inc, Pfizer, Inc., American Veterinary Medical Association, Joint Council of Allergy, Asthma and Immunology, American Society of Tropical Medicine and Hygiene, Allergan Inc., American Academy of Pediatrics, National Multiple Sclerosis Society, Monsanto Company, Arthritis Foundation, Glaxo Wellcome, Inc., American Social Health Association, Cystic Fibrosis Foundation, Bristol-Myers Squibb Company, American Association for Cancer Research, National Depressive and Manic-Depressive Association, Society of Toxicology, Research Society on Alcoholism, Theracom, Parkinson's Action Network, and the Autism Society of America.

PREPARED STATEMENT OF THE AMERICAN SOCIETY OF TROPICAL MEDICINE AND HYGIENE

The American Society of Tropical Medicine and Hygiene (ASTMH) appreciates the opportunity to submit written testimony concerning fiscal year 1999 funding for the National Institutes of Health and the Centers for Disease Control and Prevention.

The ASTMH, founded in 1903, is a professional society of approximately 3,500 researchers and practitioners who are dedicated to addressing the growing global threat of tropical infectious diseases. ASTMH members are involved in all areas of tropical disease research such as identifying biochemical and genetic factors that disrupt parasite development within mosquito vectors in order to develop novel control strategies for malaria and lymphatic filariasis.

A strong U.S. research agenda relating to infectious diseases is critical at this time when the ease of travel and openness of trade exposes the world's population, including U.S. citizens, to new and re-emerging infectious disease agents. Last year it was Cyclospora, a parasite that found its way across the border by way of Guate-

malan raspberries and lettuce. And we are all now familiar with the re-emergence of tuberculosis and emergence of new diseases such as Hantavirus within the U.S. In total, 30 new human pathogens have been recognized in the last 25 years. It also is evident in our new world economy that, in addition to humanitarian reasons, investments that help ensure healthy populations in developing countries benefit the world's population as a whole. We must continue to be vigilant in our efforts to control and eradicate infectious diseases through prevention, treatment, and continued surveillance. As we approach the 21st century, it is time to protect our national security and declare war on malaria, diarrheal disease, and the myriad of other infections caused by viral, bacterial, fungal and parasitic disease agents.

National Institutes of Health

ASTMH thanks the Committee for your strong support for medical research funding. We are particularly pleased with the 7.1 percent increase Congress provided to the NIH for fiscal year 1998, and by your continuing commitment to provide funding that will sustain our research infrastructure in the years to come.

National Institute of Allergy and Infectious Diseases

The NIH's tropical disease research program is funded primarily by the National Institute of Allergy and Infectious Diseases (NIAID) and there are several issues relating to NIAID's research efforts that we would like to highlight.

Infrastructure Issues.—From fiscal year 1993 through fiscal year 1998, NIAID has received significant funding increases for both the intramural and extramural programs of about 40 percent. Unfortunately, the research management and support (RMS) budget, which provides administrative support for the extramural program, has increased by only 0.1 percent during this same time period. This resulted from a 7.5 percent cut in fiscal year 1996 that reduced the RMS budget back to fiscal year 1993 levels. The ASTMH is concerned that we are not providing the Institute with the resources necessary to manage our important infectious disease programs. We are not arguing for large increases, but are merely calling for responsible stewardship of the extramural programs and grants to ensure that we are effectively meeting the goals and objectives of our research programs.

Malaria.—Globally, infectious diseases are the leading cause of morbidity and mortality, accounting for 1–3 times the mortality and morbidity resulting from heart disease, cancer and stroke combined. Of these infectious diseases, malaria continues to be the most devastating with a World Health Organization estimate of nearly 500 million clinical cases and 2–3 million deaths annually—and the majority of these deaths are African children under the age of 5. But even in the U.S., over 1,000 cases of malaria are reported every year, with local transmission being documented by the Center for Disease Control and Prevention (CDC) in California, Florida, New Jersey, New York, Texas, Michigan and Georgia. The Society applauds NIH Director Dr. Harold Varmus and NIAID Director Dr. Anthony Fauci for their leadership at home and abroad in advancing the international collaborative research project, the Multilateral Initiative on Malaria, and for implementing NIAID's Research Plan for Malaria Vaccine Development. Malaria is a complex disease and its control will require a significant research effort in vaccine development as well as other research areas. We are pleased that NIH recognizes this and is willing to commit significant resources towards solving this problem. We urge the Committee to be supportive as well.

International Tropical Disease Research Programs.—NIAID's support for international tropical disease research is critical for advancement of our scientific understanding of emerging, re-emerging and other tropical diseases. Through these programs, U.S. researchers are able to collaborate with their colleagues worldwide in efforts that are absolutely mandatory to gain research expertise in areas endemic for tropical infectious diseases. Two programs in particular have been critical in these efforts and the ASTMH urges the committee to not only continue these programs, but to increase support for these important projects. They are:

International Collaborations in Infectious Disease Research.—An international research program to support collaboration between U.S. scientists and foreign research institutions for work in countries where tropical diseases are endemic, and

Tropical Disease Research Units.—A domestic grant program that promotes the application of modern biomedical technologies to the development of preclinical evaluation of new vaccines, therapies, or vector control methods for tropical parasitic diseases.

Fogarty International Center

NIH also supports emerging infectious disease research and training through the Fogarty International Center (FIC). Recently FIC initiated, in concert with the NIAID, an International Training Program in Emerging Infectious Disease whereby

U.S. universities provide training for scientists from regions of the world where some of the most important emerging and re-emerging diseases are endemic. This program promises to provide a mechanism to transfer the most recent scientific advancements and technologies to endemic areas and consequently increase our understanding of the biology, epidemiology and methods for control of emerging pathogens.

The ASTMH is encouraged by the initial awards made to thirteen U.S. universities and encourages the FIC to re-issue its Request for Applications and expand funding opportunities to additional research universities. This is an extremely worthwhile program that is essential if we are to expand overseas training and capitalize on recent scientific advancements. We urge the Committee to provide sufficient funds to allow the FIC to fund as many meritorious awards as possible.

Centers for Disease Control and Prevention

The ASTMH appreciates the Committee's support for funding increases in fiscal year 1998 for the CDC's infectious diseases program. We are especially pleased with the increases over fiscal year 1997 levels for the National Center for Infectious Diseases emerging and re-emerging infectious diseases program.

Emerging Infectious Diseases Strategic Plan.—As you know, CDC is in the process of developing its second five-year plan to address emerging infectious disease threats through the year 2002. This report, titled "Addressing Emerging Infectious Disease Threats II: Entering the 21st Century" soon will be released and will provide the blueprint for the CDC's activities to combat emerging infectious diseases in collaboration with other U.S. agencies and international organizations. These efforts are critical in establishing priorities relating to surveillance, applied research, training, and disease prevention and control of emerging infectious diseases in the coming years.

Infrastructure Needs.—The Society strongly urges the Committee to support CDC's infrastructure needs that include the need for new laboratory space to handle all of the pathogens that are being examined by CDC scientists in Atlanta. With recent outbreaks of new infectious diseases, such as avian influenza in Hong Kong, CDC laboratories are at capacity and they have had to reduce existing pathogen research to make room for the new pathogens. Space limitations that require the cessation of surveillance or research activities on one pathogen to make room for work on a new disease agent is a dangerous situation that must be addressed.

Conclusion

As the 20th Century comes to a close we must change our vision of U.S. national security. We are at war, but this time infectious diseases are our enemy. Infectious disease agents have no respect for political borders, and social or economic status do little to ensure safety from new diseases or those re-emerging as a consequence of drug resistance or other causes. To be prepared for a battle that undoubtedly will intensify, we must have adequate surveillance systems and modern infrastructure, coupled with scientific expertise in both basic and clinical research, if we are to develop the tools necessary to rapidly respond to, and control, the threats posed by infectious diseases.

The ASTMH greatly appreciates your support of these activities. We urge you to continue your efforts to double the NIH budget over the next five years and towards this end we request a 15 percent increase for the NIH budget in fiscal year 1999. We also request that the Committee provide a $15 million increase for the CDC's emerging infectious diseases activities.

Thank you for providing us with this opportunity to express our appreciation and concerns.

PREPARED STATEMENT OF THE SOCIETY OF TOXICOLOGY

The Society of Toxicology (SOT) is pleased to have this opportunity to submit written testimony in support of fiscal year 1999 funding for the National Institutes of Health (NIH), and specifically for the National Institute of Environmental Health Sciences (NIEHS).

The Society of Toxicology (SOT) is a professional organization that brings together over 4,000 toxicologists in academia, industry, and government. A major goal of SOT is to promote the use of good science in regulatory decisions. With scientific data as our guide, we can use sound judgment in addressing numerous environmental issues. In particular, we work closely with the National Institute of Environmental Health Sciences (NIEHS) in addressing research related to environmental risk.

Research Opportunities

Members of the Society of Toxicology strongly believe that our investment in biomedical research must be increased and sustained over the long-term if we are going to take advantage of the many exciting research opportunities which exist in the area of environmental health sciences. We are appreciative of the outstanding research efforts of NIEHS and are supportive of the research priorities identified by NIEHS Director Dr. Kenneth Olden.

Research supported by NIEHS is helping us to better understand how our environment affects our health. Research is being conducted to study the effects of air pollution such as ozone, particulate matter, and acid aerosols on our respiratory health. NIEHS supported research has shown the harmful health effects of lead especially in children, leading to the reduction of many sources of environmental lead. Researchers are now expanding their efforts to better understand why some people are more susceptible to environmental exposures than others. The Environmental Genome Project will further explore these questions. Finally, NIEHS under the auspices of the National Toxicology Program are making progress in developing new and innovative transgenic animal models to more efficiently test the toxicity of chemicals. This increased efficiency will allow for more chemicals to be tested more quickly.

SOT also supports the research NIEHS is conducting on the potential adverse effects of endocrine disruptors. Endocrine disruptors are compounds in our environment which may have an affect on thyroid and reproductive function and development. The Society believes that additional research is needed to determine the nature and the extent to which this is a human health problem.

Superfund Basic Research Program

One program we would like to highlight is the Superfund Basic Research Program. This program is administered by NIEHS although it is funded through a pass through from the Environmental Protection Agency (EPA) to NIEHS. The Superfund Basic Research Program is the only scientific research program focused on health and cleanup issues for Superfund hazardous waste sites. It represents an important collaboration between EPA and NIEHS to ensure that environmental cleanup decisions are based on sound environmental health science.

The Superfund Hazardous Substances Basic Research Program supports university and medical school research to understand the public health consequences of local hazardous waste sites, as well as to develop better methods for remediation. Currently, there are 18 programs at 70 universities involving more than 1,000 scientists. It is important to note that this is the only university-based research program that brings together biomedical and engineering scientists to provide the science base needed for making accurate assessments of human health risks and developing cost-effective cleanup technologies.

The primary purpose of SBRP is to provide the scientific basis needed to make accurate assessments of the human health risks at hazardous waste sites. In addition, research data is used to determine which contaminated sites must be cleaned up first, to what extent clean up is needed, and how best to clean up contaminated sites in the most cost-effective manner. Research projects include basic research on the potential chemical effects on cancers, such as breast and prostate, birth defects, and other environmental health-related diseases.

Communities near hazardous waste sites want to know if hazardous chemicals are reaching their water or air supplies. They want to know if low levels of these contaminants affect their health and their children's health. They want it cleaned up. Our universities are responding with technology driven research efforts which are results-oriented and economically feasible, and are scientifically credible with the public. This is only possible because of the research effort funded through the Superfund Basic Research Program and administered by NIEHS.

Funding Request

The Society of Toxicology strongly supports efforts to double funding for the NIH over five years. To accomplish this, we urge the Committee to provide a 15 percent increase for both the NIH and NIEHS in fiscal year 1999. NIEHS is particularly deserving of this increase given the enormous role they are playing to expand our understanding of how the environment potentially affects our health. Whether it is exploring asthma incidence in children, testing the toxicity of chemicals, or better understanding the genetics underlying environmental risk factors, NIEHS supported research is leading the way in bridging the gap between public policy and environmental health science.

Thank you for considering our request. We look forward to working with you in the future as you determine the Committee's funding priorities.

PREPARED STATEMENT OF THE NATIONAL DEPPRESSIVE AND MANIC-DEPRESSIVE ASSOCIATION

The National Depressive and Manic-Depressive Association (National DMDA) is pleased to have this opportunity to submit written testimony in support of fiscal year 1999 funding for mental health research supported by the National Institutes of Health (NIH) and the National Institute of Mental Health (NIMH).

With more than 275 support groups in nearly every state, National DMDA is the nation's largest patient-run, illness specific organization committed to advocating for research toward the elimination of depressive illnesses, educating patients, professionals and the public about the nature and management of depression and manic-depression as treatable medical diseases, fostering self-help, eliminating discrimination and stigma, and improving access to care. National DMDA was founded in 1986 and is headquartered in Chicago, Illinois. A distinguished scientific advisory board of more than 65 members reviews all materials published by National DMDA, and provides critical and timely advice on important research opportunities and treatment breakthroughs. This Board includes the leading researchers and clinicians in the field of depressive disorders.

The Impact of Depressive Illness

More than 18.4 million American suffer from depression every year. An additional 2.3 million people suffer from manic-depression or bipolar disorder. Women are more than twice as likely as men to experience major depression. Depression is the leading cause of suicide in America—the financial burden of which is over $10 billion a year. Two out of three people with mood disorders do not get proper treatment because their symptoms are not recognized, are misdiagnosed, or due to the stigma associated with mental illness, are blamed on personal weakness.

According to a recent study by the World Health Organization (WHO), the World Bank, and the Harvard School of Public Health, unipolar major depression is the first-ranked leading cause of disability in the world today and bipolar disorder is the seventh-ranked cause of disability. The economic cost of depressive illnesses in the United States is estimated to be almost $44 billion per year in direct and indirect costs including absenteeism, mortality, and lost productivity. We cannot continue to ignore the seriousness of mental illness but must instead must focus our research resources on better understanding depressive illnesses, improving treatments, and seeking a cure.

Our investment in research into new treatments for depression and manic-depression has paid off in many ways. For example, more than $145 billion has been saved since 1970 as a result of the development of lithium treatment for manic-depression—almost $6 billion per year. A study supported by the NIMH showed that intervention to prevent depression in the workplace resulted in $1,314 per person in increased Federal and state taxes generated over a two and a half year period, with a cost of only $286 per person. Finally, it has been shown that every $1 spent on treatment of depressive disorders yields between $3 and $9 in net economic return on employment earnings.

Research Progress

Due to research supported by the NIMH over the past five years, we have seen the development of new, more effective medications for both depression and manic-depression. As a result of a recent clinical trial, we now know that the anti-depressant fluoxetine (Prozac) is effective in children, although it is not as effective as it is in adults—an issue which requires more study. Also, we have a better understanding of depressive illnesses and are learning more about their impact on cardiovascular disease and stroke. The comorbidity of depression and alcohol and tobacco use is also becoming more clear. Research indicates that treating only addiction and not depression leads to failure and relapse and vice versa. The comorbidity of diabetes and depression has also been documented. Unfortunately, we still have a long way to go before we are able to fully understand and treat depressive disorders.

St. John's Wort.—National DMDA is pleased that NIMH is working with the Office of Alternative Medicine (OAM) at NIH to conduct a study of the effectiveness of Hypericum perforatum, or St. John's wort, in patients with mild to moderate depression. Many consumers are trying St. John's wort as an alternative to prescription anti-depressants based on anecdotal experiences and promising results reported from European studies. These short-term studies indicate that St. John's wort may be beneficial in treating mild to moderate depression with fewer side effects than prescription anti-depressants. It does not appear, however, to be as effective in treating severe depression or manic-depression. Unfortunately, hundreds of thousands consumers are using St. John's wort with little scientifically proven information about how the herb works, what dose is appropriate, its effectiveness, potential

dangerous interactions with other prescription drugs, or the long-term effects of use. The three year OAM/NIMH study will provide us with the database necessary to answer some of these questions. National DMDA is playing an active role on the advisory committee overseeing this research effort and hopes that consumers will soon have the information they need to make an informed decision about the use of St. John's wort.

Bipolar Disorder.—We are also encouraged by NIMH's increased focus on bipolar disorder. Research in this area has been seriously underfunded in recent years. In fact, in 1996, NIMH spent only $33 million on bipolar research—less than 5 percent of its total budget. Given the WHO study cited above which shows that bipolar disorder is the seventh-ranked cause of disability in the world today, we must expand our research efforts as they relate to manic-depression. National DMDA hopes that NIMH will move quickly to implement clinical trials on the effectiveness of new antipsychotic or anticonvulsant medications such as gabapentin or lamotragive for treating bipolar disorder. In addition, research efforts must focus on the early detection and management of bipolar disorder in clinical care settings. Finally, additional research is needed on the diagnosis and treatment of manic-depression in children and adolescents.

Research Opportunities

National DMDA recently surveyed its scientific advisory board members to get their views on where NIMH's basic and clinical research efforts should be focused. In conducting this exercise we wanted to get the views of the leading scientists who are working on depressive and manic-depressive illnesses to ensure that the research we are supporting is the most current and productive. It is not surprising that the vast majority responded that the area of genetics is the most ripe for basic research. Current research indicates that there is a genetic predisposition to manic-depression. We urge NIMH to pursue this research aggressively by continuing research studies of individuals with manic-depression and their family members. Other factors to examine in relation to genetics include the role stress and the environment play in triggering depressive episodes.

Other important research opportunities include research to better characterize subtypes of depression; find treatments with fewer side effects and understand the psychopharmacology of current antidepressants; functional brain imaging and neurobiological research to understand the role gender plays in the predisposition to depressive illnesses; and studies to close the gap between what is known about treating depressive illnesses and what is practiced particularly in managed care settings. These are just a few of the research areas where great opportunities exist. Even as the Decade of the Brain comes to a close, we have only begun to scratch the surface in our understanding of brain function and mental illness. Given the advances in neurobiology in recent years, we should designate the 21st Century the "Century of the Brain" and pursue and aggressive mental health research agenda.

Funding Request

Of course, an aggressive research agenda requires sustained funding. While we recognize the Subcommittee's current budgetary constraints, National DMDA supports efforts to double the budget for the NIH and NIMH over the next five years. This will allow us to take full advantage of the many exciting mental health research opportunities that exist today. We urge the Committee to provide a 15 percent increase for NIH and NIMH in fiscal year 1999 as the first step to doubling the budget.

We appreciate your past support for medical research funding and look forward to working with you in the future to ensure the long-term sustainability of our mental health research infrastructure.

Prepared Statement of the National Alliance for Eye and Vision Research

The National Alliance for Eye and Vision Research (NAEVR), an umbrella organization of twenty-eight professional, lay advocacy and industry organizations dedicated to eye and vision research, appreciates the opportunity to submit testimony in support of funding for the National Institutes of Health and the National Eye Institute.

The National Alliance would like to begin by thanking Committee members for your commitment to medical research supported by the National Institutes of Health and the National Eye Institute. Without this support we would not be on the verge of many new discoveries in eye and vision research. We are beginning to reap the benefits of our investment due to the amazing advances in basic and clinical science, but more and more we are forced to prioritize what areas of research

to support because we do not have the funding available to fund all of the opportunities that exist. This is true in all areas of vision research, and in the public and private sectors.

Priority Setting

We understand that the Committee has expressed concern about how the NIH sets its research priorities and has asked NIH to pay careful attention to the economic and societal impact of diseases when planning its research funding allocations. It is our hope that you will closely examine the process that the National Eye Institute (NEI) has used since it was created nearly twenty-five years ago to involve the eye and vision research community and the public in setting its research funding priorities.

The NEI and the National Advisory Eye Council (NAEC) are just now completing work on their seventh strategic plan, Vision Research A National Plan: 1999–2003. This plan is the result of a unique partnership between all of the stakeholders in the eye and vision research community including NEI staff, the NAEC, research scientists, lay advocacy organizations, foundations, industry, professional societies, and the general public. In order to reach all interested parties, NEI posted several questions on its web site to gather input from the eye and vision research community about its views about the most important research accomplishments in the last five years, and the most important areas to be explored in the next five years. Expert panels in each area of vision research were assembled and, based on their expertise and the input received from the process outlined above, set goals and objectives and determined research needs and opportunities for the next five years. This report will be published soon and will serve as the driving force behind our vision research efforts leading into the 21st Century.

Those of us in the extramural community believe that this plan reflects the best in terms of balancing research opportunities with compelling societal and economic concerns.

The Importance of Vision Research

When asked what sense do you fear losing the most a majority of Americans respond "vision". In the U.S. today more than 1.1 million Americans are legally blind and an estimated 80 million are at risk of developing potentially blinding eye diseases. 120 million Americans wear corrective glasses or contact lenses and 12 million suffer from some form of visual impairment that cannot be corrected by glasses. The annual cost of eye and vision disorders is $38.4 billion. As our population ages, these costs will increase significantly and present many challenges to our health care system.

It is only through further advances in research that we are going to gain a better understanding of vision disorders that can lead to cost-effective advances in disease prevention and treatment. We now have the scientific and technological capability to make substantial progress in all areas of eye and vision research, IF an expanded research effort is supported. This research progress will only be possible if we can insure that the NEI has the resources necessary to pursue initiatives in the key areas outlined in the soon-to-be-released Vision Research Plan.

In order to give you a sense of the research needs and opportunities that exist today, we would like to outline several diseases and disorders where research has the most promise.

Age-related Macular Degeneration

The leading cause of blindness in the elderly is age-related macular degeneration (AMD), a retinal disease which causes loss of central vision. More than 1.7 million Americans over age 65 suffer from AMD and this number is expected to triple by the year 2020. At the present time, there is no cure for AMD and treatment remains limited. While laser treatment has been found to have some effect in delaying some forms of AMD, no current treatments exist that will reverse the slow loss of central vision that results from this disease. However, recent research developments are encouraging.

NEI-supported researchers are making progress in unlocking the mysteries of AMD. Scientists have mapped genes of several different forms of heritable macular disease, are exploring retinal transplantation and growth factors, and are testing new treatments including the effects of antioxidants on the progression of AMD.

The NEI is also actively pursuing studies in the use of alternative therapies for the treatment of AMD. The Age-Related Eye Disease Study (AREDS), which is designed to improve our understanding of AMD and cataract, includes the study of the effect of vitamins and antioxidants as treatments for AMD and cataract. In addition, the NEI will be sponsoring a workshop with the Office of Dietary Supplements in

February to develop a research plan to evaluate the effect of two carotenoids, lutein and zeaxanthin, on AMD and cataract.

Low Vision

A related area of concern is low vision, or vision impairment which is not correctable by glasses or contact lenses. As many as 12 million Americans suffer from visual impairments which affect their ability to read, drive, work, and perform many everyday activities we all take for granted. The most common eye diseases which cause visual impairment in adults are AMD, cataract, glaucoma, diabetic retinopathy, and optic nerve atrophy. Even more serious are the eye diseases which cause visual impairment in children. These include retinopathy of prematurity, cortical visual impairment, and coloboma. Low vision in children often affects their development and results in the need for special education, vocational training, and social services throughout their lives. The cost of these impairments is more than $22 billion each year.

Many important aspects of low vision are ripe for continued exploration. One which deserves particular mention is the advancement of technology and assistive devices to help those with visual impairments to carry out everyday functions as independently as possible. Issues to explore include providing sufficient training in the use of these devices, reducing their cost, and improving the functionability and appearance of these devices if they are to be accepted by users. Researchers remain frustrated because advances in low vision devices seem not to be reaching the people with impairments, in part because of a lack of insurance coverage for evaluations and devices. Scientists are researching better ways of presenting hard to read computer graphic user interfaces, and developing telescoping and other optical devices to improve intermediate distance tasks and peripheral vision.

Under the auspices of the National Eye Health Education Program (NEHEP), NEI is working with its private sector partners to launch a program directed at low vision in order to increase public awareness about visual impairment and the impact it has on everyday life. The program will provide information about low vision services and the devices which are currently available to assist those with visual impairments. This effort will not only be directed at those suffering from visual impairments but also to medical professionals, eye care specialists, managed care organizations, and family members. NAEVR supports this public education partnership and encourages the Committee to support it as well.

Diabetes.—Diabetic retinopathy, the leading cause of blindness in individuals with diabetes, causes vision loss in more than 24,000 Americans each year. In fact, if a person has diabetes, they are 25 times more likely than the general population to go blind. Despite the success of research in developing treatments to slow the progression of blindness, little is known about the mechanism that triggers diabetic retinopathy.

Researchers supported by the NEI are focusing their research efforts on gaining a better understanding of diabetic retinopathy by examining the cell biology of the retina, including cell growth factors; how blood flow is regulated in the retina; and the development of new drugs which inhibit an enzyme which appears to be involved in the development of diabetic retinopathy. Research in these areas will lead to better treatments, strategies for prevention, and hopefully, a cure. The recent funds made available for diabetes research in the Balanced Budget Act will help serve to push forward these important research pursuits and give hope to the millions of Americans who suffer from diabetes and risk blindness from diabetic eye diseases.

Glaucoma.—As many as three million Americans have glaucoma and approximately 120,000 are blind because of this disease. It is the leading cause of blindness in African Americans and the second leading cause of irreversible vision loss overall in the United States. Glaucoma is a strongly age-related disease and is especially prominent in "old" elderly (75–80+). Specifically, at least 5 percent of white Americans and 10 percent of black Americans in this age group have this disease.

Treatments for glaucoma are available. In the last five years, as a result of NEI-sponsored glaucoma research, three new drug therapies, which lower intraocular pressure, have been introduced. Unfortunately, however, many individuals with glaucoma are not receiving treatment because glaucoma usually has no symptoms in its early stages and they are unaware that they have the condition.

A recent national survey by the Glaucoma Research Foundation, a member of NAEVR, indicated that public awareness of glaucoma and its risk factors is extremely low—only 11 percent of African American's surveyed were aware that they are risk, and only half of the African American's surveyed had an eye exam in the last two years. Public education efforts have included the development of a public

service announcement by the NEI for use in January during Glaucoma Awareness Month.

Much progress has been made on identifying a glaucoma gene for juvenile open angle glaucoma. Since this discovery, a total of nine genes have been mapped for glaucomas or ocular diseases associated with secondary glaucomas such as congenital glaucoma, primary open angle glaucoma in adults, and Rieger syndrome. More research must be done to more fully understand genetic predisposition and the other factors which trigger glaucoma.

Tremendous advances have been made in the cellular and molecular biology of the ocular fluid formation and drainage tissues which regulate intraocular pressure, opening up new approaches to the pathophysiology and potential therapy of pressure elevation. But those with glaucoma lose vision not from high intraocular pressure per se, but from pressure-related and other types of damage to the optic nerve and retinal ganglion cells at the back of the eye, which conduct the visual signals from the retina to the brain. Recent advances in the neurobiology of how retinal ganglion cells die and might be protected have opened the possibility of treating these cells directly. Related to this is our increasing understanding and technology for evaluating the role of vascular circulation at the back of the eye in the pathophysiology and therapy of glaucoma. These are areas of great opportunity, which could be pursued even more aggressively with sufficient resources.

Cataract.—Cataract is the leading cause of blindness in the world. A cataract is a lens opacity which interferes with vision. It occurs most often in adults 50–60 years and older. In the U.S., 1.35 million cataract surgeries are performed each year to remove cataracts at an estimated cost of $3.5 billion, much of which is paid for by Medicare.

Because the U.S. population is aging, it will be important to focus our research on what aging factors lead to cataract. At this point, little is known about events which trigger cataract formation. Several major hypotheses have been proposed to explain age-related cataracts. Researchers must now turn their attention to proving or disproving these hypotheses and improving our understanding of cataract formation.

Dry Eye.—Recent advances in basic research have led to unexpected discoveries which have implications for improving the treatment of "dry eye", a symptom of Sjogren's Syndrome which affects women between the ages of 40 and 60. Further research must now be done to translate these basic research advances to improve clinical diagnosis and treatment. Animal models which are currently being studied show the link between androgen sex hormones and the lacrimal gland, which might explain why women are more likely to develop Sjogren's Syndrome than men. If this holds true, hormone modulation therapies may be used to successfully prevent and treat primary lacrimal deficiency and to treat "dry eye".

Myopia.—Myopia, or nearsightedness, occurs in approximately 25 percent of the population. Myopia results when the images of distant objects are focused in front of, instead of on, the retina and is usually due to the fact that the eye is too long. Because myopia affects such a large percentage of the population, it is important that researchers continue their work to better understand ocular growth and its affect on vision. This research will help scientists determine the risk factors for myopia and develop treatments to slow the progression of this condition.

Eye Diseases and Tobacco Use

In the past several years, there have been many studies published which implicate tobacco use as a risk factor in vision disorders such as age-related macular degeneration and cataract. For example, recent studies by vision researchers published in the Journal of the American Medical Association have shown that current smokers have a significantly higher risk of developing late age-related macular degeneration than nonsmokers. If Congress chooses to act on legislation implementing a global tobacco settlement which includes additional funding for tobacco-related research, we hope members of the Committee will remember that tobacco use is causally linked to several vision disorders. Additional funding for research directed to explore this link will help us better understand tobacco use as a risk factor and to develop new treatments and prevention strategies to address this risk.

Conclusion

The members of the National Alliance for Eye and Vision Research are supportive of an increased research focus on eye and vision disorders, such as those outlined above, and hope that the Committee will allocate additional funding to the NEI to allow these critically important research efforts to continue and expand. As we enter the 21st Century, we must ensure that we are doing our best to find ways to pre-

vent and treat eye and vision disorders, and are providing quality eye care services and devices for those who are already suffering from visual impairment.

We thank you for your continuing support for medical research funding. Because NAEVR is supportive of efforts to double the NIH budget over the next five years, we urge you to provide a 15 percent increase in fiscal year 1999 for the NIH as the first step toward doubling the budget. Furthermore, we urge you to provide $408.6 million, a 15 percent increase, for NEI in fiscal year 1999 as requested by the National Advisory Eye Council in its "Citizens Budget Proposal".

PREPARED STATEMENT OF THE NATIONAL AGING AND VISION NETWORK

The National Aging and vision Network is comprised of individuals and representatives of public and private agencies that provide vision rehabilitation services to persons who are older and blind, who reside in all 50 states, the District of Columbia, and the territories. Formed in 1994, the Network's goal is to increase the availability of responsive, high quality services for older individuals who are blind or severely visually impaired, through the vision-related rehabilitation system, the aging network, and the health care system. Network members collaborate on advocacy efforts, share vital information on service delivery mechanisms, develop outcome measures, and work to develop and maintain funding resources to support essential services.

Appropriation for Title VII, Chapter 2 of the Rehabilitation Act

For fiscal year 1999, the Network strongly urges the Subcommittee to increase the funding for Title VII, Chapter 2 to $13 million. This amount will trigger the formula funding mechanism established by Congress in the 1992 amendments to the Rehabilitation Act. Both House and Senate versions of pending amendments to re-authorize the Act retain this authority.

However, the formula will not trigger until the Chapter 2 appropriation level reaches $13 million. With an appropriation of $13 million, each state will receive a minimum of $225,000. States with larger populations of older individuals would receive proportionally increased amounts.

Since its first funding in 1986, this program has been one of the most successful and cost-effective programs initiated by Congress. In 1996–97 the grantee states used the funds to deliver services to over 27,000 older individuals. The number of persons served through this program has doubled in the five year period since a minimum funding level of $160,000 per state was established.

Documented program evaluations show that these services have enabled older individuals who become blind to continue to live independently in their own homes and communities. The program has helped these individuals to regain self-reliance by providing the skills needed to perform the most basic tasks of daily living, and to remain active and contributing members of their communities.

The types of services provided by grantee states include: training in how to travel safely; communications skills; training in activities of daily living; low vision services and adaptive devices; individual counseling and support services to family members; and community integration. The goal of all these services is to reduce the need for costly support services such as in-home and community-based services and/or premature nursing home placement.

There are already approximately 5 million individuals age 55 or over who are experiencing severe vision loss. This number is expected to double by the year 2030. Funds for vision-related rehabilitation services for this population are not provided through the Older Americans Act, Medicare, Medicaid, or any other consistent funding mechanism. Attached to this statement is a chart based on the 1995 Census Survey of Income and Program Participation showing the numbers and prevalence of severe vision impairment of individuals who are age 55 and over and 85 and over in states represented on this Subcommittee. (See Attachment A)

With funds currently available we are only able to serve a small number of these individuals. Because the $13 million dollar appropriation will trigger the formula grant process, this small increase will have a significant effect in allocating funding for these services.

ATTACHMENT A

These numbers represent individuals who on the Census Survey of Income and Program Participation identified themselves as having difficulty seeing words and letters in ordinary newsprint even with glasses or contacts or who reported not being able to see words and letters in newsprint at all.

State	Number of respondents age 55 +	Percentage of total number of respondents	Number of respondents age 85 +	Percentage of total number of respondents
Arkansas	93,960	16	19,400	47
Hawaii	20,710	9	3,430	26
Iowa	70,860	10	17,200	29
Mississippi	98,340	18	19,730	53
Missouri	133,120	11	29,750	32
Nevada	24,070	8	3,090	26
New Hampshire	20,650	9	4,190	28
North Carolina	211,820	14	37,670	43
Pennsylvania	324,720	11	64,110	32
South Carolina	109,380	15	18,370	46
Texas	464,330	14	87,930	43
Utah	26,310	9	4,920	27
Washington	96,990	9	18,960	28
Wisconsin	110,140	10	24,320	29

The data was calculated in 1997 by Emilie Schmeidler and Drew Halfmann, Programs and Policy Research, American Foundation for the Blind. It was based on state populations from the 1995 census.

Prepared Statement of the American Foundation for the Blind

Introduction

The mission of the American Foundation for the Blind is to enable persons who are blind or visually impaired to achieve equality of access and opportunity that will ensure freedom of choice in their lives. AFB accomplishes this mission by taking a national leadership role in the development and implementation of public policy and legislation, informational and educational programs, and quality services.

We appreciate the opportunity to submit our appropriations recommendations for fiscal year 1999 to the Subcommittee on Labor, Health and Human Services, Education and Related Agencies. This document is presented in tabular summary form to facilitate its readability. Additional information to substantiate the rationale for each funding recommendation will be furnished to the Subcommittee upon request. Please note that the recommendations (in millions of dollars) contained herein do not reflect adjustments for inflation. Therefore, if our recommended amount for each program or activity cannot be appropriated, we urge the Subcommittee to increase the appropriation by at least a factor for inflation.

Individuals with Disabilities Education Act national activities personnel preparation to improve services and results for children with disabilities

[Part D. subpart 2; section 673]

Fiscal year 1997 appropriation	$93.33
Fiscal year 1998 appropriation	82.1
Fiscal year 1999 authorization	([1])
President's fiscal year 1999 request	82.3
AFB fiscal year 1999 recommendation	90.0

[1] Such sums.

We remain seriously concerned about adequately funding personnel preparation to address the shortage of teachers who are trained to deal with the unique needs of blind or visually impaired children. We suggest that a funding priority be established for preparation of personnel to address this need. The shortage in the field is tremendous; within special education, the shortage of personnel for instruction of students with visual impairments ranks second when measuring staffing needs. Only the need for teachers of students with multiple disabilities, many of whom also have visual impairments, is greater in terms of shortages. We are concerned that the restructuring of the personnel preparation section and the addition of the new State Improvement Grants to address some of the personnel preparation needs in the states (and a necessary appropriation for that section), may cause a diminution in the appropriation for the personnel preparation programs that remain under fed-

eral control. A priority with sufficient funding is necessary to guarantee an adequate number of qualified personnel who can instruct blind and visually impaired students in such specialized services as orientation and mobility and the use of braille. These are skills which Congress recently recognized in the IDEA reauthorization as important to such children's education.

Individuals with Disabilities Education Act technology development, demonstration, and utilization, and media services

[Part D. subpart 2; section 687]

Fiscal year 1997 appropriation	$30.0
Fiscal year 1998 appropriation	34.0
Fiscal year 1999 authorization	([1])
President's fiscal year 1999 request	34.0
AFB fiscal year 1999 recommendation	45.3

[1] Such sums.

Access to adaptive technology, such as talking computer terminals, has a significant impact on the appropriate education for children who are blind or visually impaired. In addition, incentives for development and availability of new technologies as funded under this part are of crucial importance to students with low incidence disabilities, including those who are blind or visually impaired, because of the small size of potential markets.

Video Description

This recommendation includes $3.0 million for video description which is a $1.5 million increase over the 1998 allocation. Video description provides blind persons with narration of visual elements of television, cinema, and performing arts. The reauthorization of IDEA includes language limiting, beginning in 2001, the video description or captioning that can be funded under this section. Part of the rationale for the limiting language is that the transition to private funding of captioning should be well underway by that time due to the publication of the Federal Communications Commission's regulations on captioning in August 1997. However, the FCC has not regulated on video description and hence there will be no requirements for video described programming which would attract private funding. Additionally, video description is a newer technology which is not as advanced as captioning in its movement toward the development of private funding sources. In the eight years that funds have been available for video description production and research, the allocation has fluctuated between $1 million and $1.5 million.

Individuals with Disabilities Education Act Services for Deaf-Blind Students

[Section 661(i)(1)(A)]

Fiscal year 1997 appropriation	$12.83
Fiscal year 1998 appropriation	.....
Fiscal year 1999 authorization	.....
President's fiscal year 1999 request	.....
AFB fiscal year 1999 recommendation	29.2

[1] Such sums.

The discretionary programs reorganized by the IDEA Amendments of 1997 no longer provide a separate programmatic line for deaf-blind centers and services. However, Congress recognized the importance of the federal role in providing services to this population by including services to deaf- blind students in several sections of newly reauthorized Part D (technical assistance, regional resource centers) and by maintaining the floor of $12.83 million in the 1997 appropriation below which total funding for these students would not fall (Section 661(i)(1)(A)). While this is no longer a line item, we believe that this floor does not take into account the current needs of this population which now numbers 11,000 children, an all-time high. We believe that direction from the Subcommittee to recognize the need for increased funding to this population is imperative to assure that the $12.83 million floor does not become a ceiling beyond which additional funding will not be provided. The currently identified population of 11,000 children is an all-time high. Of these children, 5,000 are being educated in the local school districts which means that coordinators must provide technical assistance in very wide geographic areas.

This has resulted in an increasing number of special educators and general educators who need basic training in instruction of the children who are deaf-blind.

Rehabilitation Services Independent Living Services for Older Blind Individuals—Title VII, Chapter 2

Fiscal year 1997 appropriation	$9.95
Fiscal year 1998 appropriation	11.00
Fiscal year 1999 authorization	.....
President's fiscal year 1999 request	11.2
AFB fiscal year 1999 recommendation	13.0

The recommended appropriation level will trigger the formula funding mechanism established by Congress in the 1992 amendments to the Rehabilitation Act. At that level, each state would receive a minimum of $225,000. States with larger populations of older individuals would receive proportionately larger amounts. There is no other national service delivery program specifically targeted for older individuals who are blind. Funds for vision-related rehabilitation services for older people who are blind are not provided through the Older Americans Act, Medicare, Medicaid, or any other consistent funding mechanism. Prevalence data for severe vision impairment calculated from the 1995 Census Survey of Income and Program Participation shows, for example, that, in Pennsylvania, 11 percent of the population over age 55 and 32 percent of the population over age 85 has either difficulty seeing words and letters in ordinary newsprint even with glasses or contacts or can't see words and letters in newsprint at all. (Attachment A) In Iowa this prevalence rate is 10 percent for individuals over age 55 and 29 percent for individuals over age 85.

Rehabilitation Services Rehabilitation Training

[Part D. subpart 2; section 687]

Fiscal year 1997 appropriation	$399.63
Fiscal year 1998 appropriation	39.63
Fiscal year 1999 authorization	.....
President's fiscal year 1999 request	33.7
AFB fiscal year 1999 recommendation	43.6

Long-term grants under the Rehabilitation Act provide the only source of funding for college-based programs to train orientation and mobility instructors and rehabilitation teachers for the blind. As a result of the 1992 amendments to the Rehabilitation Act, the eligibility rate for clients has increased. The pending 1998 amendments to the Act will reenforce that trend. The services of these professionals are extremely important to the needs of people who are newly blind and eligible for rehabilitation services. The services these specialists provide include: using specialized adaptive devices and techniques for personal management at home and at work; using adaptive computer equipment to read information and using braille and other methods to take notes and maintain files; and using specific orientation and mobility techniques for safe and independent travel.

Rehabilitation Services Braille Training Projects

[Section 803, part B]

Fiscal year 1997 appropriation	.....
Fiscal year 1998 appropriation	.....
Fiscal year 1999 authorization	.....
President's fiscal year 1999 request	.....
AFB fiscal year 1999 recommendation	1.0

Since fiscal year 1993, more than $2.2 million has been allocated to the effort to increase braille literacy by the Department of Education. Although the authority for funding these projects is contained in Section 803 of the Rehabilitation Act, allocations for the projects were made from funds appropriated for Title III Special Demonstration Programs as a result of the budget scoring agreement with regard to Title VIII programs. These braille training projects provide braille literacy training to rehabilitation professionals, parents of blind children, and family members of blind individuals in the form of instructional materials such as computer tutorials and the creation of a national network of experts in teaching braille.

Helen Keller National Center for Deaf-Blind Youth and Adults

Fiscal year 1997 appropriation	$7.34
Fiscal year 1998 appropriation	7.5
Fiscal year 1999 authorization	([1])
President's fiscal year 1999 request	8.2
AFB fiscal year 1999 recommendation	8.6

[1] Such sums.

The Helen Keller National Center is the only entity in the world whose sole mission is to provide comprehensive training, independent living skills, and employment preparation to young people and adults who are both deaf and blind. HKNC also provides technical assistance and training to public and private service providers. Currently, there are more than 11,000 deaf-blind children under the age of 22—the greatest number in our history—who will need such services. This increase will also allow for urgent building repairs as well as equipment and training in computer and other technologies.

American Printing House for the Blind

Fiscal year 1997 appropriation	$6.68
Fiscal year 1998 appropriation	8.2
Fiscal year 1999 authorization	([1])
President's fiscal year 1999 request	8.3
AFB fiscal year 1999 recommendation	9.2

[1] Such sums.

The American Printing House for the Blind provides special education teaching aids for students who are blind, provides braille textbooks for elementary and secondary students, and develops tape recorders and other devices used by blind or visually impaired students. Most of these products would not be commercially available because of the limited market for these products. Decisions and procedures regarding the selection, purchase, distribution, and recirculation of these products reside at the state and local levels, where assessment of students can best drive such decisions. The increase will permit APH to increase the per capita allocation to states for textbooks and other educational materials and to develop guidelines for computer-administered testing of visually impaired students.

PREPARED STATEMENT OF WANDA K. JONES, DR. P.H., PUBLIC HEALTH SERVICE OFFICE ON WOMAN'S HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES

I am delighted to have an opportunity to provide information on the National Osteoporosis Educational Campaign; a public/private informational campaign designed to improve the quality of life and reduce health care costs for America's aging population.

At least 25 million Americans are afflicted with osteoporosis, most of them women. Osteoporosis robs bones of their mineral and organic reinforcements, decreasing bone density and increasing susceptibility to fractures. It is a major underlying cause of bone fractures in older women, often taking away their independence at a time they should be enjoying life. Women with bone fractures can even die from surgery-related complications, with a reported mortality rate of 20 percent in the first post-surgery year for women.

We are lucky to live in a time with new medications that can help prevent or treat osteoporosis. Even so, this disease leads to 1.5 million fractures a year, mostly in the hip, spine and wrist, and costs $10 billion annually.

Much of the pain, suffering and costs associated with osteoporosis could be avoided if women would take preventive measures early in life. Current evidence indicates that young women can increase their peak bone mass, promote long-term bone health, and reduce the risk of disease later in life by following effective dietary, exercise, and lifestyle practices. Yet we have so far not been able to effectively communicate this prevention message to young women. Studies show that less than 25 percent of adolescent females get the required daily allowance of calcium; the prevalence of smoking among female high school seniors now exceeds that for their male counterparts; over 18 percent of all adolescent females in a recent survey had used alcohol in the preceding month; vigorous physical activity was significantly less com-

mon among female high school students than among male students; and 95 percent of anorectic and bulimic patients were adolescent females.

In September 1996, the U.S. Public Health Service's Office on Women's Health (PHS OWH) convened a task force to design a blueprint for a national osteoporosis education campaign. The Task Force recommended that getting osteoporosis prevention messages to the 13 to 18 year old group should be a priority. These are the years appear when girls begin making their own decisions about diet, smoking, exercise and leisure activities, and start shifting away from their parents' advice to their peers and the popular media. These are also the years when girls are on the verge of accruing 90 percent of peak bone mass. The National Osteoporosis Foundation (NOF) and the Osteoporosis and Related Bone Diseases National Resource Center (ORBDNRC) subsequently recommended that girls ages 9–12 years also be included in this project and these organizations have joined with the PHS OWH to develop this educational initiative.

Research reveals that selecting effective health education approaches and messages for adolescent females is far from simple. So, prior to developing and implementing health education programs targeted to adolescent females, the PHS OWH, NOF, ORBDNRC, and the National Institutes of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) felt it was necessary to conduct a study to determine how to reach adolescent females with prevention messages. This study was designed to identify effective health education approaches and apply the lessons of practical experience to meet health education objectives for target populations.

There were several key strategies used to collect data. First of all, an exhaustive search was conducted of the published literature using online databases such as Medline to gather findings on adolescent females' knowledge, attitudes, and practices concerning bone health and the prevention efforts aimed at this population. Secondly, a questionnaire was prepared to use in interviews with representatives of organizations that have developed messages and implemented programs for adolescent females, including the NHLBI Education Programs Information Center, the National Maternal and Child Health Clearinghouse for Alcohol and Drug Information, Girl Scouts of the USA, Future Homemakers of America, Inc., and Girls Clubs of America. Thirdly, baseline data was gathered on adolescent females' knowledge of bone health and its relative importance to them. And finally, adolescent and young women representing diverse population groups ages 9 to 18 were recruited for focus groups to solicit and explore their responses to prepared questions concerning their knowledge of bone health and preferred prevention messages, approaches, and channels.

The principles, patterns, and criteria for developing message content, designing effective approaches, selecting and using channels, and addressing adolescent populations were identified. Apparent gaps in the knowledge base and any conflicting findings were also highlighted.

From the findings of this study, the PHS OWH is collaborating with the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH) and the NOF to establish a national education campaign on osteoporosis to increase bone healthy behaviors of women and their understanding of the importance of bone health. Attention will first be placed on 9 to 12-year-old girls, just approaching their peak bone building years, but as the campaign develops, it will expand to cover 13 to 18-year-old girls. An interesting finding of this recent study is that it is important to make efforts to change the behaviors of parents, who are critical role models on these issues for pre-teens. Thus, parents will also be targets of an expanded educational program.

The PHS OWH, NIH, CDC, and NOF would like to see significant strides made to reverse the current trend in teen health so that there is a marked increase in physical activity, a greater consumption of calcium among 9–18 year olds, and adoption of other healthy lifestyle behaviors associated with bone health. We believe a long term national campaign can help effect these changes and are committed to working with our collaborators to ensure that this educational program can continue past the initial year of funding provided by the PHS OWH.

In the past century, we have done much to increase the life expectancy of women. As a result, in the next century we will see a significant increase in the number of older women in our population. We must use visionary, long-term strategies to ensure that these bonus years for women are fruitful, rewarding and comfortable. Only by preparing women in their pre-teen and teen years for a lifetime of good health will we achieve that goal.

PREPARED STATEMENT OF CORNELIUS J. PINGS, PRESIDENT, ASSOCIATION OF AMERICAN UNIVERSITIES

The Association of American Universities (AAU), an organization of 62 public and private research universities across the U.S. and Canada, appreciates this opportunity to submit for the record testimony in support of the fiscal year 1999 budget for the National Institutes of Health (NIH) and the Department of Education's graduate education programs. We are joined in this statement by the American Council on Education and the National Association of State Universities and Land-Grant Colleges. AAU has also submitted separate testimony with these two organizations on behalf of the important Federal student aid programs funded by this Subcommittee.

We address the Subcommittee at a time of great promise for biomedical research. We are very grateful for the Subcommittee's consistent, strong support of NIH. You have been strong advocates of biomedical research, even when reductions were being made elsewhere in your appropriations bill. Your commitment to the biomedical enterprise has done much to create the current atmosphere in which support for NIH is spreading throughout the country and the Congress. We are greatly heartened by this groundswell of public sentiment for investing in biomedical research and the possibility that the burgeoning economy and the fiscal accomplishments of Congress will permit the lifting of the yoke of deficits to finance this priority.

You have received testimony from many witnesses which describes the tremendous opportunities in science and the breathtaking speed at which discoveries are being identified—discoveries which ultimately will unlock the key to disease and hold the promise of improved health for our citizens.

The AAU takes pride in the fact that so much NIH research is conducted on the campuses of AAU institutions—at their graduate schools and academic medical centers. In fact, in fiscal year 1997, over $4.5 billion was awarded by NIH through its peer review process to AAU institutions.

As institutions which support strong research programs in many scientific disciplines—including physics, chemistry, mathematics, computer science, and engineering—we want to emphasize that biomedical research is heavily dependent on the discoveries and progress of many sciences, not just those that are most closely associated with biomedical research.

Dr. Burton Richter, the Nobel Prize-winning physicist at Stanford University, uses the example of HIV protease inhibitors to make this point. Protease inhibitors were synthesized by chemists based on the structure of HIV protease determined by biologists using physicists' x-ray diffraction techniques. The drug companies then finalized their formulations using x-ray beams from synchrotron radiation sources from accelerators.

The AAU calls on Congress to support all science research with vigor, not only the biomedical sciences.

The AAU supports efforts underway throughout the biomedical community to increase substantially the funding for NIH. We join the Ad Hoc Group for Medical Research Funding in its call for a 15 percent increase for NIH in fiscal year 1999, as the first step in a five-year effort to eventually double NIH funding. As was indicated earlier, we feel it is important that the other sciences receive similar support. We are greatly encouraged by the President's request for an 8.4 percent increase for NIH as the starting point for the debate this year on the NIH appropriation.

As enthusiastic as we are about the goal of increasing NIH funding by 15 percent this year, we must emphasize that stability in funding over a multi-year period is crucial to progress of science. Dramatic fluctuations in funding increases may well be more harmful to biomedical science than consistent modest increases. Science cannot be conducted productively in single year increments—one year of generous resources, the next with cutbacks and constraints.

In advocating significant increases in NIH funding, we are acutely aware that these levels are very unlikely to be reached under the current discretionary spending caps without damage to the other important programs funded by this Subcommittee. We encourage Congress to consider making support for NIH at higher levels possible by identifying additional resources, such as through investing a potential budget surplus or designating revenues from a possible tobacco settlement.

We realize that the scientific community and the Congress have a grave responsibility to taxpayers to defend funding increases of the magnitude we are advocating. We feel confident that the scientific fields can support high quality research at these levels. The way in which science is now conducted is virtually transforming the activities and structure of the modern laboratory. For instance, the human genome project requires computing and informatics capacity that would have seemed unfathomable fifteen years ago. Substantial new resources could be applied to pro-

viding the new technologies and the properly trained personnel to help usher in a new era of scientific achievement. Our organizations hope to play a part in spurring the scientific leadership, both at NIH and among its extramural partners, to engage in comprehensive, "outside the box" planning for how significant spending increases could most productively be spent.

AAU would like to highlight needs which have too often been given short shrift and which should be addressed if new resources become available. AAU continues to emphasize the investigator-initiated grant as the bedrock on which the successful NIH enterprise is built. But we also want to focus attention on pressing needs in two areas: clinical research and institutional infrastructure.

The dominance of market forces in the health care system has drained resources that previously had been used to subsidize clinical research and support clinical investigators. Training and career support for clinical researchers at all levels—postdoctoral, new and junior researchers, and established investigators—need strengthening. The General Clinical Research Centers program, which supports inpatient and outpatient research facilities, trained research support staff, career training, and other resources crucial to clinical research, should be targeted for additional resources.

The second area of concern is institutional infrastructure. Individual research efforts cannot thrive without buttressing some of the critical infrastructure needs of the biomedical enterprise. Additional resources need to be invested in renovating outdated facilities, supporting animal research facilities, financing state-of-the-art instrumentation and developing new research technologies. In addition, the AAU encourages Congress to consider reinstituting a peer-reviewed, accountable institutional grant program that can be targeted to specific institutional needs, such as bridge grants for investigators, support for trial projects and unorthodox research ideas, aid for new investigators, and the acquisition of expensive shared resources.

We would like to conclude with a few words about graduate education. AAU continues its strong support of the graduate education programs funded by this Subcommittee—those authorized by Title IX of the Higher Education Act. These programs are the only source of fellowship support for extremely well-qualified students who have financial need in disciplines such as the humanities, which are not supported elsewhere in the Federal budget.

Thank you for this opportunity to express our views and add our voices to the growing chorus of advocates for biomedical research.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF BLOOD BANKS

The American Association of Blood Banks (AABB) offers this statement in support of increased funding for the National Institutes of Health (NIH) and the National Heart, Lung, and Blood Institute (NHLBI). The AABB appreciates the generous support that transfusion medicine researchers have received from the NIH through the Congressional appropriations process. This statement discusses the current state of transfusion medicine research and signals areas that the Association believes merit continued research support.

THE AMERICAN ASSOCIATION OF BLOOD BANKS

AABB is the professional society for 8,500 individuals involved in blood banking and transfusion medicine. AABB also represents more than 2,200 institutional members including community and Red Cross blood collection centers, hospital based blood banks, and transfusion services as they collect, process, distribute, and transfuse blood and blood components. AABB members are responsible for virtually all of the blood collected and more than 80 percent of the blood transfused in this country. Throughout its 50-year history, the AABB's highest priority has been to maintain and enhance the safety of the nation's blood supply.

Many AABB physicians and scientists conduct research designed to assure that the American people have access to the safest transfusion services possible. The NIH and other federal agencies fund much of this research.

The National Blood Foundation (NBF), founded in 1983, supports patient and donor care through medical research and education as a program of the AABB. The AABB is developing a cadre of transfusion medicine researchers by supporting early career research in issues affecting transfusion medicine. NBF grant recipients have the opportunity to demonstrate superior research ability in NBF grant sponsored research which often enables them to secure larger grants for additional research from the NIH.

SCOPE AND IMPORTANCE OF TRANSFUSION MEDICINE

Transfusion Medicine is a multidisciplinary specialty encompassing both clinical practice, broad research responsibilities and professional and public education activities. Each year in the United States, more than 23 million units of blood components are transfused into approximately four million patients, providing fundamental support for many different surgical and medical treatments. Blood is needed for the care of patients with cancer; for accident and burn victims; for newborn babies needing intensive care; for transplant patients; for millions of patients who undergo surgery; and for individuals with heart, lung, liver or bowel diseases. A ready supply of safe blood is also vital to the military. Future advances in the health care of the nation will depend on continued progress in the provision of safe and effective transfusion services.

As a direct result of transfusion medicine research—much of it funded by the federal government through the NIH—the United States blood supply is now safer than ever.[1] The NIH is currently sponsoring several important transfusion medicine research projects that can be expected to lead to further improvements in the safety and efficacy of blood transfusion. However, there are important research opportunities in this field that require additional investigation to assure that patients have access to the safest possible blood supply.

RECOMMENDATIONS FOR IMPROVING TRANSFUSION SAFETY

Despite the great progress that has been made in the selection of donors who are at low risk for disease transmission and the use of and improvements to an extensive battery of tests to eliminate infected donors, the prevention of HIV and other transfusion-transmitted infections remains a top priority of transfusion medicine researchers and all recipients of blood. The AABB urges the NIH to continue research into the development of enhanced infectious disease tests and donor screening methods to further improve blood safety.

Prevention and Early Detection of Transfusion Transmitted Pathogens

Current blood screening tests detect the presence of the antibodies produced in response to the targeted virus, rather than the virus itself. Each improvement to the test has lead to a decrease in the "window period" (the period of time between infection with a viral disease such as AIDS and Hepatitis C and the ability to detect the virus via screening tests).

To improve infectious disease tests even more, the NHLBI is funding research into the use of gene amplification technology for the detection of the genetic material of viruses that cause AIDS and Hepatitis C. If successful, this research could lead to blood screening tests that further reduce the window period. However, before this technology can be implemented for screening blood collected for transfusion, more research is needed to address substantial technical and operational challenges.

Pathogen Inactivation.—The risk of acquiring identified pathogens through transfusion is lower than ever, yet world-wide travel and changing demographics could spread new viruses, bacteria and parasites into the U.S. blood donor population. Therefore, the prevention of transfusion transmitted diseases remains a top priority of transfusion medicine research. Whereas certain technologies are already under development with private sector support, newly emerging strategies which hold promise for pathogen inactivation need federal grant support.

For example, to address these threats, technologies to sterilize cellular blood components are under development. Unfortunately, current sterilization methods also damage or destroy the blood cells. Nevertheless, emerging strategies hold promise for pathogen inactivation that does not impair the efficacy of cellular blood components. The AABB is pleased that the NHLBI co-sponsored with the FDA last year, a workshop on pathogen inactivation and is funding research on viral and pathogen inactivation in cellular blood components with clinical trials. Research in this area is also proceeding in the private sector.

Support is needed for research on pathogen inactivation related to CMV transmission. Additionally, support is needed for research that explores the biology, transmissibility and inactivation potential of Creutzfeld-Jakob disease, and other spongiform encephalopathies referred to as CJD.

Donor Screening.—Donor questioning is a critical step in maintaining a safe blood supply. Over the years, the questions presented to blood donors have been continuously revised, and today, questioning more directly addresses issues such as travel

[1] A General Accounting Office (GAO) report on blood safety released on March 12, 1997, entitled "Blood Supply: FDA Oversight and Remaining Issues of Safety," found that overall, the blood supply "is very safe."

to regions with endemic disease patterns and sexual and drug use patterns. As a result of improved donor screening and education efforts, the volunteer donor pool is now primarily comprised of persons with lower infectious disease risks.[2]

Additional research is needed to refine and validate donor screening protocols. A report of the NHLBI funded Retrovirus Epidemiology Donor Study published in the March 26, 1997 issue of the Journal of the American Medical Association concludes that, although a stringent donor screening system is in place, a small percentage of donors with risk for infectious disease continue to donate blood.[3] Although sophisticated laboratory testing that is conducted on all donated blood would have detected virtually all HIV or other infections among most of these donors, it is disturbing that this link in the blood safety process appears to be incomplete. The AABB urges the NHLBI to fund research to develop more effective donor screening methods to emphasize the potential adverse impact on patient health of providing misleading or inaccurate information during the blood donation process.

EVALUATION OF THE ROLE OF BIOLOGICAL RESPONSE MODIFIERS IN TRANSFUSION REACTIONS

Lifesaving blood transfusions carry risks other than transmission of infectious diseases. Clinical and experimental studies have identified several families of molecules which play a significant role in altering a patient's response to transfusion. These adverse responses (known as transfusion reactions) range from fever, hives, shaking chills and low blood pressure to severe allergic reactions, shock and even death. Transfusion Medicine researchers now know far more about these families of biological response modifiers which include histamine, complement, cytokines, bradykinin and other biologically active molecules. Studies of the role of these mediators in adverse reactions to transfusion and research into how to modify and control these response modifiers is needed. Basic and clinical research in these areas will provide a fruitful avenue for improving the safety of blood transfusion for adult and infant transfusion recipients alike.

IMMUNOLOGY OF TRANSFUSION

Even compatible blood transfusions are recognized by the recipient as foreign substances. Though blood transfusion is a lifesaving therapy, transfused blood components are still recognized as a foreign substance by the human body. It is known that blood transfusion can produce adverse changes in the body's natural immune defenses. These changes include the potential for decreasing the natural defenses of transfusion recipients in their fight against bacterial infection and preventing or decreasing the incidence of cancer recurrence. It may seem paradoxical, but more and more evidence is accumulating to show that blood transfusion may, in certain situations, prove to be a double edged sword. Lifesaving transfused blood may actually promote certain diseases in the recipient, while preventing the risks of blood loss. Bone marrow transplant patients, cancer patients and other immunosuppressed recipients, men and women, the very old and the very young are all at risk for these types of immunological complications. Fundamental basic research by Transfusion Medicine specialists is needed to gain vital knowledge on how to combat this adverse aspect of blood transfusion. Transfusion researchers are also poised to make great strides in understanding the molecular biology and function of blood cell antigens.

Blood transfusion involves the transplantation of living cells from the blood donor to the recipient. This procedure can suppress the transfusion recipient's immune system, thereby decreasing the recipient's defenses against postoperative bacterial infection and tumor recurrence. Preliminary research suggests that when standard blood components are modified in certain ways, such as by exposure to gamma irradiation or by removal of donor leukocytes or donor plasma, the immune altering effect of transfusion may disappear. The role of cytokines as mediators of transfusion-associated immune modulation may represent a possible avenue of research.

Blood transfusion can also stimulate immune reactions to tissue (HLA antigens), platelet antigens, and red cell antigens, significantly impairing the ability to support transfusion-dependent patients. The AABB urges the Subcommittee to support research to prevent transfusion related immune suppression.

---

[2] General Accounting Office report on blood safety released on March 12, 1997, entitled "Flood Supply: Transfussion-Associated Risks."

[3] The study found that 186 of every 10,000 survey respondents (1.9 percent) reported some risk for infectious disease that would have resulted in deferral during the donation process had that risk been revealed.

PERIPHERAL BLOOD STEM CELLS AND CORD BLOOD

Red blood cells that carry oxygen, white blood cells that fight disease and platelets that stop bleeding are all produced from a single progenitor cell known as a hematopoietic stem cell. Transplants of these stem cells are increasingly replacing bone marrow transplants for reconstituting bone marrow in chemotherapy patients. Because of their ability to multiply into many different types of blood cells, stem cells may also become the ultimate vehicle for curing diseases through gene therapy.

Recently, it has been found that considerable quantities of stem cells can be collected from the blood stream. Stem cells are also increasingly collected from the blood remaining in the placenta and its attached umbilical cord after delivery of newborn babies. Although the total volume of blood is small and is normally discarded after birth, research indicates that the amount of stem cells is great enough to perform stem cell transplantation in children with leukemia and other diseases.

The AABB is pleased that the NHLBI is funding a five-year multi-center study of the transplantation of stem cells collected from cord blood. To establish the necessary infrastructure for this research, the institute established a network of umbilical cord blood banks and transplant centers. This research will help determine the clinical efficacy of cord blood stem and progenitor cell transplants.

This initiative is expected to pose new questions on the proper use of peripheral blood stem cells and cord blood. A variety of both biological and technical issues require continued investigation. These include proper immunologic and functional characterization of the stem cell, investigation of methods of stimulating stem cell production in normal donors, and optimum methods for the collection, processing and storage of stem cells. The AABB supports basic and applied stem cell research.

Improving Transfusion Medicine research training and its clinical research infrastructure is vital to furthering Transfusion Medicine research productivity. Such an infrastructure is currently nonexistent. Accordingly, the AABB supports development of a system of linked Centers of Transfusion Excellence for Research and Training. Such Centers could provide the critical mass of resources needed the to accomplish NIH/NHLBI sponsored research initiatives in the Transfusion Medicine areas outlined above.

FISCAL YEAR 1999 FUNDING LEVELS

The AABB is sensitive to the many demands on the discretionary funds in the federal budget. However, we view medical research funding as an investment in America's future competitiveness. Consistent with the Ad Hoc Group for Medical Research Funding, the AABB endorses a 15 percent increase in NIH funding for fiscal year 1999 as a first step toward the goal of doubling the NIH budget over the next five years. This recommendation is consistent with recently articulated congressional support for doubling the amount authorized for basic science and medical research for a number of research agencies, including the NIH. Additionally, this level of funding would sustain the current rate of growth NIH has experienced during the past decade.

On behalf of the many scientists devoted to improved blood transfusion practice, the thousands of health care professionals who work daily to deliver blood services, and the millions of American transfusion recipients, the AABB appreciates this opportunity to discuss federal support for research in transfusion medicine before the Subcommittee.

PREPARED STATEMENT OF K. KIMBERLY KENNEY, EXECUTIVE DIRECTOR, CHRONIC FATIQUE IMMUNE DYSFUNCTION SYNDROME (CFIDS) ASSOCIATION OF AMERICA

Mr. Chairman, thank you for the opportunity to submit testimony to the Committee for the third consecutive year. My name is Kimberly Kenney, and I am executive director of The CFIDS Association of America. The Association is the world's largest and most active charitable organization dedicated to conquering chronic fatigue and immune dysfunction syndrome, or CFIDS, also known as chronic fatigue syndrome or CFS. With more than 23,000 members and a mailing list of nearly 200,000, The CFIDS Association is the leading non-profit 501(c)(3) organization working to conquer CFIDS. In its mission to conquer CFIDS, the Association supports education, public policy and research programs. Nearly all of the funds which support these programs are donated by persons with CFIDS and those who care about them. Since our founding in 1987, we have funded over $3.3 million in direct research grants and have distributed hundreds of thousands of copies of our magazine, The CFIDS Chronicle.

CFIDS is a serious and complex illness that affects many different body systems. The cause has not yet been identified and there is no cure. The illness is characterized by bone-crushing fatigue, persistent flu-like symptoms, intractable pain and Alzheimer-like cognitive deficits. These and other symptoms can come and go, complicating treatment and the ability to cope with the illness. In addition, most symptoms are invisible, making it difficult for others to understand the problems that persons with CFIDS have. The illness is often severely disabling and can last for many years. Further, it is often misdiagnosed because there is no diagnostic laboratory test and it closely resembles other disorders including multiple sclerosis, Lyme disease, lupus and post-polio syndrome. Studies using the restrictive research definition of CFS have reported that at least 500,000 adults in the United States suffer from CFIDS. Although little study has been done on CFIDS in children and adolescents, it is clear that kids do get CFIDS. The lack of understanding about CFIDS by pediatricians, school teachers and administrators and other children can make for a nightmarish experience for the young patient and his/her parents.

The CFIDS Association leads efforts to make CFIDS a recognized mainstream medical concern. A foundation of knowledge and experience has been created through an expanding research effort. Patient care and diagnosis remain more art than science, but meaningful advances promise to be imminent and initiatives underway to educate healthcare professionals will improve understanding of the complexity of this illness among providers.

I am honored to report to the Committee the progress being made in unraveling the mysteries of CFIDS. This committee has provided leadership and vision for the federal agencies which must meet the needs of persons with CFIDS. The CFIDS-related report language in the fiscal year 1998 appropriations bill was greatly appreciated by the CFIDS community. I ask for your continued support of activities which have been critical to this improved understanding.

Please allow me to recount some of the specific accomplishments of the past year that underscore the value of continued federal investment in these activities:

—In its first year, the Department of Health and Human Services Chronic Fatigue Syndrome Coordinating Committee (DHHS CFSCC), on which I serve as one of two patient advocates, has made important progress in raising awareness of CFIDS within the government and coordinating government activities across agencies. Yet its real and potential effects could extend far beyond the government's reach into the general public, the medical community and private research. The Committee's next meeting, April 28–29, will include a day of pediatric CFIDS science designed to identify the most promising areas of investigation. The following day the Committee will establish priorities for action and further inquiry.

—The Office of the Secretary for Health produced one of 1997's greatest achievements—a medical education program broadcast by satellite across the country. Many federal agencies and patient representatives participated in the creation of this program: it was conceptualized and written by a team of patient advocates and staff from DHHS, the National Institutes of Health (NIH) and Centers for Disease Control (CDC); promoted by the Health Resources and Services Administration (HRSA) and patient advocates; and broadcast on satellite by CDC and over the Internet by a private company.

—The Association's partnership with HRSA's Area Health Education Centers (AHEC) to promote the satellite program within the health care community was integral to the success of the program. The AHEC system's expertise in training health care workers resulted in 78 satellite viewing sites and over 1,200 provider-participants.

—The extramural CFS research effort at NIH continues to make progress. The National Heart, Lung and Blood Institute's (NHLBI) first CFS research grant was made to Harvard's Roy Freeman, MD, who is investigating abnormalities in the autonomic nervous system. Additionally, the National Institute of Allergy and Infectious Disease (NIAID)-funded CFIDS epidemiology study at DePaul University received a supplemental grant to expand its research of children and adolescents with CFIDS.

—CDC's CFIDS research program has shown improvement. The second phase of a large community-based study of CFIDS in Wichita, Kan. began in late 1997. CDC's steps to augment its pediatric CFIDS research program, as requested in fiscal year 1998's report language, are very encouraging. In addition, CDC has recommended the creation of a unique ICD–9 code for chronic fatigue syndrome. The new code, 780.71, should improve the tracking of CFS cases in the healthcare system and lead to better reimbursement by insurance companies and more useful epidemiological data.

—The association between CFIDS and the Gulf War syndrome was strengthened by CDC research which showed that primary symptoms experienced by both groups are the same—fatigue, cognitive abnormalities and widespread muscle and joint pain. This data supports the need for improved communication between civilian, military and government scientists working to define both illnesses.

—In response to pressure from CFIDS advocates, the Food and Drug Administration (FDA) approved limited distribution and a clinical study of Ampligen, a drug which has shown benefit in treating CFIDS. We remain supportive of this and other studies which give CFIDS patients access to promising drugs at the earliest opportunity.

These achievements have been facilitated through fiscal year 1997's significant, though comparatively small, combined federal investment of $14 million. While these accomplishments show clear progress in the federal commitment to battling CFIDS, it is apparent that Congressional and private support for bolstering this effort is still necessary.

—Problems with the CDC bureaucracy continue to exist. We have been extremely frustrated in our efforts to track the agency's use of funds allocated to its CFIDS program. In March, CDC officials provided The CFIDS Association with a line-item accounting of its CFS spending in fiscal year 1996 and fiscal year 1997 and a plan for fiscal year 1998 spending. In each of the three years, total spending added up to exactly $5,789,000, but the amount spent in each object class varied widely from year to year (See Appendix). For example, "Supplies" were $600,871 in fiscal year 1996, $86,027 in fiscal year 1997 and estimated at $180,222 in fiscal year 1998. We could find no explanation for these spending disparities after reviewing CDC's CFS activities over the past 30 months. Mr. Chairman, we ask that you question CDC officials about this matter when they come before you this spring.

—Similar difficulties have been experienced with the NIH. Despite repeated requests, NIH delayed for five months before providing a total for fiscal year 1997 funds spent on CFIDS. Despite the generous 7 percent increase Congress provided NIH in fiscal year 1997, total CFIDS funding was 10 percent less than NIH had planned to spend on CFIDS in fiscal year 1997, and it was only 2 percent ($150,000) more than was spent in fiscal year 1996. In addition, the fiscal year 1998 estimate is 5 percent below the funding level estimated in 1997. The erosion of NIH support for CFIDS research underscores the need for clearer direction from this Committee.

—Concerns remain high about the obstacles persons with CFIDS encounter when seeking disability benefits through the Social Security Administration. The SSA's Office of Disability has drafted a ruling to guide the adjudication of CFS disability claims. There are a number of problems with the first draft of the ruling, but SSA has committed to working with The CFIDS Association to improve it. We are cautiously optimistic, and encourage the Committee to reiterate its support for improving SSA's response to CFS disability claims.

—The scientific advances that have been made, while encouraging, have not helped the individual patients who are desperate for better care. Diagnosis is still made by excluding all other possible causes of symptoms, a long and costly process. Patients who find a physician knowledgeable and willing to treat them commonly experience a discouraging (and potentially dangerous) process of trial and error using any number of usually inadequate symptomatic medicines. Advances in biomedical research still provide the greatest hope for helping individual patients, and we hope the Committee will continue its support of expanded CFIDS research.

—A broad-based, comprehensive CFIDS education effort could also help individual patients by improving the health care industry's understanding, diagnosis and treatment of CFIDS. The satellite training program was an important first step. There is still an enormous need for more pervasive educational programs which, ideally, would again combine the resources of CDC, HRSA, researchers, clinicians and advocates.

—Per the Committee's fiscal year 1997 report language, the CFSCC formed a task force to consider the issue of changing the name "chronic fatigue syndrome" to one which more appropriately reflects the disease's pathophysiology. The task force determined that, while there is enormous support from all sectors to change the name, science has not progressed to the point of clear consensus for a suitable alternative name. We actively seek to advance understanding so that a less stigmatizing name might be adopted and broadly announced.

To encourage continued growth in the CFIDS research effort and to undertake programs that will begin to address the real-world needs of CFIDS patients for ear-

lier detection, better care, and improved access to Social Security disability benefits, we must request an expansion of resources dedicated to these crucial efforts.

The CFIDS Association of America offers the following recommendations for fiscal year 1999 appropriations and committee report language:

Secretary for Health

The Association requests that Congress earmark $1 million of the discretionary funds allocated to the Secretary of Health and Human Services to maintain the Department of Health and Human Services Chronic Fatigue Syndrome Coordinating Committee (DHHS CFSCC). We ask that the Committee include report language directing the use of this body to coordinate CFIDS research across the Public Health Service by defining priorities and creating a yearly action plan. Included in the purview of the CFSCC, we recommend oversight into programs, performance, budget allocations and priorities. Finally, we ask that the Committee support the renewal of the CFSCC's charter beyond its expiration in 1998.

National Institutes of Health

Despite the Committee's generous report language directing NIH to provide additional resources for CFIDS research, it appears that this direction has not been heeded by the agency. While the Committee's reluctance to earmark funds for medical research is well understood, the erosion of NIH funding for CFIDS research underscores the need for stronger direction from this Committee. The Association requests that Congress appropriate an additional $10 million to NIH for extramural grants focused on promising areas of CFIDS research. We support the Congressional proposal to double the NIH's budget within the next five years, as biomedical research gives us the greatest hope for conquering CFIDS. We ask that the Committee include report language continuing to direct NIH spending priorities to investigations that will define the pathophysiology of the illness and identify diagnostic markers. We also request that the Committee include report language establishing the need for a special Program Announcement dedicated to the study of all facets of pediatric CFIDS. Finally, the Association asks for report language urging NIH officials to identify appropriate NIH advisory committees for CFIDS representation and ensure appointment of qualified persons thereon.

Centers for Disease Control and Prevention

At the CDC, the Association requests that Congress appropriate a $5 million increase to expand laboratory studies (including serial analysis of genomic expression (SAGE) studies) and surveillance projects, including outreach to populations not formerly recognized as being affected by CFIDS, namely minority populations and children and adolescents. We are concerned that CDC may be delaying the addition of a neuroendocrinologist to its CFS research group as directed by the Committee, and request reiteration of the Committee's support for this addition.

Social Security Administration

Despite the regular attempts by this Committee to secure the attention of SSA officials to the unique problems that CFIDS patients encounter in the process of applying for SSDI benefits, the situation remains that CFIDS patients regularly encounter SSA employees unfamiliar with or erroneously informed about CFIDS and its diagnosis and the functional limitations the illness imposes. The Association asks the Committee to once again remind SSA, through report language, of its support for developing and implementing appropriate training agendas and materials for SSA and Disability Determination Service employees, and of its support for the formation of an active CFIDS advisory committee within SSA. Finally, we request that the Committee direct SSA to expedite efforts to investigate obstacles to benefits for persons with CFIDS and to keep medical information updated throughout all levels of the application and review process.

Health Resources and Services Administration

The Association requests an appropriation of $500,000 to HRSA to develop a training curriculum for health care providers in practice and providers in-training through the existing Area Health Education Center Program. The curriculum, once distributed, would improve the detection, diagnosis, treatment and management of CFIDS patients. Effective programs could yield healthcare spending savings equal to many times this small investment.

Department of Education

The Association requests report language directing DOE's Office of Special Education Programs to inform educators about CFIDS and the special educational needs of students with CFIDS.

Members of the Committee familiar with our issue will recognize some of these requests from previous years. The Association has strived to make consistent, reasonable requests with the goal of providing greater clarification of issues critical to those who suffer from the disease. Using this strategy, we have been rewarded through the progress in many areas which I mentioned earlier. However, there are still great challenges ahead.

We sincerely hope that, once again, Congress will work with us to secure a dedicated and effective federal response to CFIDS so that we can put an end to the suffering caused by CFIDS at the earliest date possible. The CFIDS Association of America will continue its efforts to inform Congress about CFIDS to secure support for this committee's leadership on the illness, as well as that shown by other individual Members. We will also continue our efforts to hold the federal agencies accountable for the direction delivered by Congress through the Appropriations bill and its accompanying report language.

Mr. Chairman, we have all worked diligently to develop a basic understanding about CFIDS. The investment we've made over the last decade will soon generate dividends in terms of more definitive means of diagnosing, treating and, perhaps, preventing the illness. Your commitment to this effort is needed now more than ever. We must capitalize on the opportunities now before us so that the children, teens and adults with CFIDS experience improved care and function. They wish desperately to return to productive lives as students, parents, employees and citizens. Thank you for your efforts on their behalf, for your attention to our cause and for your thoughtful consideration of our requests.

APPENDIX.—CENTERS FOR DISEASE CONTROL AND PREVENTION, NATIONAL CENTER FOR INFECTIOUS DISEASES DIVISION OF VIRAL AND RICKETTSIAL DISEASES CHRONIC FATIQUE SYNDROME DISTRIBUTION OF RESOURCES

	Fiscal year 1996	Fiscal year 1997	Fiscal year 1998 estimate
Estimate personnel	$980,198	$1,072,006	$987,521
Travel	25,290	81,875	117,236
Transportation	28	1,418	18,568
Rent/communications	8,750	159,589	90,500
Printing	.....	3,894	5,500
Other/miscellaneous	320,620	172,648	483,046
Supplies	600,871	86,027	180,222
Equipment	599,092	373,917	370,877
Extramural agreements	1,588,042	2,132,014	1,827,918
Total direct program costs	4,262,947	4,083,388	4,083,388
Program support costs[1]	1,526,053	1,705,612	1,705,612
Total costs attributed to CFS research at CDC	5,789,000	5,789,000	5,789,000

[1] Overhead to the National Center for Infectious Diseases and the Centers for Disease Control

PREPARED STATEMENT OF JOHN S. GUSTAFSON, EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF STATE ALCOHOL AND DRUG ABUSE DIRECTORS, INC.

Mr. Chairman and Committee Members, my name is Jack Gustafson and I am the Executive Director of the National Association of State Alcohol and Drug Abuse Directors or NASADAD.

Appropriations request

Thank you for the opportunity to submit this testimony on the need for the Federal government to make an increased investment in the provision of alcohol and other drug prevention, treatment and research services. Specifically, we are supporting a 15-percent increase of $254 million to the Substance Abuse Block Grant that is currently funded at $1.36 billion. The funding level of $1.36 billion includes a 2-year transfer of $50 million appropriated to provide treatment to former recipients of Supplemental Security Income (SSI) and Social Security Disability Income (SSDI). Although the legislative authority for this additional $50 million was only

for fiscal year 1997 and fiscal year 1998, we are urging that this level of funding be maintained based on the need for treatment.

We are also supportive of funding increases to the following other programs:

—$180 million each for the Centers for Substance Abuse Prevention and Treatment to support Knowledge Development and Application (KDA) programs;

—$611 million for Safe and Drug Free Schools and Communities;

—$262.2 million for the National Institute on Alcohol Abuse and Alcoholism and

—$658.9 million for the National Institute on Drug Abuse.

In supporting these increases, we emphasize the need for new and stronger linkages between these Federal programs and the Substance Abuse Block Grant that is the primary commitment to Federal funding and partnership with the states.

About NASADAD

NASADAD represents the concerns of State Alcohol and Drug Abuse Directors who administer and fund prevention and treatment services through a network of over 7,000 primarily not for profit community providers. State agencies provide a wide array of treatment, prevention, and support services to Americans of all income levels. Because substance abuse is a critical concern for many health and social service systems-our members are actively involved in issues such as AIDS, tuberculosis, health services for pregnant and parenting women, welfare reform, child abuse and neglect, employment, juvenile crime, and criminal justice.

Three key issues

I would like to discuss three key issues:

Welfare reform and need for treatment.—It is estimated that over 1 million welfare mothers have a substance abuse problem that requires treatment. As welfare reform is implemented, States are under pressure to find the resources needed to provide treatment services to get these mothers back to work. There are now long waiting lists for treatment. Without new dollars, it will be difficult for moms receiving Temporary Assistance for Needy Families (TANF) and others in need to receive appropriate treatment.

Prevention.—Prevention of alcohol and other drug problems in our youth remains a high priority. As a Nation, we continue to be alarmed by the number of youth who are initiating alcohol and drug use. The Office of National Drug Control Policy (ONDCP) has begun its media campaign on drug prevention in earnest. Now it is up to States to provide programs that will meet the increased demand for prevention services that can logically be expected as a result of that campaign.

Formula consensus.—State Alcohol and Drug Abuse Agencies take seriously the charge given last year by House and Senate appropriators to work closely with the authorizing committees, SAMHSA, and the field on developing consensus on the formula issue.

Substance abuse problems

It is important to have a sense of the scope of the problem as funding decisions are considered. The National Household Survey on Drug Abuse, funded by the Department of Health and Human Services, provides a good overview of the extent of alcohol and drug abuse problems in our country. Here are the most current statistics:

—13 million Americans use illicit drugs.

—9 million youths (under age 21) consume alcohol. Of these, 4.4 million are binge drinkers, including 1.9 million heavy drinkers.

—An estimated 10.1 million Americans use marijuana or hashish. Of these, 2.4 million are new users, many of whom were youth.

—The number of cocaine users is 2.6 million.

—There were an estimated 141,000 new heroin users in 1995. Most of these new users were under age 26. The rate of heroin initiation for the age group of 12–17 reached historic levels.

—More than half of the youths ages 12–17 reported that illicit drugs like marijuana and heroin were easy to obtain. 15 percent of youths reported being approached by someone selling drugs.

Public system

Now that you have an idea of the extent of the problem, I would like to share with you information about our current treatment and prevention efforts. In 1995, State Alcohol and Drug Agencies administered over $4 billion in substance abuse services. This level of funding supported nearly 1.9 million treatment admissions for alcohol and other drug problems. Also out of the $4 billion, States spent over $583 million on prevention services.

The Substance Abuse Block Grant is currently funded at $1.36 billion and is the primary federal commitment to substance abuse prevention and treatment. Twenty percent of the Substance Abuse Block Grant is for Prevention. The block grant represents about 1/3rd of overall funding for the State publicly supported system.

Number of persons needing treatment

Every year, NASADAD completes a survey of our State Agencies to get a rough estimate of the number of individuals who have requested or need treatment services. This survey helps to supplement the national estimates that are done on a periodic basis of individuals who have drug or alcohol problems.

States report how many people they currently have on their waiting lists as well as make projections about how many TANF or former Supplemental Security Income (SSI)/Social Security Disability Income (SSDI) recipients need treatment in their individual States. The last survey was done in August of 1997 and shows the following:

—On a national basis, States estimate that more than 1 million individuals need alcohol and other drug treatment.

—Of that 1 million, there are 52,419 on waiting lists, 240,291 are former SSI/SSDI recipients, and 779,710 are TANF recipients.

Here are some numbers from that waiting list for a few States represented on this Subcommittee: Pennsylvania: 49,721; Iowa: 9,149; Wisconsin: 20,858; Texas: 87,917; and North Carolina: 25,108

It is important to note that these numbers are just the tip of the iceberg and were collected prior to implementation of many Federal and State welfare reforms. The number of those needing treatment is expected to expand exponentially as welfare reform progresses.

Department of Labor—Welfare to work

NASADAD is well aware of how important our treatment system is to getting TANF moms and others back to work. We have been working closely with the Department of Labor and the Private Industry Councils (PICs) to help assure the success of the 2-year Welfare to Work program authorized and funded by Congress last year.

One thing that is clear to all of us—State administrators, providers, employers, and welfare experts—is that the long waiting lists for treatment serve as a barrier to getting these moms back to work. It is also clear that unless TANF recipients get the treatment they need—job retention will be a major problem for families, States, and employers.

How States would spend new dollars

The following are examples of how States would use additional block grant funds to meet the need for increased prevention and treatment services:

—First and foremost, reduce the number of people on current waiting lists;

—Place professional staff in local welfare and Private Industry Councils (PICs) offices to screen TANF recipients and provide intensive case management for those identified as having a substance abuse problem;

—Develop new services for working TANF recipients such as weekend or evening treatment programs and lunch time prevention education programs;

—Establish employee assistance programs for employers who hire former welfare recipients with substance abuse problems;

—Work in concert with child welfare agencies to provide services to children of substance abusers;

—Expand after-school programs that prevent illicit alcohol, drug, and tobacco use by children and youth.

—Create new mentoring programs that engage business leaders in reaching out to youth to build esteem and life skills as well as to avoid substance abuse.

Treatment effectiveness

One question that always arises is: How effective is treatment? I am pleased to share that a newly released longitudinal study, funded by the National Institute on Drug Abuse, overwhelmingly confirms the effectiveness of treatment. The study, called the Drug Abuse Treatment Outcome Study or DATOS, tracked more than 10,000 patients in 11 cities over a three-year period. Building on two earlier nationwide studies, DATOS investigators have amassed a wealth of information on drug abuse treatment outcomes, retention rates, and treatment histories.

Among the patients that DATOS studied, drug use dropped significantly from the 12-month period before treatment to the 12-month period after treatment began. This was true for all types of treatment studied. Treatment also led to significant

improvements in other aspects of patient's lives—such as reduced involvement in illegal activity.

Another Federal report, The National Treatment Improvement Evaluation Study (NTIES), sponsored by SAMHSA studied 5,388 patients over a 5-year period. In addition to reducing drug use, NTIES showed an 18.7 percent increase in employment and a 77.6 percent decrease in violent crime.

The DATOS and NTIES reports also echo findings of States on treatment effectiveness. In a NASADAD report. Alcohol and other Drug Treatment: Policy Choices in Welfare Reform, States documented substantial improvements in employment status and other areas of patient lives from before treatment to after treatment:

—Arkansas had a post-treatment employment increase of 127 percent.

—A women's treatment program in Pennsylvania found that 80 percent of its graduates remained sober and employed after leaving treatment.

—A Wisconsin based women's treatment program found that 65 percent of their clients had their children returned out of foster care and 61 percent went to work.

—Missouri's AOD system found that clients' employment increased by 50 percent while their involvement in the legal system was cut in half.

Prevention effectiveness

Many studies also demonstrate the effectiveness of prevention. A 1997 NIDA report found that research based prevention programs significantly reduces youth alcohol and drug use. A study by Cornell University in 1995, found that students who participated in prevention programs are 40 percent less likely to use illicit alcohol and drugs.

We are all very excited about the ONDCP media campaign on drug prevention that is now underway—and I am sure that many of you have seen the public service announcements on TV or noticed the full page ads in the Washington Post and other papers. As a result of this campaign, we are anticipating a major increase in the demand for prevention services. We will need additional dollars to provide prevention programs or we will end up with a situation where frustration on the part of parents and communities is an unintended result of the media outreach effort. I have already talked about the kinds of innovative programs States would initiate with additional dollars.

Let me just add that a Federal commitment of dollars to prevention helps to leverage additional State, Community, and volunteer resources that are needed to reach our youth and other vulnerable groups.

Formula consensus

Before I end, I want to note that NASADAD members have already met to formulate an agreement on recommendations for the Substance Abuse Block Grant Formula. At issue for States is whether or not the current formula incorporates the best available data on the need for substance abuse services and the cost of delivering these services.

On January 20 and 21, 12 State Officials—including 7 State Alcohol and Drug Abuse Directors—spent over 15 hours in discussions and negotiations on the Substance Abuse Formula. This is the first time that States have had such an opportunity to provide their input on formula elements as other reports were crafted by academic economists and policy think tanks. The agreements that were made at this meeting are still being vetted so that they will have the benefit of review by all the States. But I can share with you the essence of the discussion.

Fiscal year 1998 base funding essential.—First, States agree that large shifts in funding, as proposed by SAMHSA in the last appropriations cycle, are disruptive to the service delivery system and should be avoided. When one State has a gain of 20 percent in one fiscal year, and another States loses 20 percent, dramatic service reductions will occur. Individuals and families in treatment will have services terminated. In addition, community providers, required by the law to be non-profit, will close or down size in the face of cuts. For this reason, States agree that a base funding level of the fiscal year 1998 appropriations for all States should be maintained.

Study needed.—Second, the proposed shift to non-manufacturing wages adjusted for health specific occupations—is some improvement over the use of manufacturing wages for the Substance Abuse Block Grant. It is by no means adequate. States have concerns that the formula does not incorporate the most up to date information on wages, or other elements of the cost of services. In addition, the use of general population statistics—weighted by age—raises questions. Many States and experts believe that other data for measuring the need for services would be more accurate.

It was agreed that a study should be undertaken by an objective organization, such as the National Academy of Science (NAS), with input from the States, which

can more carefully select and recommend the most appropriate formula components to Congress. The NAS has completed several previous studies on alcohol and other drug issues and health outcome measures and is viewed as an objective and reliable body.

Interim formula.—Finally, States recognize that it could require up to two years for such a study to be completed and that a decision must be made regarding how new dollars would be allocated in the interim. It was agreed that during this interim, the fiscal year 1998 base for all States should be retained and new dollars would be distributed to all States utilizing the non-manufacturing wages adjusted for health specific occupations.

Preliminary talks with the "field" of substance abuse indicate a general support for this approach. NASADAD will be continuing to consult with States, providers, counselors, advocates and others to reach a consensus that can be utilized by the authorizing and appropriating committees for fiscal year 1999.

Thank you for the opportunity to submit this testimony.

PREPARED STATEMENT OF CAROLE S. DOWNING, MSW, NATIONAL MULTIPLE SCLEROSIS SOCIETY

NATIONAL INSTITUTES OF HEALTH

Current research and treatment possibilities make this the most exciting time in the history of MS research. Now is a time to even further increase our commitment to NIH. We are extremely grateful for the fiscal year 1998 appropriation of $13.6 billion, a 7.1 percent increase over the fiscal year 1997 appropriation. We in the MS community are pleased with the trend of recent NIH budget increases which show the commitment by Congress to NIH and its importance to the health of Americans. Thank you, too, for your fervent commitment Mr. Chairman.

National Institute of Neurological Disorders and Stroke

Important intramural and extramural research on the MS disease process is being conducted under the auspices of the NINDS. The NINDS intramural program is doing several important studies using MRI imaging and the drug Betaseron, the very first drug for the underlying disease approved by FDA in 1993. The effect of interferon beta lb (Betaseron) has now been studied in a group of 14 patients with early mild, relapsing-remitting MS to test its ability to reduce alterations in the blood-brain barrier. In those studied, all have had a dramatic reduction in lesions, with complete cessation of disease activity, as measured by MRI, for many. These findings suggest an important site of action for beta-interferon, and point to new avenues of research involving early drug intervention to be further pursued. The studies also provide further evidence of the usefulness of MRI in monitoring both disease activity and response to treatment. A study such as this could be used as a foundation for more research if there were more resources.

NINDS also supports a substantial program of extramural research on MS. If there were more resources, we would suggest that the following topics are especially ripe for further examination: sex-based differences in disease prevalence and outcomes, regeneration of lost myelin and nerve tissue, clinical-pathological correlations of disease, and adhesion molecule function in cell traffic across the blood-brain barrier. The National Multiple Sclerosis Society and the NINDS have identified target areas of MS research with enormous potential for investment including:

—Identifying the targets in the immune-system attacks in MS and developing new methods to block or repair the destruction of the myelin insulation that coats nerve fibers;

—Investigating cellular and molecular mechanisms underlying recovery, including myelin-producing cells, production of myelin, and regeneration of nerve cells;

—Conducting early phase clinical trials for new therapeutics that have not been picked up by the research pharmaceutical firms and developing new methods to enhance recovery including further research on the blood-brain barrier; and

—Increasing the number of MS clinical research centers. These research centers would focus on the interface of basic and clinical research. Such a funding scheme could help build collaborative research efforts to speed transfer of basic research finding to clinical practice and could create a nationwide network of innovative research centers. This is the kind of program that might well be supported jointly between NIH and NMSS.

The National Multiple Sclerosis Society urges a 15 percent increase above last year's appropriation of $780,713,000.00 for the National Institute of Neurological Disorders and Stroke. Surely we must step up our research on neurological disease when we are so close to more significant advances.

National Institute of Allergy and Infectious Disease

NIAID also conducts research important to solving the puzzle of MS, now identified as an autoimmune disease. During the fiscal year 1997 fiscal year over $21.4 million will be spent on MS specific research projects.

NIAID researchers have proposed the idea of a vaccine for the treatment of MS and other autoimmune diseases. They have discovered that some of the cells involved in the immune response (called T cells) attack the brain in people with MS. Drugs that suppress the immune system are being given to some patients in an attempt to suppress the activated T cells. The next step would be to develop a more specific treatment that can attack the activated T cells without affecting healthy cells. This targeted approach may serve as a model for treating other autoimmune diseases such as juvenile diabetes and lupus.

The NIAID is also undertaking an initiative on gender-based differences in autoimmune diseases. There will be collaboration with NINDS and other relevant Institutes including the Human Genome Institute. Understanding the gender-based differences in the disease process will lead to new understanding of the role of hormones, stress and/or genes in the beginning of the disease and its progression. Increasing this area of research could indeed be helpful in answering the question of why two times more women than men have MS, and what science can do about this. Another fruitful area is the study of genetic susceptibility to MS and related complex neuro-immunological disorders. The NIAID has already made good progress in this area so further resources are needed to build on this success.

These and other research grants are certainly exciting and need to be extended. Thus we also urge you to increase by 15 percent the $1.350 billion research budget of NIAID so that basic and clinical immunology and autoimmunity research can continue and advance.

National Center for Medical Rehabilitation Research

The relatively new National Center for Medical Rehabilitation Research, has great potential for those living with MS. Each of the research projects studies ways to increase the independence of persons living with disability through preserving function and creating compensatory technology. Many suggested research projects, so far, have gone unfunded. The following are just two of the areas for which investment now could yield significant results: > developing new assistive devices; < developing coping skills creating alternative ways to achieve parenting and job skills using technology.

NIH as a Whole

We are members of the Ad Hoc Group for Medical Research Funding and concur with their budget proposal for NIH. For 1999, the Ad Hoc Group supports a 15 percent increase in NIH funding across Institute lines as the first step toward the goal of doubling the NIH budget in five years. Along with others in the voluntary health organization community we recognize the difficulty of achieving the goal of a 15 percent increase to 15.64 billion under the current spending caps. A national commitment to double the NIH budget over the next five years will necessitate that the Congress identify additional resources. We would urge the Budget Committees to explore all options carefully including adjusting the spending caps, increasing revenues from a tobacco settlement and/or tax, and investing part of the surplus.

II. DEPARTMENT OF EDUCATION

Rehabilitation Services Administration

The U.S. Department of Education, Rehabilitation Services Administration provided funding to the National MS Society for a 3-year demonstration project designed to help maximize job retention and enhance job satisfaction for persons with disabling chronic illnesses such as multiple sclerosis. The model that has been implemented involves meeting directly with employers and their employees with a chronic illness who are experiencing difficulties at work. It examined job performance barriers and offered recommendations on how to provide reasonable accommodations. Through the Project Alliance intervention, it is estimated that more than 80 percent of those in the program have retained their current position.

Project Alliance is complete and now as part of an ongoing commitment to employment for people with disabilities, we ask you to encourage RSA to fund a job retention pilot program for people with chronic illness especially those with a relapsing-remitting condition.

National Institute of Disability and Rehabilitation Research

The National Institute of Disability and Rehabilitation Research (NIDRR) has two separate areas of funding requirements, its basic research program and the Tech-

nology Related Assistance Program for People with Disabilities (Tech Act). Included in high potential basic research areas are: a longitudinal survey of the impact of managed care on individuals in various disability groups; and evaluation of the effects of the Americans with Disabilities Act on the daily lives of those living with mobility disabilities.

The Society applauds the decision of the NIDRR to initiate a new MS-focused center. With proper funding the MS Research and Rehabilitation Training Center should be able to answer crucial research questions concerning the effectiveness of rehabilitative services for MS patients. The Society is already commenting to the NIDRR on the priorities for such a center. We look forward to translating the results of this research through our new clinical services programs department.

It is urgent that you consider the cost of our proposed investment in biomedical research based on future benefits and savings both to the individual and society. This is true in both biomedical and rehabilitation research. Funding programs of early intervention to keep people working prevents early eligibility for Social Security Disability Insurance and the slow dissolution of an individual's funds leading to Medicaid coverage and the need for income supports. The fact that $11 can be saved for every dollar ($1) spent on rehabilitation testifies to its cost-effectiveness. Findings of a long-term health survey published recently by Dr. Kenneth G. Manton of the Center for Demographic Studies at Duke University clearly showed that medical research reduces and delays chronic illness and disability and contributes substantial savings in Medicare.

In summary, we suggest that the only way to control health care costs, the only way to make sure that young adults with MS remain independent, productive, taxpaying citizens is to increase support for government funded biomedical and rehabilitation research. Many experts now foresee MS as a family of largely controllable diseases with preventable disability but only if research continues at a rapid pace. We ask that you consider a 15 percent increase for fiscal year 1999 for NIH and a 7 percent increase for the rehabilitation research programs at the Department of Education. Thank you for allowing me to submit this testimony.

Prepared Statement of Joe L. Mauderly, Senior Scientist and Director of External Affairs, Lovelace Respiratory Research Institute

It is proposed that the Department of Health and Human Services (HHS), through its constituent agencies, participate in an interagency effort to establish and maintain the National Environmental Respiratory Center to facilitate a national initiative to understand the respiratory health risks of combined exposures to mixtures of airborne contaminants in the outdoor, home, and workplace environments.

THE NATION FACES A DILEMMA CONCERNING THE RESPIRATORY HEALTH EFFECTS OF ENVIRONMENTAL AND OCCUPATIONAL EXPOSURES TO AIRBORNE TOXICANTS

The U.S. has a large burden of respiratory disease

Respiratory diseases now kill one out of four Americans.—Among cancers, which are the second leading cause of death, lung cancer is the single largest killer. Nearly 200 thousand new cases of respiratory tract cancer are expected this year, and 170 thousand Americans will die from these cancers. Lung cancer kills more than twice as many women as breast cancer, and more than twice as many men as prostate cancer. Excluding cancer, chronic respiratory diseases and pneumonia are the third leading cause of death in the U.S., killing over 188 thousand Americans in 1995. Pneumonia and heart-lung failure are the terminal conditions for many of our elderly and together, pneumonia and influenza are the sixth leading cause of death. Asthma, growing unaccountably in recent decades, now afflicts 15 million Americans, including 5 million children. The incidence of asthma increased 61 percent between 1982 and 1994. Asthma is the leading chronic disease of children, and asthma deaths among children nearly doubled between 1980 and 1993. Chronic obstructive lung disease afflicts nearly 16 million Americans and causes 1 million hospitalizations annually. Allergic rhinitis (hay fever) afflicts 39 million Americans, 50 percent of whom are children. Viral respiratory infections are the most common cause of hospitalization of infants and cause a tremendous loss of productivity in the adult workforce.

Despite workplace standards, occupational exposures are still associated with numerous respiratory diseases, including allergic sensitization, rhinitis and bronchitis, pneumoconiosis, and cancer. Indeed, occupational lung disease is the number one work-related illness in the U.S. in terms of frequency, severity, and degree of "preventability". NIOSH estimates that as much as 30 percent of chronic obstructive

lung disease and asthma in adults may be caused by occupational exposures, and that 20 million workers are exposed to agents that can cause these diseases. The national health burden for occupational asthma is estimated to be as high as $400 million yearly.

The relationship between inhaled pollutants and respiratory disease is not well understood

The extent and nature of the association between environmental air pollution and respiratory disease are only partially understood. Air pollution is known to aggravate asthma, emphysema, bronchitis, infections and other respiratory illnesses. For example, particulate matter (PM) is statistically associated with death in elderly persons with heart and lung diseases, and this mortality is thought to occur largely from aggravation of their preexisting diseases. It is plausible, but much less certain, that air pollution might play a role in causing some diseases. For example, secondhand tobacco smoke is suspected of playing a role in conversion of the respiratory immune responses of children from normal Th1 to allergic Th2 responses. Seemingly to the contrary, the incidence of asthma is increasing while levels of most measured pollutants in the U.S. are decreasing. The reason for this is unknown, but speculations include vehicle traffic-related increases in ultrafine particles, which may be increasing but contribute too little mass to be detected by present air quality measurements. It is often easier to establish a link between occupational exposures and respiratory disease, but the impacts of many occupational exposures are still unclear. While it is known that occupational exposures to airborne dusts, chemicals, and allergens are linked to respiratory disease, it is often difficult to determine the relative contributory roles of the occupational exposures vs. exposures in the home and general environment and personal factors such as smoking. Tobacco smoke remains the most important confounding factor in determining the effects of both environmental and occupational exposures.

UNCERTAINTY ABOUT THE HEALTH EFFECTS OF POLLUTANT MIXTURES OR COMBINED EXPOSURES TO MULTIPLE AGENTS IS AN ESPECIALLY IMPORTANT PROBLEM

Little is known about the health effects of combined or sequential exposures to multiple toxicants

Agencies, researchers, congress and the public are becoming increasingly aware that addressing the health consequences of air pollution one pollutant at a time is approaching a point of diminishing returns. Paradoxically, as levels of regulated pollutants and workplace contaminants fall due to existing controls, and the most obvious health effects are reduced, the uncertainty faced in estimating the remaining health effects of airborne agents becomes larger. Air contaminants always occur as mixtures; nobody ever breathed only one pollutant at a time! It is increasingly clear that we must improve our ability to understand and control health risks from mixtures of toxic agents, typically at low concentration, and from combinations of sequential exposures to toxicants, at different times and in different locations. The effects of involuntary exposures to environmental air pollutants are be difficult to distinguish from the effects of home and workplace exposures, the effects voluntary activities such as smoking, cooking, use of household and personal aerosols and volatile materials, and other activities involving exposures to inhaled materials.

It is difficult to link health effects to specific pollutant classes, and even more so to individual pollutants. We know that multiple pollutants can cause the same effects (eg, inflammation, cancer). We also know that some pollutants can amplify the effects of others (eg, acid particles and ozone, radon and cigarette smoking). We do not know, but can presume likely, that a mixture of pollutants, each within its individually acceptable concentration, could present an unexpected aggregate health risk that is unacceptable. Moreover, our growing understanding of atmospheric chemistry is revealing an increasing number of reaction products for which there is little or no health information. Our poor understanding of the toxicity of toxicant mixtures makes it difficult to identify and prioritize the sources or practices whose management would most efficiently reduce the effects, and to compare the potential health gains to the financial, technological, and lifestyle commitments required to achieve them.

WE HAVE NEITHER THE REGULATORY NOR THE SCIENTIFIC ABILITY TO DEAL WITH COMBINED EXPOSURES

Present environmental and workplace air quality regulations address individual pollutants, or pollutant classes, one at a time. The present approach to implementing the National Ambient Air Quality Standards under the Clean Air Act addresses the levels of six individual pollutants (eg, carbon monoxide), or pollutant classes (eg,

particulate matter), individually. In contrast, the nearly 200 Hazardous Air Pollutants regulated under the Act are addressed by controlling the aggregate emissions of any or all of the compounds on a source by source basis with little consideration of the ambient levels or the individual or combined health effects of the compounds. For occupational exposures, OSHA sets Permissible Exposure Limits (PELs) and NIOSH sets Recommended Exposure Limits (RELs) for dozens of individual compounds and a few classes of agents such as petroleum distillates, welding fumes, wood dust, etc. Neither the environmental nor the occupational air quality or exposure regulations address the potential interactions among the individual agents, or the need for special limits for individuals with other risk factors. Under this regulatory strategy, a simultaneous exposure at the maximum allowable levels to all environmental and occupational air contaminants combined would theoretically be regarded as having no greater risk than exposure to only one of the agents at its regulated level!

Regulatory approaches and their legislative foundations are not the key problem; they can be changed. The overriding issue is our lack of knowledge about the health risks of pollutant mixtures, and the lack of ongoing research and research paradigms that will provide a basis for such changes. Although several laboratory studies with two or three-component mixtures of inhaled toxicants have been done, only a miniscule portion of the nation's research effort has focused in this area. Similarly, epidemiology has undervalued the combined exposures issue. Co-pollutants are most often viewed by epidemiologists as confounders to be minimized so that the effects of the one pollutant of interest can be isolated at its highest level of statistical significance, which may be just the opposite of the approach needed to understand the greater truth about the effects of the pollutant combinations and interactions. The research strategies that presently exist for addressing combined effects and interactions are limited, and creative thinking is needed to develop new approaches. Researchers have largely limited their thinking to testing simple combinations for effects that are more or less than additive; however, the myriad possible combinations cannot all be tested this way. Another common approach is to test the components of complex mixtures to determine their individual contributions to a single effect. The relevance of this approach depends on correctly identifying the effect and understanding its mechanisms. Both these and new approaches are needed.

THE NATIONAL ENVIRONMENTAL RESPIRATORY CENTER IS A NEW INITIATIVE TO IMPROVE OUR UNDERSTANDING OF THE RESPIRATORY HEALTH EFFECTS OF POLLUTANT MIXTURES AND COMBINED EXPOSURES

The center is intended to be a long-range, interagency, interdisciplinary initiative

The Center is being initiated this year with core funding provided for in the EPA fiscal year 1998 appropriations. The scope of the needed effort extends beyond the conduct of individual studies, or even a "program project" of research as might be funded through typical granting mechanisms. Identifying the bounds of the problem, benchmarking current thinking, and identifying the best paths forward will require the organized input of health specialists, atmospheric scientists, epidemiologists, risk assessors, and regulatory strategists. A central source of information specific to the health effects of pollutant mixtures and reaction products, research underway, and specialized research resources is needed. Researchers across the country need access to specialized facilities, but these need not be duplicated in multiple locations. Intellectual input and financial support needs to be sought from a broad range of Federal and non-Federal sources. It is appropriate for this long-term and challenging activity to be undertaken by an independent organization with high credibility, experience in the combined exposures field, and a strong commitment to success.

It is important that multiple agencies support the work and objectives of the Center. No single agency has the sole mandate for addressing the combined exposures problem, although EPA is readily identified as the agency with lead responsibility regarding management of environmental exposures. The Department of Health and Human Services, through NIEHS and NIOSH, and to a lesser extent through NHLBI, and its other constituent organizations, certainly has a stake in the health effects of mixed exposures, as do the Departments of Energy, Defense, Labor (OSHA), and Commerce (NOAA). Existing interagency committees and other Federal and government-industry working groups, such as the Committee on Environmental and Natural Resources Research (CENR) and the North American Research Strategy for Tropospheric Ozone (NARSTO) touch on these issues, but none has taken up the challenge of assuming the lead role of focusing attention, facilitating communication, and conducting research on the problem.

Lovelace is experienced in combined exposures research, and committed to meeting the challenge

The Lovelace Respiratory Research Institute is an independent, nonprofit organization totally dedicated to respiratory health research. It is also among the nation's few organizations having substantial experience in evaluating the health effects of mixtures of inhaled toxicants and combined or sequential exposures. It has strong expertise in the generation of complex atmospheres, inhalation exposure, respiratory dosimetry, measurement of health responses and determining their mechanisms, and the use of radiotracers to track compounds through the body. Lovelace has researched health risks from complex chemical mixtures involved in fossil fuel technologies, diesel exhaust, and combined radiation, chemical, and cigarette smoke exposures of workers. Work for a broad range of Federal and non-Federal sponsors has focused on the mechanisms of respiratory disease, health risks from complex mixtures and their constituents, interspecies similarities and differences, susceptibility from pre-existing respiratory disease, and the utility of animal responses for predicting human health risks. As one example, Lovelace recently developed the first successful rodent model of cigarette smoke-induced lung cancer and demonstrated that smoking markedly increased the cancer risk from irradiation of the lung. Based on its past research, current involvement in national occupational and environmental health issues, and focus on reducing respiratory disease, Lovelace has a strong commitment to the success of this new venture.

Lovelace operates the taxpayer-owned, recently privatized, Inhalation Toxicology Research Institute facility, an ideal physical location of the Center. It has several specialized facilities that can serve the scientific community as user facilities, such as laboratories for working with engine exhaust, tobacco smoke, and other complex mixtures. The facility has the nation's broadest capability for capability for exposing cells, tissues, and all species of laboratory animals to airborne materials and evaluating responses from the molecular to the clinical levels.

The Center Will Meet Specific Needs to Facilitate a Broader National Effort

The Mission of the Center is to catalyze, facilitate, and participate in a long-range national initiative to understand respiratory health risks from combinations of inhaled airborne environmental and occupational pollutants. The Center's goal is to help place the respiratory health risks from variable, mixed pollutant atmospheres in their appropriate context as a basis for regulatory and technological decision making. It is the role of the Center to facilitate this initiative by complementing the efforts of other interagency and government-industry groups to raise and maintain the visibility of the issue and make progress in its resolution.

The Center will perform the following functions:

Conduct Research.—The Center will conduct intramural and collaborative research relevant to understanding the respiratory health risks of combined exposures to airborne toxicants, and the exposure-response, mechanisms, susceptibility, and interspecies extrapolation issues important to advancing our understanding of respiratory disease and the control of health risks. The advice of a scientific advisory committee and other external scientific peer review will be used in guiding the Center's research program. This effort will be expanded by complementary research funded through collaborations with external scientists making use of the Center's specialized facilities.

Provide Information.—The Center will develop, maintain, and make broadly available information related to combined exposures issues. Researchers, agencies, congress, industry, students, and the public will access listings of published research, ongoing research, relevant scientific and regulatory issues, and research resources by phone, fax, e-mail, and the internet. The Center will develop and keep current information specific to combined exposures issues that is not currently maintained in organized form by other organizations. It will also provide links to the many related data bases on air contaminants and health that are maintained by other organizations.

Facilitate Communication and Planning.—The Center will coordinate workshops and conferences on the health effects of pollutant mixtures and combined exposures. Current knowledge will be benchmarked. Particular emphasis will be given to establishing a continuing communication loop between health scientists and atmospheric scientists to focus the efforts of both research communities on the exposures and effects thought to be the most important. Multiple government and non-government research sponsors and researchers from numerous organizations and disciplines will be brought together to identify critical research gaps and optimize the use of resources. This effort will complement other interagency and government-industry coordination activities.

Provide Research Facilities.—The Center will develop and maintain certain specialized facilities needed for research on mixtures, reaction products, and combined exposures. It will make the facilities operated by Lovelace available for use by researchers in other organizations, collaborating and providing assistance as appropriate. It will also assist researchers in identifying and accessing specialized resources and collaborators in other organizations.

HHS Should Participate in the National Environmental Respiratory Center

Initial funding for the Center was provided in the amount of $2 million in the fiscal year 1998 EPA appropriation. The Center can only be successful as a long-term initiative, with a broad base of support that includes key Federal agencies. Lovelace seeks support from HHS to expand the combined exposures research program beyond the small scope possible with the core funding from EPA, and is also seeking funding from other agencies. Lovelace is also seeking funding from non-Federal entities such as individual companies and trade associations for both undesignated support for the Center and specific research projects related to the Center's mission.

HHS and its constituent agencies are clearly stakeholders in combined exposure issues. For example, Environmental health is central to the mission of NIEHS and NHLBI has interest in the role of combined exposures in the mechanisms of lung disease. NCI has expressed interest in pursuing the mechanisms by which combined exposures might act synergistically to cause cancer. Lovelace's recent development of an animal model useful for evaluating the interactions between cigarette smoking and occupational exposure is especially relevant to the mission of NIOSH. That agency's most recent strategic plan specifically recognizes the importance of combined occupational exposures and interactions among toxic agents. That plan calls for new approaches to identify synergistic effects of multiple exposures, to improve laboratory and statistical analysis methods and to develop hazard controls that take into account the components of the mixture. Support of the Center through NIOSH would ensure that the national initiative in the area of combined exposures includes occupational concerns and is not limited to agents of concern only in the general environment.

Prepared Statement of Gerald G. Krueger, M.D., American Academy of Dermatology

Mr. Chairman and members of the Subcommittee, my name is Gerald G. Krueger, M.D. I am a Professor of Dermatology at the University of Utah School of Medicine. I am also the chairman of the American Academy of Dermatology's Research Council. I am currently the principal investigator of a grant from the NICHD, and serve as co-investigator of two grants funded by the NIDA. My curriculum vitae has been enclosed for your information.

My colleagues and our patients thank you, Chairman Specter, and members of the Subcommittee for your continued support for the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). The Academy acknowledges the very difficult choices that this Subcommittee has made over the last few years. We are grateful that biomedical research enjoys bipartisan support in this Subcommittee and in the Congress.

Our Nation's biomedical research infrastructure is an intricate relationship of academia, industry, and the federal government. The NIH serves as the primary source for basic research through universities and independent research institutions. This synergy has alleviated suffering for millions of Americans by fostering the development of innovative drugs and vaccines. Biomedical research is also the foundation upon which all medical care is based. Without the NIH, we would not be the world leader in research and patient care.

Dermatologists are trained to treat over 3,000 disorders of the skin, hair, nails, and mucous membranes. Support for the NIH, most especially NIAMS, has broadened our knowledge of common as well as rare skin diseases.

The American Academy of Dermatology joins with our professional and patient advocate colleagues to support a funding increase of 15 percent for the NIH in fiscal year 1999. In addition, the Academy also requests an increase for the Centers for Disease Control and Prevention's Skin Cancer Prevention Program. This program is currently funded at a level of $1.8 million. We request that funding for this program be increased to $5 million in fiscal year 1999.

Skin cancer is the most frequent cancer diagnosis, more than all other cancers combined. This year, over 1 million new cases of skin cancer will be diagnosed in the United States. Nearly 80 percent of the new cases will be nonmelanoma skin

cancers, namely basal cell or squamous cell carcinomas. Although both basal cell and squamous cell carcinomas have a cure rate of 95 percent if detected and treated early; 1,200 Americans, like Congressman Steve Schiff, will die of these nonmelanoma skin cancers.

A recent "report card" issued by the National Cancer Institute (NCI), the American Cancer Society, and the CDC concluded that we have made great strides in reducing cancer incidence and mortality. The report stated that cancer incidence and mortality had declined, in some cases significantly, for nearly all forms of cancer. However, the report noted two deadly cancers that are on the rise—non-Hodgkin's Lymphoma and melanoma.

Melanoma is the most deadly form of skin cancer. It is estimated that 41,600 new cases of melanoma will be diagnosed this year, an increase of 3 percent over last year's levels. This year, 7,300 Americans will die from melanoma, accounting for six out of every seven skin cancer deaths. While the death rate from melanoma continues to be highest for older white males, melanoma strikes across the age spectrum and is now the most common cancer among people between the ages of 25 and 29.

Skin cancer is preventable. A determined public health effort of prevention, education, early detection, and basic biomedical research into the mechanisms of skin cancer will reduce the incidence and mortality of skin cancer. The Academy believes that this important skin cancer prevention program should receive additional resources to enhance the multi-faceted activities of the National Skin Cancer Prevention Program. If funding levels were to be increased from the current level of $1.8 million to $5 million in fiscal year 1999, the funds would be well spent. These additional dollars would allow the CDC to expand the Skin Cancer Prevention Education Program to additional states and territories, to coordinate and implement skin cancer prevention programs, to supplement its on-going Youth Risk Behavior Survey, support behavioral research, and strengthen professional education.

Skin cancer can also be effectively treated, if found early. I invite all the members of the Subcommittee to participate in an upcoming annual skin cancer screening of Congress. Members of the Washington, D.C. Dermatological Society will conduct a free skin cancer screening on May 13, 1998, between 9:30 am and noon in the Rayburn First Aid Station, Room B344.

Biomedical research is beginning to provide answers to our questions about skin cancers. Last year, researchers supported by the National Institute of Musculoskeletal and Skin Diseases (NIAMS) and the NCI significantly advanced our understanding of skin cancer. Scientists identified the gene that is the cause of a rare inherited disorder, basal nevus syndrome, and acquired basal cell carcinoma. Researchers believe that their findings may eventually lead to innovative treatments for basal cell carcinomas. We are also hopeful that NCI-supported scientists will be successful in their efforts to develop a melanoma vaccine.

The research supported by the NIH is crucial to our fight against other chronic, debilitating and sometimes fatal skin diseases. Skin diseases are an important health concern for this country, as they are the most common cause of chronic illness in the United States. This year, it is estimated that 60 million Americans will be affected by skin disease, costing our economy over $7 billion in treatment costs and lost productivity. Occupational skin diseases remain one of the most common causes of workers' compensation claims.

Psoriasis is a common skin disorder, affecting six million people in the United States. Previously, scientists believed psoriasis to be primarily a disorder of the keratinocytes, the most common cell in the outer layer of the skin. Recent investigations have greatly altered our understanding of psoriasis. Researchers now view psoriasis as an immunologic disorder, and this observation has led to new treatments for psoriasis. A tissue bank established by the National Psoriasis Foundation and supported by the NIAMS is helping scientists make progress in identifying the genes linked to this disease.

Eczema is a term often used to describe a family of conditions that include: atopic, contact, occupational seborrheic, and stasis dermatitis. Millions of Americans suffer from some form of eczema. While bench-to-bedside research pays dividends, there is much we do not know about how to prevent and best treat eczema. There is considerable interest around the world in identifying the numerous elements that trigger eczema and protecting patients from them.

Alopecia areata is a disease that causes hair loss on the scalp and elsewhere on the body. In its most severe form, alopecia universalis, all hair on the entire head and body are lost, leaving the skin unprotected from the sun and other environmental hazards. The nose and sinuses are also unprotected from foreign particles and bacteria. Children are the most often affected by this disorder. While alopecia areata is not life threatening, it is emotionally and psychologically devastating to these young children. In a recent issue of Science magazine, there was an article

describing the discovery of the "hairless" gene, the gene for alopecia universalis. While this discovery is very exciting, the discovery of the "hairless gene" does not unlock the secret of alopecia areata, and additional research is needed if we hope to develop more effective treatments or a cure.

Systemic lupus erythematosus (lupus of SLE) is a disease that disproportionately affects young African-American women, and a disease of great interest to members of this Subcommittee. Research has significantly broadened our knowledge of the genetic factors involved in lupus, including those infectious agents and other environmental factors that trigger this disease in susceptible individuals. Research has also helped us to develop special prevention and education programs in lupus. These programs have allowed us to screen many young African-American women for this disease. The severity of the disease will be drastically reduced, if we can identify and treat the disease at its earliest stages.

Scleroderma is another serious disease that predominantly strikes women of childbearing years. Scleroderma is a chronic, auto-immune disease of the connective tissue. Scleroderma patients overproduce the protein, collagen. Its cause or causes are unknown. The treatment program for these patients varies widely, depending on the severity of the symptoms. Patients with this disease may have thickening of the skin, especially around the joints; Raynaud's Phenomenon, an abnormal sensitivity to cold; gastrointestinal, renal, cardiac, dental, and pulmonary problems. The NIAMS supports both basic and clinical research on scleroderma. Recently, NIAMS added scleroderma to the list of diseases eligible for applications under the Specialized Centers of Research (SCOR) program.

Vulvodynia is a spectrum of chronic vulvar pain disorders. Today, no one knows what causes vulvodynia. Some cases of this disorder may be attributed to compression or disease of the pudendal nerve, others to Human Papilloma Virus (HPV), chronic candida infection and reactions to the anti-fungal treatments for candidiasis, but there is not clear agreement. There is also no specific test for vulvodynia and the diagnosis is often after ruling out other illnesses or infections. Unfortunately, there are no cures for this disorder, and few effective treatments for its symptoms. Additional research is desperately needed to answer the numerous questions concerning this disorder.

Sjogren's Syndrome is a third auto-immune disease that predominantly strikes women. The clinical manifestations of Sjogren's Syndrome are the result of decreased exocrine gland function throughout the body. Patients suffer a profound reduction in their quality of life, as the disease causes great discomfort in all areas of the body. In addition, Sjogren's Syndrome is associated with a number of life-threatening complications, including renal disorders and vascular complications. Currently, there is no known cure for Sjogren's Syndrome and the treatments available are aimed only at relieving the many symptoms of this syndrome.

Dermatitis herpetiformis, also known as gluten sensitive enteropathy, is an intensely itchy, chronic disorder that may start at any age, including childhood. Most patients who suffer from this disease have an associated sensitivity to gluten—a protein found in wheat, oats, barley, rye, and other grains. Dermatitis herpetiformis may often be confused with many other conditions, and patients may be misdiagnosed before being effectively treated. Like Sjogren's Syndrome, individuals with dermatitis herpetiformis have a marked increase in the incidence of certain histocompatibility antigens and it is not uncommon that these two disorders are occasionally seen in the same patient.

The Ichthyoses are a family of skin diseases in which there is abnormal development of the outermost layers of the skin. Researchers have discovered that the genes for many of the molecules involved with the structure of our skin are clustered on chromosome 1, in an area called the epidermal differentiation complex. Recent findings have linked several forms of ichthyosis, including a form that causes self-amputation, to mutations of a region of chromosome 1—the first time that disease was clearly linked to the epidermal differentiation complex.

Epidermolysis bullosa (EB) is another rare skin disease that has provided us with a great deal of information about skin. EB is characterized by extreme fragility of the skin. In EB, the slightest touch causes blistering, in many cases its symptoms resemble severe burns. EB can lead to severe loss of mobility, disability and even death. Researchers have identified specific genetic defects that cause several forms of EB. The establishment of an EB registry has allowed scientists to collect medical information and tissue and blood samples from EB patients, greatly facilitating efforts to identify the genetic causes of EB.

Pemphigus, like EB, is a blistering skin disease. In pemphigus, patients produce autoantibodies that attach the demosomal proteins that hold the skin together. The basic molecular mechanism for this blistering disease has been uncovered by research funded through the NIAMS. Future research in this disease is needed to

learn how and why the body produces these autoantibodies as well as to determine the relative role of environmental factors—such as viruses, bacteria, allergens and toxins—to this disease.

Ehlers-Danlos Syndrome is another group of rare inherited disorders that affects the skin as well as the joints and other organs. Patients with Ehlers-Danlos Syndrome have a defect within their collagen. This defect leads to extremely fragile skin that bruises and tears easily, joints that are hypermobile, and bruising and bleeding tendencies. The NIAMS has been the lead institute in research efforts to understand the mechanism of wound healing and this effort must continue to be supported.

Marfan Syndrome is a heritable disorder of the connective tissue, caused by a single abnormal or mutant gene. In addition to the skin, patients with Marfan Syndrome suffer from abnormalities in three areas: the eye, the skeletal system and the cardiovascular system. The severity of this syndrome varies greatly; and as there are no objective tests for diagnostic confirmation, diagnosis can be difficult. There is still no cure for Marfan Syndrome, although a variety of treatments have been used with some success.

Ectodermal Dysplasia (ED) is not a single disease, but a group of closely related disorders. More than 130 types of ED have been identified. Individuals with ED have absent or poorly functioning sweat glands; abnormal hair and hair follicles, and the natural hair and skin oils may be missing. Patients with ED are prone to rashes and are slow to heal when they are bruised or cut. Many are photosensitive, but the most common trait is the absence of teeth. Although many types of this disease have been identified and documented, there is a great deal that we do not know about these disorders. Additional research is needed to improve the care and management of these patients.

Pseudoxanthoma elasticum (PXE) is a heterogeneous inherited disorder, the hallmark of which is the dystrophic calcification of the elastic tissue of the skin, the eyes and the arteries. Because the skin manifestations of this disease are so prominent, the dermatologist is often the specialist who makes initial diagnosis and who can coordinate the care of the PXE patient with the ophthalmologist, cardiologist, vascular surgeon, plastic surgeon, and other health professionals. PXE may be inherited as either an autosomal recessive or dominant trait, but environmental influences may modify the clinical expression of this disease. This year, the locus for the PXE gene was isolated. This small step points us toward a cure for PXE.

Sturge-Weber Syndrome is characterized by an extensive vascular nevi or port wine stain at birth, involving the upper eyelid and forehead. In Sturge-Weber, the port wine stain is associated with various neurological abnormalities as well as irregularities in the eyes and internal organs. Children with Sturge-Weber begin to have seizures at one year of age. These convulsions are caused by an excessive growth of blood vessels on the brain, and often appear on the opposite side of the body from the port wine stain. The cause of this syndrome is unknown and more research is needed. Recent research has helped us to understand that port wine stains develop within the first 2 to 8 weeks of gestation. Additional research is needed for us to better understand the role that angiogenesis may play in these stains.

Porphyrias are a group of seven rare and complex disorders. The porphyrias are characterized by a mutation in genes that code for various enzymes of the heme biosynthetic pathway; and each porphyrias is biochemically unique. What causes these genes to mutate is still unknown. These diseases are often manifest in a variety of cutaneous lesions and patients are also very sensitive to sunlight and to many drugs. There is no cure for porphyria and treatment varies depending on the type. Additional research is needed to better understand what causes the genes to mutate. Better understanding of this process could eventually lead to the development of new and better treatments.

Vitiligo is a disease in which patients develop white spots in the skin that vary in size and location. These "spots" develop when the pigmented cells of the skin, melanocytes, are destroyed and melanin can no longer be produced. It is estimated that 1–2 percent of the population suffer from vitiligo, and in earlier times, these individuals were often associated with lepers. Although more noticeable in darker complected individuals, vitiligo strikes all races equally. More research is needed to understand why the body destroys these cells and to understand the relationship of this skin condition to its many complications, including Graves' Disease and other diseases of the thyroid, deafness and blindness.

The Academy also supports adequate funding for other institutes at the NIH, as skin disease research is supported throughout the NIH. The most important institute to skin researchers is the NIAMS; however, adequate funding levels for several other institutes is especially important to skin disease research.

The National Institute for Allergy and Infectious Diseases (NIAID) funds important research on AIDS, sexually transmitted disease (STD), and other infectious dis-

eases. Dermatologists daily treat the many cutaneous manifestations associated with HIV infection. These diseases include bacterial infections, viral infections, fungal and yeast infections, protozoal infections, hyperkeratotic and neoplastic disease of the skin. Dermatologists also treat other STDs, such as genital herpes, human papilloma virus, and genital warts. Future research opportunities for HIV and other STDs include the development of topical microbicides, new and more effective therapies, vaccines and improved prevention strategies. In addition, the NIAID also provides funding for immunologic skin disease.

Our skin is our first defense against disease and toxins in the environment. The Academy supports increased funding for the National Institute of Environmental Health Sciences (NIEHS). Our specialty has taken the lead in recognizing environmental hazards to the skin, at home and at work. Increased funding for NIEHS will allow this institute to expand research on the action spectrum for melanoma, percutaneous absorption of toxic and other chemicals and how that absorption may be affected by exposure of the skin to ultraviolet radiation.

Expanding our basic knowledge of the human skin will provide insight into other systemic diseases and may provide better treatments. The skin is an excellent delivery system for drugs. The development of skin patches and other devices allow for sustained release of drugs.

Mr. Specter and members of the Subcommittee, as I stated earlier, biomedical research is the foundation upon which all advance in medical treatment are based. I appreciate your attention and the opportunity you have given the American Academy of Dermatology today and welcome the opportunity to answer any questions.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF DENTAL SCHOOLS

The American Association of Dental Schools (AADS) represents all of the dental schools in the United States, as well as advanced dental education, hospital dental residency programs, and allied dental education institutions. It is within these institutions that future practitioners, educators, and researchers are trained; significant dental care provided; and the majority of dental research conducted. The AADS is the one national organization that speaks exclusively for dental education.

While dentistry has made significant progress in preventing oral disease and developing primary care treatments, little more than half of all Americans have access to routine dental care. A 1995 Centers For Disease Control (CDC) survey revealed that nearly half (44.3 percent) of adults report having no dental insurance. Consequently, oral diseases are still among the most prevalent and common of all chronic health conditions. A 1996 Healthy People 2000 review conducted by the CDC reports that in the United States, 94 percent of adults have evidence of past or current tooth decay, and only one third of adults age 35–44 years have all of their permanent teeth. Periodontal disease is also pervasive among adults 18 and over.

Oral cancer is more common than leukemia, Hodgkin's disease, melanoma of the skin, and cancers of the brain, cervix, ovary, liver, or stomach. Each year there are approximately 30,000 newly diagnosed cases of oral cancer, and 8,000 deaths. Accordingly, poor oral health has a tremendous economic impact on our country, causing our nation's workforce to miss more than 164 million hours of work annually.

The NIH reports that half of U.S. children already have cavities by age 7, and eighty-four percent of all children have experienced dental decay by age 17. Oral conditions left untreated severely impair a child's ability to concentrate in school and result in more than 52 million hours of time away from the classroom annually. If the nation is serious about having all children ready to learn by the time they enter school, we must improve access to comprehensive health services, including adequate oral health care. The importance of oral health will also be addressed in a U.S. Surgeon General's report that is currently under development for a release date of Spring, 1999.

Our funding requests for fiscal year 1999 reflect the expanding role of dentistry in our nation's health care system and the changing nature of the profession. Dental education institutions play an important role in providing oral health services in the community, and these institutions provide a significant amount of care to underserved and uninsured populations. Because the Subcommittee is under severe fiscal constraints, we have focused on dental education and research programs that are extremely cost-effective and will yield a significant return for the federal investment in improving access to primary health oral care.

General Dentistry Residencies.—General Dentistry Residency training programs provide dentists with the skills and clinical experiences needed to deliver a broad array of oral health services to the full community of patients. Dentists who have had the benefit of this advanced residency training consistently refer fewer patients

to specialists, which is especially important in rural and underserved urban areas where logistical and financial barriers can make specialized care unobtainable.

The General Dentistry Residency program has been a highly effective tool in improving access and availability of primary care services. Eighty-seven percent of those who receive General Dentistry Residency training remain in primary care practice. Compared to private practice, these residents treat 4 times the number of developmentally disabled, 6 times the number of medically compromised, and 26 times the number of HIV/AIDS patients.

Most current grantees include off-site rotations to underserved communities, where general dentistry residents provide oral health services to populations, such as the poor, the developmentally disabled, the elderly, and patients with infectious diseases. The following are a few examples of programs that are current or past recipients of General Dentistry Residency Training Grants, enabling these institutions to initiate or expand their training programs:

—Temple University School of Dentistry's General Dentistry Residency training program has a unique partnership with the Philadelphia Parent Child Center, a large Head Start program for 427 children in North Philadelphia. General Dentistry residents provide oral health screenings and follow-up services to 3–5 year old children enrolled at the Center. The General Dentistry Residency program at Temple also works with the University's "Outreach Program," which conducts health education, health promotion, and oral screenings to populations in the diverse neighborhoods surrounding the University. Many of these patients traditionally do not seek services from a dentist in private practice. Temple University first established its General Dentistry Residency program with four residents in 1990, with a HRSA General Dentistry Residency Training grant. A second three-year HRSA grant was awarded in 1992 which enabled the program to expand to six residents.

—The University of Iowa College of Dentistry received a General Dentistry training grant in 1991 which allowed for expansion of the residency program to include the establishment of an off-site clinic at the campus in Oakdale, Iowa, to provide residents with experience in rural practice. The College of Dentistry is currently in the process of developing a state-wide network of general dentistry training programs linked with the College and Federally Qualified Health Centers in Iowa. Expansion grant funding under the General Dentistry Residency program will be sought to support the first stage of implementation planned at the Broadlawns Medical Center located in Des Moines, which serves inner city poor and the medically indigent population of Polk County. The second phase of the project will facilitate the opening of three additional general dentistry training program sites in community-based settings.

—The University of Mississippi School of Dentistry (U.Miss) has successfully competed for two recent three-year General Dentistry grants. The first grant, awarded in 1993, established the General Dentistry Residency program at the School of Dentistry. In 1996, a second three-year grant resulted in the expansion of general dentistry residents from 3 to 5, facilitating the opening of a new dental clinic in a converted shopping mall located in one of Jackson, Mississippi's economically distressed neighborhoods. At the "Jackson Medical Mall" where the new dental clinic is located, residents gain experience providing dental care to the physically or psychologically challenged and other special patient populations that have experienced barriers to obtaining oral health services.

—At the University of Missouri-Kansas City School of Dentistry (UMKC), General Dentistry residents deliver dental care services to underserved populations in two area health clinics. One of the clinics is in a predominantly Hispanic community where most of the patients are Spanish-speaking only. The other clinic serves a large number of indigent, homeless, and HIV/AIDS patients. The UMKC general dentistry program was established with a HRSA General Dentistry grant in 1987, with four residents. The program expanded in 1993, from four to eight residents, with a second three-year HRSA grant.

—At the University of Oklahoma College of Dentistry (OU), residents participating in the General Dentistry Residency program spend two days a week providing oral health services at the ADENT Clinic located at Children's Hospital in Oklahoma City. General Dentistry residents at OU also provide a significant amount of free dental care through the Friendly Smiles Program, in which needy children are identified by the county and referred to the dental school clinic for treatment and preventive oral health care. The General Dentistry Residency program at OU was established with the support from a General Dentistry grant that ended in 1991. Today the program is self-sustaining and provides important clinical training and a valuable public health service to the community. Program evaluations confirm the success of General Dentistry Resi-

dency programs in meeting federal primary care objectives. The Bureau of Health Professions' evaluation of this program found that: "Considering the relatively modest investment of funds by the federal government, the impact on the growth and scope of General Dentistry programs and the subsequent effect on dental care has been substantial."

And all of this is achieved with start-up grants which provide federal support for no more than three years. This requires considerable skill, as General Dentistry Residency programs must attract enough self-pay patients and patients with dental insurance to offset the losses incurred in treating the indigent. Unlike their medical counterparts, dental programs cannot rely on reimbursement through Medicare because the program essentially excludes dental services, and Medicaid coverage is extremely limited, especially for adult care.

Demand for General Dentistry training continues to outpace supply for this primary care training as approximately 300 additional training positions are needed to accommodate the number of current applicants. Without Federal support, it would be extremely difficult to create new programs because of the lead time needed for these programs to become self-sufficient, and because of the high cost of start-up funding for dental equipment and instrumentation.

The 1995 Institute of Medicine (IOM) Study of Dental Education recommends that postdoctoral education in general dentistry should be available for every dental graduate and that an emphasis should be placed on creating new General Dentistry Residency positions.[1] While progress has been made in meeting the current and future demand for primary care training and care, much work still needs to be done. In 1997, the first year enrollment for all accredited dental residency programs would have accommodated only 63 percent of all U.S. dental school graduates. For these reasons, we urge the Subcommittee to support an appropriation that will permit continued progress towards achieving the workforce training goals set forth by the IOM. The AADS is seeking an inflationary increase of $200,000 over fiscal year 1998 levels for the General Dentistry Residency Training program, resulting in an fiscal year 1999 budget of $4 million for this cost-effective and proven primary care program.

The AADS would also like to bring to the attention of the Subcommittee legislation developed by the Senate Labor & Human Resources Subcommittee on Public Health and Safety, S. 1754, that would reauthorize the Title VII and Title VIII Health Professions Education and Training programs. S. 1754 would authorize the primary care dental program to include both General Dentistry Residency Training and Pediatric Dentistry Residency Training support. The AADS fully supports this expansion because, as with General Dentistry training; many applicants to Pediatric Dentistry training positions are turned away due to lack of positions. Pediatric Dentistry training positions have not expanded in the last 20 years, despite increased societal needs. Pediatric Dentistry is the dental counterpart to general pediatrics. While preventive dental care for children is one of the great successes in public health, there is still a significant unmet need, and with the establishment of the new State Children's Health Insurance Program (SCHIP) we expect the need for trained pediatric dentists to increase. Because the fiscal year 1998 appropriation provided $3.8 million for General Dentistry alone, the addition of Pediatric Dentistry to the authorization would require additional funding to ensure that critical training needs in both areas are met.

Ryan White HIV/AIDS Dental Reimbursement Program (Part F, Ryan White CARE Act).—Federal support for this program increases access to oral health services for people living with HIV/AIDS and at the same time, provides dental students and residents the education and training necessary to deliver oral health care to HIV/AIDS patients. Thus, two major federal objectives—service to patients of limited means and education of future practitioners—is accomplished with this important but very modest federal program.

As a result of immune system breakdown that occurs, HIV/AIDS patients are more susceptible to oral diseases, such as oral lesions that cause significant pain and oral infection leading to fevers, weight loss, and difficulty in eating, speaking or taking medication. Extreme pain in the mouth is frequently the symptom that motivates patients to seek care. In fact, many of the first physical manifestations of HIV infection are found in the oral cavity, and a dentist is often the first health care professional to diagnose these patients. Moreover, the development of some oral problems may signify that HIV infection is progressing.

Oral health care has continued to be a major need of HIV/AIDS patients, and consistently ranks high in surveys of health needs of HIV/AIDS patients.

---

[1] Field, Marilyn J., Ph.D., Editor, Dental Education at the Crossroads, Challenges and Change, National Academy Press, Washington, D.C., 1995, p.14.

It is important to remember that private insurance and Medicaid coverage for dental services is very limited or simply unavailable for adults. This lack of sufficient reimbursement particularly affects those dental education clinics that serve as the safety net for a significant number of Medicaid and HIV/AIDS individuals. The Ryan White HIV/AIDS Dental Reimbursement program facilitates treatment of patients by alleviating some of the financial burden faced by institutions, allowing some dental treatment facilities to stay open despite chronic under-reimbursement. This program represents a partnership between the federal government and dental education programs, in which the government partially offsets the costs dental education programs incur by serving a disproportionate share of HIV/AIDS patients. Dental education institutions accept this partnership because it helps us to continue to deliver and expand care for people living with HIV/AIDS. The program has also enhanced relationships of dental education institutions with state and local AIDS care programs.

In 1997, 104 dental education programs provided oral health services to approximately 70,000 patients, and collectively incurred $15 million in uncompensated costs. The Ryan White HIV/AIDS Dental Reimbursement program retrospectively reimbursed these dental treatment facilities a total of $7.3 million for services delivered.

A preliminary evaluation of program participants found that this program had a positive impact in the following areas: integrating oral health care with other services, increasing the support and commitment among providers to HIV/AIDS education and provision of care, increasing the providers' knowledge about infection control and treatment, and increasing patient access to oral health.

Early in the epidemic, the majority of patients seeking dental care were severely immuno-compromised. Thus, dental intervention was directed towards eliminating infection and pain with definitive procedures which had the lease likelihood of exacerbating the patient's already fragile condition. With the advent of multi-drug therapies, many patients are living longer and more stable lives. Therefore, dental intervention has increased in scope from palliative care to the full range of dental procedures like periodontal procedures, root canals, and advanced restorative procedures such as crowns, bridges, and partial dentures. Restoring oral health function is of course directly related to nutrition, which is so critical for immuno-compromised patients. We expect unreimbursed oral health costs will continue to rise as the number of individuals living with HIV increases.

For these reasons, AADS urges a modest increase of $1.2 million over the fiscal year 1998 levels for this important program, resulting in an fiscal year 1999 budget of $9 million for the Ryan White HIV/AIDS Dental Reimbursement program.

National Health Service Corps Scholarship and Loan Forgiveness Programs.—We strongly support the NHSC Scholarship and Loan Forgiveness Programs, which assist students with the rising costs of financing their health professions education while promoting primary care access to underserved areas. This is particularly significant given that the average graduating dental student debt is $82,000.

Over the last several years, and most recently in fiscal year 1998 appropriations report language, Congress has instructed the NHSC to increase dental participation in the loan repayment and scholarship awards programs. The number of dental loan repayment awards has increased slowly in recent years, yet we believe that additional loan repayments could be awarded. Problems continue to exist in the scholarship program, which has completely abandoned dental scholarships (the last dental scholarship was issued in 1994). We believe it is critical that the NHSC commitment to dentistry be maintained and strengthened as the need for dental providers is becoming more pronounced in underserved areas throughout the nation. According to a Department of Health and Human Services survey, currently 3,032 dentists are needed to service 957 designated dental Health Professions Shortage Areas (HPSAs), as compared to 1,400 dentists needed for 792 dental HPSAs prior to 1993. Accordingly, the AADS requests the Subcommittee to further pursue the need for increased dental participation in both the NHSC scholarship and loan repayment programs.

Health Professions Education and Training Programs for Minority and Disadvantaged Students.—We want to express our strong support for the various programs that play a critical role in the recruitment and retention of disadvantaged students and the recruitment of disadvantaged faculty. We request funding increases for the minority and disadvantaged assistance programs that are proportional to current funding levels within the context of the fiscal year 1999 budget request of $306 million for all Title VII and Title VIII Health Professions programs recommended by the Health Professions and Nursing Education Coalition (HPNEC). The funding levels advanced for the following programs as part of HPNEC's fiscal year 1999 budget request will maintain our nation's strong commitment to diversity and opportunity

in the health professions: Scholarships for Disadvantaged Students, Exceptional Financial Need Scholarships, Loans for Disadvantaged Students, the Centers of Excellence program, the Disadvantaged Assistance program (Health Careers Opportunity Program/Federal Financial Assistance for Disadvantaged Health Professions Students), and the Faculty Loan Repayment program.

Other Programs Under Title VII of the Public Health Service Act.—We also urge the Subcommittee to fund the following programs at the levels advocated by the HPNEC Coalition because of their importance in promoting access to healthcare for special populations: Rural Health Training and the Health Education and Training Centers programs, Geriatric Initiatives, Area Health Education Centers, and Allied Health Special Projects.

Student Loan Programs.—The AADS is concerned about the ability of students pursuing a health professions education to access affordable federal financial aid due to the phase-out of the Health Education Assistance Loan (HEAL) program. We welcomed the Secretary of Education's earlier action raising the annual and aggregate unsubsidized Stafford Loan limits. However, this action does not meet the full need of the health professions community due to the limitations accompanying the new policy. Currently, only students attending schools which disbursed HEAL loans in fiscal year 1995 are eligible. Many dental schools which did not borrow under the HEAL program prior to fiscal year 1995 now have students who need to access additional loan funds. We believe that using this eligibility time frame is arbitrary, and creates a two-tiered system, thus locking out many deserving health professions students from the lower cost federal student aid program. The AADS is urging the Department of Education to broaden the pool of students eligible for the increased annual and aggregate Stafford loan limits to accommodate all health professions students seeking assistance. We request the Subcommittee's support for this effort.

National Institutes of Health/National Institute for Dental Research.—We strongly commend and thank Chairman Specter for his leadership in the area of biomedical research, proven by the significant increases in the funding levels for the National Institutes of Health (NIH) during his Chairmanship. As the National Institute of Dental Research (NIDR) celebrates its 50th anniversary, our nation's dental education institutions are particularly thankful for the continued strong federal commitment in this area of research which over the years has opened new pathways to better diagnosis, prevention and treatment of oral disease. Support for the NIDR has yielded results applicable not only to oral health, but to health in general. NIDR's objective is to promote the advancement of research in all sciences pertaining to the mouth and facial structures, to seek ways of treating and preventing oral diseases, and to facilitate the transfer of knowledge into practical help for the public. Scientific areas providing great research opportunities on which NIDR will focus in coming year include pain research, dental and craniofacial genetics, oral and pharyngeal cancer, gene therapy using salivary glands, and biomimetics (an interdisciplinary study leading to the replication of the process of new cell growth and repair which occurs in living organisms). The AADS is particularly pleased that the NIDR plans to pursue strategies strengthening its commitment to recruiting and retaining young health professionals in the field of biomedical clinical research. The recent decline in young men and women entering this field threatens our clinical research infrastructure and the ability of our nation to fully benefit from increased investments and discoveries in the area of biomedical research. The AADS endorses the testimony of the American Association for Dental Research regarding research priorities and the request for a 15 percent percent increase over fiscal year 1998 funding levels, resulting in a budget of $240.8 million for the NIDR in fiscal year 1999.

Agency for Health Care Policy Research (AHCPR).—The AADS joins the Friends of AHCPR in supporting a budget of $175 million in fiscal year 1999. A particularly important AHCPR activity is the Dental Scholar in Residence program, which is now moving into its second year. The Dental Scholar in Residence was established in 1997 to assist the agency in conducting research to improve the delivery of effective dental and oral health services and to facilitate collaborative relationships among professional, educational, research, and other health industry sectors involved with oral health care. The very first recipient of this award focused on efforts to increase communication, cooperation, and collaboration among communities engaged in quality improvement efforts and the dental profession, and examined the integration of oral health services into comprehensive primary care systems. This work will help improve the knowledge base for informed oral health care policy.

Conclusion.—Finally, the AADS would like to recognize the achievements of the U.S. Public Health Service on the occasion of its bicentennial year in 1998. In 200 years much has been accomplished in conquering disease and disabling conditions. In this century alone, 30 years of have been added to the average life span. Fully

25 of those added years are due to public health interventions. But to continue meeting the challenges ahead we must continue to invest in a continuum of public health activity that not only includes biomedical and behavioral research, but also invests in disease prevention and health promotion, targeted health care services for vulnerable populations, education of a primary care and public health workforce, and health services research.

Mr. Chairman, I thank you again, on behalf of the AADS and its membership, for this opportunity to present our views and our budget requests for dental education programs in fiscal year 1999. We believe these programs are important public health activities essential to maintaining a highly-skilled, well-trained health professions workforce and achieving important national oral health goals.

PREPARED STATEMENT OF ALAN SHALITA, M.D., PRESIDENT, ASSOCIATION OF PROFESSORS OF DERMATOLOGY

Mr. Chairman and Members of the Subcommittee: My name is Alan Shalita, M.D. I am a Distinguished Teaching Professor at the State University of New York (SUNY) Health Science Center in Brooklyn and my curriculum vitae is enclosed. I am also the current president of the Association of Professors of Dermatology (APD). The membership of the APD includes the heads of all academy departments of dermatology, as well as all dermatology program directors. The APD receives no federal funding.

My colleagues and our patients thank you, Chairman Specter, and members of the Subcommittee for your continued support of the National Institutes of Health (NIH). The membership of the APD is grateful that biomedical research enjoys bipartisan support in this Subcommittee and in Congress.

Our Nation's biomedical research infrastructure is an intricate relationship of academia, industry, and the federal government. The NIH serves as the primary source for basic research through universities and independent research institutions. This synergy has alleviated suffering for millions of Americans by fostering the development of innovative treatments, including drugs and vaccines. Biomedical research is the foundation upon which all medical care is based. Without the NIH, we would not be the world leader in research and patient care.

To ensure that the mission of the NIH continues and that we are able to exploit the many research opportunities before us, the APD joins with our sister societies in dermatology, as well as the Coalition of Patient Advocates for Skin Disease Research, the NIAMS Coalition, and the Ad Hoc Group for Medical Research Funding to request a funding increase of 15 percent for the NIH in fiscal year 1999.

One in three Americans suffer with a serious skin disease. Our economy also suffers. The cost of treatment of skin disease will exceed $7 billion this year, and occupational skin disease ranks among the most prevalent causes of workers' compensation claims. While few skin diseases are fatal, they are chronic, costly, and common. They inhibit the ability of many Americans to live independent, productive, and taxpaying lives. They can also be disfiguring and can cause the patient to suffer emotional and psychological distress.

We are poised at the brink of an exciting new era of dermatology, during which we expect to make rapid advances in the understanding of skin biology and the pathogenesis of skin disease. This new knowledge will provide us more effective treatments for many skin diseases. It is critical that we do not lose the scientific momentum of the previous decades of NIH funded research.

Much of the skin disease research conducted at the NIH is funded by the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS). The NIAMS research portfolio is very diverse. It supports basic and clinical research encompassing an astonishing number of diseases affecting the three largest organ systems in the body. As our population ages, the debilitating diseases of the skin, joints, bones, muscles, and connective tissue will affect an ever larger proportion of our population.

A 15 percent increase in the budget of NIAMS would provide a fiscal year 1999 appropriation of $316 million. This amount represents approximately 2 percent of our annual expenditure for skin disease treatment. Without adequate funding, many promising new areas of research will not be advanced. Opportunities to relieve the pain and suffering of our patients and their families will be delayed.

There are a number of immediate opportunities in basic skin research that I would like to share with you. Advances in molecular biology and genetics have helped us to make great strides in understanding skin disease. The establishment of a basic science base has greatly assisted our search for mutated genes responsible for various genetic skin disorders. Now, the search for these genes can be more eas-

ily narrowed to candidate regions, such as the epidermal differentiation complex and other areas of chromosome 1.

Scientists now know the location of a gene that predisposes people to systemic lupus erythematosus (lupus), a chronic autoimmune disease that has been of great interest to members of this Subcommittee. Researchers have localized the gene to a region near the end of the "long arm" of chromosome 1. Additional research is needed to help us to identify those infectious agents and environmental factors that trigger this disease in susceptible individuals. In addition, funding of prevention research in lupus has helped us to develop sophisticated education programs to screen young African-American women at risk for the disease. It is hoped that these screening programs will allow us to diagnose the disease at its earliest stages, thereby reducing the severity of the disease and its costs.

The Ichthyoses are a family of heritable skin diseases in which there is an abnormal development of the outermost layers of the skin. Previously, scientists had demonstrated a linkage between certain forms of ichthyosis and mutations in a particular gene that codes for the most common proteins in our epidermis, the keratins. In more recent findings, another rare form of this disease has been shown to be linked to a mutation in a region of chromosome 1, called the epidermal differentiation complex. It is hoped that this discovery will one day lead to relief from the self-amputation that is a characteristic of the disease.

In the past decade, important advances have been made in our knowledge of the structure and function of the skin, largely through understanding the more serious forms of genetic diseases, such as epidermolysis bullosa (EB). EB is a complex group of genetic disorders that cause the skin to be so fragile that the slightest friction can cause blistering of the skin. These blisters often lead to infection. In its most severe form, the blistering of EB leads to chronic, unremitting wound healing which results in extensive scarring of the affected skin. It is our hope that EB will be the first candidate for gene therapy in skin disease. Researchers are now exploring the use of retroviruses and other exciting avenues for gene therapy in EB.

Recent studies have significantly advanced our understanding of skin cancer, the most common of all cancers. This year, over one million Americans will be diagnosed with some form of skin cancer, more than all other cancers combined. This year, 8,500 individuals will, like your colleague Steven Schiff, die from skin cancer. While we mourn these individuals, I can report that we are making progress in our battle against skin cancer.

Scientists have uncovered a gene involved with the most common form of skin cancer—basal cell carcinoma. A mutation in the gene that controls the growth and development of the skin, may be responsible for a rare, inherited disorder called basal cell nevus syndrome, as well as acquired basal cell carcinoma. Scientists hope that this discovery will lead to more novel, less invasive treatments for skin cancer. Scientists are also hard at work on the development of a melanoma vaccine.

The poets contend that the eyes are the mirror to the soul. As a dermatologist, I can tell you that it is the skin. The skin is the mirror to internal disease. There are very few diseases that do not have skin manifestations. In addition, the skin is also an efficient, important and potent delivery system for drugs for many diseases. Therefore, skin disease research is necessary if progress is to be made in treating many other illnesses.

In addition to the important research at the bench, clinical research is a very important mission and one that has been historically underfunded at the NIH. Improved support of clinical research is extremely important if we are to take the discoveries I discussed earlier and translate them into improvements in patient care.

Clinical research is in jeopardy. Managed care has significantly impacted the financial ability of our major academic health centers to support clinical research. The APD supports the recommendations of the Nathan report and an increased commitment by the NIH in the area of clinical research.

Funding basic and clinical research will be unnecessary, however, if we are unable to attract and retain the brightest minds in basic and clinical skin research. A diverse base of scientific talent is needed to ensure the survival of the NIH, academia and industry. The education of the next generation of scientists, especially physician scientists, must remain a national priority.

As a professor and researcher, I can attest to the steady decline in the number of physicians who elect to pursue a career in research. Our young people have been discouraged by the unpredictability of funding. Managed care has also played a role, inhibiting the ability of experienced clinical investigators to mentor their younger colleagues. The training of physician scientists has proven to be one of our most productive ways to integrate basic and clinical research. Physician scientists are our best hope of translating the exciting advances in molecular biology and genetics to

the bedside. The APD, therefore, supports efforts by the NIH to offer new and expanded initiatives in research training.

Our Nation's biomedical research effort is a complex, balanced system that synergizes contributions made by universities, industries, and government. Our unique biomedical research infrastructure has allowed us to lead the world in biomedical research, to reap numerous Nobel Prizes in Medicine and Physiology, and to birth the biotech industry.

I urge you to maintain our position, and again request a 15 percent increase in appropriated funding for the NIH in fiscal year 1999.

PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS

On behalf of the more than 31,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants is pleased to submit comments on fiscal year 1999 appropriations for Physician Assistant (PA) education programs that are authorized through Title VII of the Public Health Service Act.

Overview of Physician Assistant Education and Practice

As committee members may be aware, PA programs provide students with a primary care education that prepares them to practice medicine with physician supervision. The first PA program was started at Duke University approximately 30 years ago, and today there are 104 accredited PA educational programs.

Prior to admission, the typical PA student has a bachelor's degree and over four years of health care experience. PA education typically is 25 months in length and includes more than 400 hours in basic sciences, more than 149 hours in behavioral sciences, and more than 535 hours in clinical medicine. PA students also complete more than 2,000 hours in clinical rotations, with an emphasis on primary care. Upon completion of an accredited PA program, PAs must complete a rigorous national certifying exam administered by the National Commission on Certification of Physician Assistants. To maintain their certification, PAs must complete 100 hours of continuing medical education every two years and take a recertification exam every six years.

PAs work in virtually every type of medical and surgical specialty, including family/general medicine, internal medicine, obstetrics/gynecology, pediatric medicine, occupational medicine, and emergency medicine. PAs' primary employment settings include individual physician offices, group practices, managed care organizations, hospitals, and outpatient clinics.

Contribution of PAs as Primary Care Providers

The PA profession has a long standing commitment to practice in our nation's small towns, rural areas, and underserved communities. PAs play a pivotal role in expanding access to primary care services, particularly in medically underserved communities. Data collected in 1997 show that over half of the PA profession is in family/general practice medicine, general internal medicine, general pediatrics, and obstetrics/gynecology. More than a third of the profession practice in communities of less than 50,000 people.

Studies conducted by the Rand Corporation have found that PAs save costs, can perform a substantial portion of the functions in an ambulatory care practice, and are widely accepted by patients. The congressional Office of Technology Assessment studied health care services provided by PAs and determined that "within their scope of practice, physician assistants provide health care that is indistinguishable in quality from care provided by physicians."

Critical Role of the Title VII, Public Health Service Act, Programs

Despite an increase in state health insurance reforms, a reduced rate of growth in health care spending, and the emergence of a new children's health insurance program, a growing number of Americans lack access to primary care, either because they are uninsured, underinsured, or they live in a community with an inadequate supply or distribution of providers. The growth in the uninsured US population increased from approximately 32 million in the early 1990s to more than 40 million today. Simultaneously, the number of medically underserved communities continues to rise, from 1,949 in 1986 to 2,723 in 1998.

The role of the Title VII programs is to alleviate these problems by supporting access to quality, affordable, and cost-effective care in areas of our country that are most in need of health care services, specifically rural and urban underserved communities. This is accomplished through the support of educational programs that train more health professionals in fields experiencing shortages, improve the geo-

graphic distribution of health professionals, and increase access to care in underserved communities.

The Title VII programs are the only federal education programs that are designed to address the supply and distribution imbalances in the health professions. Since the establishment of Medicare, the costs of physician residencies, nurses and some allied health professions training has been paid through Graduate Medical Education (GME) funding. However, GME has never been available to support PA education. More importantly, GME was not intended to nor does it generate a supply of providers who are willing to work in the nation's medically underserved communities. That is the purpose of the Title VII Public Health Service Act Programs, which support such initiatives as loans and scholarships for disadvantaged students, scholarships for students with exceptional financial need, centers of excellence to recruit and train minority and disadvantaged students, and interdisciplinary initiatives in geriatric care and rural health care.

Title VII Support of PA Education Programs

Federal funding for PA education programs is authorized through Section 750 of the Public Health Service Act and supports the planning, development, and operation of projects for the education of PAs and PA faculty development programs. The funds ensure that PA students from all backgrounds have continued access to an affordable education and encourage PAs, upon graduation, to practice in underserved communities. These goals are accomplished by funding PA education programs that have a demonstrated track record of: (1) placing PA students in health professional shortage areas; (2) exposing PA students to medically underserved communities during the clinical rotation portion of their training; and (3) recruiting and retaining students who are indigenous to communities with unmet health care needs.

Following are three examples of how well PA programs have responded to the intent of the Title VII programs.

—A Texas PA program established the objective of having its students complete their family medicine rotation in medically underserved sites. Through assistance from Title VII funding, the PA program established sufficient clinical training sites to require each student to complete a family medicine rotation in a rural medically underserved community. As a result of this requirement, a greater percent of the program's graduates now enter family medicine and take positions in medically underserved communities.

—Several PA programs, including the University of California—Davis, the University of Texas—Galveston, and the University of Washington, have used Title VII funding to "place bound" students. The "place bound" PA students are indigenous to the underserved communities where they receive their training and return to their communities to practice after graduation. These programs specifically target Hispanic and rural disadvantaged students.

—A Washington state program recently placed two PA graduates in the Yakima Valley Farmworkers Clinic. One PA was previously a medical assistant and from a migrant family; the other PA was formerly a respiratory therapist in Walla Walla. Upon graduation, both PAs chose to practice at the farmworker clinic.

Without Title VII funding, many of these special PA training initiatives would not be possible. Institutional budgets and student tuition fees simply do not provide sufficient funding to meet the special, unmet needs of medically underserved areas or disadvantaged students. Nevertheless, the need is very real, and Title VII is critical in meeting it.

Need for Increased Title VII Support for PA Education Programs

Increased Title VII support for educating PAs to practice in underserved communities is particularly important given the market demand for physician assistants. Without the Title VII funding to expose students to underserved sites during their training, PA students are far more likely to practice in the communities where they were raised or the communities in which they attended school. Title VII funding is a critical link in addressing the natural geographic maldistribution of health care providers by exposing students to underserved sites during their training, where they frequently choose to practice following graduation.

The supply of physician assistants is inadequate to meet the needs of society, and the demand for PAs is expected to increase. A 1994 report of a workgroup of the Council on Graduate Medical Education (COGME), "Physician Assistants in the Health Workforce," estimated that the anticipated medical market demand and the estimated workforce requirements for PAs would exceed demand. Additionally, the

Bureau of Labor Statistics projects that the number of available PA jobs will increase 47 percent between 1996 and 2002.

Despite the increased demand for PAs, funding has not proportionately increased for the Title VII programs that are designed to educate and place physician assistants in underserved communities. Between fiscal year 1994 and fiscal year 1997, PA program funding went from $6.5 million down to $5.9 million and, as of fiscal year 1997 was restored to $6.376 million. PA program funding was slightly increased again for fiscal year 1998 at $6.398 million. In 1992–1993, approximately 64 percent of 55 PA programs received federal support, at an average of $143,500 per grant. In 1996–1997, less than half of 77 PA programs reported receiving federal support, at an average of $152,300 per grant.

Recommendations on Fiscal Year 1999 Funding

The American Academy of Physician Assistants urges members of the Appropriations Committee to consider the inter-dependency of all the public health agencies and programs when determining funding for fiscal year 1999. For instance, while it is important to fund clinical research at the National Institutes of Health (NIH) and to have an infrastructure at the Centers for Disease Control (CDC) that ensures a prompt response to an infectious disease outbreak, the good work of both of these agencies will go unrealized if the Health Resources and Services Administration (HRSA) is inadequately funded. HRSA administers the "people" programs, such as Title VII, that bring the cutting edge research discovered at NIH to the patients—through providers such as PAs who have been educated in Title VII-funded programs. Likewise, CDC is heavily dependent upon an adequate supply of health care providers to be sure that disease outbreaks are reported, tracked, and contained.

The critically important programs administered by NIH, HRSA, and CDC are integral components within the nation's public health continuum. One component is not more important than another, and no one component can succeed without adequate support from each of the other elements. The Academy is particularly concerned that any increase for the NIH not be made at the expense of the health professions education program or other public health programs, as recommended this year by the Senate Budget Committee.

The American Academy of Physician Assistants is particularly appreciative of the increases in funding for PA education programs that were appropriated during the 104th Congress and the 1st Session of the 105th Congress. However, these increases have not been sufficient to meet the increasing demand for PA graduates in the growing number of medically underserved communities. Accordingly, the Academy respectfully requests that PA programs be funded in fiscal year 1999 at their current authorized level of $9 million.

Thank you for the opportunity to present the American Academy of Physician Assistants' views on fiscal year 1999 appropriations.

PREPARED STATEMENT OF THE AMERICAN DENTAL ASSOCIATION

Mr. Chairman and Members of the Subcommittee: The American Dental Association (ADA) is submitting this testimony on behalf of its 140,000 members. With passage of the State Children's Health Insurance Program (CHIP), and reforms of the Medicaid program, which for some time has included a comprehensive children's oral health benefits program, last year was truly the year of the child. This subcommittee contributed significantly to the efforts to address the health needs of children through its continued support of dental education, research, and disease prevention.

The ADA believes this year offers new opportunities for this subcommittee to target funding for programs designed to address the continuing oral health care needs of the children in this nation, especially those in the underserved populations. While almost half of the children entering school in this country are free of tooth decay and fillings, we recognize these gains have not been realized equally by all Americans. Among school age children, 25 percent suffer 75 percent of the tooth decay. That 25 percent typically represent children who are from low income or socially disadvantaged families or live in non-fluoridated states. For example, in Hawaii, which has a fluoridation rate of only 13 percent, 80 percent of the children under the age of 6 suffer from tooth decay.

MATERNAL CHILD HEALTH—FLUORIDATION GRANTS

The Association would like to thank the subcommittee for its support last year for funding SPRANS activities within the Maternal Child Health block grant that enhanced community water fluoridation efforts. This grant money will be used by

states with less than 25 percent community water fluoridation to help those states develop plans for expanding their level of participation. For example, the city of Los Angeles receives water from 40 different systems. A great deal of planning must take place before fluoridation can begin.

The American Dental Association recommends that the subcommittee continue to fund these efforts for the third and final year of the grants at the current level of $500,000.

DIVISION OF ORAL HEALTH

As the federal agency with primary responsibility for community-based programs designed to prevent oral disease and promote oral health, the Division of Oral Health (DOH) within the Centers for Disease Control and Prevention (CDC) works closely with state and local governments to develop and implement prevention and control efforts, including water fluoridation and dental sealant initiatives. The reduction of severe tooth decay (caries) is a major priority for the DOH as 53 percent of children ages 6–8 and 78 percent of 15-year-olds have experienced dental caries, and more than 100 million Americans lack the benefits of fluoridated water despite its proven effectiveness in fighting dental decay.

Once the seven states that qualified for SPRANS grants determine how to increase their fluoridation rates, they will look to the DOH within the CDC for assistance to implement those plans. CDC issues grants to states for preventive health services. The Association believes that providing funding for fluoridation efforts should be a high priority for CDC. The demand for fluoridation funding will be driven by not only the states receiving SPRANS grant money, but also by states that need to replace worn equipment or expand access for new communities due to growth and development.

Another effective preventive strategy commonly used for protecting permanent molars in children is the application of dental sealants. Healthy People 2000 calls for 50 percent of the children to have these protective barriers against dental decay. A recent national study found that children with sealants had significantly less untreated dental decay than children without sealants. However, despite their effectiveness, less than 30 percent of U.S. children have received dental sealants and only half the states have school-based programs to extend this important preventive intervention to the neediest youth. The DOH will examine which states provide the best model programs and then will encourage others to adopt them.

The Association recommends that $6 million be appropriated for the DOH to increase and expand community-based and school-based efforts to improve the oral health of children.

NATIONAL INSTITUTE OF DENTAL RESEARCH

The Association also recognizes the need for increased research by the National Institute of Dental Research (NIDR) to better understand the various oral diseases that afflict children, including disorders, diseases, and to study normal development that affects tissues of the craniofacial-oral-dental complex.

Last year the NIDR held a conference on "Early Childhood Caries." The NIDR conference concluded that the prevalence of early childhood caries continues to be a significant societal problem and federal agencies must work together to address this important public health issue. Oral diseases can cause serious illness, debilitation, significant pain, interference with eating, poor self-image, over use of emergency rooms and valuable time lost from school. In fact, in 1989 over 51 million school hours were lost due to dental-related illness.

These diseases and disorders cause untold pain and suffering for those afflicted, but they also adversely affect our society as a whole, reflected in increased health care costs and loss of productivity. For example—one in every 33 babies born in 1995 had at least one anatomical birth defect, three-fourths of which affected the head, face, and neck. The most common craniofacial defect is cleft lip, affecting one in 500 births. Lifetime costs for the treatment of clefts and associated speech, hearing and other problems are estimated to be $100,000 per patient.

Genetic research being carried out by the NIDR, including that to determine the causes of craniofacial birth defects, is fundamental for identifying which gene(s) cause(s) these conditions. Furthermore, additional research being done by NIDR scientists is focusing on how to correct these conditions through the growth of new bone and soft tissue—a process called biomimetics.

Periodontal disease may be one of the contributing factors resulting in the approximately 250,000 low birth weight (LBW) babies born each year. In fact, it has been established that women with periodontal disease are seven times more likely

to have LBW babies. Other studies show that there may be an association between periodontal disease and cardiovascular diseases.

NIDR has long been a leader in pain research. The NIH Pain Research Consortium encourages information sharing and collaborative research efforts within NIH, and it sponsored a major symposium in November 1997, fostering new ideas and collaborative studies on pain research. Some diseases or disease treatments cause chronic pain at an estimated cost of $100 billion a year according to pain specialists, so the benefits emanating from the agency's efforts in this arena should reach far beyond oral health care concerns.

The Association recommends a funding level of $240.8 million for NIDR so that it can expand its research and help reduce oral diseases that afflict children.

AGENCY FOR HEALTH CARE POLICY AND RESEARCH

The Agency for Health Care Policy and Research (AHCPR) is working to facilitate the introduction of advances in biomedical research into the dental practice setting, improving the quality and cost-effectiveness of oral health care.

It is important to provide sufficient funds for continuation and enhancement of the Medical Expenditure Panel Survey (MEPS), which began in 1997. However, the dental care component of this survey must be improved, to provide more accurate estimates of utilization patterns, composition of services, and costs of care and how these are influenced by characteristics of patients, providers, and insurance plans.

The findings from research supported by NIH and AHCPR are openly shared within the scientific and professional communities to maximize the benefits to the public of this investment. There must be support for a continuum of research—from basic, biomedical (bench), and clinical research, through controlled clinical trials, outcomes research, and cost-effectiveness trials.

We must understand not only what causes diseases and how they can be prevented or treated, but also what works in dental practice and how much it costs. Research supported by AHCPR will assist dental practitioners by providing the evidence base for selecting among alternative dental treatments. AHCPR's research is also needed to improve the system providing health care, so that the fruits of biomedical research are readily available to all citizens.

The Association supports the expansion of AHCPR's outcomes and effectiveness research program, which has the potential to improve the evidence base for selecting among alternative diagnostic and dental treatments. Advances in this program, for example, would enable AHCPR to improve the treatment of musculoskeletal disorders, including temporomandibular disorders (TMD), improving the science base for both medical and dental practitioners and providing information needed to establish reimbursement policies that would enable patients to receive the treatment most appropriate for their needs.

The Association recommends a funding level of $175 million.

DENTAL EDUCATION

General Dentistry Residencies Program.—The General Dentistry Residencies program furnishes young dentists with valuable clinical experience, while offering care to underserved populations. The training is similar to that experienced by primary care physicians in their internships. Most graduates of the program remain in primary care with many establishing practices in underserved areas. This helps to meet the federal goal of increasing access to primary care.

The Association would also like to bring to the subcommittee's attention the increasing need for more pediatric dentists. Between 1993 and 2020 the number of children under the age of 15 will increase by 8.1 million. However, we are not training enough pediatric dentists to replace those who retire or have the bad judgment to die. Today there are fewer than 4,000 pediatric dentists in the nation. This is a critical shortage because pediatric dentists treat approximately 42 percent of Medicaid children and 57 percent of medically compromised children. Therefore, the Association is supporting authorizing language to include pediatric residencies in the health professions program.

The Association recommends that $4 million be appropriated for fiscal year 1999 for the General Dentistry Program, which is $200,000 above the current funding level. If Congress should approve an authorization for pediatric dental residencies, the ADA will provide the subcommittee with a more accurate funding request.

The General Dentistry program is part of the Health Professions Training and Nursing Education Program. The ADA also endorses a request from the Health Professions and Nursing Education Coalition for a funding level of $306 million for all of the programs.

Ryan White HIV/AIDS Dental Reimbursement Program.—The Ryan White HIV/AIDS Dental Reimbursement program helps fund oral health care services for people living with HIV/AIDS. Dental students and residents also benefit as they gain extensive experience in caring for patients with special dental needs. In fiscal year 1997, 104 institutions participated, serving over 70,000 patients.

By covering the costs of providing quality care to people living with HIV/AIDS, this program can prevent much more serious and expensive health complications. Oral disease left untreated can lead to significant pain, oral infections, and fevers; difficulty in eating, speaking or taking medication; and medically dangerous weight loss. Furthermore, dental services under Medicare and Medicaid coverage for adults is often inadequate, so receiving a prompt diagnosis and appropriate treatment for these oral conditions is often difficult for uninsured poor individuals.

The Association requests $9 million for the Ryan White HIV/AIDS Dental Reimbursement program, an increase of $1.2 million over the current funding level.

National Health Service Corps Scholarship and Loan Forgiveness Programs.—We strongly support the NHSC Scholarship and Loan Forgiveness Programs, which assist students with the rising costs of financing their health professions education while promoting primary care access to underserved areas.

Over the last several years, and most recently in fiscal year 1998 appropriations report language, Congress has instructed the NHSC to increase dental participation in the loan repayment and scholarship awards programs. However, the number of dental loan repayment awards has increased slowly in recent years. According to a Department of Health and Human Services survey, currently 3,032 dentists are needed to service 957 designated dental Health Professions Shortage Areas (HPSAs), as compared to 1,400 dentists needed for 792 HPSAs prior to 1993.

We ask the subcommittee to further pursue the need for increased dental participation in both the NHSC scholarship and loan repayment programs.

Health Professions Education and Training Programs for Minority and Disadvantaged Students.—We request funding increases for the minority and disadvantaged assistance programs that are proportional to current funding levels within the context of the fiscal year 1999 budget request of $306 million for all of Title VII and Title VIII of the Health Professions programs recommended by the Health Professions and Nursing Education Coalition (HPNEC).

Other Programs Under Title VII of the Public Health Service Act.—We also urge the subcommittee to fund the following programs at the levels advocated by the HPNEC Coalition because of their importance in promoting access to healthcare for special populations: Rural Health Training and the Health Education and Training Centers programs, Geriatric Initiatives, Area Health Education Centers, and Allied Health Special Projects.

Student Loan Programs.—The ADA is concerned about the ability of students pursuing a health professions education to access affordable federal financial aid due to the phase-out of the Health Education Assistance Loan (HEAL) program. We welcomed the Secretary of Education's earlier action raising the annual and aggregate unsubsidized Stafford Loan limits; however, this action does not meet the full need of the health professions community due to the limitations accompanying the new policy. The ADA is urging the Department of Education to broaden the pool of students eligible for the increased annual and aggregate Stafford loan limits to accommodate all health professions students seeking assistance. We urge the subcommittee to support this effort.

We also request the subcommittee's continued support for the Health Professions Student Loan (HPSL) program, which could provide additional low cost student loan funds to meet the financial needs of health professions students previously served by the HEAL program. HPSL funds should be used to assist institutions in developing and maintaining a sufficient revolving fund.

Thank you, Mr. Chairman and members of the subcommittee, for your thoughtful consideration of the ADA's recommendation.

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF RETIRED PERSONS

The American Association of Retired Persons (AARP) appreciates this opportunity to comment on appropriations for various programs which benefit older Americans, especially the low-income and minority elderly. Our recommendations are summarized as follows:

—At a minimum, maintain Older Americans Act programs at current services levels;

—Provide no less than $1.215 billion in regular funds for the Low Income Home Energy Assistance Program;

—Make available sufficient resources for: Medicare+Choice Provisions; the Agency for Health Care Policy and Research; the Inspector General's Office, Department of Health and Human Services; State Survey and Certification activities; the Social Security Administration; and the National Senior Service Corps.

Older Americans Act (OAA)

Since its enactment over thirty years ago, the Older Americans Act has enabled millions of older citizens—especially those with disabilities—to remain independent and productive. Many of these individuals would have been institutionalized, were it not for the home and community-based services provided by this landmark legislation. AARP urges at least an inflation adjustment for these vital programs next year, an amount that is roughly $29 million over the existing $1.305 billion appropriation. The Administration proposes no increases.

To the extent additional resources are available, we recommend increases above inflation in all OAA programs. This is particularly critical for Title IV Training, Research and Discretionary Projects, which were substantially reduced in 1996. These activities are necessary if we are to expand our knowledge about the needs of an aging society.

We applaud Congress for providing modest increases this year in many OAA activities. Among other things, the extra funds mean nutritional meals for more seniors, particularly those who are isolated and frail. OAA's Home-Delivered Meals Program is very often the only human contact some of these persons have in a given day. And their lives are enriched by these visits in ways which cannot always be measured. Over 240 million congregate and home-delivered meals are delivered annually. The increases will also provide additional supportive services—services which include more than 40 million rides for doctor and pharmacy visits, nearly ten million personal care visits to those in need, and roughly one million legal counseling sessions.

As one of the national sponsors of OAA's Senior Community Service Employment Program (SCSEP), the Association has first-hand knowledge regarding its effectiveness. SCSEP has made a real difference in the lives of many unemployed, low-income older Americans by providing part-time employment in useful community service activities. Many of the nutrition programs and other services for seniors, as well as important programs serving the broader community, such as library services and day care centers, are dependent on work provided by older persons through the Senior Community Service Employment Program. Compared with younger workers, older workers—once unemployed—tend to be jobless longer and are likely to earn less when—and if—hired. More than 94,600 older Americans were SCSEP participants in the 1996/97 program year.

Low Income Home Energy Assistance Program (LIHEAP)

The Association strongly urges at least $1.215 billion in regular funds next year for this critical program, an amount equal to the total spending level in fiscal year 1997. Because this program is advance funded, Congress provided $1.1 billion for fiscal year 1999 in the fiscal year 1998 appropriation. We are recommending an increase of $115 million over that level for the coming fiscal year. We also recommend the same amount for the fiscal year 2000 advance appropriation. The Administration is proposing $1.1 billion for this purpose. LIHEAP is important to all of its beneficiaries, but none more so than low income older persons. Housing, health care, energy costs—all of these factors add to the stress of living on a tight budget. For some, the question of how to heat their homes is actually a matter of life or death.

Some LIHEAP recipients are 'working poor' or elderly who do not receive any other public assistance through welfare, food stamps, SSI, or subsidized housing. LIHEAP is a vital measure of last resort for these individuals. Because they are more likely to live in older, poorly insulated homes, older persons—particularly the elderly minority poor—also have a heightened risk of hypothermia. Among low income households, the proportion of income expended for energy consistently amounts to 3–4 times the proportion spent by households across the board. Based on the latest available data, of the 29 million households eligible for LIHEAP assistance in 1995, roughly 41 percent had at least one person over the age of 60. Only 13 percent of these eligible elderly households actually received heating assistance. Program funding reached its peak in 1985 when Congress appropriated $2.1 billion. By 1996, funding had dropped to $1 billion, and the number of participating households declined that year from 5.8 million to 4.4 million.

Implementation of Medicare+Choice

The new Medicare+Choice program in the Balanced Budget Act of 1997 (BBA) established a number of new Medicare delivery system options. By the end of 1998 the new law anticipates that the Health Care Financing Administration (HCFA) will

conduct a major public education campaign to provide Medicare's 38 million beneficiaries with the information they need to make educated choices about their Medicare coverage. The success of Congress' effort in the BBA to expand the choices available to Medicare beneficiaries will depend heavily on whether HCFA has the resources and staffing needed to implement the specific and extensive requirements of the law. The Association recommends appropriate funding next year to implement the Medicare+Choice program. Currently, HCFA's funding for implementation of the BBA is only about $2.40 per beneficiary. This will not be adequate to ensure that beneficiaries have the information they need to make informed choices about their health care.

Agency for Health Care Policy and Research

The Association urges adequate funding for the Agency for Health Care Policy and Research, and in particular the Medical Treatment Effectiveness Program (MEDTEP). If we are to find ways to lower the growth in the cost of health care without jeopardizing quality of care, the outcomes research undertaken by this Agency will be critical.

Office of Inspector General—Department of Health & Human Services

AARP urges adequate funding for the Department of Health and Human Services' Office of Inspector General. In order for fraud and abuse in the Medicare and Medicaid programs to be reduced, adequate resources must be available to detect, investigate and prosecute unscrupulous providers. This should include appropriate funding for maintaining and expanding the Inspector General's fraud hotline, an integral part of the effort to reduce fraud.

Medicare Contractor Funding

Medicare contractors are a source for information about changes in the Medicare program. Currently, most contractors have outreach programs for the physicians in their region. Given the magnitude of changes in the program required by the Balanced Budget Act of 1997, outreach by contractors to address beneficiaries' questions and provide clear and accurate information will be critical. We urge the Subcommittee to provide adequate funding for Medicare contractors that takes into account the need for beneficiary outreach activities. This funding should not substitute for the resources needed by the Health Care Financing Administration to implement the new Medicare+Choice program.

Survey and Enforcement

The Association supports sufficient funding to provide adequate levels of survey and enforcement activities to assure that home health agencies and skilled nursing facilities deliver quality care to Medicare and Medicaid beneficiaries. Currently, inadequate funding has meant that nursing homes cited for deficiencies during the survey process do not receive follow-up visits to guarantee that they have come into compliance. As a result of limited funding to make the revisits, the appropriate sanctions cannot be imposed. Any additional reduction in funding could have a significant adverse effect on the quality of care, particularly given the added responsibilities placed on HCFA and the states in the Balanced Budget Act of 1997.

Displaced Homemaker Program

AARP supports providing sufficient funds to begin implementing the Displaced Homemakers Self-Sufficiency Assistance Act. For many older women who have been outside the workforce for decades, workforce re-entry is extremely difficult. As the workforce ages, and the older workforce becomes increasingly female, the services provided by the Act and similar programs will assume correspondingly greater importance.

Social Security Administration (SSA) Staffing Levels

We remain concerned that inadequate funds for SSA could hamper the agency's ability to deliver quality service. The most noticeable evidence of deteriorating service is the ongoing backlog of disability applications, which continue despite agency initiatives. AARP urges the Subcommittee to provide sufficient resources next year to address this backlog and for other critical activities, such as implementing the congressional mandate for electronic transfer of all federal payments.

National Senior Service Corps (NSSC)

The NSSC programs—namely, Foster Grandparents, Senior Companions, and Retired Senior Volunteers—have been successfully matching skilled older Americans with unmet community needs since 1973. We appreciate the additional funds provided by Congress this year and urge at least an inflation adjustment for these critical activities.

Thank you again for this opportunity to comment on programs which benefit older Americans.

PREPARED STATEMENT OF THE AMERICAN PSYCHIATRIC ASSOCIATION

Introduction and background

Chairman Porter and members of the Subcommittee, the American Psychiatric Association would like to present recommendations regarding the fiscal year 1999 appropriations for the National Institute of Mental Health (NIMH), National Institute on Drug Abuse (NIDA), the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the Center for Mental Health Services (CMHS) at the Substance Abuse and Mental Health Services Administration (SAMHSA). The APA wishes to associate this statement with the statement of the Ad Hoc Group for Medical Research Funding, which calls for a 15-percent increase in NIH funding for fiscal year 1999, as a first step toward doubling the NIH budget over five years.

The prevalence and impact of mental illness and addictive disorders is generally underestimated, but the magnitude of the problem is expressed in the "1997 Update on Progress in Brain Research" published by the Dana Alliance. When one considers the toll in medical morbidity and mortality, lost productivity, along with the costs of law enforcement and treatment, the aggregate burden of severe mental illness in our society exceed $300 billion annually. These illnesses and their associated costs include:

[In billions of dollars]

Depression/manic depressive illness	30
Schizophrenia	30
Drug addiction	160
Alcoholism	100

However, thanks to the research advances of the last two decades, we now know that severe mental illness and addictive disorders are not a consequence of inadequate parenting, lack of will power, poor self-control, or moral failure. They are diseases of the brain whose development is influenced by a host of genetic biological and psychological factors that are just beginning to be understood. More importantly, we now know these disorders are treatable and that the results of treatment are equal, if not better than, in patients with illnesses like heart disease or diabetes. The personal and societal costs of mental illness and addictive disorders are high, but advances in research and treatment will help save lives, strengthen families, and save taxpayer dollars.

NIMH Research and Mental Illness

In the past five decades, research supported by the National Institute of Mental Health has defined the core symptoms of the severe mental illnesses, including schizophrenia, manic depressive illness, and major depression. Research has shown that these and other mental illnesses involve specific brain dysfunctions and research has contributed directly to developing an array of effective treatments, including both medications and specific psychotherapies. The development of new major classes of psychotropic drugs—antipsychotics, antidepressants (including lithium), and anti-anxiety medications—have profoundly altered the lives of mentally ill people. Through long-term treatment with appropriate medications, many patients now can effectively control their illnesses and lead stable, essentially normal lives. In addition, the discovery that psychotropic medications are effective provided proof that mental illnesses are biologically based—not a consequence of moral failure—and greatly lessened the stigma associated with these conditions.

NIMH research has contributed significantly to the discovery, development, improvement and clinical use of psychotherapeutic drugs. The knowledge developed through this research has, in turn, provided a greater understanding of the causes of mental illness. Collaboration between NIMH researchers and the pharmaceutical industry often resulted in a discovery that a drug developed by industry for another use had unsuspected efficacy against a mental disorder. For example, a drug developed in the 1950's as an antihistamine (chlorpromazine) was found to be the first effective antipsychotic; another compound synthesized, but not used, by a drug company was found to be valuable as an antidepressant (imipramine). Such early discoveries by psychiatric researchers stimulated the pharmaceutical industry to search for other psychotherapeutic drugs.

One of the many NIMH "success stories" involving medications development is the development of Lithium treatment. Lithium has freed many individuals with manic-depressive illness from months or years of hospitalization. Before the introduction

of lithium, people with manic depressive illness experienced severe disruptions of their lives and marked losses of productive capacity. They, in many cases committed suicide. Although many people with this illness remain untreated today, those patients treated with lithium usually respond well and live greatly improved lives. And the benefits to society have been enormous. For example, lithium therapy has saved the U.S. economy more than $145 billion since 1970. NIMH clinical research played a large role in establishing the effectiveness and treatment conditions for lithium therapy; this role was particularly important because lithium is an inexpensive, non-patentable medication—hence not commercially attractive.

This example and other NIMH sponsored research make major differences in the lives of thousands of Americans and their families. Kathleen who suffered from schizophrenia explains "Today I am happy to be alive. Taking a new anti-psychotic drug [olanzapine] has changed my life and my attitude." NIMH researchers helped build the groundwork for development of this new generation of atypical anti-psychotic medications, including olanzapine.

Kathleen says "the fifteen years before I found this medication were not easy," At age 31 Kathleen started to have schizophrenic episodes. "My husband divorced me . . . my children became ashamed of me," Kathleen explains, "I lost my family, my home and nearly my life."

In 1993, Kathleen started taking a new medication called olanzapine. She no longer suffers from symptoms of schizophrenia. Her family is together again and proud of her recovery. "I am ever so thankful for my success in overcoming my mental illness with this drug." (Quotation Courtesy of National Mental Health Association).

But much more needs to be done. APA particularly supports NIMH's commitment to expand scientific knowledge and research on mental illness among our children. An estimated 20 percent of American youth, 11 million in all, have serious emotional or behavioral disorders and an estimated two-thirds of all youth are not receiving the mental health treatment they need. The effects of these illnesses on the lives of our children and their families are enormous. Children with untreated cognitive or emotional disorders cannot learn adequately or benefit from the kind of peer and family relationships essential to becoming a healthy and productive adult. These children are also at increased risk of alcohol and drug abuse, criminal behavior, and suicide. We urge continued support for the child health initiatives currently underway at the NIMH.

NIDA: Drug Addiction Research

Drug addiction is one of the most serious public health problems that our Nation faces. Drug addiction takes a tremendous toll on both the individual and on society as a whole. Not only are the economic costs associated with drug use staggering, but illicit drug use is inextricably linked to the spread of infectious diseases like AIDS, hepatitis, and tuberculosis, and is also associated with family violence, child abuse, violent crimes and suicide.

As we move into the 21st century, ever changing drug use patterns, the continuing transmission of HIV infection among drug abusers, and the need to develop effective treatment and prevention interventions underscore the importance of research in finding new and better ways to alleviate the pain and devastation of addiction. Because drug addiction is such an enormous and complex problem, the National Institute on Drug Abuse (NIDA) has a broad research portfolio that addresses the most fundamental questions about drug abuse, ranging from the molecule to managed care and from DNA research to community outreach.

Besides a better understanding of addiction, we now have the research to show in detail what drugs are actually doing to, and in, the brain. Scientists have identified and cloned receptors in the brain for every major drug of abuse. Researchers have discovered not only the specific brain circuits involved in drug experiences, but are starting to uncover the changes in activity patterns in these brain circuits over time, during the processes of addiction and during drug withdrawal. Research also shows that addiction occurs as a result of the prolonged effects of abusable drugs on the brain. In fact, just a few weeks ago NIDA-supported researchers found a critical link between nicotine addiction and the feeling of pleasure nicotine use can produce. This discovery brings researchers closer to the development of an effective treatment for nicotine addiction including the possible development of anti-nicotine medications targeting this site in the brain.

APA strongly supports NIDA's strong research effort to combat drug abuse among children and adolescents. NIDA's efforts focus on the prevention of initial drug use and prevention of the health consequences of drug abuse for the individual, his/her children, and society. As part of this effort NIDA will support basic cognitive and behavioral research on processes like behavior change to better inform prevention

approaches. Specifically, NIDA will enhance its efforts to look at the role of risk and protective factors including peer pressure in increasing or decreasing the probability that a child will become addicted to drugs. Other critical NIDA work in this area includes a study of children exposed to drugs prenatally in order to clarify the long term effects of such exposure, and a study of the differential effects of drugs on the brain and behavior of children at different ages.

NIAAA: Research on Alcohol Abuse and Alcoholism

As a substance that is both legal and culturally accepted in our society, the health, behavioral, and social problems that are associated with misuse of alcohol are markedly different from those associated with illicit drugs. Alcohol dependence, characterized by chronic and heavy drinking, produces such medical consequences as liver disease and pancreatitis and contributes to cardiovascular disorders, certain cancers, immune, and endocrine system illness. Alcohol can also induce congenital defects, growth retardation, learning disabilities, and other disorders.

One major NIAAA success is research which helped demonstrate the effectiveness of a new medication to treat alcoholism, naltrexone, which blocks both the craving for alcohol and the pleasure of getting high. Studies show that when combined with behavioral interventions naltrexone allows as many as 75 percent percent of those being treated to avoid relapse, compared with fewer than 50 percent of those who receive counseling alone.

One mother who was an alcoholic reported that when taking naltrexone, "I just didn't seem to have the desire to drink even though there were lots of stresses at the time. Ultimately, my self-esteem improved, and I have not had a drink in over eight months. Because I wasn't drinking I had the courage and insight to make the changes that I needed to . . . Life is 100 times better now for my children and myself. I feel like my old self. As I look back, I'm so glad I [took the medication and started the counseling] and my children are delighted." Indeed we can be very proud of the many thousands of individuals whose lives have been transformed, if not saved, by NIAAA-funded research.

The American Psychiatric Association strongly supports the high priority NIAAA places on researching genetics of alcoholism. Research has shown that a significant portion of the susceptibility of alcoholism is inherited. Investigators sponsored by the National Institute on Alcohol Abuse and Alcoholism are searching the entire human genome for genetic markers which are linked with alcoholism. In the process of this search, they will be able to test rigorously the involvement of a number of genes hypothesized to contribute to the susceptibility to alcoholism and perhaps discover contributions from other genes not yet suspected of involvement with alcoholism. Further research is critical to identify the genes located within certain specific chromosomal locations.

The APA proposes that the research budgets for the NIMH, NIDA, and NIAAA be increased to a level minimally appropriate to the quality of the science which merits support, as follows: $970 million (20 percent) for NIMH; $658 million (25 percent) for NIDA; and $262 million (15 percent) for NIAAA. These recommendations include critical research training and research management and support activities, as well as support for AIDS research. These recommendations are based upon expert analysis of the scientific opportunities which could be capitalized on at each Institute to ensure further research breakthroughs in mental illness and addictive disorders.

SAMHSA and CMHS Treatment for Mental Illness

As we all know, all the medical knowledge in the world will not help unless patients who are ill receive medically appropriate treatment. APA recognizes the great importance of the work of the Substance Abuse and Mental Health Services Administration (SAMHSA) and calls for an increase for SAMHSA significantly above that proposed by the President. Mental health services programs are now administered by the Center for Mental Health Services (CMHS) at SAMHSA. Congress has called on CMHS for a vigorous federal leadership role in mental health services delivery and policy development. In some states, SAMHSA-funded services constitute up to 39 percent of all non-institutional mental health services.

The Committee has made known its interest in changing the current Community Mental Health Block Grant into Performance Partnerships. The Association supports this and wants to recognize the efforts of the Substance Abuse and Mental Health Service Administration (SAMHSA) to move toward a more flexible but accountable system of federal support for community mental health services. Critical to this effort, though, are funds to help states to develop an infrastructure for collecting, analyzing and reporting on performance data. As the key priority for

SAMHSA, we urge the Subcommittee to consider $30 million to help states develop the capacity they need for implementation of such a system.

We also present for your consideration the following funding recommendations:

One of the most successful programs at CMHS is the Children's Mental Health Services Program. As you know, the program authorizes grants to states and communities to stimulate the development of interagency systems of care for children and adolescents with mental, emotional or behavioral disorders. The philosophy of the program is child-centered, with requirements for individualized services (sometimes known as wrap-around services), and on services which support families to care for very sick youngsters at home. We recommend a funding level of $87 million.

$79.9 million for the Knowledge Development and Application Program at the SAMHSA Center for Mental Health Services. Rather than directly providing services to beneficiaries, the KDA program is designed to: emphasize information dissemination; develop new and innovative approaches to service delivery, training and technical assistance; and assess the cost-effectiveness of model services. These functions are performed with an emphasis on under served populations, such as children, adults with severe mental illness, ethnic minority populations, rural populations, and the elderly. This role will take on critical importance as states move vulnerable populations of people with severe mental illness into managed care arrangements.

$355.4 million for the Community Mental Health Block Grant program states are allowed to utilize block grant dollars for a range of critical services for people with serious mental illnesses including community-based treatment, case management, homeless outreach, juvenile services and rural mental health services. The demand for community based mental health services has dramatically increased in recent years. To help remedy this distressing situation the block grant program should receive a significant increase particularly since, when inflation is taken into account, the program's funding has declined by $56 million since fiscal year 1993.

APA also recommends $33 million for the PATH Homeless State Grant Program; $30 million for Protection and Advocacy; and $20 million for Direct Operations.

The APA applauds the subcommittee's leadership in funding support for research and treatment of mental illness and addictive disorders. These are dollars well invested which have proven to translate the promise of scientific discovery by NIMH, NIDA, and NIAAA into saving and improving the lives of millions of Americans. We will also be submitting to the subcommittee separately, a more detailed list of recommended research priorities for mental illness, drug abuse, and alcoholism research at NIH. Thank you for the opportunity to submit this statement for the record.

PREPARED STATEMENT OF THE COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION

The Council of State Administrators of Vocational Rehabilitation (CSAVR) is comprised of the chief administrators of the public agencies providing rehabilitation services to persons with disabilities in the 50 States, the District of Columbia, and the territories.

These Agencies constitute the State partners in the State-Federal Program of Rehabilitation Services for persons with mental and/or physical disabilities, as authorized by the Rehabilitation Act of 1973, Public Law 93–112, as amended.

While the Rehabilitation Act is the cornerstone of our Nation's commitment to assisting eligible people with disabilities to obtain competitive employment and to live independent and productive lives, it is severely underfunded.

When one considers that a Louis Harris and Associates study estimates that two out of every three adults with a disability are unemployed, and that the Rehabilitation Program has the resources to provide services to only one in twenty eligible people, this underfunding constitutes an unacceptable tragedy for the millions of people with disabilities who need services in order to become employed, yet are unable to receive them.

The great responsibility placed upon the Rehabilitation Program became even more acute, with the passage and implementation of the "Americans with Disabilities Act" (ADA). The ADA vastly expands opportunities for all Americans with disabilities. It is vital therefore that the Rehabilitation Program assist people with disabilities to fully realize the promise of this landmark legislation.

Vocational rehabilitation services: basic State grants

[In billions of dollars]

Fiscal year 1999 CSAVR recommendation	3

Vocational rehabilitation services: basic State grants—Continued

Fiscal year 1998 authorization ..... ([1])

[1] Such sums.

Basic State Service Grants are the lifeblood of the Vocational Rehabilitation Program, financing the provision of vocational rehabilitation services to eligible individuals with mental and physical disabilities for placement in competitive employment.

These Federal dollars, matched with state monies, permit State Rehabilitation Agencies to provide, or to contract with private organizations and agencies to provide individualized, comprehensive services to eligible persons with mental and/or physical disabilities, for the purpose of rendering these individuals employed and independent.

Such services may include evaluation; comprehensive diagnostic services; counseling; physical restoration; rehabilitation engineering; the provision of various kinds of training and training supplies, tools and equipment; prosthetic devices; placement; transportation; post-employment services; and "any other service" necessary to rehabilitate an individual into employment.

For fiscal year 1996, the latest year for which the Federal Government has statistics, the Rehabilitation Services Administration advises that the $2,118,834,000 appropriated for Basic State Vocational Rehabilitation provided services designed to lead to gainful employment for 1,483,073 people with disabilities of which 69.3 percent were severely disabled. Of this number, 184,030 were placed in competitive employment.

Despite this expenditure, there still are not sufficient funds to serve all those eligible, disabled people who have the potential and desire to work and who need rehabilitation and training services to obtain employment and self-sufficiency.

In carrying out the Congressional mandate to give priority of service to the rehabilitation of individuals who are severely disabled, State Agencies have found that the costs—in time, effort, and money for services—are much greater than the cost of rehabilitating people less severely disabled.

At the same time, it is alarming to note that the purchasing power of the resources available has remained virtually stagnant since 1980.

With these statistics in mind, the Council strongly urges that the Congress assist us in facing this challenge by providing Federal appropriations for Basic State Vocational Rehabilitation Services in the amount of $3,000,000,000 for fiscal year 1999, an increase of $753,112,000 over the fiscal year 1998 appropriation. With this increase in resources, the CSAVR estimates that nearly 270,000 more persons will receive services and 92,500 more will be placed in competitive employment.

The justification for higher funding levels stems from the purpose for which the money is spent—the prevention of an incalculable waste of human potential, a purpose on which no price tag can be placed.

Over the decades, Vocational Rehabilitation has more than paid for itself by helping persons with disabilities become gainfully employed; increase their earning capacity; by freeing family members to work; and/or by decreasing the amount of welfare payments, health services, and social services they might need; as well as by assisting them to become taxpayers.

Appropriating additional monies for Vocational Rehabilitation Services reduces the Federal Deficit. Indeed, the Congressional Budget Office has stated that "a reduction of funds for rehabilitation * * * would generate increases in other parts of the federal and state budgets." Funds appropriated for Vocational Rehabilitation are a sound investment of the Public's money.

Other Programs Authorized by the Rehabilitation Act

The Rehabilitation Act is recognized as the most complete and well-balanced piece of legislation in the human services field. In addition to the Basic State Vocational Rehabilitation Services Program, the Act contains provisions for (1) an innovation and expansion program; (2) a training program; (3) a research program; (4) a comprehensive services for independent living program; (5) a supported employment program; and, among others, (6) special projects and demonstration efforts. The CSAVR strongly supports adequate funding for all Sections of the Act.

PREPARED STATEMENT OF THE HELEN KELLER NATIONAL CENTER FOR DEAF BLIND YOUTHS AND ADULTS

PRELIMINARY STATEMENT

The Helen Keller National Center (HKNC) is an unique national resource: It is the only entity in the world whose sole mission is to provide comprehensive training, independent living skills, and employment preparation to young people and adults who are both deaf and blind. Because of its unique mission HKNC must rely primarily on support through Federal funding. But HKNC has not received a funding increase above inflation for the past five years. This circumstance has resulted in severe constraints on HKNC's ability to cope with increasing demand for its services and at the same time keep its physical plant in adequate repair.

On behalf of thousands of children, young people, and adults who are both deaf and blind, the Helen Keller National Center (HKNC) urges this Committee to recommend an appropriation for fiscal year 1999 at a level which will enable HKNC first and foremost to increase its capacity to provide technological training to deaf-blind individuals in order to enhance their employment opportunities; to address capital repair needs, and also to bring about the technological improvements and information gathering capability essential to reaching a higher level of efficiency and effectiveness. An appropriation of $8.55 million would reasonably address HKNC's requirements in the next fiscal year.

The Helen Keller National Center is very pleased and deeply grateful that the Department of Education requested, and the Administration agreed to, a substantial increase over the fiscal year 1998 appropriation. The budget amount of $8.176 million includes a cost of living increase, and a one time infusion of funds for urgent capital repairs and equipment and training in computer and other technology for our deaf-blind students.

While we appreciate the first real funding increase in 5 years, there are three areas (representing increases over the President's budget in the amount of $375,000), which we urge this Committee to recommend in its fiscal year 1999 appropriation bill for the Departments of Labor, Health and Human Services, and Education. The specific requirements for the amount over the President's budget are $100,000 to establish a national registry of deaf-blind individuals; $100,000 for the Center's endowment fund; and $175,000 for followup services for those deaf-blind youths and adults who have completed training. The total amount we are asking for—$8.55 million—is very small in Federal budgetary terms, but it will enable hundreds of deaf-blind Americans to live independently, including employment in productive jobs.

Deaf-blindness is by any measure one of the most devastating and most severe of disabilities. The number of deaf-blind Americans is increasing substantially on both ends of the age spectrum: Among children, and also in the elderly population. The reduction of dependency and the huge cost burden such dependency requires, results in a human and financial benefit that is incalculably greater than the funding we request. This modest appropriation would save many times that amount in Federal, State, and local funds.

BACKGROUND

The Helen Keller National Center is established by Federal statute and is funded primarily through Federal appropriations, and secondarily through State agency fee payments and corporate and individual donations. Its mission and its services are unique in the Nation and in the world: HKNC provides diagnostic evaluation, comprehensive rehabilitation, training, job preparation, and placement services for individuals who are both deaf and blind. HKNC also conducts research, and provides a national program of technical assistance and training to States and service agencies. From its headquarters in Sands Point, Long Island, New York, the Helen Keller National Center administers a national network of 42 affiliate agencies, under which agencies are provided financial support and technical assistance by HKNC to serve deaf-blind children, youth, and adults in their own home States.

CONGRESSIONALLY MANDATED RESPONSIBILITIES

The mission and responsibilities of the Helen Keller National Center, established by Congress in 1967, have expanded over the years. In 1992 the Helen Keller National Center Act was extended and amended. Additional responsibilities—and additional costs—were imposed on HKNC. For example, the Center is now required to train family members of individuals who are deaf-blind. The definition of deaf-blindness was expanded in the 1992 amendments. The result has been the opening up of the rehabilitation system to serving additional deaf-blind clients.

This year, we are seeking a further amendment to the Act which would enable HKNC to establish and maintain a national registry of deaf-blind individuals. The Rehabilitation Act reauthorization bill (S.1579) introduced and ordered reported by the Senate Labor and Human Resources Committee includes a section authorizing the registry, along with specific funding authority. Although this provision is not yet law, we urge this Committee to recommend an appropriation in an amount sufficient to enable HKNC to initiate this vitally important project.

Congress also created an endowment fund for HKNC, providing for a federal match of money from sources other than federal appropriations. The endowment, if it were funded, could help defray some of the appropriation burden. Apart from regular and preventive maintenance, HKNC's physical plant has not been refurbished since its inception nearly a quarter century ago. It is imperative that sufficient funds be provided to correct the most urgent deterioration, and to bring the HKNC residential campus into conformity with Americans with Disabilities Act standards for accessibility. Over the past five years Congress has appropriated funds for HKNC in the amounts requested in the President's budget; unfortunately, however, these amounts barely have been sufficient to offset the costs of inflation, and certainly have not been enough to expand needed services or repair our facilities.

SPECIFIC REQUIREMENTS FOR CAPITAL REPAIR AND PROGRAM IMPROVEMENT

HKNC requests this Committee's assistance in its efforts to maintain and strengthen its capacity to serve deaf-blind youths and adults, to repair its deteriorating physical plant, and to establish and maintain a national registry of deaf-blind people. We respectfully ask this Committee and the Congress to accord HKNC a high priority for federal support for the next fiscal year. Justification for the increase is set forth below:

Capital repairs.—The residential, training, and administration facilities comprising the Helen Keller National Center are now 22 years old. Because of limited funding HKNC has not been able to make necessary capital repairs and improvements. The most urgent of these are (1) removal and replacement of existing underground fuel oil tanks to comply with Federal, State, and local environmental requirements; (2) installation of underground electrical feeder lines for emergency power; and (3) renovation of some building interiors for additional accessibility, and to ensure compliance with the Americans with Disabilities Act. The total estimate cost for these capital repairs is $500,000. The President's budget would provide approximately half the funding needed for this purpose.

Increased service needs and the National Registry.—Three important factors have emerged to create additional pressures to expand HKNC's services. There are more than 11,000 deaf-blind children under the age of 22—the greatest number in our history—who will need such services. The definition of deaf-blindness in HKNC's enabling legislation was expanded to include those with progressive vision and/or hearing loss leading to deaf-blindness, as well as individuals who cannot be tested by traditional methods, but who are functioning as deaf-blind. The Rehabilitation Services Administration, Council of State Administrators of Vocational Rehabilitation, the American Association of the Deaf-Blind, and HKNC, have entered into a cooperative agreement under which the parties agreed to a model state plan for deaf-blind services. This will result in a statewide approach to serving people who are deaf-blind.

If these developments are to have any value or utility, HKNC must establish and maintain a national registry to ensure that all deaf-blind Americans receive the services they need. Creation of a national registry of deaf-blind children, youths, and adults by HKNC has been approved by the Rehabilitation Services Administration. Although it is urgently needed, however, HKNC has not had the financial resources to establish and maintain the nationwide listing. Establishment and initial operation of the registry will require an expenditure of $100,000. Lesser annual amounts would be necessary to acquire the data to maintain the registry in future years. The President's budget does not include any funds for the registry.

Endowment fund.—The endowment authorized by the 1992 amendments to the Helen Keller National Center Act has not yet been initiated, because the Federal funds required to trigger its establishment have not been appropriated. Funding for the endowment would enable HKNC to reduce gradually its dependence upon Federal appropriations. HKNC is now in a better position to attract outside funding, and those efforts would benefit greatly from even a small endowment. The President's budget does not include funds for this purpose. We urge the Committee to include a modest amount—$100,000—in the fiscal year 1999 appropriation.

Technology training.—Within the amount we request, HKNC would apply $250,000 of the appropriation toward the establishment of a "state of the art" tech-

nology capability, including the purchase of computers and technology equipment, and providing the following benefits to its deaf-blind clients, enhancing their job skills and marketability:

(1) Skill development, including classroom learning and on-the-job use of current computer hardware and software;

(2) Training for professionals (including rehabilitation counselors and independent living teachers), utilizing the HKNC Training Team, in teaching computer skills to deaf-blind clients; and

(3) Increasing knowledge and awareness on the part of deaf-blind consumers about available technology and its potential value in employment and home settings. The President's budget includes support at the amount HKNC requests, and we respectfully ask the Committee to provide these funds.

Followup services.—The Helen Keller National Center has found that, all too often, after intensive, comprehensive, one-on-one training is provided to a deaf-blind youngster, upon returning home the individual does not have the support structure necessary to retain the skills for independence and employment. With followup services provided by specialized HKNC training teams, the training the deaf-blind individual received can be reinforced, and the likelihood of permanent stability, independence, and a steady job, will be enhanced. As part of its request, HKNC urges the Committee to provide $175,000 for this purpose for fiscal year 1999.

Other issues.—Although HKNC's funding request for fiscal year 1999 is limited to addressing the foregoing urgent needs, the Committee should be aware of some additional requirements for which funds would be effectively used, should the Congress be in a position to provide them:

Affiliate network.—HKNC's network of 42 State and local affiliate agencies is extremely cost-effective, and should be expanded to enable 400 additional deaf-blind clients to be served through at least two new affiliate programs.

Family training.—Providing training and support to families is extremely effective in enabling them to acquire necessary services for the deaf-blind family member. Since the family often must serve as case manager, advocate, and primary care provider, such training eliminates the cost of supporting habilitation and rehabilitation positions in state agencies. Currently HKNC supports parent organizations in 28 States and Puerto Rico, and provides a vital communications link to about 2,000 parents. Parent training, transportation, and coordination have had to be deferred because of a lack of funds.

The aging population.—With the graying of America, the number of adults 55 and older with age-related hearing loss and blindness is increasing rapidly. This population increasingly requires services to maintain independence—services provided through the Helen Keller National Center. The ballooning caseload is imposing a tremendous burden, both on the rehabilitation system and on HKNC.

CONCLUSION

Deaf-blindness is one of the most severe of all disabilities. Most of us cannot conceive of living and functioning in a world without either sight or hearing. Training for independence, and even employment, for people who are deaf-blind, is not only possible but is being accomplished, successfully, every day at HKNC. Such rehabilitation and training is extraordinarily difficult, time consuming, and labor-intensive.

For a quarter century the Helen Keller National Center has operated as the only organization in the United States which provides, directly and indirectly, throughout the country, a comprehensive program of services and training for this relatively small population of our disabled citizens, and it does so with very modest funding from this Committee and the Congress. With the burgeoning population of deaf-blind children and older Americans, with the aging of its physical plant, and with more requirements it is becoming increasingly difficult for HKNC to adequately serve those who need our services.

We respectfully, but urgently, request this Committee to continue its recognition of, and support for, the needs of children and youth with the most severe combination of disabilities, and their families. We ask that Congress preserve the Nation's modest but essential investment in the Center and the people it serves by appropriating $8.55 million for the Helen Keller National Center for fiscal year 1999.

PREPARED STATEMENT OF THE AMERICAN LUNG ASSOCIATION AND THE AMERICAN THORACIC SOCIETY

The American Lung Association and its medical section, the American Thoracic Society, appreciate the opportunity to comment on the Senate Labor, Health and Human Services and Education Appropriation legislation for fiscal year 1999.

We first would like to thank the Committee for its continued support for biomedical research and public health programs. Without the Committee's leadership and strong bipartisan support many of the recent research and public health advances would not have been possible. For the Committee's support, we are deeply grateful.

We are also grateful for the support and leadership that the National Heart, Lung, and Blood Institute has provided over the past 50 years. As you may know, the NHLBI is celebrating its 50th anniversary. In those 50 years, the advances in research and public health have been phenomenal. In the 1940s, children with asthma sat on the sidelines while other children played sports. Today, athletes within asthma win Olympic gold medals. In the 1950s, premature babies with respiratory distress syndrome (RDS) died with hours of delivery. Today, not only can doctors successfully treat RDS babies, in many cases they can prevent RDS with drug treatments in the pregnant mother. In each of these advances, NHLBI was leading the way. Truly the 50th anniversary of NHLBI is a cause for celebration.

Although our comments will focus on lung-related research, the American Lung Association and American Thoracic Society feel that research into all health conditions is a valuable investment. We also recognize that biomedical and behavioral research are only part of a continuum of public health endeavors that include health services research, targeted health care delivery, health professions training, and prevention activities. We encourage this Committee to support the entire public health community.

There has been a great deal of excitement and anticipation about windfall revenues from the budget surplus and the proposed tobacco deal. Plans have been made by the Administration and leaders in Congress based on expected tobacco deal revenues. We strongly urge Congress and the Administration to make funding decisions based on the regular appropriations process. Enactment of the proposed tobacco deal is neither eminent nor necessarily in the best interest of America.

Summary: Funding recommendations

[In millions of dollars]

National Institutes of Health	15,696.0
National Heart, Lung, and Blood Institute	1,825.7
National Institute of Allergy and Infectious Diseases	1,554.4
National Institute for Environmental Health Sciences	379.6
National Institute of Nursing Research	73.1
Centers for Disease Control and Prevention	2,800.0
National Institute for Occupational Safety and Health	208.8
Tuberculosis Control Programs	220.0
Office on Smoking and Health	70.0

Magnitude of Lung Disease

Every year 335,000 Americans die of lung disease. Lung disease is third leading cause of death in the U.S., responsible for one in every seven deaths. More than 30 million Americans suffer from a chronic lung disease. Lung diseases cost the U.S. economy an estimated $85 billion annually.

Lung diseases represent a spectrum of chronic and acute conditions that interfere with the lungs ability to extract oxygen from the atmosphere, protect against environmental or biological challenges and regulate a number of metabolic processes. Lung diseases include; chronic obstructive pulmonary disease, lung cancers, tuberculosis, pneumonia, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, sarcoidosis, and a problem of growing concern in the U.S.—asthma.

Asthma

Asthma is a chronic lung disease where the bronchial tubes of the lungs become swollen and constrict, preventing air from getting into or out of the lung. These obstructive spasms of the bronchi are caused by a broad range of environmental triggers that vary from one asthma sufferer to another.

Asthma is on the rise. An estimated 14.6 million Americans have asthma; 4.8 million are under the age of 18. Since 1984, the prevalence of pediatric asthma has risen 72 percent. Rates are increasing for all ethnic groups and especially for African American and Hispanic children. While some children appear to "out grow" their asthma when they reach adulthood, most, 75 percent will require life-long treatment and monitoring of their asthma condition.

Asthma is expensive. The growth in the prevalence of asthma will have significant impact on our nation's health expenditures, especially Medicaid. Currently, asthma costs the U.S. over $12 billion a year. Asthma attacks bring 1.6 million people to

the emergency room each year. According to recent studies, asthma accounts for 17 percent of all pediatric emergency room visits.

Asthma kills

In 1994 5,487 children died as a result of an asthma attack. That is a 6 percent increase from 1993 and over a 100 percent increase from 1979. A disproportionate share of these death were in African American families. In 1994, the age-adjusted death rate for blacks was three times high than that of whites.

Asthma Research Advances

The good news on asthma is that research is beginning to bring answers, and with answers come hope for new treatments and a cure. NIH-supported research has provided greater understanding of what is actually going wrong in a person suffering from asthma; why exposure to airborne substances cause bronchial inflammation, why the immune system hyper-responds and what kinds of cell-to-cell communication mediate this response. Even more promising is that NIH-sponsored researchers are beginning to establish linkages between candidate genes and asthma. In the near future, we expect that this research will identify the genes that cause asthma.

Researchers are also developing better ways to treat and manage chronic asthma. NHLBI-supported research has shown that regularly scheduled use of beta-agonists, though safe, provides no additional benefit over their use only as needed in patients with mild asthma. Based on this research, patients with mild asthma need not take regularly scheduled doses of a beta-agonist. Because over half of all asthma patients have mild asthma, this finding is expected to result in large reductions in the cost of asthma care.

Researchers supported by NHLBI have developed better animal models to allow expression of selected asthmatic genetic traits. This will allow researchers to develop a greater understanding of how genes and environmental triggers influence the onset, severity and long-term consequences.

Population-based research is also leading to improvements in the management of asthma. NIAID's National Cooperative Inner-City Asthma Study is designed to identify and mediate those factors in the patient's home that lead to increased morbidity and mortality in the inner-city minority population. Data from NIAID's Inner-City Asthma Study show that by combining medical treatment and asthma case management with a reduced exposure to these triggers can lead to a significant reduction in hospital costs for study populations.

NIEHS-supported research is providing greater insight on the potential interactive and independent effects that exposure to areoallergens, like ozone and fungal molds, have on asthma symptoms.

NINR-supported research has shown a correlation between biological markers of airway inflammation and symptoms in adults with asthma. Further NINR studies are investigating whether Asthma Education Intervention impacts both clinical markers of asthma and biological marker of airway inflammation.

Research advances and opportunities

NHLBI funded researchers have localized the gene defect that causes primary pulmonary hypertension (PPH)—a rare disease that kills nearly half of its victims within four years. While inherited PPH is uncommon, PPH due to interaction with drugs and other diseases is far more common. Understanding the mechanism of inherited PPH will lead to better treatments to prevent PPH or stop its fatal outcome.

Eighty to 90 percent of all chronic obstructive pulmonary disease (COPD), which includes emphysema and chronic bronchitis, is caused by smoking. However, only 15 percent of smokers develop COPD. Non-smoker also can develop COPD. These facts taken together strongly suggest a genetic link in the development of COPD. With appropriate resources, NHLBI researchers can develop a greater understanding of the genetic component of COPD and how genetics interact with other components like smoking, environmental exposures, diet and exercise.

NHLBI-supported researchers have found that retinoic acid can reverse the effects of emphysema in laboratory rats. Further research is needed to explore the role retinoic acid plays in lung tissue rejuvenation. Such research may lead to better treatment for emphysema and other degenerative lung diseases.

Scientists supported by NHLBI have discovered a new family of chemical in the lung—beta-defensins—that kill disease-causing bacteria. Other researchers have begun to describe the role surfactant proteins play in the lung defense. A fuller understanding of the role these natural chemical play in the lung's immune system may greatly improve treatment for a number of diseases—ranging from cystic fibrosis to prevention of lung-related infection in AIDS patients.

Vaccine researchers supported by NIAID have developed a pediatric acellular pertussis vaccine for "whooping cough" that is safer and more effective than the previous whole cell vaccine. Further research may soon yield an adult pertussis vaccine and a pediatric vaccine that requires a single dose, rather than the current multiple injections.

Researchers at NINR are looking at end-of-life issues. Many terminally ill patients suffer from dyspnea—troubled breathing. Current treatment of dyspnea is often ineffective and cause side effects that diminish the "quality of life" of dying patients. NINR research well help finds better ways to care for those who are dying.

Job-related illness and injuries cost the U.S. economy over $121 billion year. With proper research, we believe many occupational illnesses are preventable. We would like to bring to your attention the National Occupational Research Agenda (NORA) at the National Institutes of Occupational Safety and Health (NIOSH) at CDC. In 1996, NIOSH convened a panel of experts from the scientific, labor and corporate communities to layout a plan for occupational health research. The goal of this research plan is to collect sound scientific data to document and develop strategies to prevent job-related illness. We strongly recommend the committee provide $15 million to support the National Occupational Research Agenda at NOISH.

Responding to crisis

The public health community watch with great interest and more than a little bit of anxiety, the recent a outbreak of avian flu in Hong Kong. The threat of a new viral pathogen poses to an unprotected human population is sincere and severe.

The response of CDC and NIAID to this crisis was swift and decisive. Both CDC and NIAID sent experts to Hong Kong. NIAID also sent reagents and assisted in typing the avian flu virus. A potential vaccine was developed. Additionally, a tour of South China was organized to see if there were other cases of avian flu in humans. No cases outside of Hong Kong have been documented. So far, it appears as though a public health crisis has been avoided, thanks in part to expertise and materials contributed by CDC and NIAID. It is important to ensure we maintain the ability to respond to infectious disease threats around the globe, much like was done in Hong Kong.

RMS

We are concerned that while the NIH research budget has increased, the administrative budget or research management and support (RMS) function has remained flat. Administrative functions of the NIH play a vital role in the advancement of science. Awarding and monitoring grants, ensuring scientific and ethical standards in the research community, developing and disseminating patient and provider education materials, and convening state of the art scientific meetings are just of few of the functions that NIH conducts with its administrative budget. If the administrative budget of NIH continues to shrink relative to other NIH activities, the eventual result will be a reduction in the quality of NIH-supported science.

Education

Closely linked to the research management and support (RMS) budget issue is the funding for NIH Public and Professional Education Programs. NIH education programs are vital for improving patient care and education. The NHLBI has been a leader in producing patient and provider education materials. The NHLBI initiated the National Asthma Education and Prevention Program (NAEPP) in 1989 to raise awareness that asthma is a serious chronic disease and to promote more effective management of asthma through patient and professional education. NAEPP at NHLBI recently revised the Guidelines for the Diagnosis and Treatment of Asthma and has also published Asthma Management in Minority Children to provide information to health care providers serving minority children with asthma. We are pleased that the Committee included report language in last year's appropriation bill to exempt these kinds of important educational activities from restrictions on the RMS budget. We encourage you to continue this exemption.

Critical care medicine

Critical care medicine is a multi-disciplinary treatment approach that involves such specialities as anesthesiology, internal medicine, pediatrics and surgery and is usually practiced in the hospital intensive care unit (ICU). Noting that critical care medicine accounted for 28 percent of total acute care hospital costs, in 1993 this committee directed the NHLBI to support research to enhance effective practices and treatments in critical care medicine. In 1994 the NHLBI Task Force on Research in Cardiopulmonary Dysfunction and Critical Care Medicine released a report on critical care medicine, including recommendations on training and basic, clinical, and epidemiological research on critical care medicine. The American Lung

Association and the American Thoracic Society urge the committee to continue its support for research in critical care medicine.

Tuberculosis research and control initiatives

Although tuberculosis is a preventable and curable disease, it still persists as a public health problem in the United States. As a direct result of increased federal investment in TB control programs at CDC, TB case rates have begun declining nationally. However, TB cases continued to increase in some areas. Twenty of the 50 states and the District of Columbia reported either no change or an increase in TB cases. 1996 was marked by sporadic outbreaks of MDR-TB. Sporadic cases of "Strain W," a deadly TB strain resistant to the best anti-TB drugs, originally reported in New York, New Jersey and Florida have now been found in South Carolina, North Carolina, Colorado, Ohio, Pennsylvania, Georgia, Nevada, California and Puerto Rico.

Recent investment in TB control programs are beginning to pay off. National TB case rates have declined for 4 consecutive years. Although data is still preliminary, we expect that CDC will soon announce a fifth straight year of decline in domestic TB rates. This good news is a direct result of efforts by the CDC and public health officials. It is important to continue this area of support throughout the period it takes to control TB. Preventive Health Projects for Tuberculosis administered by CDC should be continued in fiscal year 1999 and funded at the recommended level of $220 million.

There are several steps that should be taken to maintain the current decline in TB rates. The first step must be the expansion of existing prevention and control methods. Tuberculosis is successfully prevented and controlled by a variety of public health methods. The American Thoracic Society and the CDC revised a joint statement, The Control of Tuberculosis in the United States, that provides guidance for establishing tuberculosis control activity. It is intended for use by persons working in tuberculosis control programs and related programs in such sites as correctional facilities and homeless shelters.

To combat TB in the U.S. and eliminate tuberculosis worldwide will require far more than just intensified and widespread use of existing prevention and control methods. Combating TB will also require the development of new drugs to treat MDR-TB. The last new drug developed to treat TB became available in 1972. Today, the fight against TB requires new diagnostic and prevention technologies, and the rapid transmission of newly developed technologies to the field.

Progress is being made on TB. In fiscal year 1998, the Foreign Operations Appropriation Subcommittee provided USAID's with funds for international infectious disease control, including TB. USAID, NIH and CDC, have begun a cooperative dialogue to decide how best to use these international TB funds. We are pleased that the American Lung Association and the American Thoracic Society has been invited to participate in many of these discussions. To ensure appropriate coordination between U.S. domestic TB control, research, and international efforts we strongly encourage CDC, NIH and USAID to enter a formal interagency cooperative agreement regarding US TB control activities. We also recommend that USAID, in conjunction with CDC, NIH, the World Health Organization and volunteer and professional organizations like the American Lung Association and American Thoracic Society develop an international plan to eliminate TB.

Federal support for tuberculosis research is concentrated within the National Institute for Allergy and Infectious Diseases. The overall support within this Institute for research specific to M. tuberculosis has increased from $323,000 in fiscal year 1979 to $37.6 million in fiscal year 1998. NIAID has developed an agenda to intensify tuberculosis research efforts including improvement of existing diagnostic tests which are not sensitive enough to detect TB reliably and early in individuals with HIV infection, development of an effective vaccine to protect those at risk of infection and identification of more effective treatments for those already infected.

In conclusion, lung disease is a growing problem in the United States. It is America's number three killer, responsible for one in seven deaths. The lung disease death rate continues to climb while rates for America's first- and second-ranked causes of death—heart disease and cancer—are dropping. Overall, lung disease and breathing problems constitute the number one killer of babies under the age of one year. Worldwide, TB kills 3 million people each year, more people than any other single infectious agent. The level of support this committee approves for lung disease programs should reflect the urgency illustrated by these numbers.

Thank you.

PREPARED STATEMENT OF TERRY-JO MYERS, INTERSTITIAL CYSTITIS ASSOCIATION

Honorable Chairman and Members of the Committee: Thank you for giving me the opportunity to present written testimony. I would like to tell you about interstitial cystitis and ask for continued funding of research to find a cure for this painful, debilitating disease. My name is Terry-Jo Myers and I am a professional golfer completing my 13th year on the LPGA tour. I also have interstitial cystitis, or IC. While I appear healthy to anyone who meets me, that is because the effects of interstitial cystitis are not visible to others. I can, however, assure you that my work, my family and social life, and my pursuit of many dreams have all been dramatically affected by my experience with IC. Many of you may already know that my IC story has had a happy ending, for have been able to find relief.

Interstitial cystitis is a chronic inflammatory bladder condition. Its cause is unknown and there is no uniformly reliable treatment. The symptoms, which can be severe and unrelenting, include urgency and frequency of urination—up to 60 or more times in 24 hours—and pain in the bladder which IC patients have described as burning, like "electric shocks," or like "razor blades in the bladder."

I was diagnosed with IC shortly after I developed symptoms at the age of 21, and I was told that nothing could be done. Doctors said I would just have to live with the pain—a prescription that far too many IC patients still receive. Every step I took was painful, and for a tour player it was torture. Often I could not even bend down to line up a putt. I had to urinate about 50 times a day, including 10 to 20 times at night. I played in non-stop pain and had constant anxiety about being able to make it to the next bathroom.

Because travel is especially difficult for many people with IC, I arrived at tournaments exhausted. While my fellow players were practicing, I was often forced to remain in the locker room.

Saddest of all for me personally, IC affected my golf game. As a junior athlete, I won many tournaments. As a professional with IC, my performance was terribly hindered by the disease. Because LPGA rules prohibit players from leaving the course for any reason, I had to withdraw from tournaments in the middle of a round because I needed to go to the bathroom. In 1988, I won the Mayflower Classic, but I attribute much of that win to the fact that there were two rain delays that allowed me to go to the bathroom and keep playing.

For the last three years, I have been able to complete a full schedule in relative comfort, and look forward to continuing to do so. I am very happy to report that last season I won the Los Angeles Women's Championship, as well as the Sara Lee Classic, finishing the year with a career high $313,000 in earnings. I attribute much of my success to the oral drug Elmiron, which was recently approved by the FDA for marketing. Unfortunately, Elmiron provides relief in only about one third of the IC sufferers who try it.

For me, last year was a dream come true. My story appeared in newspapers and magazines all across the nation. I was featured in People magazine. I appeared on countless television talk shows to share my story of success. The most gratifying result of all this publicity, beyond my own sense of achievement, was the fact that the Interstitial Cystitis Association, the ICA, was able to reach out to more IC sufferers than ever before.

In mid-December, I received the Heather Farr Award at the LPGA 1997 Awards Luncheon. This award, voted on by Tour players, recognizes a player who demonstrates determination, dedication, and spirit through the game of golf. Heather Farr, who was a close friend of mine, died of breast cancer in 1993. As I told the New York Times, I never told Heather that I had IC, but watching her fight cancer helped me continue my fight against IC. She fought her battle in public, and she was never angry or bitter. I guess I just borrowed some of her strength. For that reason, this award is especially meaningful to me.

As if that were not enough gratification for any athlete, earlier this month I received a letter from the Golf Writers Association of America indicating that I had been voted the Ben Hogan Award, presented annually to someone who has continued to be active in golf despite a physical handicap or serious illness. This beautiful bronze statuette of Ben Hogan has been awarded to such golf heroes as Ken Venturi, Lee Trevino and President Eisenhower! I will be attending the awards dinner in Augusta on the eve of The Masters Tournament in April.

Although I am immensely grateful for my reclaimed success, there are many many others who have not been as fortunate. I have had IC for fourteen years. It has been only 6 years since I was able to find a doctor to help me. This doctor put me in touch with the ICA and motivated me to take steps to begin to cope with my illness. This doctor was also aware of Elmiron and made sure that I was able to take it as soon as the FDA approved its distribution here. Not all IC patients can

say this. Many can't travel, work, or meet their family obligations. Many become financially destitute as they lose their health insurance coverage and try to keep up with their IC treatments. Some have their bladders removed, only to encounter a whole new array of medical problems. My success story is not one that all IC patients can claim.

Because it is a comparatively rare disease that affects mostly women, and historically, urology and urological research have focused primarily on male urological problems, interstitial cystitis is a disease that continues to be ignored by many members of the medical community. It is serious and it can be costly. An epidemiological study sponsored by the Urban Institute found that an estimated 450,000 people in the U.S.—men and women both—may suffer from IC, with an economic impact as high as $1.7 billion per annum.

Fortunately, there is hope. Thanks to previous Congressional funding, the NIDDK built the IC Database, an extensive pool of IC patient information collected at nine sites around the U.S., and stored and analyzed at the Pennsylvania State University, Hershey Medical Center. Researchers have already begun to publish reports analyzing data obtained from this study, with the expectation that the Database will provide clues as to how IC develops, how to diagnose and categorize patients, and how to treat the disease more effectively. In short, the Database has provided the first systematic long-term look at a large number of IC sufferers. Thanks to your support the IC Database is now moving into Phase 2, which will test and study new treatments for IC.

The Interstitial Cystitis Association and all IC patients are so grateful to all Members of this Subcommittee, and in particular, to Chairman Spector and Senator Reid for their ongoing support of research on IC and other urological diseases. Without your help, we would be nowhere in our struggle. Because of your commitment, we are beginning to see some progress. In conclusion:

To continue this research initiative, we request that the Committee provide additional funds to the Urology Program of the NIDDK in fiscal year 1999 to be used for expanding the cadre of investigators doing research on IC. These funds should be used to support further research specifically into IC. Proposals should be solicited through a series of Request for Applications (RFAs) for individual research grants and pilot studies which would look into: (1) new strategies for IC symptom relief; (2) epidemiology; (3) further understanding the basic science of IC. The Committee requests that the NIDDK prepare a report of ongoing research studies and areas for research solicitations, demonstrating where advances can be made in the effective treatment and prevention of IC.

We still have far to go. Yet we are confident that with your help and with adequate, continued funding for IC research through the NIDDK, results will be no less than miraculous. As a victim of IC, I know what it is like to endure chronic, unrelenting pain. Please help us to end our suffering. Help us find a cure for interstitial cystitis. Thank you.

PREPARED STATEMENT OF FATHER WILLIAM L. GEORGE, S.J., AND FATHER T. BYRON COLLINS, S.J., SPECIAL ASSISTANTS TO THE PRESIDENT OF GEORGETOWN UNIVERSITY

In the current fee-for-service Medicare program, 10 percent of Medicare patients use 70 percent of Medicare services. Therefore, any desire to optimize the quality of care delivery and improve the efficiency of service delivery for Medicare patients must begin by addressing the issues related to care delivery for this segment of high utilization Medicare patients. The health Care Financing Administration has begun an initiative to address the needs of Medicare fee-for-service patients with chronic medical illness. In response to this need for increased cost-effective service delivery Congress authorized, in Section 4016 of Public Law 105–33, the implementation of nine Medicare Coordinated Care Demonstration Projects intended to: improve the quality of items and services provided to target individuals; and reduce expenditures under the medicare program under title XVIII of the Social Security Act (42 U.S.C. 1395 et seq.) for items and services provided to target individuals. (SEC. 4016 (a)(1))

Among these programs is "1 project within the District of Columbia which is operated by a nonprofit academic medical center that maintains a National Cancer Institute certified comprehensive cancer center" (SEC. 4016 (b)(C). In response to Public Law 105–33, Georgetown University proposes to undertake a program combining clinical pathways and case management strategies to more effectively manage the care of these chronically ill patients. The goal is to improve quality of care and cost-effectiveness of service for the chronically ill.

In order to attract program participants, $3 million dollars was appropriated to the Georgetown demonstration through District of Columbia Appropriations in Pub-

lic Law 105–100. This $3 million will, for the most part, cover copayments and deductibles that would normally be paid by Medicare fee-for-service beneficiaries when they receive care. Coverage of these patient out-of-pocket expenses will encourage Medicare beneficiaries to participate in the program. Coverage of copayments and deductibles will be arranged, in part, with the help of religious ministers in the District of Columbia. It is essential that these funds be used for this purpose. These funds were appropriated by the District of Columbia Appropriations Subcommittee because of language contained within Public Law 105-33, SEC. 4016 (e)(1)(A)(ii):

—*Cancer hospital*.—In the case of the project described in subsection (b)(2)(C), amounts shall be available only as provided in any Federal law making appropriations to the District of Columbia.

This language is misleading and is currently being amended in the form of a technical correction. The $3 million received from District of Columbia Appropriations in Public Law 105–100 was a one-time fund disbursement. In the future, funding for patient out-of-pocket costs must be received through other Federal sources.

We request that future funding for planning and ancillary funds of the Georgetown University Medical Center Medicare Coordinated Care Demonstration Program be appropriated to The Department of Health and Human Services for distribution to Georgetown. In fiscal year 1999 we request a total of $5 million. This request consists of $3 million for previously explained coverage of copayments and deductibles as well as $2 million to cover administration and infrastructure costs necessary for successful program implementation. This $2 million will cover the cost of critical pathway design, patient recruitment, education/wellness programs, and other necessary administrative costs.

We request that this $5 million be accompanied by an additional $15 million appropriation to the Department of Health and Human Services. This funding, along with the $5 million to the Georgetown demonstration, will amount to $20 million in additional funding to the Health Care Financing Administration for "Research, demonstrations, and evaluation projects" (Budget of the United States Government, Appendix, fiscal year 1999). In fiscal year 1998, the Health Care Financing Administration requested $50 million for research, demonstrations, and evaluation projects but was appropriated $53 million by the Senate. We wish to have additional funds appropriated to this line item again in fiscal year 1999.

Appropriation of the above funds to the Health Care Financing Administration will allow for the successful exploration of new and innovative modes of delivering quality care to chronically-ill, high risk individuals in a cost-effective manner.

Prepared Statement of Antonio De La Cruz, MD, FACS, President, American Academy of Otolaryngology-Head and Neck Surgery, Inc.

Members of the subcommittee, ladies and gentlemen, I am Dr. Antonio De la Cruz, President of the American Academy of Otolaryngology-Head and Neck Surgery, Inc. (AAO-HNS), the world's largest organization of otolaryngologists and head and neck surgeons. There are more than 10,000 members, including 97 percent of all Board-certified otolaryn-gologists.

Mr. Chairman, I and the members of the AAO-HNS and the patients that they are privileged to care for all owe an immense debt of gratitude to you and your colleagues on this subcommittee for your hard work in providing greatly increased funding for the National Institutes of Health (NIH) for fiscal year 1998 and particularly for the

National Institute on Deafness and Other Communication Disorders (NIDCD)

National Institute on Deafness and Other Communication Disorders (NIDCD) The NIDCD has a mission of unique importance to the nation's health and to its economic and social well being—including insuring the optimization of communication skills regarding hearing, voice, speech and language.

NIDCD-supported scientists have made extraordinary strides in the understanding of and the basic processes which underlie the many diseases and disorders of hearing, balance, taste, smell, voice, speech and language.

These advances have come from the many different fields of science.

—The genetic bases of deafness is being unraveled.

—Promising studies in animal models indicate that it is possible to protect the inner ear through the use of growth factors or the introduction of viruses whose DNA has been altered so that appropriate protective substances are produced and released in the inner ear.

—Further work along the same lines is being undertaken to repair the damage which has occurred and to replenish the cells of the inner ear which have been destroyed.

All of these studies will soon be tested in patients.

— Further advances have been made in the prostheses for the hearing impaired, including hearing aids and the cochlear implant. Many of these advances have been directly applied to patients enabling them to communicate with others and contribute to the economic and social well being of our society.

—Advances in our basic understanding of the human voice have resulted in surgical procedures which have restored voice to those who could only speak in a whisper.

—Linguistic studies are one of the most important areas of the NIDCD mission. NIDCD-sponsored scientists are defining the biological bases of language. This work is being accomplished through the observation of infants, the use of human electro-physiology and the utilization of the advances of brain imaging. The 2 information gained from these studies will enable physicians to diagnose and treat the many language disorders which put so many at disadvantage in our communication-based society.

The NIDCD, one of the newest institutes at NIH, has made rapid progress and is at a point in which there are more needs than resources. This is especially true in two areas: translational research—applying the fruits of basic research to the patients and clinical trials, and evaluation of the effectiveness of different therapies.

The science which is required in these areas is expensive but necessary and the NIDCD needs to have the additional resources so that it can continue to take advantage of all of the advances in the various forms of basic research but also to carry out needed translational and clinical studies. The investment in the NIDCD will have substantial economic as well as health advances for it insures optimal economic productivity through improved communication abilities for our citizens.

Dr. Ruben and I, along with colleagues from our Academy and others attended a conference recently called by the NIDCD on Economic and Social Realities of Communication Differences and Disorders. This conference was called for in bill report language last year, urged by Dr. Ruben. The conference dealt with issues of diagnosed and undiagnosed childhood communication disorders, including learning disabilities and dyslexia, deafness, specific language impairment, and stuttering, as well as the impact of such diseases and disorders on crime and incarceration.

The conference revealed that the economic bases of our society—the way in which people make their livelihoods—has undergone fundamental change during the last half of the 20th century. In the past, we depended largely on manual labor. Today we depend upon communication skills. This, in turn, has a profound effect on definitions of illness, and on society's expectations and demands of the medical profession.

This revolutionary change in "making a living" is reflected in the labor statistics for New York City. In 1900, manual labor accounted for 94 percent of the 149,000 jobs in the city. By the middle of the century, in 1950, only 31 percent of the 3.5 million jobs were in manual labor; the other 69 percent (2.6 million) were based primarily upon the communications skills of the workers. The trend has continued—in 1996, 88 percent of the 3.2 million jobs in New York City were dependent upon communication skills. In real numbers, from 1950 to 1996 the number of manual labor jobs was reduced by 66 percent from 1,163,000 in 1950 to 392,024 jobs in 1996. At the same time, the number of workers who rely on communication skills increased by 9 percent from 2,588,700 in 1950 to 2,832,000 in 1996; 771,676 manual jobs no longer exist: these have been replaced by communication-based employments. Bureau of Labor projections for the United States as a whole indicate that by the year 2005 employment will increase by 17.7 million jobs of which at least 92 percent (16.2 million) of these new jobs will be based on communication skills.

The NIDCD mission is to provide the knowledge which is needed to prevent, cure and care for all of the diseases of communication so that this country may have a communicatively healthy and competitive population.

National Institute of Environmental Health Sciences (NIEHS)

Our Academy has long been interested in issues affecting environmental health of humans, and the health of the environment generally. In several instances, we have cooperated with the National Institute of Environmental Health Sciences (NIEHS) in conferences and meetings dealing with air pollution, water pollution and soon, hopefully, on the issue of environmental noise and its impact on hearing and upon the environmental well being of people generally.

For example, the Academy participated as a founding organization of the National Association of Physicians for the Environment, at its founding conference in 1993, supported by the NIEHS. Also, we played a major role in the "National Conference

on Air Pollution Impacts on Body Organs and Systems" and the recent "International Conference on Water Pollution and Health," both supported in part by the NIEHS.

Michael D. Maves, MD, MBA, now serves as Chairman of the National Council on Healthcare Energy Efficiency and "Greening" of Healthcare of the National Association of Physicians for the Environment, working to improve energy efficiency in healthcare and medical research facilities. The National Institutes of Health has won several energy efficiency awards for its work at the Bethesda campus; the NIEHS has worked to improve energy efficiency at the North Carolina campus and is now considering how to assist extramural researchers to do the same in their facilities.

We believe that human health is inseparable from a healthy environment.

We have watched as the NIEHS has worked hard in recent years to reach out to all the constituencies which affect or are affected by a polluted environment. We believe major strides have been made in this regard.

We therefore urge a significant increase for the NIEHS of at least 15 percent.

Mr. Chairman, we fully support the request of the Ad Hoc Group for Medical Research Funding, of which we are members, for a 15 percent increase overall for the NIH. Because of the special importance and the extraordinary demands of outstanding science upon the NIDCD we request an 18 percent increase for NIDCD. We also urge an increase of 15 percent for the NIEHS.

Mr. Chairman, thank you for the opportunity to testify and I will be pleased to answer any questions which you may have.

Prepared Statement of Arthur L. Day, M.D., American Association of Neurological Surgeons

Mr. Chairman and Members of the Subcommittee, My name is Arthur L. Day, M.D. I am a professor of Neurological Surgery at the University of Florida in Gainesville, Florida, and I appear here today on behalf of the American Association of Neurological Surgeons (AANS) and the Congress of Neurological Surgeons (CNS), which represent over 4,000 practicing neurosurgeons in the United States. The AANS and CNS thank you for the opportunity to comment on the fiscal year 1999 neuroscience agenda for the National Institutes of Health (particularly the National Institute of Neurological Disorders and Stroke) and the Agency for Health Care Policy and Research.

Past funding requests

Before presenting our recommendations and justifications for program support in fiscal year 1999, we wish to briefly outline our previous funding requests during the Decade of the Brain. Spinal disorders, vascular diseases of the brain, and genetic disorders (including brain tumors) represent the three most common afflictions of the nervous system impacting the health of the American public. In the past, we have focused on these three areas and have requested funding for biomedical research for: (1) brain tumor research centers, (2) stroke and cerebrovascular disorders, (3) gene therapy for brain tumors and other diseases of the nervous system, (4) basic research on spinal cord injury, spinal degenerative diseases, and the biomechanics of spinal instability, and (5) stereotactic surgery of the brain and spine. The Committee has been very receptive to these requests, and we urge the Committee to continue to intensify its efforts in these areas to build on the foundation of prior Decade of the Brain initiatives.

Fiscal year 1999 funding requests

For fiscal year 1999, we urge the Subcommittee to direct its funding attention to five areas of research: (1) head and spinal cord injury, (2) stroke and cerebrovascular disease, (3) molecular biology as it applies to tumors and other nervous system disorders, (4) spinal disorders and pain, and (5) outcomes research into the effectiveness of new therapies for neurological disorders.

Treatment of head and spinal cord injuries.—Trauma to the brain and spinal cord remains a major public health issue in the United States, and is a leading cause of death and disability among children and young adults. Head injuries are present in 75 percent of fatal automobile accidents. The direct and indirect costs of traumatic spinal cord injuries are estimated to be over $7 billion annually. New pharmacologic protection agents can now be shown to decrease the amount of brain and spinal cord damage produced in experimental animals subjected to vascular or traumatic injury. In a recent NIH-funded study, the early administration of methylprednisolone improved the neurologic recovery of patients with spinal cord injuries. Functional recovery can also be improved by prompt treatment. Thus, head

and spinal cord injury patients should be promptly evacuated to centers ready to treat them with effective surgical and chemical support.

A number of important treatment questions about such injuries remain that should be the subject of carefully designed clinical trials to determine the optimal treatment paradigm. The value of early versus delayed decompression of spinal fractures with spinal cord injury represent one such issue. Ultimately, of course, the ability to restore function of injured brain and spinal cord tissues is the key to central nervous system injuries and treatment, and we believe that basic research targeted at this goal should be a major priority of this Committee.

Stroke and cerebrovascular disease research.—The term "stroke" is often applied to capture a number of conditions in which the brain's blood vessels either rupture or become blocked, resulting in some degree of neurologic injury. Stroke is the third leading cause of death in the United States, and between 1992 and 1995, stroke deaths have increased by ten percent. Stroke is also a leading cause of long term disability. Each year, 500,000 new cases are diagnosed, at an estimated annual cost of $30 billion. More than half of this total is attributed to acute, rehabilitative and nursing home care, while the remaining costs are due to lost productivity, alteration in lifestyle, and the economic burden assumed by family members and other caregivers.

In recent years, the catastrophic consequences of stroke have diminished, in part through better understanding of the basic chemical and physiological processes that result in brain cell death. Aggressive medical treatments before or early after the onset of stroke symptoms can now significantly improve outcomes by enhancing the recovery of function, results of surgery, and the outcome of rehabilitation. For example, the intraoperative administration of barbiturates to certain patients undergoing carotid artery surgery or certain intracranial vascular procedures can significantly reduce the stroke risks inherent in such operations.

Recently, the concept of "Brain Attack," similar in its implications to a heart attack, has gained the support of the National Stroke Association, American Heart Association, and many neurologists and neurosurgeons across the country. The major thrust of the Brain Attack initiative is early diagnosis and administration of therapeutic agents and operations, in the hope of limiting or reversing the damage produced by the stroke. The immediate goals of stroke treatment include the rapid restoration of blood flow to areas of the brain lacking circulation, protection of brain cells (neurons) from irreversible damage, and rescue of those cells that have undergone molecular and biomechanical changes from lack of nutrients and oxygen. Restoration of the circulation and delivery of drugs must be rapidly carried out within a "window of opportunity" before irreversible brain damage occurs. The acute treatment of these disorders has only recently become feasible and models the demonstrated medical and economic successes of heart attack treatment though early recognition, resuscitation and organ protection. Prototypical agents for decreasing brain damage and increasing efficiency of restored blood flow already exist. We are convinced that your continued support will lead to substantial life-saving and function saving progress.

Molecular approach to treatment of brain tumors and other disorders.—Brain tumors represent the third leading cause of cancer deaths in middle-aged males and tumors of the nervous system are the second leading cause of cancer deaths among children. Each year more than 10 percent of the 400,000 new patients with other types of cancer eventually see their disease spread to the brain and spinal cord. In many such patients, the nervous system tumor constitutes the single most immediate threat to their life and function.

The recent application of molecular biologic techniques to the central nervous system has revolutionized our understanding of how brain tumors grow and spread. For example, we now know that the absence of some genes, which normally act as "brakes" on tumor development, can cause diseases such as neurofibromatosis, a condition associated with multiple nervous system tumors.

Neurosurgeons have been leaders in the development of new methods of drug delivery into the nervous system, and these techniques can be used to deliver genes and hormones. Therapeutic agents can be directly injected into the brain by modern image-based stereotactic techniques, while cells in other parts of the body are shielded from potential injury. Genetic material can be linked to immunological agents and other chemicals to cause the death of tumor cells, and insertion of normal genes into the brain may help control the expression of brain cancer. Similar research in such disorders as Parkinson's disease, Tay-Sach's, Huntington's disease and Alzheimer's dementia is already underway, and may reduce the $100 billion annual burden faced by the American public. Your continued support can lead to the discovery of the full range of genetic abnormalities that underlie the development of brain tumors and degenerative diseases. Once these "targets" are identified, new

molecular bullets can be designed and directly entered into the nervous system to fight these deadly and costly diseases.

Research into spinal disorders.—Disorders of the spinal cord, the spinal nerve roots and the bony spine are some of the leading causes of pain and disability in the United States today. Each year 15–20 percent of the population will have an episode of back pain, and during their lifetime, about 70 percent of U.S. citizens have an episode of serious back and/or leg pain caused by diseases of the spine. Currently, back and leg pain are the second most common reason for physician visits in the United States.

Recent progress in basic neuroscience research has markedly enhanced our understanding of basic mechanisms of pain, and has allowed us to have a much better understanding of how the spinal cord controls movement and integrates sensation. Further basic research is needed to investigate and identify mechanisms that underlie the loss of function and production of pain whenever the spinal cord or nerve roots are compressed by discs or bone spurs into the spinal canal, thus allowing more effective pharmacological and less invasive treatment modalities to be developed to improve the lives of so many people who suffer from degenerative diseases of the spine.

Clinical and outcomes research is also needed to help us to understand the optimal utilization of both non-surgical and surgical treatments of spinal diseases. It is clear that some patients with serious spinal disorders can only be helped by surgery. Clinical research in this area would help physicians more expeditiously evaluate patients with spinal disease and more appropriately select patients for operative treatment, thus limiting the patient's time of anguish before definitive and pain-relieving surgical intervention is performed.

Outcomes research.—Technology is now driving the contemporary treatment of neurologic disorders at an unprecedented degree. New drugs to treat stroke, genetic agents to treat brain tumors, and radiosurgical devices and spinal instrumentation all represent significant financial investments. Pallidotomy, a highly technical surgical disconnection of the malfunctioning areas of the basal ganglia, is very successful in halting tremors and other symptoms for Parkinson's disease patients. The costs of these therapies are easily justified if the benefits of decreased suffering and additional years of useful survival outweigh the amortized costs of therapy. Outcomes research can do much to guide patients, their physicians and policy makers in therapeutic decision making and resource allocation. We urge you to provide funds to the Agency for Health Care Policy and Research to: (1) improve the methodology of outcomes research in neurological disorders, and (2) support pilot studies in the treatment of stroke, brain tumors, degenerative diseases and spinal disorders.

These funding priorities will be costly, but can have a major impact on the quality of life for our citizens. The brain does not lend itself to surgery in the way that other organs do. It cannot be cut and stitched back together. It does not naturally heal and regain function. More research is therefore needed to discover new treatments and therapies for neurological disorders.

Mr. Chairman, and members of the Subcommittee, as we approach the final year of the Decade of the Brain and the new millennium, the AANS and CNS hope that Congress will continue its commitment to biomedical research for nervous system disorders. These funding priorities are costly, but can have a major impact on the quality of life for our citizens.

Thank you for your consideration.

Prepared Statement of the American Association of Nurse Anesthetists

The American Association of Nurse Anesthetists is the professional association that represents over 27,000 certified registered nurse anesthetists (CRNAs) in the United States. AANA appreciates the opportunity to provide our experience regarding federal funding for nurse anesthesia educational programs under Title VIII, the Nurse Education Act (NEA). Many members of our association have benefited greatly over the years from the Title VIII programs, which in turn has benefited the health care system by assisting in the maintenance of a stable supply and adequate number of anesthesia providers.

Background information about CRNA's

In the administration of anesthesia, CRNAs perform many of the same functions as physician anesthetists (anesthesiologists) and work in every setting in which anesthesia is delivered including hospital surgical suites and obstetrical delivery rooms, ambulatory surgical centers, health maintenance organizations, and the offices of dentists, podiatrists, ophthalmologists, and plastic surgeons. Today, CRNAs

administer more than 65 percent of the anesthetics given to patients each year in the United States. CRNAs are the sole anesthesia provider in 70 percent of rural hospitals which translates into anesthesia services for millions of rural Americans. CRNAs are also front line anesthesia providers in underserved urban areas, providing services for major trauma cases, for example.

CRNAs have been a part of every surgical team since the advent of anesthesia in the 1800s and until the 1920s, anesthesia was almost exclusively administered by nurses. In addition, nurse anesthetists have been the principal anesthesia provider in combat areas in every war the United States has been engaged in since World War I. Though CRNAs are not medical doctors, no studies have ever found any difference between CRNAs and anesthesiologists in the quality of care provided, which is the reason no federal or state statute requires that CRNAs be supervised by an anesthesiologist. Anesthesia outcomes are affected by such factors as the provider's vigilance rather than the title of the provider—CRNA or an anesthesiologist. That is why the Harvard Medical School Standards in Anesthesia focus on monitoring the patient; the standards are based upon data that indicate that anesthesia incidents are usually caused by lack of attention to detail and insufficient monitoring of the patient.

The most substantial difference between CRNAs and anesthesiologists is prior to anesthesia education, anesthesiologists receive medical education while CRNAs receive a nursing education. However, the anesthesia education offered is very similar for both providers and both professionals are educated to perform the same clinical anesthesia services: (1) preanesthetic preparation and evaluation; (2) anesthesia induction, maintenance and emergence; (3) postanesthesia care; and (4) peri-anesthetic and clinical support functions, such as resuscitation services, acute and chronic pain management, respiratory care, and the establishment of arterial lines.

There are currently 85 accredited nurse anesthesia education programs in the United States, all of which are required to offer a master's degree.

Are there enough providers to meet the goals?

The Health Professionals Scholarship program was created to address certain needs of the population, including increased access to primary care, increased access in rural and underserved areas, and improved distribution of providers. But before we can begin to focus on the goals of the Health Professionals Scholarship Program, there must be assurances that our programs are producing enough graduates to serve the population as a whole.

The overall number of primary care physicians providing patient care rose by 75 percent between 1975 and 1990; yet, the population as a whole rose by only 17 percent. The result has been a physician surplus. Yet the same is not true for other health care professions. The surplus of physicians does not necessarily translate to a surplus of all providers. Nurse anesthesia programs across the country have stabilized, not increased, in the number of graduates produced each year, averaging approximately 900–1,000 new nurse anesthetists entering practice annually.

Data have shown that a continued supply of 1,000 graduates per year will provide the country with a stable, adequate source of anesthesia providers. Previous research by Michael Fallacaro, CRNA, DNS, Assistant Professor at the School of Nursing, State University of New York at Buffalo, established that the current ratio of approximately 8.5 CRNAs per 100,000 population is adequately meeting societal demands. In addition, his research showed that adding 1,000 new nurse anesthetist graduates into the system each year through 2020 would ultimately result in a similar ratio of 8.5 to 9.6 CRNAs per 100,000 population, depending on the average retirement age. Therefore, by continuing the trend of graduating approximately 1,000 students per year, nurse anesthesia programs appear to be producing not a surplus of providers, but an adequate number to meet societal needs.

In order to maintain this number of graduates, CRNA students need continued federal support. Nurse anesthesia programs require a rigorous course of study that does not allow students the opportunity to work outside their educational program. Nurse anesthesia programs are virtually all full-time, with part-time study a rare occurrence. Therefore, nurse anesthesia students rely heavily on federal funding to assist them in meeting financial obligations during their study. Without this assistance, the number of nurse anesthesia graduates would surely decline. A decline in the number of nurse anesthetists would then result in a decline in the accessibility to services, primarily in rural areas that depend on non-MD providers for the majority of their care.

The Goals of the Health Professionals Education Program

Title VIII has supported the education of our nation's nurses since the 1960s. It provides programs for direct student assistance as well as grants to institutions for

expansion or maintenance of education. While initially the programs focused on increasing enrollments, in the mid-1970s they began to shift toward increasing the number of primary care providers and increasing the number of professionals serving in rural or underserved areas.

In the last reauthorization of Title VIII in 1992, Congress directed that Title VIII programs target funds to schools placing graduates in medically underserved communities and emphasized primary care. Likewise, the Health Professions Education Reauthorization Act of 1994, which passed the Senate Labor and Human Resources Committee, also identified the goal of improving the distribution of health professionals in underserved areas. The investment in the education of nurse anesthetists would assist in all of these goals:

Increased access to primary care.—CRNAs are traditionally not defined as primary care providers, but provide services that support primary care. For example, a facility or professional that provides obstetrical care to pregnant women is generally recognized as providing primary care. Offering an epidural during labor and delivery is part of that obstetrical care; therefore, the CRNA provides services and supports primary care, and is vital to the quality of primary care. Often the CRNA is the only provider of such services in rural areas. Because of the interdependence between primary care and anesthesia, continued federal support for nurse anesthesia education will assist in reaching the federal goal of increasing access to quality primary care across the country.

Access and distribution in rural and underserved areas

CRNAs are the sole providers of anesthesia in 70 percent of rural hospitals. Anesthesia provided by CRNAs allows these rural facilities to provide obstetrical, surgical, and trauma stabilization that would otherwise not be possible for millions of Americans in rural areas. Continued federal support of Title VIII programs will ensure a stable supply of CRNAs to rural facilities all across the country. In addition, many nurse anesthesia programs are located in medically underserved urban areas and produce graduates that eventually enter practice after graduation in these same communities.

While there continues to be a stable supply of nurse anesthesia graduates, there remains a problem with distribution of anesthesia providers (both nurse anesthetists and physician anesthesiologists) between urban and rural areas. As is the case with many types of providers, there tends to be a concentration in urban settings, with far fewer providers located in rural areas. Taking into account that there are fewer people requiring services in rural areas, the maldistribution of providers is still evident.

The following graph illustrates the percentage of CRNAs located in urban vs. non-urban areas, demonstrating clearly that urban areas retain far greater percentages of anesthesia providers. Keep in mind, however, that the data vary widely from state to state depending on its makeup. For example, because the state of New York is one of the most urban states in the country there will naturally be a greater number of providers in urban areas because the state is primarily composed of urban counties. Fallacaro's data show that 90 percent of New York CRNAs are located in urban areas, with the remaining 10 percent situated in rural New York. Compare that to a very rural state, North Carolina, in which only 77 percent of CRNAs are providing services in urban areas and 23 percent are in rural areas. The national average is 81.3 percent of CRNAs practicing in urban areas, compared to 18.7 percent in non-urban areas.

[In percent]

	Urban areas	Rural areas
Urban State—New York	90.0	10.0
Rural State—North Carolina	77.0	23.0
Average	81.3	18.7

Generally there is a greater number of anesthesia providers per 100,000 population in urban areas than in non-urban areas. Recent research by Dr. Fallacaro has revealed that, on average, there are 8.55 nurse anesthetists per every 100,000 people, and an average of 8.22 anesthesiologists (MDAs) per 100,000 people (see middle bar below). A breakdown of urban and rural areas show that there are more than average numbers of anesthesia providers in urban areas, and fewer than average in non-urban areas.

[Ratio of providers per 100,000 population]

	Urban	Non-urban	Average
CRNA's	8.57	7.76	8.55
MDA's	9.42	3.14	8.22

It is likely that the problem of distribution will only get worse, as an aging CRNA population is concentrated more in non-urban areas than in urban. Looking at the CRNA population as a whole, approximately 19 percent provide services in non-urban areas. Focusing solely on the CRNA population aged 55 and older, approximately 29 percent provide services in non-urban areas. This indicates that a disproportionate number of CRNAs in rural areas are aged 55 or older. As these CRNAs retire, it remains unclear what will happen to anesthesia services in those areas without continued incentives such as the Health Professionals Scholarship Program.

Recommendation for fiscal year 1999

In the past, CRNAs had a $4 million authorized line-item appropriation within Title VIII which was divided between direct student support in the form of traineeships, faculty fellowships to increase the number of doctoral-prepared faculty, and toward the start-up costs and expansion for nurse anesthesia programs. This line-item has proven extremely successful in the past, and each year the appropriation for nurse anesthetists has been totally expended. AANA would like to see it continue in the future. However, we realize this Congress has moved in the direction of a consolidated appropriation. AANA understands the need for increased streamlining and administrative reductions, and supports the Committee's efforts in this regard.

AANA would appreciate and certainly utilize a substantial increase in funding, but recognizing the budgetary constraints faced by this Committee we would recommend continued federal funding for all nursing education at the level of $64.738 million, including a $2.833 million set-aside for nurse anesthetists in fiscal year 1999. This is equivalent to the House-passed level in fiscal year 1998.

Thank you for your consideration of our concerns.

PREPARED STATEMENT OF MARIANNE PUCKETT, ASSOCIATE PROFESSOR OF MEDICAL LIBRARY SCIENCE, LOUISIANA STATE UNIVERSITY MEDICAL CENTER LIBRARY ON BEHALF OF THE, MEDICAL LIBRARY ASSOCIATION AND THE ASSOCIATION OF ACADEMIC HEALTH SCIENCES LIBRARIES

Mr. Chairman and members of the subcommittee, I am Marianne Puckett, associate professor of medical library science at the Louisiana State University Medical Center Library in Shreveport, La. Thank you for the opportunity to provide written testimony on behalf of the Medical Library Association (MLA) and the Association of Academic Health Sciences Libraries (AAHSL) regarding the fiscal year 1999 budget for the National Library of Medicine (NLM).

As you may know, MLA is a professional organization representing over 4,000 individuals and 1,200 institutions involved in the management and dissemination of biomedical information to support patient care, education and research. I might add Mr. Chairman, that MLA's headquarters are located in your home town of Chicago. In addition, we are very proud this year to be celebrating our centennial anniversary.

AAHSL, is comprised of the directors of libraries of 142 accredited U.S. and Canadian medical schools belonging to the Association of American Medical Colleges. Together, MLA and AAHSL address health information issues and legislative matters of importance to the medical library community through a joint legislative task force which I currently have the honor of chairing.

Mr. Chairman, first let me thank you and the members of the subcommittee for your leadership in securing a 7.2 percent increase for the National Library of Medicine in fiscal year 1998. With respect to NLM's budget for the coming fiscal year, I would like to touch briefly on the following three issues; (1) basic services and personnel, (2) outreach activities, and (3) access to health care information.

NLM basic services and personnel

As we approach the next century, the medical library community believes that basic library services must still be the foundation for NLM's long-term success as a service agency. Unfortunately, the level of demand for basic NLM services and the

rate of increase in the cost of medical journals and books have both been in the 10 to 15 percent range in recent years, far outstripping the Library's budget increases. Moreover, the level of staffing at the Library has been held level over the past several years. Maintaining the current standard of acquisitions, indexing, cataloging, database searching, and lending will become more and more difficult, if not impossible, unless NLM's budget and level of staffing are increased to reflect these rising workloads and costs. As a result, we urge the subcommittee to consider the need for increasing support, in both budget and staff positions, so that NLM can meet its increasing service needs and insure that the quality of its programs is not compromised.

Outreach programs

NLM's outreach programs are of particular interest to both MLA and AAHSL. These activities, designed to educate medical librarians and other health care professionals about NLM and the information services it provides have proven to be extremely successful in improving the quality of our nation's health care.

Although NLM has been able to educate a significant number of health care professionals through its outreach initiatives in the 1990's, more work needs to be done in this area. There are still far too many health care workers in all parts of the country who are unaware that NLM and the National Network of Libraries of Medicine even exist. The need for a vigorous outreach program is now more important than ever. In 1997, NLM's databases became available free over the Internet and World Wide Web, opening them up to the general public and health professionals alike. Mr. Chairman, NLM's outreach mission will not be complete until all who need access to science-based health knowledge are familiar with NLM and the information resources it provides.

Access to quality health care information

Mr. Chairman, the National Library of Medicine, continues to be the critical investment agency for increasing the public's access to health care information. This is especially true for people living in medically underserved areas. For example, my institution maintains several telemedicine and distance learning sites throughout rural Louisiana. With the support of NLM technology we provide access to health information and education resources to some of our state's most at-risk citizens. In addition to its support of telemedicine, NLM's High-Performance Computing and Communications initiative and free Internet MEDLINE information service have empowered Americans with the ability to access the world's most extensive library of medical data directly from their personal computer.

We in the health sciences library community applaud the Congress for having the foresight to provide NLM with the necessary resources to develop these programs. There is no question that these technologies are having a profound influence on the delivery of health care across the country. In order to realize the full potential of these programs it is crucial that Congress continue to provide NLM with adequate funding in fiscal year 1999.

Fiscal year 1999 recommendation

Mr. Chairman, as we celebrate the 200th anniversary of the Public Health Service this year it is important that we continue to prepare for the future. With the seemingly endless advances of the information age it is obvious that the National Library of Medicine will play a major role in the delivering health care in the 21st Century.

Therefore, the Medical Library Association and the Association of Academic Health Sciences Libraries recommend a 15 percent increase in funding for NLM in fiscal year 1999. This figure represents a $24 million increase over fiscal year 1998 and would bring the Library's total fiscal year 1999 appropriation to $185,362,750.

In closing, I would like to make clear that although the medical library community strongly supports the concept of doubling NIH's overall budget in the next five years, we do not believe that these increases should come at the expense of other important Public Health Service programs.

Once again, Mr. Chairman, thank you very much for the opportunity to present the views of the medical library community. If you have any questions please do not hesitate to contact me.

PREPARED STATEMENT OF WALTER DIGIUSTO, PRESIDENT, ESA, INC.

Mr. Chairman, thank you very much for the opportunity to submit written testimony regarding fiscal year 1999 appropriations for the National Institutes of Health (NIH), and the Centers for Disease Control and Prevention (CDC). I am Walter DiGiusto, President of ESA, Inc. of Chelmsford, MA.

ESA is a biomedical research and technology development firm dedicated to improving the quality of our nation's health care through innovative instrumentation and services. In my testimony, I will discuss four issues of specific interest to our company and millions of Americans; (1) Lead Poisoning Prevention (2) Neurodegenerative Disorders, (3) the Small Business Innovative Research Program, and (4) Alternative Medicine.

Lead poisoning prevention

For over 25 years, ESA has focused on developing electrochemical sensors for the early detection and treatment of several chronic, environmentally induced disorders. These abnormalities include; lead poisoning, cancer in young children, brain injuries, metabolic disorders, and Alzheimer's and Parkinson's diseases. We began in 1970 with the development of an instrument which allowed for the measurement of lead levels in children at the part per million level. This was done at the request of the Centers for Disease Control and Prevention which had been given the task of determining the degree of childhood lead poisoning in the United States.

With the support of this subcommittee and CDC, we have recently developed a new hand-held, portable lead screening instrument. I very am pleased to inform the subcommittee that last September, Secretary of Health and Human Services Donna Shalala announced that the Food and Drug Administration (FDA) had given final approval to ESA's LeadCare System for use as a medical device.

Mr. Chairman, the availability of the LeadCare System is truly a major step forward in the fight against childhood lead poisoning. Currently, blood samples from children tested for exposure to lead must be sent to a laboratory for clinical evaluation. With the LeadCare System, a sample of a patient's blood obtained by a finger stick can be analyzed by the System within 3 minutes, and the results are instantly displayed. Moreover, clinical studies conducted by ESA indicate that the new test is as reliable as established laboratory screening methods. Both ESA and the Department of Health and Human Services believe that the expediency of the LeadCare System will allow health care professionals practicing in urban, underserved areas to screen more high-risk children in transient inner-city communities.

Finally, Mr. Chairman, I would like to state for the record ESA's strong support of the Centers for Disease Control and Prevention's Childhood Lead Poisoning Prevention Program. This program, funded at a level of $38 million last year, has played an effective role in increasing public awareness regarding childhood lead poisoning and the need for early detection. I encourage the subcommittee to continue its support of this important public health campaign.

NEURODEGENERATIVE DISORDERS

In addition to our lead screening devices, ESA has developed several sophisticated analytical instruments which measure a broad range of neurochemicals. As a result, we have become extremely active in research related to neurodegenerative disorders like Alzheimer's and Parkinson's diseases. In studies conducted with NIH support, we have shown that it is possible to separate neurodegenerative diseases by their biochemistry patterns. When considered as a whole, the pattern of hundreds of compounds in an individual with Alzheimer's is uniquely different from those in a healthy individual or a person afflicted with Huntington's or Parkinson's. In addition to these findings, we have been encouraged by follow-up studies suggesting promising preventive therapies for neurodegenerative diseases, including the use vitamin E and other anti-oxidants.

Mr. Chairman, ESA is committed to continuing to develop technologies that will assist the scientific community in the fight against neurodegenerative disorders. We are very pleased that in fiscal year 1998, the NIH Office of the Director received $22 million dollars for the study of these devastating diseases. We encourage the subcommittee to continue to emphasize the importance of brain disorders research as we approach the next millennium.

SMALL BUSINESS INNOVATIVE RESEARCH PROGRAM

Mr. Chairman, I am aware that questions have been raised regarding the merit of SBIR research projects funded by the National Institutes of Health. I would like to make it clear that the SBIR program is critical to the success of biotechnology firms like ESA. Throughout our existence, ESA has worked on several joint initiatives with NIH and CDC under the SBIR program. As a result of these collaborations, we have seen a positive return on the public's investment in the areas of job creation, balance of trade, reduction of health care costs, and the alleviation of suffering. Simply stated, the SBIR program has allowed ESA to successfully pursue research projects that we would have otherwise had to forego.

ESA strongly supports President Clinton's fiscal year 1999 budget request of $289 million (an increase of $27 million over fiscal year 1998), for NIH SBIR/STTR grants. We urge the subcommittee to support this vital program in fiscal year 1999.

ALTERNATIVE MEDICINE

Mr. Chairman, as you know, there has been an explosion in this country during the past decade in the field of alternative medicine. Public interest in the use of dietary and herbal supplements, vitamins, hormones, and other "natural" products for the purpose of disease prevention has spawned tremendous concern about safety and truth-in advertising. As a result, ESA has embarked on a analytical program aimed at identifying compounds and anti-oxidants found in vitamins, health foods, natural products, and cereals. Our goal in this endeavor is two-fold; (1) assist researchers and manufacturers of dietary supplements in the development of quality products, and (2) provide consumers with piece of mind in knowing that the products they use are safe.

As the alternative medicine industry continues to expand, we look forward to increasing our role as one of the few firms in the country able to provide this type of sophisticated service. It is clear that the federal government will also play an enhanced oversight role in the years to come. Specifically, ESA views the Office of Alternative Medicine (OAM), and the Office of Dietary Supplements (ODS) at NIH as critical to insuring the integrity of the alternative medicine industry. We urge the subcommittee to provide adequate funding to both OAM and ODS in fiscal year 1999.

Mr. Chairman, once again thank you very much for the opportunity to present our views. In closing, I would like to associate ESA with the Ad Hoc Group for Biomedical Research's recommendation of a 15 percent overall increase for the National Institutes of Health in fiscal year 1999. We look forward to continuing to work with the subcommittee to improve the quality of health care for all Americans. If you have any questions please do not hesitate to contact me.

PREPARED STATEMENT OF JOANNE BAKKEN PEASE, IMMUNE DEFICIENCY FOUNDATION

Mr. Chairman, thank you very much for the opportunity to submit written testimony on behalf of the Immune Deficiency Foundation (IDF) regarding fiscal year 1999 appropriations for programs under the jurisdiction of the Subcommittee. My name is Joanne Bakken Pease, I am a volunteer with IDF's Washington State Chapter and I would like to tell you the story of my family's struggle with primary immunodeficiency diseases.

My three sons and nephew have all been diagnosed with primary immunodeficiency diseases, which means that they were born with incomplete immune systems. In November 1985, my eldest son Curtis received his vaccine for measles, mumps and rubella. Curtis got the mumps from the vaccination in February 1986, and the doctor told me simply—these things happen. After three years of constant colds and pneumonia—Curtis was diagnosed with X-linked Agammaglobulinanemia. I was thankful when I learned there was treatment available for him. However, the treatment consisted of a very painful injection administered intramuscularly every ten days. This treatment, a pooled plasma derivative, replaced portions of his incomplete immune system. However, the pain involved caused this therapy to be a source of terror in our household, requiring four adults for administration.

When my second son Jeff was ten months old we learned that he had contracted polio from the oral vaccine, signaling the presence of the same immunodeficiency. He was left with a withered right leg and a terribly deformed foot. Now both my beautiful boys received these painful shots. Three years later they both started getting their vaccine intravenously. Intravenous immune globulin was less painful and more effective, it reduced our infusions to once a month.

Jeff has had six very painful orthopedic surgeries including, tendon transfers and releases, hip reconstruction, leg rotations and ankle repositioning. He is now ready for his seventh and eighth operations which will be complicated leg lengthenings. In addition, my nephew Joshua (born in 1988) and my third son Mitchell (born in 1990), were both born with XLA and have begun their treatments.

Mr. Chairman, my children's lives are not what I had envisioned for them. Although we have learned to cope with the care necessary to keep them alive, the pain that I feel for the loss of my dream will never go away. We need to continue to focus on medical research so perhaps future generations will have the option of gene therapy and not have to suffer years of chronic care. In addition, we must continue to do everything we can to protect the nation's blood supply. To give you an indication of how important this is, our four boys receive a total of 70 infusion per year!

For fiscal year 1999, the Immune Deficiency Foundation recommends that the National Institute of Allergy and Infectious Diseases (NIAID) receive a 15 percent increase over last year. This percentage translates into $202.7 million over fiscal year 1998 and would bring NIAID's total appropriation to $1.55 billion. In addition, Mr. Chairman, I would like to make clear that although IDF strongly supports the concept of doubling NIH's overall budget in the next five years, we do not believe that these increases should come at the expense of other important Public Health Service programs.

Finally Mr. Chairman, I would like to mention the important work being done at the Immune Deficiency Foundation on behalf of the approximately 40,000 people suffering from primary immune deficiency diseases. The Foundation, through a grant from NIAID, is developing a national registry of U.S. patients suffering from the most common immunodeficiencies. The registry is providing an important resource to physicians and investigators by giving them access to a more complete clinical understanding of these diseases. The clinical information contained in these registries will help determine the frequency of complications, long tem prognosis, and possibly open the gateway for gene therapy. I am very proud of the work of the Foundation, and I would like to express the need for these important initiatives to continue.

Mr. Chairman, once again, thank you very much for the opportunity to submit written testimony on behalf of IDF. As you make your funding decisions regarding the fiscal year 1999 budget for NIAID I would ask that you please remember my boys.

NATIONAL INSTITUTES OF HEALTH

PREPARED STATEMENT OF FRANCIS T. VENTRE, PRESIDENT, MONTGOMERY COUNTY [MD] STROKE CLUB

My name is Francis T. Ventre. I am president of the Montgomery County [MD] Stroke Club, a nonprofit organization for stroke survivors and caregivers, mostly family members. This club consists of some 425 members as well as 100 professionals—physicians, therapists, hospitals, retirement homes, units of government and other caregivers.

Our members range in age from the twenties to the eighties. Some manifest little visible signs of stroke. Others either have lost the ability to speak or need assistance to walk, dress, bathe, and eat. More than 1 million in this land have disabilities from stroke.

Let me tell you about my stroke. I was professor of architecture and city planning at Virginia Tech since 1983. In 1988, Macmillan signed me up to write on the subject of "building regulation" for The Dictionary of Art, the 34-volume exposition with 6,700 contributors it was planning to publish.

In February 1990, when I was swimming at Virginia Tech's War Memorial pool, I was struck with a transient ischemic attack [TIA], or a mini-stroke. Two days later, at North Carolina Baptist/Bowman-Gray Hospital in Winston-Salem, I suffered a major stroke, a "left cerebral infarct in the middle cerebral artery distribution following the spontaneous dissection of the right internal carotid artery during an angiogram." I was left with an "mild Broca's aphasia with verbal aphasia: [or a "language problem" and a "residual right hemiparesis," [or my right arm didn't work]. There was my stroke.

I was home when I thought of the "building regulations" article I had to writes, so I resumed. The Dictionary of Art came out in October 1996, and the New York Times Book Review came out in August 24, 1997. My "building regulations"—along with two others—as cited as "those sections among the most memorable precisely because they're unconventional, hence thought-provoking." That's my story.

Stroke, the third leading cause of death in the United States, strikes 600,000 Americans each year, killing more than 157,900. Stroke is the leading cause of permanent disability in the United States. Thanks to medical research, today, there are about 4 million stroke survivors in the United States and I am one of them.

What do stroke survivors face? They face years of severe physical and mental impairment, loss of memory, cognitive skills, personality disorders, emotional distress and overwhelming medical expenses. Stroke will cost this nation an estimated $43 billion in medical expenses and lost productivity in 1998. My own expenses were $18,000 at the Bowman Gray Hospital in Winston-Salem plus many more thousands of dollars at rehabilitation, including physical therapy, occupational therapy and speech-language pathology and many more thousands of dollars at the National Re-

habilitation Hospital in Washington, DC, and the Treatment and Learning Center in Rockville, MD.

There is one thing that I want you to know about National Institute of Neurological Disorders and Stroke researcher John Marler, M.D. It came from the November 24, 1997 copy of USA TODAY, headlined "Overhaul Urged for Handling of Strokes," upgrading stroke to a "time-dependent, urgent medical emergency." The report, "Rapid Identification and Treatment of Acute Stroke," describes how physicians, emergency care personnel and the public should respond to the finding that a drug called tissue plasminogen activator or t-PA, destroys the clots that dam up arteries, restoring blood flow to the brain. The drug t-PA, to be effective, must be given within 3 hours of the initial symptoms. Given in time, the drug improves the patient's chances of having minimal or no disability by 33 percent three months after surviving a stroke.

I wish that the t-PA were available in 1990.

PREPARED STATEMENT OF ERIN BOSCH, ON BEHALF OF THE NATIONAL COALITION FOR HEART AND STROKE RESEARCH

Mr. Chairman, honorable members of the Committee, I am honored to have the opportunity to speak to you today. My name is Erin Bosch. Some of you may recall that last year I addressed this Committee on behalf of the National Coalition for Heart and Stroke Research. Today, I am here to represent not only myself, but also, the 32,000 children in the United States who are born with congenital heart defects each year.

Most of us are aware that heart disease is the No. 1 killer and a leading cause of disability in adults in this nation. But few recognize that heart defects are the most common birth defect of the newborn. Of the 32,000 children born each year with heart defects, about 2,300 die before their first birthday. The rest of us live with the consequences of heart disease, and many have their lives cut short from heart failure.

Thanks to the past funding for heart research about 1 million Americans born with heart defects are alive today. While we are grateful for each day to be alive, we unlike other healthy children, have not been able to experience what it is like to run the length of the soccer field without struggling for our next breath, nor have we experienced the thrill of scoring the winning basket for our school basketball team.

I was born with a genetic heart disease called Hypertrophic Obstructive Cardiomyopathy. This disease has caused the heart muscle to overgrow and block the blood flow in and out of my heart. It also effects the valves of my heart causing the blood to back up in the wrong direction. This disease causes high risk for heart attack and sudden death from dangerous heart rhythms.

One year ago in October, I was at the Mayo Clinic having open heart surgery. The procedure, called a septal myectomy, is designed to shave away a portion of the heart muscle that causes the obstruction. This procedure was originally pioneered at the National Institutes of Health's National Heart, Lung, and Blood Institute and was my last resort aside from transplant.

It is funding that this Committee has provided that has allowed this type of successful research. Without this funding the option of a healthier lifestyle would not have been possible for me. I am one of the lucky ones. My surgery was successful and after one month at the Mayo Clinic I was able to return home. There have been some advances for children like me, although many still die prematurely.

Most people think heart disease is a problem that only affects older people. But, I am living proof they are wrong. According to recent studies, 36 percent of young athletes who die suddenly have undiagnosed Hypertrophic Cardiomyopathy. Presently, there are at least 35 different types of recognized congenital heart defects effecting the newborn population. Some can be corrected surgically—others cannot yet be repaired and these children die. One of these children might one day be your child or grandchild.

I have great faith in the determination of our scientific researchers who work day and night to find new treatment methods for those who suffer with illness and disease. I also have great faith in you as the doorkeepers of governmental funding for the National Heart, Lung, and Blood Institute to provide the necessary funds for children, who through no fault of their own, have been born with heart defects.

Thank you for the opportunity to speak to you today. I am confident that you will not forget me and the other young people like me who depend on you for this funding and subsequent research. We, too, desire to live long, productive lives.

PREPARED STATEMENT OF JACK LAVERY, CHAIRMAN OF THE BOARD, THE LUPUS FOUNDATION OF AMERICA

My name is Jack Lavery, and while my full-time job is that of Senior Vice President of Merrill Lynch & Company, I am here today representing the Lupus Foundation of America as its Chairman of the Board. I am also representing the nearly 1.4 to 2 million Americans living with lupus. One of those people is my daughter.

The Lupus Foundation of America is a national advocacy organization dedicated to finding the cause and cure for systemic lupus erythematosus, a chronic inflammatory disease in which the body's immune system fails to serve its normal protective functions and instead forms antibodies that attack healthy tissues and organs. In layman's terms, it is the body turning against itself. Lupus is incurable and extremely difficult to diagnose because, generally, no two people with systemic lupus have exactly the same symptoms. Moreover, it is a devastating illness. Thousands of Americans die each year from lupus-related complications. For those living with the illness, the disease wreaks havoc on their quality of life, with the side-effects for current treatments of lupus-related problems often causing worse problems than the disease itself.

Lupus is often called a "woman's disease" because 90 percent of lupus patients are women. The relative incidence of lupus is even greater among African American, Asian American, and Hispanic females than among Caucasian females. A market research study conducted by the Lupus Foundation of America in 1994 showed that as many as 1 out of every 102 women, as well as 1 out of every 62 women of color, may have lupus. Lupus can therefore be seen as a diversity issue in 1998.

The Lupus Foundation of America wishes to thank you, Mr. Chairman, and the members of this committee for your leadership role in ensuring the continuation of research on the immune system at the National Institutes of Health and, in particular, the National Institute for Arthritis, Musculoskeletal and Skin Diseases (NIAMS). We want the Subcommittee to understand how important such high quality research on immune dysfunction is to those with lupus. I therefore urge the members of this committee to support funding for the NIAMS at the $315.9 million dollar level recommended by the Ad Hoc Group for Medical Research Funding and supported by the NIAMS Coalition. This level of funding represents a fifteen percent increase over last year's funding and would be a significant step toward recognizing the importance of increasing medical research funding. This level of funding is crucial for three reasons.

First, it is a pivotal time for lupus research. The outlook for lupus patients has improved in some respects over the last two decades, but the side effects of the conventional treatments can ultimately be as dangerous as the disease itself. Better diagnostic techniques and evaluation methods have given physicians the tools to manage lupus symptoms and complications more effectively. However, a cure is still not within our reach. While scientists believe there is a genetic predisposition to the disease, environmental factors—such as infections, ultraviolet light, the sun, stress, and certain drugs—are also thought to play an important role in triggering lupus. We must know what causes lupus before we can develop a cure, and this is where research plays a critical role.

NIAMS funds many individual researchers across the United States who are studying lupus. To help scientists gain new knowledge, NIAMS has also established Specialized Centers of Research devoted specifically to lupus research. In addition, NIAMS is funding a lupus registry that will gather medical information as well as blood and tissue samples from patients and their relatives. This will give researchers across the country access to information and materials they can use to help identify genes that determine susceptibility to the disease. Promising areas of research include identifying the lupus susceptibility genes, searching for environmental agents that cause lupus, and developing drugs or biologic agents that cure lupus.

Recently, researchers at the University of California at Los Angeles, with funding from NIAMS, the NIH Office of Research on Women's Health, and the Lupus Foundation of America, have identified the location of a gene that predisposes people to systemic lupus across ethnic groups. This discovery and others like it provide important new insights on why people get the disease and may help researchers develop new treatments. It is a significant and positive step toward finding a cause for lupus—a breakthrough where additional research is still critical.

In November 1997, the National Institutes of Health, the SLE Foundation, and the Lupus Foundation of America were among several cosponsors of a historic scientific conference entitled Novel Perspectives on Systemic Lupus Erythematosus: From Basic Research to Clinical Applications. The conference represented a signifi-

cant recognition of the importance of continuing new research which will hopefully lead to important clinical applications for lupus patients.

Second, I believe lupus is the prototype for autoimmune diseases, as well as for the management of chronic disease more generally. Research on lupus, therefore, has far-reaching consequences. Any insight we can gain from high quality research on immune dysfunction could provide important information on other autoimmune diseases and could potentially reveal new and different ways to control other chronic diseases.

Finally, LFA research indicates that as many as 2 million Americans report having been diagnosed with lupus. This year, we estimate that many thousands of people will call our organization's hotline. Most of the callers are individuals recently diagnosed with lupus or their family members who seek answers to questions about this disease. Only through further research will we find ways to improve both the prognosis and the quality of life of the many people living with lupus, including my own daughter, Dena.

Dena developed lupus at the age of 13, although it was initially incorrectly diagnosed as juvenile rheumatoid arthritis and then as vasculitis, a non-specific inflammation of the blood vessels. At 19, she was finally correctly diagnosed with systemic lupus. She is 29 now. She has been close to death at least twice and has permanently lost her vision in one eye as a result of lupus-related optic neuritis.

The side effects of treatments for lupus are often as devastating as the disease itself. As in my daughter's case, protracted use of steroids can cause osteonecrosis (i.e. bone death). She also has had to undergo multiple core decompressions in an attempt to regenerate blood vessel growth. These involved individual operations drilling her left and right knees, left and right hips, and left elbow. Though at an age when most of her peers do not even have to think about such operations, my daughter has now also had surgery for a bilateral hip replacement (i.e. two prosthetic hips). Lupus is active in her kidneys, and her treatment has involved the toxic chemotherapy drug cytoxan. The side effects of this drug can grow cumulatively with protracted use and can include sterility, bladder cancer, and lymphoma.

I am proud to say that, despite these setbacks, my daughter has moved forward with her life like a true fighter and is currently a high school English teacher. She is an example of the courage of the many Americans who fight lupus everyday.

Last year, members of the Lupus Foundation of America and its many chapters spent a significant amount of time raising funds which are used to fund our own research, education, and support programs. However, the amount of funds lupus patients and their families can raise on their own is limited and relatively small compared to what is needed. Federal support of medical research in general is critical if we are to find a cause and a cure for lupus and other autoimmune diseases. The Lupus Foundation is committed to developing and maintaining a partnership between the private and public sectors on lupus research. Only through such a collaboration can we ensure that the highest-quality research is conducted and leads to a cure for this devastating disease.

In summary, funding of lupus research is critical because we are at a pivotal time in lupus research; research on lupus could benefit those suffering from other autoimmune and chronic illnesses; and, finally, many thousands of Americans suffer a decreased quality of life due to the devastating nature of this disease. The Lupus Foundation of America is committed to push for federally supported research dollars which will yield answers to this mysterious disease. I cannot stress enough the importance of your support so that research on autoimmune dysfunction continues without interruption. Thank you for your attention, and my daughter also thanks you, as I'm sure all lupus patients and their families do.

The Lupus Foundation of America neither receives grants or subgrants from the Federal Government nor has any contracts or subcontracts with the Federal Government. Through the generosity of Federal employees throughout the United States and around the world, we receive contributions of approximately $500,000 per year through the Combined Federal Campaign.

Prepared Statement of Lorne M. Mendell, Ph.D., on Behalf of the Society for Neuroscience

Mr. Chairman, my name is Dr. Lorne M. Mendell. I am the president of the Society for Neuroscience and a professor at the Department of Neurobiology and Behavior at the State University of New York at Stony Brook. I am testifying on behalf of the Society for Neuroscience, the largest scientific organization in the world dedicated to the study of the brain and spinal cord. The Society for Neuroscience consists of more than 28,000 basic and clinical neuroscience researchers affiliated with

universities, hospitals and scientific institutions throughout North America and abroad. Mr. Chairman, we are very grateful for this opportunity to give our testimony, and I want to express our gratitude to this Subcommittee, and especially to you Mr. Chairman, for the high priority you have placed on continued funding for biomedical research at the National Institutes of Health.

The field of neuroscience, only a quarter of a century old, has already made major contributions to the welfare of our nation's citizens. New insights and effective treatments have been developed for previously hopeless diseases. For example, current research has allowed us to understand mechanisms of pain so that various remedies may be developed for burn victims, arthritis sufferers, and many others to end unnecessary pain and suffering. Without adequate funding, our fight against neurological diseases and disorders such as Alzheimer's, Parkinson's, mental retardation, stroke, severe depression, schizophrenia, and spinal cord injury, to name just a few, would suffer a serious setback.

We at the Society for Neuroscience are extremely grateful that this Subcommittee is committed to supporting our work by increasing funding for NIH; your efforts are truly appreciated. We were especially pleased, Mr. Chairman, by your efforts last year concerning fiscal year 1998 appropriations. We know that with your leadership on this Subcommittee, biomedical research has a champion in the Senate and know that you will strongly support NIH for fiscal year 1999. We fully support the goal of doubling the budget of NIH over the next 5 years, as has been advocated by many in the Congress.

We have at our fingertips the necessary tools and resources to make significant progress in our fight to cure neurological diseases and disorders; all we need are the necessary funds to build upon what we already know. Twenty years ago, the field of neuroscience was little known to the general public. Now, every one of us knows someone who suffers from some type of neurological problem. In addition to personal experience through our family and friends, we see everyday when we open up a magazine, or turn on the television, that too many people are suffering from neurological disorders. We at the Society have become more involved with our patient advocacy groups, as they are the people who are truly affected by our research. After hearing from them, we learn of their day-to-day struggles. As researchers, patient advocacy groups and members of Congress work together, the nation will become more familiar with the progress that is occurring in our labs and will recognize that funding is still needed to expand upon what we already know. If we can double the budget of NIH, we can change some of these sad, and all too-familiar stories, into medical success stories.

Brain diseases affect more than 50 million Americans annually at costs exceeding $400 billion in direct costs for clinical care and in lost productivity. The more than 1,000 disorders of the brain and nervous system result in more hospitalizations than any other disease group. The prevalence of brain disorders in the United States, together with high annual costs for treatment, combine to make these conditions the number-one public health problem now confronting this nation.

But there is good news that needs to be told, and as I've said, we are making progress. The cost- effectiveness of investing in biomedical research has been proven as there are many examples of cost savings from research conducted at NIH. A few examples of the estimated annual economic costs of several diseases include stroke ($40 billion), Alzheimer's disease ($90 billion) and all mental disorders ($148 billion). In addition to improving people's lives by seeking cures for these and other diseases, we can also save money in the long run if we invest now. In the mental illness field, consider patients diagnosed with schizophrenia. A drug, clozapine, has enabled schizophrenic patients to leave hospitals earlier than in the past and in some cases even return to work. These cost savings total $23,000 per patient annually, which translates into an approximate overall savings of $1.4 billion annually. Another example includes lithium therapy for manic-depressive illness, which has saved the U.S. economy more than $145 billion since 1970, over $5 billion per year. In addition to these examples of mental illness, one can also look to the progress being made in stroke research. About 400,000 people suffer from strokes caused by blockage of blood flow (ischemic stroke) each year. Patients who endure ischemic strokes and who receive emergency treatment with the clot-dissolving drug t-PA within three hours of the start of their symptoms are 30 percent more likely to survive a stroke with little or no disability. A soon-to-be-published analysis of the economic benefits of using t-PA shows that when the drug is appropriately used, there is a considerable decrease in the long-term care costs of stroke, particularly costs of nursing home and rehabilitative care. A final, more general example, involves drug abuse. For every dollar spent on drug use prevention, communities can save $4 to $5 in costs for drug abuse treatment and counseling. These are just a few examples, and it is important to note that NIH is working on an economic analysis

that will be available in the near future that highlights even more areas of cost savings.

We at the Society for Neuroscience realize the difficulty in finding money for biomedical research. However, modern neuroscience is on the threshold of making important scientific breakthroughs in a number of brain diseases, which, for centuries, have perplexed clinicians and ravaged those affected. To lose this momentum now would be detrimental for the health of the nation, to say nothing of its economic health. This makes increased investment in neuroscience research not only an absolute necessity, but among the highest priorities for the appropriations made by this Subcommittee. We feel that it is vital that the necessary funds are appropriated to continue to achieve the tremendous advances and breakthroughs that are within our reach. It is our hope that funding for all biomedical research will be increased, as discoveries at one Institute carry over to work being done by other Institutes at NIH. The main goal is to increase funding overall, so that further progress can be made in the hopes of ending these debilitating disorders and diseases.

Thanks to this Subcommittee's dedication and hard work, biomedical research has become a priority in this nation. When this Subcommittee increased funding at NIH for fiscal year 1998, you let us know that you were doing everything possible to see that our goals are reached. It is encouraging for our members to know that they have the support of the Senate Appropriations Subcommittee on Labor-HHS. With this in mind, the members of the Society for Neuroscience will continue to work diligently to continue making progress in research in the neurosciences to benefit the health and well-being of the American public.

It is for these reasons, that we recommend a 15-percent increase over fiscal year 1998 for NIH. We support the proposal of the Ad Hoc Group for Medical Research Funding, made up of approximately 200 patient and voluntary health groups, medical and scientific societies, academic and research organizations and the biotechnology industry, which are dedicated to the future of the nation's biomedical and behavioral research. Our recommendation calls for a 15-percent increase as a first step toward doubling the NIH budget over the next 5 years. We recognize the difficulty in achieving this goal under current spending limits, and encourage the Congress to explore all possible options to identify the additional resources needed to support this increase.

In conclusion, the Society for Neuroscience is grateful for this opportunity to present testimony to this distinguished Subcommittee. We encourage members of the public and the Subcommittee to visit Brain Briefings, our monthly newsletter, on our Web site (http://www.sfn.org/briefings/) to learn how basic neuroscience discoveries lead to clinical applications. This testimony is also available on our Web site (http://www.sfn.org/legislative/index.html).

Thank you again for your continued support.

Prepared Statement of Tish Tanski, President, Association of Independent Research Institutes

On behalf of the Association of Independent Research Institutes, I am pleased to submit this statement to the Subcommittee on Labor, HHS, Education and Related Agencies of the Senate Committee on Appropriations regarding the fiscal year 1999 proposed budget for the National Institutes of Health.

AIRI is an association of 85 not-for-profit, independent research institutes that conduct basic and clinical research in the biomedical and behavioral sciences. Our members receive about 10 percent of the extramural funds awarded by the National Institutes of Health (NIH), as well as a significant proportion of National Science Foundation awards. AIRI institutes also receive funding from other federal agencies, including the Centers for Disease Control, Department of Energy, and the Department of Defense, as well as from voluntary health agencies, private foundations, and corporations.

AIRI members are distinct from other organizations involved in research—such as universities, hospitals, and for-profits—in their organization, mission, and size. They are independent; their primary mission is research; and their institutes tend to be relatively small in size—with budgets from less than $1 million to many tens of millions of dollars.

Over the past few years, this subcommittee could have sacrificed NIH funding in the name of deficit reduction or for other subcommittee priorities. But instead, you stood firm in your support of NIH and its mission. Now, we ask you to demonstrate your support for the work of NIH once again—by providing a 15-percent increase in funding for fiscal year 1999, as called for by the Ad Hoc Group For Medical Re-

search Funding. Such an increase is an essential first step in realizing the goal of doubling the NIH budget over the next five years.

As a direct result of this subcommittee's support over the last decade, an ever-expanding base of scientific knowledge about health and disease is being developed, a base that has already begun to revolutionize both the concept of scientific inquiry and the practice of medicine. AIRI supports the Ad Hoc Group's position that sustained growth in funding for the NIH is needed to build upon past scientific achievements, address present medical needs, and anticipate future health challenges. Volatility and dramatic fluctuations in support levels can be as harmful to the enterprise as inadequate growth rates.

Strong, steady growth for the NIH budget is needed not merely to continue at an accelerated rate the science and the tools of the past decade. The fundamental way science is conducted is changing at a revolutionary pace. It requires investment in new technologies, new infrastructure, and personnel with new sets of skills. The higher level of investment is necessary to ensure that the research community can maximize these fundamentally new approaches to discovery.

AIRI institutes perform biomedical and behavioral research of the highest quality. Our researchers have a significantly higher than average success rate in competing for NIH research project grants. Our institutes understand what has been accomplished with NIH support, and we know how much more could be done with additional NIH funding.

Here are just a few examples of the biomedical and behavioral sciences work in which AIRI institutes—with critical support from the National Institutes of Health—are taking the lead:

At the Whitehead Institute for Biomedical Research in Cambridge, Massachusetts: Dr. Peter Kim and his colleagues produced the first high-resolution picture of the protein fragment that enables HIV (the AIDS virus) to invade human cells—work that has immediate implications for new drug design.

At the Oklahoma Medical Research Foundation in Oklahoma City: Researchers have been able to establish a powerful association between Epstein-Barr Virus (EBV) and lupus, a serious autoimmune disorder.

At the Neuropsychiatric Institute in Fargo, North Dakota: Researchers are evaluating the importance of taste preference in determining the vulnerability to substance abuse.

At the John B. Pierce Laboratory in New Haven, Connecticut, researchers are working to determine:

—The means by which cells lining the blood vessel walls communicate with each other to convey messages about blood flow control—thus acting to prevent blockages leading to stroke;

—The source of production of nitric oxide in lungs during infection—which acts to dilate lung airways and thus act to prevent adult respiratory distress syndrome; and

—The biological basis for the increased resistance to chronic diseases such as myocardial infarction, stroke, and diabetes conferred by increased physical activity in older people.

On behalf of the AIRI membership, I want to extend our appreciation to you and the members of the Subcommittee for your support of NIH and its missions. We hope you will consider our statement in strong support of a 15-percent increase for NIH as you prepare the fiscal year 1999 Labor, HHS, Education and Related Agencies appropriations bill.

Thank you for your consideration of AIRI's views on the NIH budget.

PREPARED STATEMENT OF GLORIA E. REICH, PH.D., EXECUTIVE DIRECTOR, AMERICAN TINNITUS ASSOCIATION

I represent the American Tinnitus Association and speak for more than 50 million people in this country who have tinnitus and especially for the 300,000 people who have contacted our organization for help. These people for the most part consider this hearing problem, tinnitus, to be a major deterrent to normal living. Imagine, if you will, listening to sounds like ringing, hissing, roaring or clicking within your head for 24 hours a day for the rest of your life.

Tinnitus is most commonly caused by exposure to loud noise. It often goes along with hearing loss and thus, formerly, was thought to be a condition afflicting the elderly. Today's generation of hearing damaged people in their thirties and forties forces us to rethink that position and we now realize that tinnitus is a condition that can adversely affect the lives of people of any age.

Every day our mail brings hundreds of requests for help. Perhaps this brief sampling of letters will help you understand the distress of this invisible condition.

"I received your letter concerning tinnitus and I thank you so much. I don't know who to turn to or what to do. I have spent almost all of my savings on paying doctor bills that my insurance didn't cover." I have lost friends over what I have, my family still finds it hard to believe I have tinnitus. I don't know anyone with tinnitus and my family and co-workers have never heard of it. This sizzling in my ears seems to be getting worse. When I couldn't work for 2½ months people thought I was crazy. I was scared and still am." (SD, female, age 46)

"I received your magazine Tinnitus Today and I look forward to receiving it. I have tinnitus very bad. Many times I thought of ending my life as sometimes it is unbearable. I've gone to so many ear, nose and throat doctors and spent so much money on help. They treat my sinuses or prescribe Niacin or other vitamins that don't help. I had CAT scans too. I've tried everything I can find but with no relief. I hope some help is on the way." (CN, female, age 75)

"I am writing to you in total desperation. My father has tinnitus and it has become progressively worse in the last year. We have tried going to ear, nose and throat specialists, numerous other doctors, including neurologists, but with no luck. My father's health is deteriorating each day as the ringing is constant. It has been loud and constant for him for the past 6 months. He hardly ventures out of bed anymore. He is also blind which makes it that much worse. Please, please I am begging you not to disregard this letter. You are probably our last attempt at some kind of help or support. I am afraid that I may lose my father because of this "crazy" problem." (JC, from Delaware; family was referred to well established tinnitus support group and audiologist at Greater Baltimore Medical Center)

"My name is Bob and on many occasions when my ears were ringing real bad I thought of killing myself. I didn't as somehow my conscience wouldn't let me. But now this ringing is in my left ear as well with a different sound from the right one. Most of the time these sounds are so loud I lose my balance and my sense of direction and forget everything. My doctors tell me to bear with it, don't worry, and everything will be alright. They can't understand what its like unless they have it too. Maybe then they would help!" (RH, male, from Nebraska)

"I am 39 years old and the thought of living with this the rest of my life is more than I can handle. I have to deal with this ringing that is literally driving me insane. I can't sleep and I can hardly concentrate at work." (LP, female from Florida)

"My life is in shambles because of the intensity of ringing in my ears. It has left me without a job. I cannot study or work well at anything. (PT, male from Texas)

"I am a registered nurse and have been fired from my job and labeled professionally incompetent because I have tinnitus. They implied I was mentally ill because I described these head noises. Absolutely nothing was done at work to accommodate my handicap in spite of my good reputation as a nurse." (HL, 60 yr. old female from New Mexico)

"I've tried to continue my job which I have had for over twenty-six years, but I had to give it up after four months of overwhelming stress from the intense ringing in my ears. I can't sleep and my physical condition is weakening." (JD, male)

"In the course of the last seven years of suffering with tinnitus, I've lost my job of seventeen years, my automobile, life and health insurance, real estate, money, and a considerable portion of my sanity. It is with much hope that I appeal to you for help." (AP, male, from California)

"My life has become a horror story since I cannot find any peace and it has become impossible for me to function normally. I have been submerged into depression because my quality of life is altogether gone. I cannot even concentrate at work." (FB, 37 year old male from California)

"I am an electronics engineer and my home life and job are in jeopardy. I have had the ringing for some time but it has gotten worse to the point where I can no longer read effectively or concentrate for any length of time." (JV, male, from Connecticut)

Many celebrities have been identified as having tinnitus but few of them have been willing to speak out. Tony Randall has spoken about his tinnitus both on television and before the Senate Appropriations subcommittee. William Shatner told the House subcommittee of acquiring tinnitus while on the set of Star Trek. "Rock" musicians are particularly susceptible to hearing loss and tinnitus; Pete Townshend of "The Who", and Mickey Hart of the "Grateful Dead" are just two who have identified themselves as having "musical self-inflicted tinnitus". Bob Hope and Al Unser have it as does Barbara Streisand and Lisa Minelli. Even former President Reagan and former first lady Rosalyn Carter experience tinnitus. Needless to say, many veterans have tinnitus from the loud noises of artillery fire and heavy equipment. The Veterans Administration spends some $90 million a year in compensation for

tinnitus. Airplane pilots and drivers of large trucks, railroad workers, steelworkers, automobile body builders, miners, farmers who drive tractors, even housewives who run vacuum cleaners, lawnmowers and other household equipment have found their hearing damaged by loud sounds.

ATA along with other hearing related organizations worked for the establishment and funding of the National Institute on Deafness and Other Communicative Disorders. Along with our joy at seeing the new institute underway came the dismay of once again seeing tinnitus take the hindmost with respect to research project funding even though 2½ times as many Americans suffer from tinnitus as have hearing loss. We were, however, nothing if not optimistic and hoped that research about tinnitus would increase. Our patience was rewarded when the NIDCD held a tinnitus workshop in 1995 and subsequently funded nearly $1 million in studies. Those studies have spawned more, and this year the NIDCD awarded a larger grant of $1.5 million for tinnitus research. There'll be another workshop this year too, for refining goals and defining projects. We're satisfied with this good beginning, but we're hopeful that it is only a beginning and that more funding and more research will bring the cure that tinnitus sufferers want and deserve. ATA has done its share as well. Over the last 17 years we've given more than one million dollars for tinnitus research. The six latest of these projects have provided the pilot data required by the NIDCD for tinnitus studies they have been funded over the last 2 years. In spite of these great strides people ask us all the time why can't progress come more quickly.

Allow me to cite an example. In 1937, Robert Lewy reported tinnitus relief for varying lengths of time and in varying types of tinnitus through the use of procaine hydrochloride. It took 40 years for researchers to stumble on a similar effect with a comparable drug, lidocaine. Now, it has been another 20 years and although there have been more than 40 studies since the late 1970's about these types of drugs and their effect on tinnitus, nothing clinically useful has emerged. The medical community generally concedes that intravenous lidocaine suppresses or stops tinnitus in almost all cases. In the early 1980's an oral analog of lidocaine called tocainide (Tonocard) was developed and tested with disappointing results. Since then little if any progress has been made toward further investigations to isolate the critical ingredient in lidocaine that has a positive effect on tinnitus. Can you see why people with tinnitus find it so frustrating when their problem is either ignored or trivialized by the medical community? Admittedly, tinnitus itself is not life threatening, in fact people with tinnitus may look the perfect picture of health. The letters and telephone calls we receive, however, confirm that a large number of people with tinnitus experience significant stress which interferes with their lives and their ability to work and to interact socially.

People with tinnitus want help in their lifetime. They are experiencing a problem which has high social costs for our country. A small survey in the mid-80s revealed that about 14 percent of those with tinnitus had to change jobs or quit working because of it. 14 percent of the estimated 50 million cases is 7 million people who are no longer productive members of our society. You, as legislators, look for ways to trim costs of government. Here is a classic example of how money spent for research and treatment development can directly effect the economy. If tinnitus could be alleviated, these people would be able to resume working, become contributing members of society, and experience a better life.

The people who are suffering have told their story far better than I can. Hear their plea and help them by funding significant tinnitus research through the National Institute on Deafness and Other Communication Disorders.

PREPARED STATEMENT OF JEFFREY KERN, M.D., PRESIDENT, AMERICAN FEDERATION FOR MEDICAL RESEARCH

Thank you for the opportunity to present formal testimony to your subcommittee. The American Federation for Medical Research (AFMR) is a national organization of 7,000 physician scientists—primarily medical school faculty members—engaged in basic, clinical, and health services research.

The AFMR wants to express its deep appreciation for this Subcommittee's strong support for the National Institutes of Health. We are encouraged by proposals introduced in the House and Senate to double the NIH budget over the next five years. However, it is important to assure that a significant portion of these additional funds be allocated to much needed initiatives to strengthen NIH extramural clinical research programs. We commend Subcommittee Members Cochran and Reid for their leadership in sponsoring H.R. 3001, the Clinical Research Enhancement Act, authorizing additional funding for new clinical research career development and re-

search project awards. Unfortunately, while we await enactment of this legislation, American clinical research continues its decline. The AFMR urges this Subcommittee to move forward this year and propose additional NIH funding to revitalize our nation's clinical research effort.

THE PROBLEMS CONFRONTING CLINICAL RESEARCH

Through clinical research, basic science discoveries are applied to the study of human physiology, to research on a disease or condition, or to the initial study of a potential therapeutic intervention. Sometimes referred to as "translational" or "integrative" research, clinical research leads to the ultimate dividend of the NIH investment in basic science: improved methods of preventing, treating or curing disease and disability. Challenges to clinical research slow progress in medicine. Accordingly, it is critically important that steps be taken immediately to address the problems confronting clinical researchers and their patients. These include:

—The loss of a generation of young clinical investigators faced with enormous medical school tuition debts and the absence of structured, well-supported training and career development programs;

—The inability of academic medical centers to sustain internal mechanisms of support for clinical research because of cost-containment required by fierce competition in the health care marketplace; and

—The declining infrastructure for clinical research, most notably the insufficient funding provided to the NIH-funded General Clinical Research Centers.

It should be noted that private industry provides significant support for clinical research and clinical trials aimed at the development of new products. However, funding is extremely limited for clinical research that may not offer a product "pay off." In the past, this research was subsidized internally by our nation's academic medical centers. However, competition and cost-containment have all but eliminated the ability of these institutions to continue as the principal funders of early-stage translational research. Today, and for the foreseeable future, such research requires NIH funding.

In addition, of course, NIH funding is critically important for the training and career development of clinical investigators. Our major difficulty in mounting and continuing major studies across the nation is the inability to recruit and sustain a sufficient cadre of clinical investigators to oversee the effort and interact with the patients. Steps must be taken to initiate a virtual crash program for the training of clinical investigators.

SOLUTIONS TO THE CLINICAL RESEARCH CRISIS

The challenges confronting clinical researchers and their patients have received much attention but little action over recent decades. Of particular importance, in September of 1994, the Institute of Medicine of the National Academy of Sciences published a report on the opportunities and challenges confronting clinical research. The IOM recommendations are the foundation of the Clinical Research Enhancement Act (H.R. 3001). More recently, in December of 1997, the NIH Director's Advisory Committee on Clinical Research presented its report offering similar recommendations. Attachment 1 is a side-by-side analysis demonstrating the close concurrence between H.R. 3001 and the Advisory Committee's recommendations.

The AFMR believes that this Subcommittee must take action to provide additional funding for the initiatives that have been recommended by the Institute of Medicine, the NIH Director's Advisory Committee, and the 140 organizations that support H.R. 3001. This would require an additional $60 million—less than half of a percent of the NIH budget—to fund these initiatives including:

—$1 million to expand the existing NIH loan repayment program for intramural scientists to include physician-scientists in the extramural community;

—$3 million to support grants to fund Masters' and Ph.D., programs in clinical investigation;

—$3 million for the creation of a 5-year career development award for clinical researchers; and

—$52.5 million to establish an "innovative medical science awards" program.

In addition, the AFMR urges this Subcommittee to take steps to increase substantially funding for the NIH-sponsored General Clinical Research Centers across the country. These "safe havens" for clinical research are vitally important. As noted in the Institute of Medicine report, funding for the GCRCs has not kept pace with NIH-wide budget growth in recent years. The importance of the GCRCs is emphasized in the report of the NIH Director's Advisory Committee for Clinical Research:

The GCRC program has been highly successful and has contributed significantly to clinical research. It provides one of the few government mechanisms that allows

for quick turn-around of small-scale pilot clinical studies. The Panel considers that the importance of the GCRCs to the national clinical research enterprise, both as infrastructure for the conduct of research and for the education and training of clinical researchers, cannot be overemphasized. It believes that the NIH should increase its financial support for these important centers.

Last year, in the report accompanying the fiscal year 1998 appropriations bill, this Subcommittee expressed concern about the reductions made in GCRC grants below advisory council-approved budgets. The Subcommittee requested a report from the National Center on Research Resources (NCRR) as to the funding necessary to bridge this gap. For fiscal year 1999, the AFMR recommends a budget increase for the GCRCs sufficient to:

—Bridge the average 25 percent cut below Advisory Council approved budgets for the GCRCs (estimated $30–40 million);
—Cover the cost of increased hospital ancillary expenses as well as the increased complexity of illness for patients seen in GCRCs ($10 million);
—Fund three additional centers ($5 million);
—Expand the Clinical Associate Physician and Minority Clinical Associate Physician training programs in the GCRCs ($2 million); and
—Expand the GCRC clinical scholars program ($0.5 million).

In summary, to enable the GCRCs to maintain the vital clinical research programs of academic medical centers, the GCRC budget should be increased from $167 million to a level of at least $215 million.

As you consider our proposal for specified additional funding for clinical research initiatives, please keep in mind that such funds would not be directed to particular diseases or investigators. These funds would go to peer reviewed proposals to translate basic scientific discovery to the study of any disease. Rather than special interest set-asides, these initiatives are more comparable to the Subcommittee's directives to fund the extramural facilities construction program and the new clinical research center on the NIH campus. They will advance the goals of the NIH as a whole, will benefit all NIH Institutes and Centers, and will boost existing NIH efforts focussed on women's health, minority health, and prevention.

Improvements in patient care and the prevention of disease depend on clinical research that brings basic scientific discoveries to the benefit of human beings. The fruits of clinical research are often taken by industry and developed into new drugs, vaccines, or health care products. These new products boost our economy and create jobs. The international implications of allowing clinical research to falter are enormous. We are beginning to see signs that other nations are picking up the clinical research banner that America is dropping. Please do not delay further. Just as you have moved forward to rebuild the clinical research capacity on the NIH campus, please move forward this year with much-needed investment in the extramural clinical research capacity of our nation's academic medical centers. I would be happy to respond to questions.

Prepared Statement of Christine Stevens, Secretary, Society for Animal Protective Legislation

The first time I heard a proposal by an NIH official for funded retirement of research chimpanzees was around 1980 at an NIH symposium. This sound, humane suggestion was slow to take root, but now the National Academy of Sciences has given it authoritative consideration. The vast majority of the NAS committee rejected euthanasia as a solution and advocated a sanctuary for the chimpanzees who have completed their research service. On behalf of the Society for Animal Protective Legislation, I request funding in the amount of $50 million to make possible the erection of a chimpanzee retirement sanctuary.

The housing of retired chimpanzees in a sanctuary will reduce government expenditures for those same chimps. The reason for this is that a comfortable and easily maintained building with access to the outdoors is less costly than keeping chimpanzees singly caged in existing buildings which are mainly in cities where rent and maintenance are high. The Institute for Laboratory Animal Resources (ILAR) cites a per diem cost for chimp maintenance of $15 to $20. This can readily be reduced to $10 a day in a sanctuary setting. ILAR estimates that there are 1,000 chimpanzees now living in institutions in different parts of the country who have been retired from research. A capable Animal Technician familiar with the care and handling of chimpanzees receives on average $30,000 a year. ILAR estimates that such an individual can now handle the care of 10 to 12 chimpanzees. In a sanctuary setting where the animals would be much more at ease, a well-trained Animal Techni-

cian would be capable of caring for as many as 24. In other words, the cost to government would be cut in half.

I would like to quote a paragraph from an article in Laboratory Primate Newsletter, a synopsis of an article in the Journal of Medical Primatology by leading experts, including Jane Goodall and Michael Balls. The statement reads: "It is now generally accepted that chimpanzees must be retired at the end of their involvement in research, to live under conditions which provide for their social and psychological well-being, for the remainder of their 40–50 year life span. For this reason, no experiment should be carried out unless the supporting agency has guaranteed to provide the funds necessary for such retirement. Such funds must be kept in a secure annuity account. At present, approximately $30,000 to $60,000 per chimpanzee are standard charges for this purpose."

A coalition of animal protective groups are doing their best to raise funds for the needed sanctuary. However, the cost is such that it is vitally important that the government contribute substantially in order to make it a reality. Plans have been drawn up and are available from Carole Noon, Project Director of The Institute for Captive Chimpanzee Care and Well-Being.

The reason why there are so many chimpanzees being held by scientific institutions in the United States relates to the original expectation that they would be important to AIDS research. That expectation has not developed. However, there are many chimpanzees that have been used for studies of hepatitis and other diseases, and also the Air Force chimpanzees which have been declared "surplus" to any current needs of the U.S. Air Force. A serious problem exists with respect to these particular animals because of potential donation of them to The Coulston Foundation, a New Mexico facility. The Coulston research laboratory has been cited repeatedly by the U.S. Department of Agriculture for violations of the Animal Welfare Act.

In 1993, three chimpanzees died a grisly death after a heater malfunctioned, making their quarters a blistering 140 degrees, according to USDA's Veterinary Inspector. The USDA complaint further listed four monkeys found dead or dying in their cages. "They had gone without water for at least three days. Although the caretakers were trained to test the animals' automatic waterers every day, they had in fact simply been checking off that task on their daily logs without actually performing the test," stated an article in U.S. News & World Report. On another occasion, four monkeys who had been left outside in 100 degree heat died, apparently having choked on their own vomit.

In each case, it took weeks for the problems to come fully to light, due to stonewalling and secrecy from the laboratory. Not reporting the first deaths to USDA was a clear violation of federal law, and the laboratory's Animal Care and Use Committee (of which Coulston himself was a voting member, and which included no one who actually cared for the chimpanzees) saw no reason to investigate either incident.

The National Institutes of Health will not renew a $3 million yearly contract with the Coulston laboratory. Coulston has boasted that "We are the sole source of chimpanzees for research."

I would like to cite the National Research Council's 1997 report, Chimpanzees in Research. It calls for a five-year breeding moratorium because increasing the number of chimpanzees would result in overcrowding at existing facilities. It is estimated that this moratorium will result in a 15-percent decrease in operating costs by the fifth year. Following are relevant quotations from the National Research Council report:

The concept of sanctuaries capable of providing for the long-term care and well-being of chimpanzees that are no longer needed for research and breeding should become an integral component of the strategic plan to achieve the best and most cost-effective solutions to the current dilemma. [p. 3]

[Sanctuary chimpanzees] require less intensive management than animals in research facilities, and therefore entail lower costs of daily care. [p. 23]

Sanctuaries offer an opportunity for substantially reducing costs of long-term maintenance of chimpanzees without compromising high standards of well-being. [p. 57]

The report also offers two citations, as follows:

Large outdoor enclosures are relatively inexpensive to build and maintain, and provide natural stimulation for the chimpanzees.

Formation of one or more retirement facilities to which animals from existing colonies could be transferred. It is anticipated that group housing and reduced handling of animals would reduce operating costs below those typical of research facilities.

Chimpanzees are so closely related to us humans that they share 98.4 percent of our DNA. Their mental capacities are becoming more and more understood and appreciated as studies reveal their remarkable capabilities. A book by Roger Fouts en-

titled: "Next of Kin" reports on the unusual achievements of the chimpanzee Washoe and four other chimpanzees that are being studied by Dr. Fouts and his team at Central Washington University's Psychology Department. These chimpanzees use American Sign Language to communicate with humans and with each other. Dr. Fouts describes in his book the amazement of a scientist who found it hard to accept the cognitive abilities of chimpanzees until, driving past the Fouts's home, he observed the young Washoe seated in the top of a large tree turning the pages of a magazine and signing to herself about the contents.

Television viewers were deeply impressed by a segment on ABC in which Hugh Downs accompanied Roger Fouts to a laboratory to renew Dr. Fouts' acquaintance with a chimpanzee, Booie by name, whom he had not seen for 16 years. Booie was living in a small laboratory cage, and when Dr. Fouts came in, Booie immediately recognized him. They talked in sign language, and Booie signed a nickname for his old friend that Dr. Fouts himself had nearly forgotten. This moving meeting and sad parting brought a mass of letters from viewers. There is no doubt that the American public wants to see the laboratory chimpanzees retired after use as human substitutes in experimentation.

Recent studies in the field by Sue Savage-Rumbaugh show that bonobos, or pygmy chimpanzees, leave messages for one another which scientists have been able to decipher. These small chimpanzees, traveling through a dense forest, leave signs of the direction they are traveling so the other members of their troop can follow without error. Sometimes the branches of saplings are bent over, indicating the direction; or where a trail divides, leaves are laid in the path with the pointed tip indicating which trail should be followed.

On behalf of the Society for Animal Protective Legislation, I urge this distinguished Subcommittee to make possible retirement for chimpanzees who have done their stint in research laboratories for the benefit of human beings.

Request for Change in NIH Policy on Acquisitions of Dogs and Cats Used by NIH Grantee Institutions

The National Institutes of Health does not acquire dogs for the Institute's in-house research from Class B dealers. This wise policy should be expressed also in its funding of grants to other institutions. The number of Class B dealers selling dogs and cats for research and testing has decreased as a result of examination of their practices and premises by academia and commercial laboratories.

The U.S. Department of Agriculture, which licenses dealers who sell purpose-bred dogs and cats (Class A) also continues to license the dwindling number of dealers who acquire "random source" dogs and cats (Class B). USDA has uncovered many instances in which a Class B dealer has reported obtaining animals from persons who, in fact, do not exist, did not provide the animals or, in some cases, were dead. The practice of shipping dogs across the country from one dealer to another makes a mockery of any attempt to locate an owner's lost or stolen companion. In one case, USDA Inspectors found that names obtained from driver's license applications found in a wastebasket, were presented to them as the source of numerous laboratory dogs.

In Congressional testimony presented last year, Dr. Robert A. Whitney, former Deputy Surgeon General, U.S. Public Health Service, stated:

I have an extensive background in this and other issues of public concern about the procurement and use of animals for biomedical research. Before becoming Deputy Surgeon General in 1992, I served as Director, National Center for Research Resources (NCRR) of the National Institutes of Health (NIH). In my 22 years at NIH I was responsible for production, procurement, and care of animals used in NIH intramural research. I also served as chairperson of the NIH Animal Care and Use Committee, Chairman of the U.S. Government Interagency Research Animal Committee (IRAC), and Director, NIH Office of Animal Care and Use. At NIH, the use of dogs from Class B dealers, otherwise known as random source dogs, ceased many years ago.

Over the past 25 years I have been involved in the development and update of most of the federal policies and regulations governing appropriate care, use, and welfare of animals used in biomedical research. This experience has led me and many of my colleagues to believe that our inability to guarantee the quality of procurement and care of animals from Class B dealers creates many problems in public perception for the biomedical research community, and potentially in the research itself. Despite the small number of animals obtained from these sources, their use portends many more problems than the benefits which might be derived.

We urge NIH to require grantees to certify that they will not use Class B random source dealers as a source for dogs and cats in their proposed research.

PREPARED STATEMENT OF ANNE R. PEBLEY, PRESIDENT, POPULATION ASSOCIATION OF AMERICA [PAA], AND PETER J. DONALDSON, PRESIDENT, ASSOCIATION OF POPULATION CENTERS [APC]

Thank you, Mr. Chairman for this opportunity to present the position of the Population Association of America (PAA) and the Association of Population Centers (APC) to the Subcommittee on Labor, Health and Human Services and Education on fiscal year 1999 funding for the National Institutes of Health (NIH), specifically the National Institute on Aging (NIA), and the National Institute of Child and Maternal Health (NICHD). You are a long-standing friend of both organizations and we want to emphasize how grateful we are for your appreciation and support of demographic research.

As you know, PAA is a scientific and educational society of professionals working in demographic research. APC is a consortium of 27 leading American population research centers. In addition to their academic roles, members of both organizations provide federal, state and local government agencies, as well as private sector institutions, with data and research to guide decisionmaking.

In this testimony, we wish to express our support for the National Institutes of Health (NIH), specifically NIH support for demographic, social and behavioral research, and share recent demographic trends and research findings of interest with Congress.

Demographic research covers many issues important to our nation, such as retirement, minority health, disability and long term care, child care, immigration, labor force participation, worker retraining, family formation and dissolution and population forecasting. The United States is undergoing far-reaching shifts in its demographic composition and distribution. Such changes often are not recognized or understood until they confront society with new and immediate needs—often requiring federal and state expenditures. Incorporating demographic, social and behavioral research into long term policy discussions allow such changes to be tracked and anticipated in a manner that promotes more coherent and efficient planning and policy implementation.

NIH, specifically the National Institute of Child Health and Human Development (NICHD) and the National Institute on Aging (NIA) provide primary support for demographic research. We would like to take this opportunity to share with you information concerning aging, trends in adolescent health, the incidence of teenage pregnancy and abortion prevalence and changes in fatherhood.

THE NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD)

NICHD has a well-established, successful population research program. NICHD is currently funded at $674 million with $39.6 million of the budget for research funded through the Demographic and Behavioral Sciences. Among the many areas of demographic research supported by NICHD are families and households; marriage and family change; fertility and family planning; teen pregnancy; mortality; HIV prevention; and population movement, distribution and composition. NICHD also funds a highly regarded population research centers program. Population research centers provide a critical core of professionals who conduct research in a cost-effective manner. Further, the centers' training programs are an essential source of population scientists who bring fresh perspectives, ideas and improved methodologies to demographic research.

As you can see from the wide range of research topics listed above, NICHD-supported demographic research provides important, ongoing information critical to policymakers. Last year's committee report for the fiscal year 1998 NICHD appropriation specifically mentioned the National Longitudinal Study of Adolescent Health, also known as the Add Health Survey, and this committee's interest in continued reporting on this study. We are pleased to provide some information in this testimony that focuses on Add Health, your interest in the decreasing rates in teen pregnancy and abortion, the Fatherhood Initiative, and the Family and Child Well-Being Research Network.

Add health

The Add Health survey is the first comprehensive national study of the social, psychological and environmental determinants of adolescent health. This study provides information that is valuable to parents, educators, researchers and policymakers. Although teens are generally a very healthy sub-group in the population, one in five has a serious health problem which are often costly and affect adult health. Each year, in the mid-1980's, the lifetime cost of injuries to young people 15–24 years of age were estimated at $39.4 billion; public support for families headed by adolescents cost $16.7 billion per year; treatment costs for adolescents with

mental health problems were estimated at $3.5 billion annually; and $2.0 billion or more per year was spent on facilities for delinquent adolescents.

One of the key findings from the Add Health study was that "family connectedness" played a central role in protecting adolescent health: adolescents who felt loved and cared for by their parents and were satisfied with their family relationships were least likely to smoke, drink or use illegal drugs; least likely to become sexually active at a young age; least likely to be emotionally distressed or contemplate or attempt suicide, and least likely to engage in violence.

Determining how to prevent and treat adolescent health problems will contribute to a stronger and healthier society. PAA and APC hope this committee will continue to support research, such as the Add Health study, that adds to our understanding of changes in the teenage and adult population.

Teen pregnancy and teen abortion

There are encouraging trends in teen pregnancy and the prevalence of abortion. The teen birth rate has been steadily decreasing in recent years. Since 1991 the rate has declined 12 percent to 54.7 per 1,000 in 1996. Between 1991 and 1995, the teen birth rate dropped 17 percent among non-Hispanic blacks and by more than 9 percent among non-Hispanic whites. The teenage Hispanic population did not show a comparable decline in birth rates between 1991 and 1995. Another encouraging note is that there was a decline in the teen abortion rate in the early 1990's. These data suggest that the decrease in the teen pregnancy rate is not being driven by an increase in abortion.

Although rates of teen pregnancy are decreasing, the United States still has one of the highest teen pregnancy rates among industrialized countries. NICHD is currently supporting a study to identify key groups of young women who are at a higher risk of becoming a teen parent. One such group, younger sisters of pregnant and parenting teens, have more permissive childbearing attitudes than do their age and socio-economic status-matched peers who do not have an older sister who is a teen parent. Realization of this type of information will prove very important when creating intervention programs targeted at further decreasing the teenage pregnancy rate.

Fatherhood

The declining significance of marriage has the particular effect of weakening the ties of men to women and children, with a resulting burden to the welfare system and to women and children themselves. Thus, it is important to understand the conditions which help to sustain men's obligations to family members. NICHD, in conjunction with the Federal interagency Forum on Child and Family Statistics and the National Center on Fathers and Families, launched a Fatherhood Initiative to review the capacity of the federal statistical system to conceptualize, measure and gather information from men about their fertility and role as fathers. This same study identified ways to improve data collection and research in this area.

Family and child well-being research network

Finally, we wanted to bring you up-to-date on NICHD's Family and Child Well-Being Research Network—an interdisciplinary data system focusing on child- and family-related research that relies on cross-agency cooperation. The network is comprised of scientists from seven universities collaboratively working with federal officials from NICHD, the Office of the Assistant Secretary for Health, of the Department of Health and Human Services (DHHS), the Administration of Children and Families, of DHHS, the Census Bureau and the Department of Education. This network currently addresses a variety of questions about the interrelations between parent characteristics, family structure and organization, neighborhood attributes and different forms of social support. The network is committed to increasing the visibility of basic research findings to those involved in formulating public policy. Projects such as the Family and Child Well-Being Research Network perform the important task of helping synthesize research into sensible policy solutions.

NICHD's Family and Child Well-Being Research Network, in cooperation with federal statistical agencies and the research community developed a comprehensive set of indicators of child well-being. Information from these indices are published annually by executive order. The first report titled, America's Children: Key National Indicators of Well-Being, was released in 1997. This report provides a much improved information base that summarizes the changes in the overall well-being of American children and families on an annual basis.

PAA and APC enthusiastically support initiatives such as NICHD's Family and Child Well-Being Research Network that provide quick access to data and are efficient and effective resources for policy-related research in cross-disciplinary fields.

The National Institute on Aging (NIA)

The NIA also has a well established and widely respected demographic research program which provides crucial information on the implications of an aging of the American Population for our country. Currently, the NIA is funded at $519 million, with $38 million of that budget dedicated to demographic research—training, career development, and demographic, economic and epidemiologic research. As the US population ages and Congress contemplates changes in Medicare and Social Security, the demography of the elderly steadily become more important. The NIA has a strong history of supporting the collection of data which allows demographers to study questions of concern to policymakers. Chief among these are the NIA-supported studies, the Health and Retirement Study (HRS) and its auxiliary survey, the Asset and Health Dynamics of the Oldest-Old (AHEAD) study. You have been a solid supporter of these two studies over the years, Mr. Chairman, and we would like to express our gratitude for your support.

Health and retirement study (HRS)

As you know, the HRS focuses on retirement decisions and includes data on disability, work history, health and health insurance, pensions and retirement plans and obligations to family that may bear on retirement decisions. Using HRS data, researchers are able to explore issues related to health, disability and labor force participation; prospects for economic security; cognitive changes, health insurance coverage in the decade before Medicare eligibility.

HRS research conducted by economists at the University of Pennsylvania, for example, indicated that while pre-retirement savings appears to be substantial ($340,000 for the median household), the present value of Social security wealth accounts for a large share of average total wealth (about $145,000). To meet a post-retirement income target of 70–80 percent, an average couple in their mid-1950's would have to save $10,700 each year until age 65. This would translate into a savings rate of 23 percent, far greater than typical savings rates in the U.S. Persons in poor health are even less well prepared for retirement, with only $5,000 in pension wealth and $80,000 in Social Security wealth.

Asset and Health Dynamics of the Oldest-Old [AHEAD]

The companion survey of HRS, AHEAD, provides unique information on the dynamics of health, economic resources and health care services. The study provides badly needed data on the costs and burdens of chronic disease and the consequences for the extended family. Over time, AHEAD will provide data on how families redistribute their resources across generations, and how these flows interact with public sector transfers. Such a study is needed to make informed policy decisions on initiatives such as Medicare/Medicaid coverage for community long-term care and health-care reform.

AHEAD data and research are also providing insights into the complex family support system which sustains persons of all ages in times of need. Despite the stereotype of the "greedy geezer", analyses of AHEAD indicate that financial transfers overwhelmingly flow from parents to children, even when the parents are very old. These transfers disproportionately target adult children in the family who are relatively less well off than their siblings. Adult children who benefit from such transfers, however, are far more likely to provide personal care as their parents become disabled in later life.

HRS and AHEAD data also provide opportunities to track the cognitive performance of older persons as they age. In the total non-institutionalized population age 70 and over, about 5 percent have severe cognitive impairment and another 48 percent score below average. As expected, persons of low education and limited financial resources are more likely to evidence cognitive deficits in middle and late life.

Finally, PAA and APC are interested in and support the current efforts to strengthen the Federal Forum on Aging Related Statistics that coordinates data across federal agencies. The forum is an example of NIA's interest in supporting NIH's innovative endeavor of streamlining federal databases and making data accessible to researchers from varied fields.

PAA and APC would like to thank you for the opportunity to present this information. Demographic data and research are important tools for policymakers that can both save public funds and promote more informed decision-making. If this vital research is to continue producing relevant and timely information, adequate funding and Congressional support are needed. The Population Association of America and the Association Population Centers support a 15-percent increase in funding to sustain the momentum of demographic research in the National Institutes of Health as part of the broadly based support to double the the funding for the NIH over the next 5 years.

PREPARED STATEMENT OF ROGER P. KINGSLEY, AND SHARON MOSS, ON BEHALF OF THE AMERICAN SPEECH-LANGUAGE HEARING ASSOCIATION

The American Speech-Language-Hearing Association (ASHA) appreciates the opportunity to provide testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. Our statement focuses on funding needs in fiscal year 1999 for an area that is very important to many members of this association: health research. Specifically, the statement will address activities, needs and recommendations concerning the National Institute on Deafness and Other Communication Disorders (NIDCD).

ASHA is the national professional, scientific and accrediting association for over 93,000 speech-language pathologists, audiologists, and speech-language-hearing scientists serving the needs of people throughout the United States who have communication and related disorders. Speech-language-hearing scientists receive funding to support research activities through the National Institutes of Health. Research awards have enabled these scientists to conduct research that leads to better communication for all Americans.

The ability to communicate effectively is fundamental to other life activities, i.e., learning, interpersonal relationships, and vocational pursuits. Any loss or limitation in communication ability can be detrimental to an individual's development, accomplishments, and overall quality of life.

Communication impairment is the nation's most prevalent disability: approximately 42 million Americans have some kind of communication disorder. These disorders result in huge costs to the economy in lost productivity, special education, rehabilitation, health care expenditures, and lost revenues. It has been estimated that costs associated with hearing loss alone approximate $56 billion a year.[1] Costs associated with traumatic brain injury have been estimated at $25 billion annually.[2] These costs to society are expected to grow, due to several factors:

First, increasing numbers of infants and small children have or are at risk of developing communication disorders. As more infants survive because of medical technological advances, the number of children with severe disabilities, often including speech, language and hearing disabilities, necessarily increases. With higher incidence of substance and alcohol abuse, lead poisoning, and other human and environmental factors, there is a growing population of children and youth with disorders of communication. Accidents, particularly those involving motor vehicles and firearms, also have increased the number of communicatively impaired individuals as a result of traumatic brain injury—especially among teenagers and young adults.

Noise-related hearing loss, resulting from machinery, music amplification, and other environmental and self-imposed factors, is still another increasingly prevalent phenomenon.

Secondly, the prevalence of communication disorders will increase dramatically as the population ages. Impairment in the ability to speak, hear, or process language is often associated with diseases and conditions that occur as people get older: Alzheimer's Disease, resulting in cognitive and language dysfunction; Parkinson's Disease and other progressive neurological disorders resulting in oral-motor dysfunction; stroke, resulting in aphasia; cancer of the larynx, resulting in laryngectomy and voice loss; and presbycusis, or degeneration of auditory function resulting in hearing loss.

Many of the costs relating to these conditions are borne by federal and state governments. The populations targeted by research through the NIDCD are many of the same populations which receive services through the IDEA, the Rehabilitation Act, Medicare, Medicaid, Social Security Disability Income and other public programs. Research that focuses on detection, diagnosis, treatment and prevention, should result in a reduction in the need for special education, rehabilitation, and health care services.

The NIDCD is the major institution for coordinating and funding of speech, language, and hearing scientists who are engaged in intramural and extramural research that focuses on disorders of communication. The Institute's work holds forth great promise that some of the difficult challenges within the field of communication disorders can now be addressed. We strongly support many of the initiatives proposed by the NIDCD, particularly those addressing hearing, language, voice, and speech: diagnostic and intervention strategies following neonatal hearing screening;

---

[1] Research in Human Communication, 1992 Annual Report of the National Deafness and Other Communication Disorders Advisory Board, U.S. Department of Health and Human Services—National Institutes of Health, 1993.

[2] Progress and Promise: In 1992-A Status Report on the NINDS Implementation Plan for the Decade of the Brain, the National Advisory Neurological Disorders and Stroke Council, Department of Health and Human Services—National Institutes of Health, December 1992.

mechanisms of learning and relearning after brain damage; and communication disorders following stroke in multicultural and multilingual individuals. Continuing the acceleration in federal funding support will allow the Institute to promote research in areas that have the potential of improving the lives of people of all ages.

Studies addressing the identification of hearing loss in children and infants are sorely needed and could lead to the development of more innovative, and less expensive behavioral audiometric tests, better speech and language materials for children, and highly sensitive parent inventories. Examining how language learning and relearning take place subsequent to brain injury is crucial to the understanding of the brain and behavioral mechanisms related to first language learning acquisition, and to maximizing and understanding the recovery processes of acquired language disorders.

More research also is needed on the prevalence and incidence, long-term functional outcomes and post-stroke quality of life issues of aphasia among multilingual and multicultural populations. In addition, efforts should be directed toward the development of culturally sensitive assessment and intervention instruments for persons from different ethnic populations following stroke-induced aphasia. ASHA is also supportive of NIDCD's program initiative of research in the area of sickle cell anemia in children because of the communication disorders that result subsequent to stroke, and the high risk of stroke in this population.

ASHA is supportive of many other efforts that advance the knowledge about mechanisms and processes of human communication, and that improve the approaches to prevention, diagnosis, and treatment of communication disorders. For example, studies that examine the human brain using imaging tools during various communication events; the molecular mechanisms that underlie hair cell regeneration in the inner ear; the efficacy of the cochlear implant prosthesis; and mechanisms for early and more precise diagnosis of specific language impairment in children.

ASHA is supportive of a research portfolio that includes behavioral and clinical research, as well as basic research activities. We also support the continuation of efforts to fund the clinical trials program beyond the current levels. Members of ASHA have been able to utilize this program to test the efficacy of different treatment approaches, thereby having a significant impact on current public health and health care financing discussions.

ASHA also supports research that allows for collaboration with other Institutes such as: the National Institute on Aging, National Cancer Institute, National Institute of Child Health and Human Development, National Institute of Mental Health, and National Institute of Neurological Disorders and Stroke. Research that supports the development of improved diagnosis and more effective intervention strategies for autism, velocardiofacial syndrome, and recurrent otitis media is greatly needed and is encouraged by ASHA.

ASHA supports the recommendation made by some members of Congress and by the Ad Hoc Group for Medical Research Funding, of which we belong, for an increase of 15 percent overall for the NIH. As one of the newer institutes and having lagged behind other research institutes with respect to funding increases, we concur with the recommendation by the American Academy of Otolaryngology-Head and Neck Surgery for an increase of 18 percent for the NIDCD.

Mr. Chairman, we appreciate the opportunity to provide these comments and recommendations to your Subcommittee. We look forward to working with you and your staff as well as with the other members of the Subcommittee and their staffs as the fiscal year 1999 appropriations process moves forward.

PREPARED STATEMENT OF THE CHUCK LUDLAM, ON BEHALF OF THE BIOTECHNOLOGY INDUSTRY ORGANIZATION

CONTRIBUTIONS TO NEW MEDICINE FROM GOVERNMENT-FUNDED BASIC BIOMEDICAL RESEARCH

The Biotechnology Industry Organization (BIO) submits this statement in support of substantial increases in appropriations for the National Institutes of Health (NIH). BIO represents over 750 biotechnology companies, academic institutions, and state biotechnology centers in 46 States and more than 25 nations. BIO members are involved in the research and development of the life sciences including health care, agricultural, and environmental biotechnology products.

BIO is a member of the Ad Hoc Group for Medical Research Funding, a coalition of voluntary health groups, medical and scientific societies, academic and research organizations and industry representatives. BIO supports the Ad Hoc Group for

Medical Research Funding proposal which calls for a 15-percent increase in NIH funding for fiscal year 1999. This increase should be the first step towards doubling the NIH budget over 5 years. BIO recognizes the difficulty in achieving such a goal under the current spending limits, and therefore, encourages the Senate Appropriations Subcommittee to explore all possible options to identify the additional resources needed to support this increase.

This statement outlines how society benefits from increased NIH funding. This statement also emphasizes and documents the vibrant partnership the biotechnology industry has with the NIH and its grantees, a partnership which helps ensure that basic biomedical research is developed into products for the benefit of patients.

NIH-BIOTECHNOLOGY INDUSTRY PARTNERSHIP

There is a synergy between the U.S. biotechnology industry and the NIH and its grantees based on technology transfer programs which are essential for the application of basic biomedical research to human needs.

The transfer of technology is fundamental to the partnership between non-profit, federally-funded basic biomedical research and for-profit commercial firms. This partnership builds upon the strengths of each: government funding for NIH research (predominantly basic biomedical research); company funding for basic and applied biomedical research (which explores ways to develop basic biomedical research into products which treat disease). The technology transfer process provides a fundamental justification for continued funding increases for basic biomedical research.

Unlike basic biomedical research conducted by private companies, federally-funded basic biomedical research must be transferred to a private firm to become available to patients. In the American economy neither the government nor government-funded laboratories commercialize products. This is the indispensable role of the biotechnology and pharmaceutical industries. To commercialize a product the biotechnology industry has to: raise immense amounts of capital needed to take a product through clinical trials and the Food and Drug Administration (FDA) product approval process; secure appropriate intellectual property protection for inventions which occur in the drug development process; and manufacture and distribute the final product to patients. It is critical to patients, therefore, that federally-funded basic biomedical research is transferred to biotechnology and pharmaceutical companies. Only then does this research lead to new medicines and treatments for disease. Over 100 million people have been helped by the 60 biotechnology therapies and vaccines on the market today.

Federally-funded basic biomedical research is extremely important to the biotechnology and pharmaceutical industries. In fact, the fruits of this research helped create the biotechnology industry with the discovery of recombinant DNA in 1973. Since then, what has enabled the biotechnology industry to grow so rapidly for so long has been the effective technology partnership system that developed in the 1980's. From the 1980's onward technology partnerships between government-funded researchers and the private industry have remained one of the driving forces for growth in the biotechnology and pharmaceutical industries.

Increased funding for the NIH will generate even more basic biomedical research which can be transferred to the private sector for commercialization. From 1992 to 1996 between 68 percent and 72 percent of research grant applications went unfunded.[1] This problem is only made worse by the fact that many of these unfunded grant applications are for ongoing research projects which were funded in previous years. From 1992 to 1996 between 51 percent and 55 percent of grant application renewals went unfunded.[1] These grant applications could not be accepted because the NIH did not have sufficient appropriations to fund them. This high percentage of application rejection occurs in spite of the fact that in 1996 about 85 percent of the NIH budget was used to provide support to these extramural researchers (researchers that are not employees of the NIH).

With increased funding many more grants will be awarded and will lead to medical breakthroughs that can be commercialized by the biotechnology and pharmaceutical industries.

The NIH and its grantees have established effective mechanisms to ensure that basic biomedical research breakthroughs will be transferred to the private sector for development into products. Technology partnerships take a number of forms depending on whether they involve the NIH or NIH-funded research. In each case the

[1] National Institutes of Health home page (http://www.nci.nih.gov/admin/fmb/e65.htm).

biotechnology industry is open to paying royalties for the patent rights to medical technologies. The principal technology partnership mechanisms are listed below:

TECHNOLOGY PARTNERSHIP MECHANISMS

Cooperative Research And Development Agreement (CRADA).—A CRADA is an agreement through which researchers at the NIH and private companies negotiate terms for cooperative research and define the rights of the parties to use licenses for any patents which might be created as a result of the research. CRADAs are the cornerstone of the basic biomedical research partnerships between the NIH and the biotechnology and pharmaceutical industries. In many cases the corporate partner provides funding and other resources to conduct research at the NIH. This corporate partner will then take the new technology and develop a marketable product. The figures in the chart on page six show a direct relationship between increases in NIH funding and increases in both CRADAs executed and royalty income attributed to the sale of new inventions. In fiscal year 1996 and fiscal year 1997 the number of CRADAs increased dramatically. This increase in CRADA activity also led to increases in patents issued to companies which, in turn, will likely lead to the approval of new drugs in the market place.

Bayh-Dole Agreements.—A Bayh-Dole Agreement is the corollary to the CRADA for NIH grantees (universities and foundations). Bayh-Dole Agreements are agreements between universities or medical institutes and biotechnology companies or pharmaceutical companies in which the parties define the licensing rights to patents that might be created and agree on how to share funds, materials, and scientists in the collaborative research effort. Bayh-Dole Agreements, like CRADAs, generate patent income.

The two charts below show a relationship between the amount of NIH funding a university receives and the amount of royalties generated on patented inventions attributed to the NIH-funded research.

TOP FIVE REVENUE GENERATING UNIVERSITIES

	In fiscal year 1995[1]—	
	Royalties received	Research expenditures from Federal Government sources[2 3]
University of California System	$57,272,000	$835,637,000
Stanford University	38,900,000	316,000,000
Columbia University	34,194,811	204,000,000
Michigan State University	15,279,521	277,900,000
W.A.R. F./University of Wisconsin-Madison	12,380,000	197,626,417

[1] Association of University Technology Managers, AUTM Licensing Survey fiscal year 1991–95 (Norwalk, CT: Association of University Technology Managers, 1996) 76.
[2] This funding is predominantly from NIH.
[3] Association of University Technology Managers, AUTM Licensing Survey fiscal year 1991–95 (Norwalk, CT: Association of University Technology Managers, 1996) 100.

JOHN HOPKINS UNIVERSITY PATENT AND LICENSING ACTIVITY[1]

	Fiscal year—					
	1991	11992	1993	1994	1995	1996
NIH grants (millions of dollars)	$162.8	$203.9	$230.8	$258.0	$254.4	$262.7
Inventions reported to NIH[2]	19	32	41	44	44	58
Patents applications filed from NIH sponsored inventions	13	20	26	27	43	48
Royalties received (millions of dollars)	$1.69	$2.24	$2.29	$2.18	$1.25	$1.63
Royalties received from NIH funded inventions (in thousands of dollars)	NA	NA	NA	NA	$692.835	$948.336

[1] Theodore O. Poehler, Vice Provost for Research, Office of the Provost, John Hopkins University, Baltimore, Maryland (1998).
[2] Includes Arts and Science, Engineering, Hygiene, and Public Health, Medicine, Nursing, Academic Centers, and Health Division Administration.

Licensing of patents.—These partnerships focus on the licensing of patents on basic biomedical research discoveries. These licenses are critical to the relationship

between biotechnology and pharmaceutical companies and the NIH and its grantees. Without patents to protect the taking of an invention by a competitor, a company cannot justify its research investment. It is crucial that the NIH and its grantees, therefore, secure patents on their inventions so companies that invest money in developing these inventions can benefit from their investment. The licenses require companies to make royalty payments to the proprietary owner of the license, or licensor, based on any sales of products attributed to the licensed patent.

The biotechnology industry expects to pay royalties as a part of a license agreement. Companies frequently license technology from one another and the norm is to include royalty payments. It is important for the NIH and its grantees to set royalty payment that are competitive to those which a company would expect to pay another company. Otherwise, companies would tend to seek technology from sources other than the NIH or its grantees. The government has a reasonable expectation that its investment in research will be rewarded with royalty payments. No company would expect the government or its grantees to license technology without receiving a return on its investment. This return, in the form of royalty payments, can be used by the government to fund additional research.

In 1997 the total royalty income the NIH received was $35,692,000 or .281 percent of its budget for the same year ($12.7 billion; this information is available on the chart on page 6). It is clear that this small amount of royalty income is not likely to ever grow enough to support the entire NIH budget. It is unlikely, therefore, that the NIH will ever be able to rely on its royalty income to support its research budget.

Small Business Innovative Research (SBIR) and Small Business Technology Transfer (STTR) programs.—The SBIR and STTR programs—supported by federal government funding through the NIH—provide funding to biotechnology and pharmaceutical companies to conduct research and development of new or improved technologies that have the potential to succeed as commercial products. For 1998 the total estimated funding for SBIR and STTR programs combined is $280.6 million. These two programs are indispensable to the biotechnology industry as a source of seed capital for early stage biotechnology companies. BIO supports these programs and has worked with the NIH to provide recommendations on how to improve these programs and to assist in outreach to the biotechnology community. For specific funding levels for the SBIR and STTR programs see the chart on page 7.

NIH technology transfer reform

The effectiveness of the NIH technology transfer program has increased dramatically in recent years. The unconditional repeal of the ''reasonable price'' clause in April of 1995 has been critical to this success. Congress should support NIH's decision and not move to force it to reinstate the ill-conceived price review policy. To do so would jeopardize the gains we have seen in the effectiveness of its technology partnership program.

The repeal of the price reviews policy was both decisive and justified. Among biotechnology companies it has substantially increased interest in collaborating with the NIH and other Public Health Service (PHS) agencies. It reassures companies who enter into collaborations with NIH and PHS grantees that their agreements will not someday be subject to a pricing clause. The functioning ''reasonable price'' clause prior to April 1995 deterred companies from collaborating with NIH and decreased NIH's ability to transfer its basic biomedical research into marketable products.

The impact of this repeal has been dramatic as shown in the figures in the following chart. For example, the number of CRADAs rose from a low of 31 in 1994 to 87 in 1996 and 153 in 1997. The number of licenses grew from a low of 75 in 1993 to a high of 208 in 1997. Royalties also grew substantially. These figures demonstrate the wisdom of the NIH decision to repeal the clause.

SUMMARY OF NIH TECHNOLOGY TRANSFER ACTIVITIES FISCAL YEAR 1993–97 [1]

	Fiscal year—				
	1993	1994	1995	1996	1997
Number of issued patents	88	75	95	107	119
Executed licenses	75	125	160	184	208
Executed CRADA's	41	31	32	87	153
Royalties (thousands of dollars)	$13,494	$18,487	$19,388	$26,995	$35,692

SUMMARY OF NIH TECHNOLOGY TRANSFER ACTIVITIES FISCAL YEAR 1993–97 [1]—Continued

	Fiscal year—				
	1993	1994	1995	1996	1997
NIH budget authority (billions of dollars) [2]	$10.3	$10.9	$11.3	$11.9	$12.7

[1] National Institutes of Health home page (http://www.nih.gov), following this sequence of directories: Scientific Resources, The NIH Office of Technology Transfer, Technology Development and Licensing Programs, Patents and Licensing Statistics or at http://www.nih.gov:80/od/ott/nih93–97.htm. For questions contact MaryAnn Martinez, Secretary to the Director, Office of Technology Transfer, National Institutes of Health.
[2] Contact Mitchel Goldstein, Department of Health and Human Services Budget Office.

SUMMARY OF NIH SBIR AND STTR ACTIVITIES FISCAL YEAR 1993–97 [1]

[Dollars in millions]

	Fiscal year—				
	1993	1994	1995	1996	1997
STTR's (awards)	NA	48	90	109	111
STTR's	NA	$4.7	$8.7	$13.9	$14.7
SBIR's (awards)	1,011	943	1,038	967	1,251
SBIR's	$121	$128.7	$175.1	$184.9	$246.2

[1] Contact Sonny Kreitman, Special Programs Officer, Office of Extramural Programs, National Institutes of Health.

In 1995 and 1996 amendments to the NIH appropriations bill were offered in the House of Representatives to reinstate the "reasonable price" clause. These amendments were decisively rejected. BIO strongly opposed these amendments and believes the NIH's mission is research, not the pricing of medicines developed. Issues of pricing or access only should arise once a medicine has been developed and approved by the Food and Drug Administration (FDA). Raising issues of pricing or access during the research stage is premature and counter-productive. It undermines the ability of our companies to convince investors to fund a collaborative research program with the NIH. When medicines are developed from NIH basic biomedical research, then the NIH has completed its mission and deserves praise—and royalties—for its fundamental contribution to the health of patients and the advancement of science.

A great many experts have found that pricing reviews are damaging to the NIH technology partnership program:

—Reasonable price clauses "discourage technology transfer and the development of new therapeutic products by imposing price restrictions that may limit the ability of any company to recover its costs of research and development. Royalty provisions or payments to reimburse the government laboratory for its costs or, in appropriate circumstances, the supply of clinical materials (rather than restrictions on the pricing of products) may be more appropriate mechanisms to fairly and appropriately compensate the government laboratory for the use of its technology in commercial development." Final Draft Report of the External Advisory Committee of the Director's Advisory Committee, The Intramural Research Program, National Institutes of Health, April 11, 1994.

—The NIH insistence on price controls "nearly ruined the system," said Dr. Steven Paul, the former scientific director of the National Institute of Mental Health and a creator of the NIH technology transfer program. Cited by Dr. Robert Goldberg in "Race Against the Cure: The Health Hazards of Pharmaceutical Price Controls," Policy Review, Spring 1994 (number 68) at 34.

—A report by the HHS Inspector General noted that the controversy at NIH over CRADA pricing threatens support for the program (Office of Inspector General, Dept. of HHS, Technology Transfer and the Public Interest: Cooperative Research and Development Agreements at NIH (OEI–92–01100) (Nov. 93)). This report finds that the use of an arbitrary and unpredictable "reasonable price clause" is undermining the transfer of NIH patents to private companies. Many private biomedical research companies now refuse to participate in CRADAs. This fact undermines the rationale for appropriating so many billions of dollars to fund this basic research.

—Dr. Bruce Chabner, Director of the National Cancer Institute's (NCI) Division of Cancer Treatment, in testimony at a congressional hearing last year discussed specific instances in which companies have discontinued projects or suspended CRADA negotiations because of concerns raised by the "reasonable pric-

ing clause." Chabner noted that "Other companies have simply refused to become involved with the NCI in early drug development * * *. NCI has no doubt that companies will not accept the risks of investing large sums in the development of a government product if their freedom to realize a profit is restricted. These companies are not willing to put their corporate fate in the hands of a government-appointed committee of experts. There are less risky ways for companies to make a profit." Testimony of Dr. Bruce Chabner, Director of the Division of Cancer Treatment, National Center Institute, before the House Subcommittee on Regulation, Business Opportunities and Energy of the House Committee on Small Business (Jan. 25, 1993).

—The Committee to Study Medication Development at the National Institute on Drug Abuse states that the "reasonable-pricing clause required in (DHHS CRADAs) in the last year has been identified by NIDA as a major deterrent to attracting private-sector partnerships." The Committee "recommends a change in the reasonable pricing provisions of DHHS CRADAs so that licensees or manufacturers of medications know explicitly the ultimate pricing or pricing structure for their potential therapeutic agent." Development of Anti-Addiction Medications: Issues for the Government and Private Sector, Institutes of Medicine, 1994.

—An article cites NIH officials attributing the price control clause for the precipitous decline in CRADA's. "Many pharmaceutical companies are reconsidering CRADA's, and NIH officials say four of the largest—have told NIH that they plan to forego new CRADA's unless the pricing clause is removed." Christopher Anderson, "Rocky Road for Federal Research Inc.", Science, 497 (October 22, 1993).

—The Cancer Letter published a draft "Action Plan on Breast Cancer" developed from a recent NIH conference convened by Secretary Donna Shalala which recommends "increase(d) efforts to speed the translation of basic research into clinical applications" and "review of the reasonable pricing clause in relation to CRADAS, as they impact of the flow of industrial funds into clinical research and, thus, affect collaborations." Cancer Letter, March 25, 1994.

It is clear that the increased effectiveness of the NIH technology partnership program would be jeopardized if Congress moves to force NIH to reinstate its pricing review.

Five reasons for supporting increases in NIH funding

This explanation of the technology transfer reform and the partnership between government-funded and private-sector funded basic biomedical research explains why the biotechnology industry so strongly supports increased NIH funding. Five fundamental reasons follow for why it is in the national and public interest to increase the NIH fiscal year 1999 budget by 15 percent as the first step toward doubling its budget over five years.

Reason No. 1: Better health and less suffering

Basic biomedical research is a noble undertaking that provides better health and less suffering for Americans with disease. About 85 percent of the NIH's budget is spent on the extramural program supporting 25,000 different research grants each year which go to more than 50,000 scientists, doctors, and researchers at 2,000 different institutions across the country. Another 10 percent of the NIH budget goes to the intramural program which supports research projects conducted by medical scientists in NIH's more than 20 institutes and centers. This clear commitment to research has led to strong health benefits for Americans.

Within the past 25 years mortality rates related to heart disease and stroke have decreased by 40 percent and 60 percent, respectively. A vaccine for hepatitis B has been developed. Americans live free of diseases such as polio, tetanus, and small pox. Death rates from cancer have started to decline in the United States. The number of Americans who survive cancer for five years or longer has increased by more than 50 percent. And yet many Americans take these medical advances for granted and are not aware that NIH funding helps make these medical advances possible.

To focus only on past achievements would underestimate the success the NIH is having. To give doctors and patients more effective tools to combat disease, the NIH is currently directing research programs such as the Human Genome Project which involves constructing a human genetic map to aid in identifying disease genes. Some of the first beneficiaries of the Human Genome Project will be families with a high risk of colon cancer. This is because this research will make it possible to determine which family members carry colon cancer genes and enable them to obtain appropriate health care. Because of research conducted at the NIH and subsequently de-

veloped by companies, those living with Parkinson's disease, cancer, Alzheimer's disease, AIDS and other diseases are already living longer.

To give an example, according to Senator Tom Harkin (D–IA), Dr. Steven A. Rosenberg, Chief of Surgery, Division of Clinical Sciences, National Cancer Institute at the NIH, has created a treatment for melanoma, a kind of skin cancer, which so far has had a 50-percent success rate.[4]

In order to take full advantage of these scientific advances and find cures for these and other diseases, NIH Appropriations increases are required.

Reason No. 2: Basic biomedical research is not self-sustaining

Basic biomedical research is not self-sustaining. The biotechnology and pharmaceutical industries cannot provide the funding to conduct the level of basic biomedical research required to keep both industries growing. As it is, the biotechnology and pharmaceutical industries already conduct billions of dollars worth of basic and applied biomedical research. The reason this research is so expensive is because biotechnology companies are advancing basic and applied science at the same time. In partnership with the NIH, biotechnology and pharmaceutical companies conduct some basic biomedical research, but primarily they conduct applied research, which builds upon basic research.

In 1997 the NIH annual budget was $12.7 billion of which the vast majority was spent on basic biomedical research. This is much more than the $9 billion the biotechnology industry spent on all types of research in the same year, of which only a small portion was spent on basic biomedical research. Furthermore, the large research investment incurred by the biotechnology industry comes at a great risk. These risks are clearly reflected by the fact that only about one percent of biotechnology companies are profitable. In 1993 only 13 of America's 1,300 biotechnology companies were profitable. In 1997, the biotechnology industry lost $4.1 billion which was a nine percent decrease in losses over the previous year ($4.5 billion in losses).[5]

To understand why biotechnology companies are unable to pay for the basic biomedical research conducted at the NIH one has to look at the following facts about the biotechnology industry:

In 1993, on average, biotechnology firms spent $59,000 per employee on research. In the same year the U.S. corporate average was $7,476. According to Business Week's "1995 R&D Scoreboard" in 1995 the five U.S. companies that had the highest investment in research and development per employee were biotechnology firms. For details turn to page 13.

Because of the high research costs involved and the limited number of profitable biotechnology companies, the biotechnology industry can not ever be expected to replace the crucial role of the NIH. Therefore, the best funding source for basic biomedical research has been and can only be the Federal government.

Reason No. 3: NIH funding saves money long term

By investing in the NIH the Federal government saves money in the long term. This savings is attributed to the fact that it is much less expensive to invest in cures for diseases than it is to treat patients who already live with disease. "The National Institutes of Health (NIH) plays a critical role in facilitating innovations that lead to significant reductions in health care costs. In a series of case studies published in 1993, the NIH identified 34 examples of clinical trials and applied research studies that have resulted in savings in treatment costs and reductions in lost productivity due to disease, disability, and premature death. Together, the examples yield an estimated annual potential savings ranging from $8.3 billion to $12 billion."[6]

Below are examples of cost saving cures for diseases which are a large economic burden to the U.S. economy:

The NIH discovered a gene that is a major risk factor for Alzheimer's disease and NIH-funded research continues to explore the role genes play in causing this disease. With adequate funding this research will prevent or delay the onset of Alzheimer's. Members of Congress often state that doing this would save Medicare from

---

[4] Senator Tom Harkin (D–IA), speech on NIH funding, NIHx2 Press Conference, March 19, 1998, Senate Dirksen Office Building.

[5] Ernst & Young, New directions: The Twelfth Biotechnology Industry Annual Report, 6. (1998).

[6] The Ad Hoc Group for Medical Research Funding's home page (http://www.aamc.org/) under the heading "Fact Sheets About NIH" and subheading "Examples of Cost Savings from NIH Research" or directly located at (http://www.aamc.org/research/adhocgp/costsav.htm).

bankruptcy in the 21st century. This is because the total national cost to care for Alzheimer's patients is more than $100 billion annually.[7]

A solid return from Congress's investment in the NIH can be seen in the development of a two-stage diagnosis-treatment of breast cancer. While the cost of developing this diagnosis-treatment was $14.3 million a year for 15 consecutive years, this technology generates an estimated $263 million to $526 million in annual savings in avoided medical costs.[8]

NIH-funded research has already provided great benefits in the case of melanoma, a kind of skin cancer. According to Senator Tom Harkin (D–IA), Dr. Steven A. Rosenberg, Chief of Surgery, Division of Clinical Sciences, National Cancer Institute at the NIH, has developed a treatment for melanoma. Dr. Rosenberg's treatment has had a 50-percent success rate for patients so far. While the economic savings has not been calculated yet, any cure for a kind of cancer would save money and prevent needless suffering.[9]

According to Selma J. Mushkin, author of "Biomedical Research: Costs and Benefits," every dollar invested in biomedical research between 1900 and 1975 produced a $10 to $15 return in savings.[10]

In conclusion, it is clear that investing in basic biomedical research is an effective way to find cures and therapies for disease. Furthermore, increasing NIH funding can bring significant savings with early cures and prevention that will avoid higher future health care costs.

Reason No. 4: Generates jobs and secures U.S. economic leadership

NIH funding generates jobs and investment in the private sector. In the last 25 years biotechnology has become an expanding industry, employing over 140,000 people in 1997, a nineteen percent increase over 1996 (118,000).[11] In 1997 product sales were at $13 billion, a 20-percent increase over 1996 ($10.8 billion).[11] Over the last four years the biotechnology industry's market capitalization (value of the entire capital assets) has gone from $41 billion [12] to $93 billion.[11]

One reason why the biotechnology industry has created so much growth in jobs and product sales is in large part attributed to its high levels of investment. Business Week conducted the "1995 R&D Scoreboard" which measured the level of research and development investment per employee in U.S. companies. In this study, five of the top ten U.S. companies were biotechnology firms. The complete R&D chart is listed below.

Business Week R&D Scoreboard 1995 [1]

Rank	
Biogen [2]	($210,653.5)
Genetics Institute [2]	(114,942.5)
Genentech [2]	(112,029.8)
Immunex [2]	(102,719.1)
Amgen [2]	(91,265.8)
S3	(82,548.3)
Adobe systems	(70,993.0)
Platinum technology	(69,787.3)
Cirrus logic	(68,745.6)
Network computing devices	(68,308.0)

[1] 1995 "R&D Scoreboard," Business Week 3 July 1995.
[2] Biotechnology companies.

Reason No. 5: Training of scientists

Many of the most talented and knowledgeable scientists hired by the biotechnology and pharmaceutical industries are trained at the NIH or at affiliated universities, or they were previous recipients of NIH grants. In 1997 about 50 per-

---

[7] Speaker Newt Gingrich, "Personal Experiences Spur Speaker of the House To Campaign for Increased NIH and NAS Funding," Roll Call February 23, 1998.
[8] Senator Barbara A. Mikulski, "NIH Needs More Money to Continue Its Biomedical Legacy,"Roll Call February 23, 1998.
[9] Senator Tom Harkin (D–IA), speech on NIH funding, NIHx2 Press Conference, March 19, 1998, Senate Dirksen Office Building.
[10] Selma J. Mushkin, Biomedical Research: Costs and Benefits (Cambridge: Ballinger Publishing Co. 1979).
[11] Ernst & Young, New directions: The Twelfth Biotechnology Industry Annual Report, 6. (1998).
[12] Ernst & Young, Biotech 95: Reform, Restructure, Renewal, The Industry Annual Report, 2. (1994).

cent of biotechnology companies surveyed (39 of 79) had at least one NIH-trained scientist working for them; some companies had over 50 NIH-trained scientists.

While it is very difficult to estimate the number of scientists that have been formally trained by the NIH it is accepted as fact that the United States has the world's leading graduate education institutions, of which NIH is one. Many Nobel Laureates and other research pioneers benefit from the NIH's state-of-the-art facilities and strong financial resources. For the United States to remain the world leader in innovative research and basic biomedical scientific inquiry requires increased NIH funding. Increasing funding will enable the NIH to provide more training for scientists who will find cures for diseases previously believed incurable.

CONCLUSION

The United States is the world leader in research and development for health related technologies providing patients with treatments and therapies for disease. Basic biomedical research benefits Americans and all of humanity. It generates jobs and investment. It trains the world's best scientists. But basic biomedical research is not self-sustaining and depends on government funding. In order to save money in the long term and maximize the benefit of previous scientific discoveries, the Federal government needs to strengthen its commitment to the NIH. The Biotechnology Industry Organization believes the single best way to do this is to increase NIH appropriations by $2 billion for fiscal year 1999 and double the NIH budget over the next five years.

We appreciate this opportunity to present this statement.

PREPARED STATEMENT OF DONNA MELTZER, AMERICAN ASSOCIATION OF UNIVERSITY AFFILIATED PROGRAMS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES, CHAIR, ON BEHALF OF THE FRIENDS OF NICHD COALITION

Mr. Chairman, I am pleased to be able to testify today on behalf of the Friends of NICHD, a coalition of nearly 100 organizations that support the extraordinary work of the National Institutes of Health with a special focus on the National Institute of Child Health and Human Development. Our coalition, which is in its 12th year, includes scientists, health professionals, and advocates for the health and welfare of women, children, families, and people with disabilities. Pursuant to clause 2(g)4 of House Rule XI, I would like to note for the record that the coalition does not receive any federal funds.

Since its inception in 1963, the National Institute of Child Health and Human Development (NICHD) has compiled an impressive record of achievement, conducting and funding research on the prevention and treatment of many of the nation's most devastating health problems: infant mortality and low birthweight, unintended pregnancy, birth defects, mental retardation and other developmental disabilities, and pediatric AIDS.

A recent quote I read in an article in the Washington Post said, "I will protect my child from everything except a life lived passionately." I noted this quote as it seemed to summarize exactly the way my husband and I hope to raise our children. While I can encourage my young son to live passionately, the opportunity to do so will ultimately be his. However, as a parent, it is my job to protect his health and nurture his well-being in every way possible.

Thanks to the work of the NICHD, I and many others like myself have been able to deliver healthy, happy babies and do a better job of protecting their health. With testing such as that for PKU, a test which was perfected in a mental retardation research center funded by NICHD, parents are able to prevent, to the best of our ability, the occurrence of mental retardation in our babies. We now know that we must put our babies to sleep on their backs to prevent SIDS, and we working moms can feel better about having our children in day care thanks to the information NICHD has been collecting in their ongoing Child Care study.

I am especially pleased today to have the opportunity to thank you Mr. Chairman, and the members of this Committee for the very strong support you have given to NIH, its Institutes and Centers. In spite of the very difficult funding decisions you have had to make in recent years, you held fast to your belief in investing in America's health. I know that you personally remain committed to the NIH and you worked with us, the Friends of the NICHD to coordinate a visit for appropriations staffers to the NICHD. Last winter we were able to bring nearly 50 appropriations staffers to the Bethesda campus where they were able to see first hand what it's like to be both a patient at NIH as well as a lab researcher. In addition, they were able to meet with and ask questions of Dr. Alexander and several researchers.

It is our hope to expand that knowledge to all Members of Congress and their staffs in June when the Friends of NICHD will host, as part of the NICHD's 35th Anniversary year, a scientific exhibition and reception. This event will provide researchers, scientists and Member of Congress an opportunity to interact and answer questions about the research currently being conducted across the country with NICHD support.

It is unbelievable to all of us to think that just two short years ago we had a budget deficit of $292 billion. Now, in 1998 we are hearing a different and exciting word—budget surplus. If in deed such a surplus exists, the Friends of NICHD would like to see surplus equal solutions.

For 35 years, the NICHD has been providing solutions through basic and applied research. The NICHD devotes its research to ensuring the birth of healthy babies and the opportunity for each infant to reach adulthood and achieve full potential, unimpaired by physical or mental disabilities. This critical research provides solutions for the world, the nation, and the families that live in your town. In order to continue to find solutions, the Friends of NICHD recommend that the NICHD receive $776 million in funding for fiscal year 1999. We also support an overall NIH funding increase, as recommended by the Ad Hoc Group for Medical Research Funding, of 15 percent for fiscal year 1999.

Through its broad mission, the NICHD is working to find solutions. The NICHD is structured by an intramural program, which largely targets basic research related to human development, and an extramural program which includes the Center for Population Research, the Center for Research for Mothers and Children, and the National Center for Medical Rehabilitation Research. NICHD also supports 15 Mental Retardation and Developmental Disabilities Research Centers which pursue both biomedical and behavioral research leading to understanding the causes of mental retardation and other developmental disabilities. The NICHD has long served as a strong example of an institute that looks not only to the physiological factors affecting health, but recognizes that behavioral research is essential to this strategy. NICHD supports psychological research ranging from studying ways to prevent developmental detours to understanding more about adolescent health and risk-taking behavior to finding ways for children with disabilities to lead more independent and productive lives. As Congress seeks more effective, less-costly solutions to many of today's issues and problems, NICHD-supported research offers highly relevant insights.

I would like to share with you today some of the newest and most exciting solutions being discovered through NICHD research.

Finding Solutions for Autism through Early Intervention: Recent work on brain development strongly suggests that early educational language instruction actually re-wires the brain of the developing child. Research designed to better understand the processes underlying neuroplasticity may make it possible to increase this window of opportunity for early intervention which is so critically important for children with disabilities. The NICHD has launched a major autism research program at Yale University, UCLA, University of Chicago, University of Pittsburgh, and the University of Washington. The research study is designed to provide a better understanding of ways to prevent and treat autism, and to provide a better understanding of ways to provide more targeted educational services to youngsters with autism spectrum disorders. It appears that many children in the early stages of autism spectrum disorders can be spared from developing the most seriously debilitating symptoms through intensive early language and social intervention.

Finding Solutions for Genetic Disorders: Advances in genetics research methods have now made it possible to explore the relationship between genetic errors and specific behavioral and psychological consequences of those defects. Projects on Fragile X Syndrome, Rett Syndrome, Down Syndrome and others have made substantial strides in recent years. NICHD research at several leading universities have linked specific errors on human Chromosome 15 to highly specific behavioral disorders of major health importance. Research has shown that most people with Prader Willi Syndrome, a genetic disorder which also causes life threatening obesity, also have Obsessive Compulsive Disorder (OCD), a psychiatric disorder affecting 5 million Americans. Researchers are homing in on the critical region of Chromosome 15 to identify which genes in this region are responsible for specific aspects of this condition. Once the gene product is identified, the search for a more effective treatment, or even a cure is possible.

Finding Solutions for Increased Research in Obstetrics and Gynecology: In late 1997 the NICHD announced plans to establish several new centers to foster training of young investigators in the field of obstetrics and gynecology. Establishment of these centers was supported by Congress when the committee report accompanying the House Labor/Health and Human Resources/Education appropriations legislation

for fiscal year 1998 urged NICHD to work with the NIH Office of Research on Women's Health to address the ongoing dearth of obstetric-gynecologic research. The intent, according to the report, is to offer financial assistance to would-be researchers to ''provide a bridge between their early training and their launching careers as independent investigators.'' NICHD believes that the approach used in these new ''Women's Reproductive Health Research Career Development Centers'' will lead to an increased cadre of skilled clinicians and exciting new developments in obstetrical and gynecological care for women. NICHD plans to allocate approximately three million dollars to the new program, funding the first centers early this year.

Finding Solutions for Premature Delivery: Researchers are identifying potential causes of premature birth which often leads to infant mortality or life-long disability. It increasingly appears that not only can a maternal infection cause amniotic infection, but that the actual impetus for the labor comes from the fetus itself. It appears that the fetus stimulates the initiation of labor as a means of protecting itself from a dangerous uterine environment. However, the resulting premature birth may pose an even greater threat to the fetus. NICHD research is developing a rapid method for detecting amniotic infection allowing clinicians to intervene with antibiotics more quickly to help eliminate the threatening intrauterine environment that triggers the labor-inducing response from the fetus.

Finding Solutions for Sudden Infant Death Syndrome: As you well know, the NICHD is home to the ''Back to Sleep'' campaign. Prior to 1994, when the campaign began, there were approximately 5,000 infant deaths annually due to SIDS. Through a combination of research and a public education campaign, the SIDS death rate has been reduced since 1992 by 38 percent. In fact, the latest data in from the State of California shows a 50-percent decline in SIDS related deaths. This remarkable public/private information campaign has, along with other advances from NICHD, had a profound effect on the infant mortality rate of this country which dropped from 26.0 deaths per 1,000 live births in 1960 to 7.2 deaths per 1,000 live births in 1996, the lowest rate ever recorded in the United States.

Finding Solutions for Risky Adolescent Behavior: We all know that adolescence for many can be a healthy and exciting time of life. But for others, it can be a stressful, difficult time that can lead teens to engage in risky behaviors with possible life-long consequences. There is good news, however. A recent NICHD-supported study has found that adolescents who are emotionally connected to their families and schools are consistently healthier than those who are not. These adolescents suffer less from emotional distress, are less likely to smoke, drink, or use marijuana, less likely to begin having sexual intercourse at an early age, less likely to be involved in violence, and less likely to consider or attempt suicide. Emotional connectedness to family and school was found to be more strongly protective of health than specific parenting behaviors or school characteristics. The study also found that adolescents who had easy access to guns at home were more likely to be involved in violence and to consider or attempt suicide; and those with easy access to alcohol, tobacco, and illegal drugs within the home were more likely to use the substances.

The above information was gleaned from the National Longitudinal Study of Adolescent Health (Add Health). This study is the first nationally representative and comprehensive study of the factors that promote health and healthy behavior among young people. NICHD funded the study with collaboration from 17 other NIH institutes and federal offices in response to a directive in the 1993 NIH Revitalization Act. Using a unique design, the study collected data to show the impact of school, family, peer group and neighborhood influences on health over a two-year period. Study data have been made available to researchers nationwide to investigate protective and risk factors in the lives of youth.

Finding Solutions for Better Learning and Reading: Approximately 10 million children have difficulty reading. In order to find the causes and develop solutions to this problem, the NICHD has supported research in neuroimaging using a variety of computerized tools and has helped to identify core cognitive, genetic, and neurobiological defects involved in reading disabilities. Over the years, NICHD-supported scientists have found that reading disabilities represent a disorder of language, and more specifically, an impairment in a child's ability to process phonemes, or individual bits of sound. Using this knowledge, the researchers have developed a number of prevention and remediation programs to help children at risk for reading disabilities. This approach is now providing the basis for reading intervention programs in classrooms in Houston, Texas; the District of Columbia; Atlanta, Georgia; Tallahassee, Florida; Boston, Massachusetts; Boulder, Colorado; Seattle, Washington; and throughout California.

Finding Solutions to Prevent Osteoporosis and Bone Mass Loss: NICHD's Milk Matters public awareness campaign is targeting youngsters, with a special focus on

adolescents and young women, to increase calcium intake to prevent against bone mass loss and osteoporosis. Recent NICHD studies show that a "window of opportunity" exists to add to the bone bank during the teen years. NICHD researchers have found that supplementing the diets of girls, ages 12 to 16, with an extra 350 mg. of calcium produced a 14-percent increase in their bone density, in comparison to unsupplemented girls. If this 14-percent increase in bone density could be maintained, its impact would be striking—for every 5 percent increase in bone density, the risk of later bone fracture declines by 40 percent. However, without continued supplementation, it appears the added bone density could be lost. The NICHD's campaign is educating parents and physicians about the importance of including the appropriate amount of calcium in the daily diets of young children and adolescents. Using print media, the milk mustache ads, NICHD is educating young people and showing them that it's "cool" to drink milk.

Mr. Chairman, as you are well aware, the above mentioned examples are but a few highlights of work currently being done at the NICHD. So much more remains to be done. As the nation moves toward the new millennium, the NICHD plans to support an array of major efforts that not only fall into the important NIH areas of emphasis, but hold great promise for improving the health and the quality of life of the nation's children and families. With birth defects the leading cause of infant mortality, and contributing greatly to lifelong disabilities, the NICHD will expand support of grants studying the complex mechanisms controlling the normal and abnormal development of organs and the nervous system, including studies using the latest computer-assisted technologies. Similarly, researchers now understand that the biologic origins of such serious adult chronic diseases as diabetes and hypertension stem from multiple genetic sources. By supporting projects that will scan the human genome to identify and map multiple variations in the coding sequences and regulatory regions of the genes that might contribute to a chronic disease, researchers may be able to develop tests that can identify children at risk for the disease later in life.

NICHD will focus significant efforts to prevent children and adolescents from experiencing adult diseases and disabilities. Work will continue to develop vaccines for tuberculosis and E. coli 0157, helping to improve the safety of our food supply. The number of research units providing the infrastructure to test a wide range of pediatric drugs will expand, and interventions to prevent our children and youth from smoking and driving recklessly are planned.

Additionally, the NICHD is in a unique position to find innovative ways to improve the quality of life for persons with disabilities. One initiative will support full-scale clinical trials that will test promising new methods to improve the ability of persons with incomplete spinal cord injury to once again walk. Scientists will also be encouraged to develop novel materials that can serve as biodegradable scaffolding for tissue and organ regeneration, replacements for lost structures, novel prostheses, and even the basis to form artificial ones may become reality.

President John F. Kennedy, whose efforts helped to establish the NICHD said, "We have conquered the atom, but we have not yet begun to make a major assault on the mysteries of the human mind." We have come a phenomenally long way since President Kennedy made that statement in 1961. But there is a long road ahead. With the continued strong support and leadership of this Subcommittee we can launch a major assault on many of the mysteries that affect our health. We thank your for your leadership which offers healthier futures for all of our children. Thank you.

Prepared Statement of the American Physiological Society

The American Physiological Society appreciates the opportunity to submit its views on fiscal year 1999 funding for the National Institutes of Health for the record. The APS appreciates the very strong support this Subcommittee has provided to the NIH in the past. Its phenomenal growth and impressive record of scientific discovery has been possible because of your efforts on its behalf.

The American Physiological Society (APS) is a academic society comprised of scientists who study fundamental processes in cells, tissues, and organs as well as their integration into the whole, living organism. The APS was founded in 1887 and now has more than 8,700 members. The majority of our members conduct research and educate the next generation of physicians and scientists at colleges, universities, medical schools throughout the U.S. Others are engaged in research and related activities in industry and government.

The American Physiological Society (APS) supports current efforts to bring about a doubling of the NIH budget. Specifically, we support the goal of a 15-percent in-

crease in fiscal year 1999 as recommended by the Federation of American Societies for Experimental Biology and by the Ad Hoc Group for Medical Research Funding. We believe that important scientific opportunities are waiting, and NIH should be given the means to pursue them as rapidly as possible.

The ambitious "Human Genome Project" to identify the estimated 100,000 genes that comprise the genetic map of the human being is nearing completion. We must begin preparations now to take the next step to find out what these genes do and how they affect our health.

Research directed at determining the functions of various genes has already been undertaken in certain bacteria, plants, and relatively simple animals such as the fruit fly and zebra fish, whose genetic maps and genomes have been developed in parallel with the human genome. Thanks to these efforts we have learned that many genes operate similarly in different plants and animals. This means that we can use information about genetic function in lower organisms as a starting point to figure out how particular genes affect human health. In some cases, it is not one gene but combinations of two, three, or more genes that cause a health problem or determine what course it may take.

The APS believes that NIH should lead the way in making it possible to use the findings of the Human Genome Project to provide tangible benefits for human health. At a February, 1997 meeting at the Banbury Conference Center at Cold Spring Harbor, NY, the American Physiological Society brought together a group of internationally renowned. academic and industry scientists with expertise in molecular genetics, physiology, and pharmacology to discuss what needs to be done now to translate what we know about human genes into medical knowledge.

The participants at the Banbury Conference identified the need for a "Genes to Health Initiative" to lay the groundwork. This initiative would bring together scientists representing disciplines such as molecular genetics (to identify genes and determine their molecular function); physiology (to discover how genes function in living organisms); pharmacology (to understand how and why certain drugs work differently depending upon what genes or combination of genes are causing a disease); medical informatics (to develop ways to use advanced computer technology to collect and share this mass of information); and clinical scientists (to identify and address the manifestations of complex hereditary diseases).

This is a new area of medical science, and many gaps in our knowledge must be filled before we can proceed to commercial development of the next generation of diagnostics, preventatives, and therapies. The APS believes that the health interests of the American people will be best served if the NIH leads the way in this important next step in the Human Genome Project. NIH's guiding principle is scientific excellence in service to public health. The NIH's involvement at this stage will provide assurance that public health concerns are given priority.

The Genes to Health Initiative represents an important area with implications for understanding and treating many different diseases and health problems. The APS respectfully urges you to provide the NIH with new funding in fiscal year 1999 and to encourage it to undertake new initiatives such as this one and once again thanks this Subcommittee for its strong support of the NIH.

Prepared Statement of the American Optometric Association

The American Optometric Association represents over 33,000 practicing Doctors of Optometry across the Nation. As a profession devoted to improving the vision care and health of the public, doctors of optometry provide preventive and remedial services for diseases and disorders of the vision system, the eye and associated structures as well as the diagnosis of related systemic conditions.

The American Optometric Association supports the goal of NEI conducting research for new treatment and cures for eye diseases, visual disorders, and the preservation of sight. Since the NEI was founded in 1968, optometrists have been active participants in projects managed by the Institute, the results of which have improved the quality of life for American citizens.

We applaud the research achievements of NEI over the past 30 years and support efforts to double the NIH budget over the next 5 years. We urge you to provide a 15-percent increase in fiscal year 1999 for the NIH as the first step toward doubling the budget. Furthermore, we urge you to provide $408.6 million, a 15-percent increase, for NEI in fiscal year 1998 as requested by the National Advisory Eye Council in its "Citizens Budget Proposal".

Vision and eye health problems are the second most prevalent, chronic, health care problem in the U.S. population, affecting more than 120 million people. Visual disorders reduce the educability of the child and hasten the loss of independence in

the elderly. Visual disorders and disabilities impose billions in direct and indirect costs on our society each year.

Finding a cure for vision disorders and eye diseases is essential to prevent consequent handicaps. The two age groups at highest risk for vision problems are children and the elderly.

Fear of blindness is second only to fear of cancer among our nation's elderly. Vision and eye health problems increase significantly in frequency and severity with age and are more prevalent in those over 60. Vision problems among the elderly are often a key reason for the abandonment of independent living and frequently require rehabilitative services. Over 1.1 million Americans are legally blind; over 12 million Americans suffer from some form of irreversible visual impairment. No part of an individual's life is free from some risk to their vision.

The annual cost of eye and vision disorders is $38.4 billion. Adequate visual rehabilitation can reduce the costs to individuals and society for lost wages and welfare payments. While research support by NEI has made advances in developing effective optical aids to maximize remaining vision, there is much research that still needs to be done.

The NEI has conducted and supported research which has resulted in the early diagnosis and prompt treatment of eye diseases. Age related macular degeneration (AMD) is the most common cause of severe visual impairment in older Americans. Approximately 1.7 million have decreased vision and 100,000 are blind from the disease. While there is currently no cure for AMD, NEI is conducting research to test new treatments including the effects of antioxidants on the progression of AMD.

A related area of concern is low vision which is broadly defined as any chronic visual condition that is not correctable by glasses or contact lenses that impairs everyday functioning. The leading causes of low vision are diseases that are common among older adults: age-related macular degeneration (AMD), cataracts, glaucoma and diabetic retinopathy.

There are many areas in low vision in which further research is merited. One which deserves particular mention is the advancement of technology and assistive devices to help those with visual impairments to carry out everyday functions as independently as possible. Issues to explore include providing sufficient training in the use of these devices, reducing their cost, and improving the functionability and appearance of these devices if they are to be accepted by users. Researchers remain frustrated because advances in low vision devices seem not to be reaching the people with impairments, in part because of a lack of insurance coverage for evaluations and devices. Scientists are researching better ways of presenting hard to read computer graphic user interfaces, and developing telescoping and other optical devices to improve intermediate distance tasks and peripheral vision.

Most people with chronic eye conditions have residual vision and with the aid of devices and rehabilitation, can maintain an independent, productive way of life. While low vision rehabilitation services and devices are available, most people with low vision do not appear to be aware of their availability or use them. To address this problem, NEI, under the auspices of the National Eye Health Education Program (NEHEP), is working on a national program directed at low vision in order to increase public awareness about visual impairment and the impact it has on the quality of life. The program will provide information about low vision services and the devices available to assist those with visual impairment. As a partner organization with NEHEP, the American Optometric Association supports this public education program and encourages the committee to support it as well.

The NEI has funded a clinical trial planning grant to study screening tests to identify 3 year old children in need of vision care for amblyopia (“lazy” eyes), strabismus (crossed eyes) and significant refractive errors. The NEI budget should permit funding of grants at a high level in the areas of strabismus, amblyopia and refractive errors. Since more than 120 million Americans wear glasses, research in the cause and prevention of refractive error and visual function should continue.

The value of clinical trials to the public cannot be overestimated. NEI has a remarkable record of scientific breakthroughs attributed to clinical trial research beginning with the diabetic retinopathy study in the 1970s. By identifying the appropriate treatment for diabetic retinopathy which prevents the loss of vision, enough public dollars are saved each year to pay many times over the cost of treatment as well as the cost of conducting the trial. NEI clinical trials involve many institutions, hundreds of health professionals and thousands of patients.

We recognize the importance of research in eye conditions which have a greater prevalence in the elderly, but also encourage substantial funding to continue research progress in the area of children's vision. Children are at high risk because of the impact of uncorrected vision handicaps on their educational and developmental progress. Vision problems may interfere with a child's ability to learn. Al-

though a number of studies have suggested a significant relationship between visual functioning and reading, a randomized, prospective, multi-center clinical trial is needed to evaluate treatment therapies.

We support NEI's research of the eye complications from acquired immune deficiency syndrome (AIDS). The results from NEI researchers demonstrating the effectiveness of drug therapy against CMV retinitis in people with AIDS is very encouraging in the fight against this public health problem. It is important that research dollars continue to support research activities to prevent, treat and cure AIDS.

Optometric researchers are grateful for the commitment that Congress has demonstrated to the NEI and its mission. The investment made in eye/vision research has paid great dividends to the American people through major breakthroughs in eye care and vision. Yet, there is still much more to be done to preserve and enhance vision. We encourage this committee to continue its commitment to NEI and eye/vision research by providing the $408.6 million funding level recommended in the citizens budget. Thank you again for the opportunity to present this testimony.

PREPARED STATEMENT OF MARY KAYE RICHTER, ON BEHALF OF THE NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

I greatly appreciate having the opportunity to appear before you this afternoon. My name is Mary Kaye Richter. I am the Executive Director of the National Foundation for Ectodermal Dysplasias, a former member of the Board of Directors of the National Organization for Rare Disorders and a member of the Board of the National Alliance for Oral Health. Today, I am appearing on behalf of one hundred thousand men, women and children who are affected by conditions known as ectodermal dysplasias and millions of children and adults affected by other rare disorders.

Through this hearing process, you will listen to many individuals, including myself, who espouse the doubling of the budget for the National Institutes of Health within the next 5 years and to begin that process with a 15-percent increase fiscal year 1999. Sufficient funding of scientific and clinical research is the cornerstone upon which dynamic improvement in our understanding of disease and disease processes must be built. While some people would encourage you to earmark dollars for specific disease entities, I would urge you to leave such decisions with the National Institutes of Health leadership, which is in the best position to do so. It would indeed be unfortunate if research funding was prioritized by the effectiveness of lobbying rather than the effectiveness of science.

For a moment, I would like for you to consider what it must be like to have an infant affected by a condition about which no one can tell you anything. You and everyone near you, including your physician, have a feeling that all is not right, but no one has an idea of what may be happening. There is no doctor to confirm a diagnosis, no resource to which you can go for information and no hint of what should or could be done. As frightening as such thoughts may be, thousands and thousands of families encounter this scenario each year.

Such is frequently the case for families faced by the challenges of ectodermal dysplasia (ED). In a nutshell, the ectodermal dysplasias are genetic conditions that are identified by abnormalities in derivatives of the ectoderm. The hair, teeth, sweat glands and nails are affected in these conditions of which there are more than 150 variations. Some of the syndromes are mild in their affects and others are devastating. The most common form of the condition is hypohidrotic ectodermal dysplasia which is identified by sparseness of hair, absence of sweat glands and many missing teeth. While a diagnosis is relatively easy in families with a history of the condition, diagnosis is extremely difficult in families where the condition has not previously appeared. It is estimated that more than 100,000 people are affected by these conditions.

Once the diagnosis of a rare condition has been made, families encounter more challenges as they search for useful treatment information and knowledgeable care providers. Only the savviest will make their way to organizations like ours. What happens to those families for whom no advocacy organization exists? What happens when there are no available clinicians to make a diagnosis? What happens when the effects of a condition exacerbate as a result of a lack of a diagnosis? What happens when there is no place to turn and you have no hope? How does it feel to bury a child? The answers to these questions are illusive-not because of a lack of concern on our parts but rather because we seem unwilling to do those things that must be done in order to give appropriate answers.

In 1988, the National Commission on Orphan Diseases conducted a survey that indicated that 15 percent of the families affected by rare conditions endured more

than five years of searching before arriving at a diagnosis. Another 31 percent of families indicated that their search for a diagnosis lasted for more than a year. Only 51 percent of such families, suggested that their diagnosis was received in a timely manner of less than a year. Just this week, I talked with a mother in Chicago whose daughter is experiencing problems so severe that the child has been removed from school. In spite of visits to several premiere institutions within the U.S., no one can explain what may be happening. Meanwhile, her symptoms exacerbate. Earlier this month, a seventeen-year-old from New York died as a result of complications associated with ectodermal dysplasia about which nothing is known.

There is an office that is in a position to make a difference for families in such dilemmas, the Office of Rare Diseases (ORD) within the National Institutes of Health. However, funding for the office has been woefully inadequate, preventing the kinds of accomplishments that are needed. The ORD could play the critical role of pivot point for the operation of Diagnostic Research Centers.

As mentioned earlier in this testimony, nearly a majority of those affected by rare conditions do not receive a diagnosis within a year. For many, a 5-year wait can be expected. Currently, there are 75 General Clinical Research Centers, 6 Pediatric Clinical Pharmacology Research Centers and many special research centers as identified by individual Institutes across the United States. I am asking you to consider funding that would enable the Office of Rare Diseases to select a minimum of 15 Diagnostic Research Centers that would focus on the diagnosis and treatment of rare conditions. With such a network in place, real progress can begin. Families who are desperate for diagnosis will travel to any length to unlock the mystery of a child's condition. Such centers, geographically dispersed, would be a giant step forward. Between 20 to 25 million patients with 6,000 rare and genetic disorders in the United States are waiting for the hope and help only the Congress can provide.

A key function of the Office of Rare Diseases is the sponsorship of scientific workshops. These may be done with cooperation from applicable research Institutes and Centers at the National Institutes of Health. Workshops enable the following outcomes.

—Establish research priorities;
—Develop research goals;
—Establish collaborative research assignments;
—Provide support to develop patient and tissue registries;
—Develop plans to initiate clinical trials;
—Create animal models for research;
—Prepare program announcements to solicit research grant applications;
—Establish criteria for diagnosing and monitoring rare diseases; and
—Inform targeted professional and voluntary organizations through published proceedings.

One workshop, held just more than one year ago, focused on the ectodermal dysplasias. The success of the event provides ample evidence of the benefits of such workshops. The ectodermal dysplasias are conditions of interest to several of the Institutes, namely the National Institute for Dental Research, the National Institute for Arthritis, Musculoskeletal and Skin, the National Child Health and Development Institute as well as to the Office of Rare Disease Research. In 1996, all of these groups joined together to hold the first ever scientific symposium to discuss ED.

The event attracted outstanding researchers from the U.S., Canada and Europe. The symposium was a revelation to the attendees, as the overlap of key biological issues became apparent. It is clear that improved understanding of the developmental biology associated with ED will help unlock the doors of knowledge to the growth of hair, nails and teeth and the function of sweat and sebaceous glands. While most members of Congress would not clamor for research into ED, they could appreciate the value of science that may ultimately grow hair where none was present, replace teeth with human biological material rather than metal or plastic or find a way to maintain normal body temperature. Such solutions could well be the result of scientific and clinical research into ectodermal dysplasia.

Not only did the meeting serve as a stimulating exercise for those individuals who participated, it also served as a springboard for scientific research. This spring, the NFED will award a minimum of $50,000 in grants to winners in our current competition. Our hope is that our grants can serve as a bridge to enable researchers to gather sufficient data to successfully compete for N.I.H. funding. An example of such success is that of Jonathan Zonana, a genetic researcher at Oregon Health Sciences University. With funding from the NFED, he secured sufficient data to obtain funding from N.I.A.M.S. and the N.I.D.R., which ultimately led to the identification of the gene for x-linked hypohidrotic ectodermal dysplasia. Currently, we are providing similar bridge grants, which are aimed at finding the genes for

Clouston's ectodermal dysplasia and ectrodactyly-ectodermal dysplasia-clefting, an especially troublesome syndrome.

Currently, the ORD sponsors or co-sponsors approximately 30 workshops per year. With thousands and thousands of rare conditions, the number of workshops must be increased to give more of those individuals affected by these syndromes some hope that attention will be given to their disorder sometime in their life time. Increasing the budget of the ORD by just $500,000, for workshops, would significantly increase the number of rare disorders that are examined.

The Office of Rare Diseases could also serve as a much-needed focal point for information relative to which doctors and researchers are doing work with a particular rare disease entity. Currently, families can only guess where they might go for help. How much better it would be to have a resource at hand that could elucidate critically needed care and research information. Currently, the ORD has a budget of $1.6 million dollars. I implore you to make this office what it needs to be by increasing its budget to $4.8 million dollars-a pittance when compared to some amounts being spent on some individual single conditions.

The operation of and funding for the Rare Disease Office is of importance to families affected by rare conditions but so is the funding for individual divisions of the National Institutes of Health. Both scientific and clinical research are needed to improve our understanding of and treatment for rare disorders. It is important to remember that although a condition being investigated may be rare, it may have tremendous impact on a large number of individuals. For example, several years ago, the National Institute for Dental Research sponsored a program in its clinical center whose researchers placed osseointegrated dental implants into the jaws of nearly fifty individuals affected by ED. Not only did the project underscore the value of implants in edentulous adults, it also supported the procedure for use in children. The procedure was found to be safe and efficacious. The children and teens that participated in the program will tell you that it also enabled them to eat any food that they chose instead of being limited to soft foods. It allowed them to speak with classmates without fear that their dentures would slip and also prevented them from embarrassment from things so simple as a first kiss. The implants gave them a freedom they had never known.

It was your support for the National Institute for Dental Research that made the research possible and your support that helped improve our understanding of the use of implants for anyone missing a tooth. It is also important to note that the research at the National Institute for Dental Research has had an additional benefit. Now, thanks to cooperation from several outstanding dental schools, their staffs and Implant Innovations, Inc. and Nobel Biocare, both manufacturers of implant components, the NFED offers special implant programs at the dental schools associated with Southern Illinois University, the University of North Carolina and the University of Washington. The private sector has now picked up that which was begun in the public sector. Collaborative efforts between the public and private sectors can provide an increasingly exciting opportunity. However, in our case, the collaboration is fruitless unless the public sector plays a preliminary and meaningful role. Our organization would never have been able to put our program into place if the extraordinary work had not been done at the Dental Institute.

Although the bulk of my testimony is devoted to funding for the National Institutes of Health, the value of the General Dentistry Residency program is worthy of comment. It is our hope that this program can be sufficiently funded to include funding for Pediatric Dentistry Training as the reauthorization proposal suggests. The program not only improves the depth of training for dentists but also enables individuals needing specialized care to identify practitioners and programs where help may be available. On nearly a daily basis, our office receives calls from individuals needing extraordinary oral health care who have difficulty in finding qualified clinicians to provide the care. While insurance companies may have us believe that teeth are only cosmetic, as their frequent denial of benefits indicates, nothing could be further from the truth. Diet, speech, self-esteem, student success and employment are all impacted by the condition of the mouth. When all that is present in the mouth are a couple of fangs, as in ectodermal dysplasia, or teeth worn down to the gum line, as in osteogenesis imperfecta, all of life is affected. The General Dentistry Residency program serves as a beacon of hope to those needing care. We support the position of the American Association of Dental Schools for funding of at least $4.0 million with the caveat that additional funds be added should the reauthorization include Pediatric Dentistry Training.

Basic scientific research is also of great interest to us. We are especially concerned about funding in this area for both the National Institute for Dental Research and the National Institute for Arthritis, Musculoskeletal and Skin. I remember a time when I used to dream about the day when my own son could eat an apple or bite

into a steak. Thanks to the National Institute for Dental Research and its implant research those dreams have come true. But I also dream of young children who would like to play baseball, who would love to throw their arms around Mickey Mouse at Disney World or play on a jungle gym with friends. When they are unable to perspire, such children find all of their activities hampered. Our families have every reason to fear the potential of heat stroke that accompanies their everyday activities.

An absence of hair, most often thought of only in terms of mature men with male pattern baldness, is an even more significant problem for children. This is especially so when wearing a wig compounds the problems of overheating. Little girls should have ribbons and bows to wear in their curls, not baldheads with wisps of uncontrollable, coarse hair. And young boys should not have to fear taking off a cap, the doing of which may reveal an embarrassing lack of hair. Basic developmental research can help identify the mechanism that makes hair grow and ultimately lead to hair growth for all that desire it.

One last concern that I would like to share with you is inadequate funding for investigators who begin their research careers as fellows. During their tenure, exciting projects may begin for which financial support is lost at the end of the fellowship. As a result, promising research comes to an end just when preliminary documentation is beginning to bear fruit. In the case of rare diseases, just when families have hope that a researcher is beginning to make strides in understanding of the condition, the hope diminishes when funding ends and the fellow must leave. There is also the question of what happens to the research when the fellow leaves an Institute. If there is no replacement to carry on the work, all can be for naught. There needs to be a system whereby fellowships, involving rare disorders, can be extended with adequate financial support when warranted. Wasted effort benefits no one.

My list could go on and on. Congressman Porter, I know that you are well aware of the anguish of parents whose children are affected by rare conditions. My hope is that you and members of this committee will encourage your peers to support a doubling of funding for our jewel of government, the National Institutes of Health. My hope is that you will spearhead an effort to increase the role and budget of the Office of Rare Diseases. And my hope is that you will allow those individuals in a position to make sound decisions relative to the spending of research dollars to do so at the National Institutes of Health. Please do not succumb to the desires of individuals who lobby for earmarked funding for specific conditions. All that those of us challenged by rare disease want is a fair chance at a better tomorrow for our children.

Prepared Statement of Michele and Ryan Licursi, on Behalf of the Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.)

My name is Michele Licursi. I am testifying as a mother and a representative of the Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.). I have been a Regional Support Network (RSN) Coordinator with F.I.R.S.T. for 3 years.

Testifying with me today is my son Ryan. He has a type of ichthyosis called Epidermolytic Hyperkeratosis (EHK).

I wish to thank the subcommittee for this opportunity to testify regarding funding for skin disease research and the budget of the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS).

The Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.) is a voluntary organization dedicated to providing support, information, education and advocacy for individuals and families affected by ichthyosis. F.I.R.S.T. supports research into causes, treatment and a cure for ichthyosis.

The Foundation receives no grants or sub-grants, and no contracts or sub-contracts, from the federal government. It does receive contributions of approximately $2600.00 per year from federal employees through the Combined Federal Campaign (CFC).

Ichthyosis is a family of genetic skin diseases characterized by dry, thickened, scaling skin. These diseases are caused by genetic defects that are usually the result of genetic inheritance. Currently, there is no cure for ichthyosis, and there are no truly effective treatments.

Epidermolytic Hyperkeratosis causes the skin to be very fragile. The slightest bump can cause the skin to break away. Blisters are common. They can be spontaneous or the result of a sleeve, a sock, or a collar touching the skin. Scaling and flaking are continuous. The skin is tight and cracks. The palms and soles are thick, making something as simple as holding a pencil or as natural as walking difficult and painful. Overheating is dangerous and infections are a constant threat. We are

experts now, but 12 years ago, like most people, we had never even heard of ichthyosis.

We learned together the hard way. We found out that diapers rubbed the skin off of Ryan's legs, that car seats and high chairs had to be lined with sheepskin, that his daily skin care routine took several people and a couple of hours. Relatives had to be taught how to pick him up and how to hold him. We no longer shopped for cute little outfits. We looked for any clothes that his skin would tolerate. Shoes were out of the question for years and still continue to be a big problem.

Ryan has been hospitalized for infections. Simple medical procedures are complicated. Our days and activities are planned around his skin care. We get stares and questions from strangers. Most are trying to be nice, but many are rude, accusing us of all kinds of child abuse. While the physical aspects of ichthyosis are obvious, the blows to ones self esteem can be even more damaging.

I am very thankful for the support we received from other members of F.I.R.S.T. We were lucky to find F.I.R.S.T. very early in Ryan's life and the advice and concern we received helped us find our way. As a coordinator for the RSN, I talk with people in different stages of coping with ichthyosis. I talk with new parents who are shocked to learn that their baby's skin could have such problems and be such a threat and now have to learn how to care for them. I talk with parents who share their child's heartbreak as they try to socialize and fit in, or when they refuse to socialize because of embarrassment. I talk with parents of teenagers who are rebelling and refuse to care for their skin properly, thereby making things worse. I talk with young adults who are experiencing difficulties in school or the workplace. I talk with people struggling with the cost of topical treatments not covered by insurance. I talk with adults who are guilt ridden because they have passed this condition on to their new baby. Currently ichthyosis is a life-long battle. Hopefully, this will change in the future.

School has been great and Ryan has lots of good friends, but that is not the case with many kids with ichthyosis who are not as outgoing and confident as Ryan. Confident enough to tell you a little bit about living with Epidermolytic Hyperkeratosis (EHK).

Ryan Licursi: Hello, I am twelve years old and in seventh grade. As you know, I have Epidermolytic Hyperkeratosis and it stinks. There are many things that other kids can do that I can't because of my skin. It is very dry and fragile, and I blister very easily. Any contact sport is out. I can't be on a basketball team because if anyone bumps into me, or knocks me over, my skin will rip. I can't be on a soccer team because if someone kicks me or I get hit with a ball, my skin will come off. I often have blisters on my feet. I can hit the ball in baseball, but getting around the bases is another story. I'm always the last one picked for teams in gym class. In winter, I even have trouble writing because the skin on my hands gets stiff and cracks.

Another problem with having EHK is that every day I have to get up an hour earlier than other kids in order to soak in the tub for a half an hour, have cream put all over my body, and let it soak in before I put on my clothes. If I didn't do this each day, I would be so stiff and dry that I could not stand it. It hurts to do it, but it would be worse if I didn't.

People in my town and my school know me and understand my physical condition, but when I go to the mall or any other public place, people stare and make comments.

Any place I go, I leave a trail of skin. You'll know that I was sitting in this chair. I would really appreciate any research that can be done to cure this condition.

We recognize this Subcommittee's strong history of bipartisan support for medical research funding and the NIH. In 1992, researchers identified the sites of two genetic mutations that account for 70 to 80 percent of all cases of EHK. Since that time, genetic mutations that cause several other forms of ichthyosis have been identified and scientists and physicians have a better understanding of the disease process.

We are excited about this progress, and about the current research into gene therapy. We are hopeful about the possibility for an effective treatment or cure on the horizon, but at this point it is still just hope. We continue to be frustrated by the lack of effective treatment options.

We are also discouraged by the lack of available testing facilities. Genetic testing is possible today for the types of ichthyosis for which the specific mutations have already been identified. However, with the exception of one of the milder forms of ichthyosis, (Recessive X-linked Ichthyosis) testing is only being done on a limited research basis and there are no clinical laboratories that routinely offer these services. These tests are complex and time consuming (in some cases the particular genes are difficult to work with). However, they can provide valuable information

for the purposes of genetic counseling (for carrier detection in certain recessive forms of ichthyosis and risk of recurrence) and pre-natal diagnosis. They can also help to plan appropriate intervention for those at risk for labor and delivery problems and premature birth that are common with some forms of ichthyosis.

The Foundation for Ichthyosis and Related Skin Types (F.I.R.S.T.) urges a 15-percent increase in NIH funding in the next fiscal year, which would allow NIAMS to support a greater number of worthy research projects, conduct more clinical trials and expand it's intramural research program.

F.I.R.S.T. also supports increased investment in translational research, which would build upon this new scientific knowledge to develop practical applications for those with ichthyosis and other skin diseases. The recent discovery of many of the genes involved in specific skin diseases is just the starting point for improving diagnosis and treatment.

In 1992 a member of F.I.R.S.T. testified before this committee regarding the need for a national registry. Today, as a direct result of your interest and support, we have the National Registry for Ichthyosis and Related Disorders. To date, several hundred patients, and their physicians have participated in the detailed enrollment process, and enrollment is proceeding at an ever increasing rate. The registry helps generate researcher interest in ichthyosis, and provides investigators with an essential tool—a pool of affected individuals with a confirmed clinical diagnosis. The availability of this pool of information results in significant savings in research time and dollars which would have normally been spent identifying eligible patient populations.

Current funding for the National Registry for Ichthyosis and Related Disorders expires in 1999, but the work of the registry must continue. Continued funding of the skin disease registries will ensure that these resources will be maintained and will continue to be a valuable tool for investigators.

On behalf of our members, those with ichthyosis and their families, we thank this Congressional Subcommittee for their time and attention.

PREPARED STATEMENT OF W. BRUCE FYE, M.D., M.A., F.A.C.C., CHAIR, CARDIOLOGY DEPARTMENT, MARSHFIELD CLINIC, ON BEHALF OF THE AMERICAN COLLEGE OF CARDIOLOGY

The American College of Cardiology (ACC) is a professional medical society and educational institution whose mission is to foster optimal cardiovascular care and disease prevention through professional education, promotion of research, and leadership in the development of standards and guidelines and the formulation of health policy. I am W. Bruce Fye, M.D., M.A., chair of the cardiology department at Marshfield Clinic, a 525 physician multi-specialty group practice in Central Wisconsin. As chair of the ACC's Government Relations Committee and the ACC's historian, I am pleased to present to the Subcommittee the views of the College on behalf of its 24,000 members with respect to fiscal year 1999 funding for the National Heart, Lung, and Blood Institute (NHLBI).

This year the NHLBI celebrates 50 years of accomplishments in the prevention, diagnosis, and treatment of cardiovascular disease. The first congressional appropriation to the NHLBI was less than $1 million. Since then, the NHLBI's budget has grown to $1.51 billion thanks to the Subcommittee's long-standing support. Again this year, the ACC asks the Subcommittee to maintain that commitment.

Our nation's citizens, many of them potential cardiac patients, do not want us to become complacent as we celebrate the successes of the past 50 years that have resulted from our nation's pioneering research and educational programs. The unsettling reality is the staggering number of deaths attributable annually to cardiovascular disease. Since 1910, with the exception of the great influenza epidemic, heart disease has and continues to claim more lives each year than any other disease. This year alone, one million Americans will die as a result of cardiovascular disease.

More than 50 million Americans, about one-fifth of the population, are living with some type of cardiovascular disease. Fortunately, most of them are living better and more productive lives as a result of new drug and device therapies, surgical innovations, enhanced emphasis on prevention, and innovative educational programs—all made possible through NHLBI-sponsored research. For example, last year an important discovery was made as a result of the Antiarrhythmics vs. Implantable Defibrillators Trial. This trial proved that implantable cardiac defibrillators improve overall survival in patients with serious ventricular arrhythmias. What researchers have learned throughout the 20th century about cardiovascular disease has saved millions of lives and has improved the quality of tens of millions more.

Regardless of these advances, however, heart disease continues to greatly affect the lives and productivity of too many people. Fortunately, the prospects for progress in the 21st century are vastly greater than scientists could have ever foreseen in 1948. Now more than ever it is critical that the Subcommittee renew its long-standing support for the NHLBI.

MEDICAL RESEARCH FUNDING AND COST SAVINGS

In 1998, the total economic impact of heart disease in the United States is projected to reach $175.3 billion, of which about $98 will be directly attributable to the costs of providers, hospital and nursing home services, medications, and home health. The remaining $77 billion will come from lost productivity. Think of the impact that research had on tuberculosis and polio—major public health programs just a few decades ago. In this extraordinary era of molecular biology, NHLBI-funded researchers are on the brink of making major discoveries that should yield significant benefit in the area of cardiovascular disease.

—Nearly 14 million Americans alive today have a history of heart attack, heart-related chest pain or both. Researchers may be close to being able to predict through a simple blood test whether some individuals, who are otherwise apparently healthy, may be at risk of a first heart attack years before symptoms appear. The results of this research could offer opportunity to develop potential new avenues for prevention and treatment.

—Congestive heart failure is projected in 1998 to cost nearly $19 billion in medical expenses and lost productivity and is the leading cause of hospitalization for people age 65 and older. New findings from the NHLBI's Systolic Hypertension in the Elderly Program have revealed that treatment with a low-dose diuretic antihypertensive drug reduces the risk of heart failure by 50 percent in older persons with isolated high systolic blood pressure, and by 80 percent among individuals who have already suffered a heart attack. Heart failure is a common and very serious problem that we must work hard to prevent. Because there are more than 400,000 new cases of heart failure annually in this country, the potential benefit from this type of research could be enormous.

—Heart deformities are the number one birth defect in the United States, affecting 32,000 newborns each year and killing more than 2,500 babies before age one. NHLBI scientists have created two mouse models with a specific gene defect to replicate malformations that occur in two common human congenital heart diseases. Further research is under way to determine whether a similar gene defect exists in humans and may eventually lead to the development of gene-based diagnostic tests and therapies to prevent malformations of the heart, save infant lives, and reduce the need for corrective surgery after birth.

Last year, members of Congress demonstrated their commitment to medical research by increasing funding to the National Institutes of Health (NIH) and the NHLBI for fiscal year 1998 and, also, through the introduction of several legislative proposals which would significantly increase over the next several years the financial resources dedicated to the NIH. The ACC applauds these efforts, especially in light of the constraints placed on the federal budget and the pressure of competing domestic spending priorities. To provide for a stable funding source beyond annually appropriated amounts, the ACC supports initiatives to establish a biomedical research trust fund.

In his State of the Union address, the President announced that his fiscal year 1999 budget proposal will contain the largest funding increase for the NIH in the nation's history, providing $1.6 billion to the NHLBI for heart, lung and blood research. The College strongly supports the proposed $1.6 billion for the NHLBI.

GENETICS AND MOLECULAR MEDICINE

Innovative research in human genetics and molecular biology holds great promise for the prevention and early diagnosis of cardiovascular disease. We are just beginning to realize the enormous potential of this fertile area of research. In the next century, it is possible that patients with hypertension will be distinguished by genotype, allowing preventive and therapeutic approaches to be tailored to meet the needs of specific subgroups. It has been discovered recently that people with certain genetic defects are more likely to develop hypertension and atherosclerosis if they are exposed to risk factors such as a high-salt or fatty diet.

Furthermore, researchers with the NHLBI Framingham Heart Study have identified a genetic marker for hypertension which links a mutation in the gene for angiotens in converting enzyme which regulates blood pressure in men. Genetic research suggests that someday new treatments and ways to prevent or even reverse the progression of cardiovascular disease will be available. Early reports from

NHLBI-funded researchers working on gene transfer techniques are very promising. Preliminary findings suggest that this innovative approach might slow the development of atherosclerosis in vascular grafts, such as those used in coronary artery bypass surgery. Other studies suggest that it may be possible to promote recovery of cardiac function after a myocardial infarction by introducing healthy heart cells into the weakened heart muscle.

EDUCATION AND PREVENTION

Over the last decade, much has been learned about the prevention of cardiovascular disease. We know that heart disease is linked definitively to hypertension, high cholesterol, diabetes, smoking, physical inactivity, and obesity. The NHLBI's public education programs—the National High Blood Pressure Education Program, the National Cholesterol Education Program, and the National Heart Attack Alert Program—make information readily available to patients, families, and health professionals.

As physicians, educators, and public health officials, we acknowledge there is much to be done to ensure that the preventive measures that have proven to be effective are being used to fight cardiovascular disease. A renewed commitment, under the guidance of the NHLBI, is needed by physicians and patients to reduce the risk factors that are plaguing Americans. Just recently, the NHLBI's National High Blood Pressure Education Program released new physician guidelines for the prevention and treatment of high blood pressure. The NHLBI will also convene a special emphasis panel which will provide recommendations for dissemination research to improve treatment and prevention programs in clinical and community settings.

WOMEN AND MINORITIES

In every year since 1984, cardiovascular disease has claimed the lives of more females than males. Exciting new research has found that estrogen deficiency may be linked to the higher prevalence of coronary heart disease in postmenopausal women. While estrogen replacement therapy has been recommended as a preventive measure against heart disease, the benefits are not conclusive and there are potential side effects. The NHLBI is pursuing research into the development of "designer estrogens" that could protect against heart disease without undesired effects.

Black men and women continue to suffer disproportionately from cardiovascular disease and many of its related causes, particularly hypertension. The NHLBI continues to emphasize the importance of including minorities in clinical research and trials. The NHLBI has also started a new program that targets Latinos living in the United States. The "For the Health of Your Heart" initiative is designed to increase the awareness of the heart disease risk factors and promote lifestyle changes to reduce the chances of developing heart disease.

NUTRITION

The NHLBI continues to make considerable progress in understanding the role of nutrition in cardiovascular disease and has increased its involvement in this important area. The NHLBI Dietary Approaches to Stop Hypertension trial has shown that a diet low in fat and high in vegetables, fruits, and low-fat dairy foods has the similar effect of reducing high blood pressure as single-drug therapy. Through the Cardiovascular Health Promotion Project, the NHLBI is promoting the adoption of heart healthy behavior among children and their families through schools, community organizations, and recreation facilities.

OTHER AREAS OF RESEARCH

Other areas of important NHLBI research opportunities in need of support include the following:

—*Cell Transplantation*.—Exciting new developments are occurring in cardiac cell transplantation. The ability to increase the number of functional cells in a diseased heart could ultimately eliminate the need for mechanical support or heart transplantation. Preliminary animal studies suggest that engrafting cells into heart tissue can replace the damaged tissue. Further research is needed on genetic, molecular, and cellular approaches to transplanted cells into heart tissue.

—*Cell Loss and Heart Failure*.—Little is known about the underlying causes of heart muscle loss during end-stage heart failure. Molecular, cellular, and genetic research is needed to learn what role cell death has on the development of heart failure. If scientists can better understand cell loss, perhaps new interventions for the prevention and treatment of heart failure can be developed.

—*Cholesterol in Embryonic Development*.—The role of cholesterol in embryonic development is just beginning to be understood. Genetic cholesterol-deficiency syndromes have been identified, and it is known that certain genetic characteristics lead to multiple abnormalities, including cardiovascular defects. The NHLBI is convening a special emphasis panel which will examine the role of cholesterol in embryonic development, and the potential effects of cholesterol lowering in pregnancy.

—*Viral Genes and Atherosclerosis*.—Recent evidence suggests that viral agents may play a role in the initiation and progression of atherosclerosis, a condition in which the artery walls become narrowed due to the build-up of fat, cholesterol and other substances, thereby causing the reduction of blood flow. Modern methods of genetic and molecular research offer opportunities to explore the viral mechanisms of atherosclerosis and other cardiovascular diseases which could eventually lead to interventions that may prevent or lessen the consequences of heart attacks and congestive heart failure.

CLOSING REMARKS

Beyond better public awareness, reducing the number of cardiovascular-related deaths is greatly dependent upon research sponsored by the NHLBI. The United States must prepare itself, both scientifically and fiscally, for the inevitable increase in the incidence of cardiovascular disease that will accompany the graying of the so-called baby-boomer generation. I hope the Subcommittee shares my optimism about the unique opportunities that our scientists and clinical investigators now have to achieve their long-standing goal of conquering this nation's number one killer. In summary, the American College of Cardiology would like to encourage the Subcommittee to generously fund the NHLBI. It is a wise investment in our nation's future.

PREPARED STATEMENT OF REV. GARY HUTCHESON, VOLUNTEER ADVOCATE, ON BEHALF OF THE NATIONAL PSORIASIS FOUNDATION

Mr. Chairman and members of the Appropriations subcommittee: My name is Gary Hutcheson. I am speaking to you as a volunteer advocate both for myself and on behalf of the 6.5 million American men, women and children who are battling psoriasis—a chronic, debilitating skin disease. It is a disease without a cure, and without universally effective treatments. Until a cure or more effective treatments are found, millions of people with psoriasis face a lifetime fighting this ravaging disease.

Over three billion dollars are spent annually on treatments for psoriasis and each year psoriasis patients make approximately 2.4 million visits to dermatologists.

In fact, psoriasis is chronic, unpredictable and often unrelenting, and treatments may be successful for only relatively short periods of time for only some people. The thick, red, scaly patches on any or all parts of the body, and painful joints, can limit daily activities and interfere with physical, occupational and psychological functions. Skin affected by psoriasis may itch, burn, sting, and easily bleed. Physically, psoriasis can range in severity from mild to disabling.

The occupational impact of the disease poses a significant economic burden for the nation and a financial hardship for the person with psoriasis. Emotionally, psoriasis can be devastating. The social rejection and physical suffering of psoriasis has led people to suicide.

Some types of psoriasis may require hospitalization and can even be life-threatening. Each year approximately 400 people with psoriasis are granted disability by the Social Security Administration because of debilitating disease. Perhaps even more difficult is the fact that three-quarters of a million people diagnosed with psoriasis are under the age of 10.

Though I do not want to sensationalize my personal situation, I have had psoriasis for the last 20 years. I can relate something of the pain and discomfort, public humiliation and embarrassment, private disgust, gnawing doubt and shattered self-image, that the vast majority of psoriasis sufferers struggle with throughout their lives.

Twice I have been hospitalized for extended periods of time to treat the disease. On numerous occasions I have received multiple injections directly into the psoriatic patches. As many as 30 injections have been given in a single doctor's office visit.

Moderate-to-severe psoriasis dramatically inhibits a person's ability to maintain a normal, healthy, active lifestyle because so much time must be devoted to the ongoing, daily treatment of the disease. Early in my ministerial career I was compelled to change my vocational direction from working with troubled teenagers to a pas-

toral ministry setting due to the rapid advance of my psoriasis. More than once, while playing volleyball or swimming with the young people entrusted to my care, I was innocently asked, "Hey Pastor Hutch, do you have some kind of creeping, jungle rot?"

The severity of my condition has progressed to the extent that I can no longer even participate in those kinds of simple, fun, anxiety-relieving, stress-reducing activities.

I have even relocated my family from one part of the country to another in an effort to find the most advantageous combination of climate, UV radiation from the sun, and specialized medical expertise, for treating this tenacious, debilitating malady.

A task as simple as taking a bath has become a painful, time-consuming ordeal. In fact, the derogatory comments, uneasy stares of strangers, and subtle but evident attitude of friends who "keep their distance", are not as traumatic as the countless hours spent: soaking in coal tar baths; applying numerous topical steroid creams and ointments; wearing occlusive plastic suits to bed; administering various medicated oil and liquid steroid treatments to the scalp; undergoing regularly scheduled liver biopsies; receiving weekly UVB or PUVA ultraviolet light radiation treatments; and having blood drawn on a monthly basis.

These treatment regimens represent only a partial list of the continual maintenance regimen for many, many people afflicted with psoriasis. Also, the frustration and demoralization of this kind of schedule is greatly increased when one considers the limited efficacy of these treatments in controlling and relieving psoriatic symptoms. The vast majority of psoriasis patients are all too familiar with the devastating emotional "roller coaster" ride from the "trial and failure" scenario of current treatment options. And, I've not even mentioned the enormous financial burden created by the very expensive medications, doctor's fees, and treatments.

I know that my experience is not unique. Through my affiliation with the National Psoriasis Foundation I have come to understand that my struggle with this disease has not been nearly as devastating as that of hundreds of thousands of other victims.

Like diabetes, arthritis, and heart disease, psoriasis requires lifelong treatment. Unlike these diseases, however, psoriasis is not, or should I say was not, a top priority for many researchers. However, thanks to focus and funding provided by NIAMS, recent research has identified several possible sites for the genes that may cause this inherited condition.

Excellent research conducted by NIH and NIAMS has shown that effective treatment and a cure for psoriasis is within reach. Sufficient funding will enable medical science to complete the puzzle and find a cure for this affliction. So many pieces are in place; we must not hesitate now.

This will not only benefit the 6.5 million American children and adults now suffering with this chronic disease, but will also help the over 200,000 new cases of psoriasis diagnosed every year. Better treatments or a cure for psoriasis will result in savings both to the public and the government in treatment costs, lost work days, and Social Security disability claims.

Therefore, on behalf of the 40,000 members of the National Psoriasis Foundation, and the 6.5 million Americans with psoriasis, I urge you to approve an increase of 15 percent over current funding levels for NIAMS for fiscal year 1999. This increase will have significant health and socioeconomic benefits for the millions of Americans who are affected by psoriasis and by other diseases under the purview of NIAMS. Thank you for your time and your support.

PREPARED STATEMENT OF WARREN GREENBERG, PH.D., PROFESSOR, HEALTH ECONOMICS AND HEALTH CARE SCIENCES, GEORGE WASHINGTON UNIVERSITY, ON BEHALF OF MENDED HEARTS, INC.

My name is Warren Greenberg. I am a professor of health economics and of health care sciences at The George Washington University. I am married and have a 23-year-old daughter.

I advocate an increased appropriation for the National Heart, Lung, and Blood Institute. I am a victim of heart disease and as a beneficiary of the efforts of medical researchers to overcome this disease. I might also add that I am a member of Mended Hearts, Inc., a support group of 24,000 members throughout the United States. I have been appointed lobbying and legislation chairperson of that group—a volunteer position.

I am 54 years old. I was born with aortic stenosis, a narrowing of the heart valve. Throughout my entire life I have lived with heart disease, often incredibly severe.

When I was in my early teens, my physicians did not allow me to play high-school inter-mural sports, although I was a fine young athlete. At the age of eighteen I was told not to play ball under any circumstances. In my early 20s I was told to climb no more than two flights of stairs. By my early and mid-thirties I began to climb steps more and more slowly, often pausing to rest. I never carried an attaché case home from work. It was too heavy. I would often balance a large book on my hips, rather than carrying it outright, in order to blunt the weight. I would walk two or three blocks on a level street to avoid going up three or four steps at the end of particular blocks. I could barely lift my newborn child; I could not help my wife take in the grocery bags.

On May 7, 1982, at the age of 39, I had open-heart surgery at the Cleveland Clinic to replace my diseased valve with the valve of a pig. After my 6-week recuperative period I was amazed to find that not only was I able to walk, but was also able to play tennis, to jog, and to exercise. I was able to live a normal life.

By August 1988, however, my new valve had failed. On August 31, I again had cardiac surgery at the Cleveland Clinic to replace the failed pig valve with an artificial plastic valve, known as the St. Jude's valve. I am again able to live a relatively normal, very productive life. And I am deeply thankful for it.

I still take a blood-thinning medicine, coumadin, which helps prevent clots on my new valve. At the same time, because of the medicine, I must be cognizant and careful of excessive bleeding. In 1983 I contracted bacterial endocarditis, an infection of the heart valve, from dental surgery which kept me in the hospital for six weeks. Whenever, I have dental work, I now get intravenous penicillin to protect me against such infections. I realize that my valve, as a mechanical device, may fail at any time in the future.

For nearly 16 years, thanks to the fruits of medical research, I have been able to travel abroad at least once a year, to jog in the park, to be a productive author of many scholarly articles and a number of books on the health care economy. I have been quoted often on my views of the U.S. health care system and have made many television appearances. If it were not for the advances in research leading to improved techniques in open-heart surgery, I would not have seen my fortieth birthday. I would not be able to look forward to a life of many rewards and enjoyments.

As an economist. I observe continually the link between monetary resources and the development of innovation and technology. Health care research, and cardiovascular research in particular, is no exception. I also understand as an economist that there are always competing uses for appropriated monies. However, cardiovascular diseases last year killed more than 960,000 Americans, about 154,000 of whom are under age 65.

Despite advances in medical research, these diseases remain the number one killer in the United States and a leading cause of disability. From my personal perspective and for those in Mended Hearts Inc., and others in the United States who have heart disease or will get it in their lifetime, consistent with congressional resolutions for the NIH, I ask for a doubling of NHLBI budget in five years. To reach this funding goal, I advocate a fiscal year 1999 appropriation of $1.825 billion for the NHLBI to help reduce further the incidence and degree of heart disease.

Prepared Statement of Alan G. Kraut, Ph.D., Executive Director, American Psychological Society

Mr. Chairman, Members of the Committee: Thank you for allowing me to testify on fiscal year 1999 appropriations for the National Institutes of Health (NIH). I am Alan Kraut, Executive Director of the American Psychological Society (APS), the national organization devoted to the science of psychology. APS members include the most distinguished academic researchers and leaders in scientific psychology. Many receive NIH funding for research in such areas as brain and behavior, addiction, human development, aging, mental illness, violence, hearing, vision, and chronic pain, to name just a few relevant topics in our field.

On behalf of the 16,000 members of APS, let me begin by expressing sincere gratitude for your support of health research—for the substantial increase you appropriated to NIH for the last few years, and also for your consistent and visible messages about the importance of research in public health. We applaud your efforts to devote additional resources to this essential public health enterprise. We look forward to working with you to double the NIH budget over 5 years. APS is part of the Ad Hoc Group for Medical Research Funding and we join the Ad Hoc Group in urging a 15-percent increase for NIH in fiscal year 1999 as a first step toward that goal.

But can NIH absorb this increase in so short a time? I can assure you that behavioral science research can. We are poised, both in terms of the role of behavior in causing serious health problems and in terms of the field's capacity, to proceed in a number of critical directions. As the Committee already knows, critical health concerns are reflected in such questions as: What goes on in the thinking of young people that leads them to start smoking, drinking, or taking drugs? What are the behavioral underpinnings of craving? When in our development do we acquire the behavioral patterns that may be with us for a lifetime? What are the connections between stress and health? What are the root causes of violence? What can we do to help memory as we age? And there are many others. But NIH's neglect of these kinds of questions continues despite a significant body of specific recommendations from Congress, from independent scientific agencies such as the National Academy of Sciences (NAS), and even from its own Institutes concerning new ways to develop behavioral approaches to health.

TRAINING

National Research Service Awards.—The clearest evidence of NIH's resistance to behavioral research is seen in the lack of response to Congressional and NAS recommendations on training young investigators in behavioral science. In a 1994 Congressionally-mandated report on the Nation's personnel needs in biomedical and behavioral sciences, NAS called for an increase in the size of stipends awarded under the National Research Service Awards (NRSAs) and for an increase in the number of behavioral science investigators, health services researchers and investigators in other areas, while holding the number of biomedical NRSA awards at the current level. The NAS set forth a specific number of NRSA awards needed in behavioral science and offered a compelling rationale for the increase. In 1995, this Committee began what turned into an annual ritual in which the Committee (and the Senate Committee as well) requested NIH to develop a plan and timetable for implementing the recommendations. NIH ignored both the NAS and Congress until a few months ago. In response to the fiscal year 1997 request from this Committee, NIH issued its response that the NAS recommendations will be selectively implemented. Specifically, NIH will increase the NRSA stipends, but not the number of awards in behavioral science or other areas.

It is ironic that even with the recent increases in NIH's annual budget and all the talk of doubling the NIH budget, NIH is citing budget concerns as the rationale for this selective implementation. They suggest that presumably neither the NAS nor this Committee "fully appreciated the costs" of increasing the number of behavioral trainees. And what is the cost? The behavioral science recommendation—to add less than 400 trainees—would add about $4 million over 3 years across all of NIH. Clearly, cost is not the concern here.

To build a stronger behavioral science research infrastructure that will improve NIH's ability to respond to the Nation's most urgent health problems, we ask the Committee to direct NIH to increase the number of National Research Service Awards for behavioral science investigators, as recommended by the National Academy of Sciences.

B/START.—Several Institutes on their own have recognized the need for more behavioral researchers. With encouragement from this Committee and from the Senate, they have developed Behavioral Science Track Awards for Rapid Transition (B/START), which are small grants to new Ph.D.'s in psychology or behavioral science. These are aimed at a critical juncture in a scientist's career—a time when choices are made about what research to pursue, a time of intense competition for entry-level academic research positions, and a time to develop pilot data before submitting a regular (R01) grant proposal. It is also a time when many excellent scientists drop out because of a lack of support. These issues are addressed by B/START, which began at the National Institute of Mental Health and has spread to the National Institutes on Drug Abuse and on Aging. We commend NIMH, NIDA, and NIA for undertaking this approach to training behavioral investigators, and we ask this Committee to encourage the use of B/START mechanisms throughout NIH.

Office of Behavioral and Social Sciences Research (OBSSR).—Like clinical research, behavioral science should be supported in virtually every NIH Institute, Center and Division. We see the Office of Behavioral and Social Sciences Research, created by Congress in the office of the NIH Director, as taking the lead on the training objectives described above, and on ensuring that behavioral priorities are pursued aggressively throughout NIH—there is a great deal of catching up to do. In its short existence under Director Norman Anderson, OBSSR has been an effective coordinating body on a number of cross-NIH initiatives and has increased the visibility of behavioral science at NIH. But OBSSR's budget is only $2.67 million,

a minute amount compared to the budgets of parallel units within the NIH Director's office. Additional funding would give OBSSR the capacity to develop training initiatives, requests for applications in the most promising areas of behavioral science, and more effective responses to Congressional directives, recommendations from NAS and from individual Institutes, and advice from the field concerning future directions for research and training. We are in an era of exceptional promise in behavioral science, but we need a more encouraging federal environment to realize this potential. Increasing the budget of the OBSSR would be a significant step in creating that environment. We recommend an increase in the OBSSR budget to $20 million in fiscal year 1999.

In the rest of my testimony, I want to concentrate on examples of what is currently being done and what more could be done in behavioral science research at several individual Institutes.

National Institute of Mental Health (NIMH).—NIMH is the leading supporter of behavioral science research at NIH. Last year, I told you about the Institute's reorganization which increased the visibility of behavior in its structure. In addition, NIMH Director Steven Hyman pledged to strengthen connections between basic behavioral research and clinical applications, and in connections between the brain and behavior. But even our friends at NIMH resist some behavioral science priorities. For example, NIMH has yet to implement "Basic Behavioral Science Research for Mental Health," a 1994 plan by its own advisory council in the same mold as NIMH's plans for schizophrenia and neuroscience. This Committee circulated the NIMH report to Congress and has for several years urged NIMH to increase its emphasis on basic behavioral research by implementing the national plan. NIMH has not responded. Similarly, this Committee has expressed support over several years for the 1996 NIMH report "Reducing Mental Disorders: A Behavioral Science Research Plan for Psychopathology" which was compiled by outside experts with NIMH support. Again, the Institute has not responded. These plans document the contributions of behavioral research in mental health and mental illness, and they identify promising behavioral research opportunities. The plans on basic behavioral research and on psychopathology are resources that should be the basis for requests for applications, program announcements, training priorities, and other NIMH initiatives. We ask this Committee to encourage NIMH to report on how these two plans will lead to research and training in behavioral research related to mental health and illness.

National Institute on Drug Abuse (NIDA).—NIDA is a model of how we hope every National Institute would approach its behavioral science and public health responsibilities. Under psychologist Alan Leshner, NIDA has been strengthening its behavioral science portfolio in important directions, bringing to bear new perspectives on treating and preventing drug abuse and addiction. Drug addiction is a brain disease, but it doesn't start out that way. Why do young people initiate drug use? This question requires understanding the basic mechanisms of peer pressure, of how attitudes develop, and of the processes involved in cognition. Why do some go on to addiction, while others stop? This question requires identifying risk and protective factors in individuals, families, and communities. What is the effect of drugs on learning and behavior? This question involves connections between the brain and behavior, between thinking and acting.

Another question is: How do we treat addiction? NIDA's efforts in behavioral science are paying off here. We've known for some time that behavioral interventions are central to the treatment of addiction. They are the only available treatments for many drugs. Even where medications are available to treat addiction, the most effective courses of treatment have included behavioral interventions. Now, a NIDA-sponsored study shows that for cocaine, the effectiveness of newly developed medication is contingent on having a behavioral intervention first. In other words, medication doesn't work unless the person first has behavioral therapy.

Given the central role of behavior in drug abuse and addiction, and given NIDA's aggressive pursuit of behavioral research, we strongly urge the Committee to do everything possible to ensure that NIDA receives the largest possible increase for fiscal year 1999.

National Institute on Alcohol Abuse and Alcoholism (NIAAA).—Similar gains are being made in behavioral research at NIAAA, where Director Enoch Gordis is expanding behavioral science. There are new initiatives in the social psychology of group identification; behavioral genetics to understand the biological and environmental factors in vulnerability to alcoholism; the psychophysiology of alcoholism; and basic behavioral research on craving and on the effects of alcohol abuse on memory and cognition. NIAAA also is moving forward on more applied research. The Institute published an impressive plan for its health services research, and is about to launch an initiative aimed at reducing drinking at college. We ask the

Committee to support to NIAAA's aggressive pursuit of new behavioral science research and to ensure that NIAAA receives the largest possible increase for fiscal year 1999.

NIH Grant Review Reorganization.—When NIMH, NIDA, and NIAAA were transferred to NIH by Congress, their peer review systems remained separate from NIH. The integration of those systems which is now underway has triggered a reorganization of the entire NIH peer review system. Here is an opportunity for NIH to strengthen its behavioral science infrastructure. Adding these three Institutes means there will be considerably more behavioral science research being reviewed in the NIH system. NIH must take deliberate and appropriate steps to ensure that the new system is equipped to handle these grants. These steps include having the appropriate balance of expertise on review committees—putting the peer in peer review—and establishing a scientifically appropriate referral process. Because of the enormous budgetary and public health implications of NIH grant review, we ask the Committee to monitor this peer review reorganization and request from NIH a report on its plans for ensuring the appropriate review of behavioral research grants.

National Institute on Aging.—NIA supports much research on behavioral and social factors in aging. I want to focus on one area: cognitive psychology. With links ranging from neuroscience to social and developmental science, there may be no more exciting and productive area of aging research. Anyone over 40 has experienced normal memory glitches. "Where did I put those car keys?" "What is that person's name?" But when we start forgetting what the car keys are for, or can't recognize a loved one, those are signs of serious problems, possibly Alzheimer's or some other dementia. Early identification and treatment of these problems is likely to come from cognitive science, which is allowing us to look at the aging mind and better understand the effects of growing older on the ability to process information and to make decisions. NIA is exploring ways to expand its support of this promising frontier in research on aging and behavior. We ask the Committee to support NIA in its pursuit of new directions in cognitive psychology.

National Institute of Child Health and Human Development.—Together with the community, NICHD has begun an effort to identify areas of behavioral research and training that are ripe for major breakthroughs as well as areas of research that require further nurturing. This effort included a conference entitled "Progress and Promise in the Behavioral Sciences," at which the leaders in the field recommended specific actions, among them: Increase pre- and post-doctoral research training and mentoring; support cross-disciplinary training mechanisms; support basic behavioral research on development to generate methodological and conceptual advances in research; and give priority to understanding the effects of poverty, different family structures, and technology on child physical and intellectual development.

NICHD has just reorganized its behavioral research programs into a new Child Development and Behavior Branch, headed by developmental neuropsychologist Reid Lyon. This Branch is well suited to respond to these recommendations. We are urging NICHD to aggressively pursue the recommendations of the "Progress and Promise" conference, and ask the Committee to request that NICHD develop a plan and a timetable for doing so.

National Institute of Nursing Research.—NINR has been designated the lead Institute in a new NIH initiative that addresses end-of-life issues. This is one of the least researched phases of life. The NINR initiative includes improved treatment for pain, but also addresses diagnosis and treatment of behavioral symptoms such as cognitive problems, delirium, and depression. With its research in symptom management, decision making for patients, caregiving, and optimal environments for critically-ill patients, NINR brings impressive experience to the lead role in end-of-life research. We ask that this Committee support NINR in this initiative.

In the interest of brevity, I am able to describe only a few of the contributions and importance of behavioral research in addressing the Nation's health concerns. Other Institutes with behavioral science portfolios include the National Heart, Lung, and Blood Institute, which supports investigations into the links between stress and heart disease; the National Institute of Neurological Disorders and Stroke, which supports research on brain and behavior; the National Cancer Institute, which has just formed a new prevention branch that should support increased of behavioral research; and the National Institute on Deafness and Communication Disorders, which supports psychologists' research in auditory perception and language development.

Despite all this activity, NIH still needs to recognize behavioral science as a core element in its dual missions in health research and public health. Priorities in research and training have been identified in numerous behavioral science areas but are not being pursued. This Committee has shown extraordinary largess in increasing the annual NIH budget and we are grateful for that support. Now, we ask you

to ensure that the health of the Nation receives the full benefit of behavioral science research by encouraging NIH's leadership to take meaningful steps, such as those I have outlined above, to reverse the underfunding of behavioral science research.

PREPARED STATEMENT OF MARTHA HILL, R.N., PH.D., PRESIDENT, AMERICAN HEART ASSOCIATION

You are a target

Chances are heart attack or stroke will be the death or disabler of you or someone you love. You are not alone. Heart attack, stroke and other cardiovascular diseases are America's No. 1 cause of death and a main cause of disability. Cardiovascular diseases account for nearly 1 of every 2 deaths in the U.S. The American Heart Association is dedicated to reducing death and disability from heart attack, stroke and other cardiovascular diseases. We commend this Committee's support of the National Institutes of Health and the Centers for Disease Control and Prevention. But, we are concerned that our government is not devoting sufficient resources for research and prevention of America's No. 1 cause of death—heart disease—and to our country's No. 3 cause of death and most disabling disease—stroke.

How you can make a difference

Now is the time to capitalize on progress in understanding heart attack, stroke and other cardiovascular diseases. Promising cost effective breakthroughs in research and prevention are on the horizon. The AHA challenges our government to significantly increase funds for heart and stroke research and to translate research into effective clinical and community interventions. These actions will help reduce health care costs and improve quality of life. For fiscal year 1999 we urge you to do the following: Appropriate a 15 percent increase over current funding for the overall NIH, the first increment toward the goal of doubling the budget in five years. This goal is echoed by Research!America and the Ad Hoc Group for Medical Research Funding.

NIH research provides cutting-edge treatment and prevention strategies, cuts health care costs, creates jobs and maintains America's status as the world leader in biotechnology and pharmaceutical industries. Provide a 15-percent increase over fiscal year 1998 funding specifically for NIH heart research and stroke research.

Heart and stroke researchers are on the brink of advances that could pave the way to prevention and even a cure so you or someone you love will be spared pain and suffering from heart disease and stroke. Allocate $21 million for the CDC Cardiovascular Health Program.

We must make our science real and applicable through community interventions that encourage Americans to make heart healthy lifestyle choices.

Still No. 1

Heart attack, stroke and other cardiovascular diseases have been the leading cause of death since 1919. Some 58 million Americans—1 in 5—of all ages suffer from one or more of these diseases. Millions of Americans have risk factors for these diseases—about 50 million have high blood pressure, 38 million have high blood cholesterol and 50 million smoke. As the baby boomers age, the number of Americans afflicted by these disabling diseases will increase substantially. Cardiovascular diseases put an enormous burden on our economy. Americans will pay an estimated $274 billion for cardiovascular-related medical costs and lost productivity in 1998. These diseases constitute 4 of the top 5 hospital costs for all payers, excluding childbirth and its complications, and 4 of the top 5 Medicare hospital costs.

Heart and stroke research benefits all Americans

Thanks to advances in addressing risk factors and in treating cardiovascular diseases, more Americans are surviving heart attack and stroke. Heart and stroke research and prevention breakthroughs are saving and improving lives of your friends and those you love every day. You and your family have benefited directly from heart and stroke research. Several cutting-edge examples follow.

—*Emergency Cardiac Care.*—Every day more than 1,000 Americans suffer a sudden cardiac arrest, the unexpected, abrupt loss of heart function. Researchers have discovered a particular sequence of actions known as the "chain of survival," which offers hope for these individuals. Early use of both breathing and chest compression techniques of cardiopulmonary resuscitation (CPR) and delivery of a powerful electrical shock to the heart are critical to restore life. Each minute of delay in returning the heart to its normal pattern decreases chance of survival by 10 percent. An estimated 100,000 lives could be saved each year if automatic external defibrillators (AEDs) were widely available.

—*New Surgical Heart Techniques.*—Medical research has revolutionized surgical techniques in the cardiovascular field. You probably know someone who has benefited from the research breakthroughs called heart bypass surgery and Percutaneous transluminal coronary angioplasty (PTCA). Patients who undergo conventional bypass surgery to improve blood flow to the heart require several weeks to recover. But, those who experience the new "keyhole" or "minimally invasive heart bypass surgery" need only several recovery days. Surgeons operate via a three-inch incision. Keyhole surgery can provide an alternative for the growing number of Americans who endure the traditional surgery to eliminate chest pain, increase ability to exercise and reduce fatigue and need for medicine. In 1995, an estimated 768,000 patients benefited from bypass surgery and PTCA to improve blood supply to the heart.

—*Surgery to Reduce Risk for Stroke.*—When the main artery to the brain becomes blocked, in many cases surgeons now can remove the buildup of plaque to prevent stroke. This procedure benefits not only stroke survivors, but also helps patients who experience stroke symptoms or even those who have no symptoms but a partially blocked artery.

—*State-of-the Art Life-extending drugs.*—Research has produced amazing new drugs to help prevent and treat heart attack and stroke. Cutting-edge drugs to control blood pressure and cholesterol are more effective than ever in saving lives and enhancing life quality of millions of Americans. When prevention fails, revolutionary "clotbuster" drugs can reduce disability from heart attack and stroke by dissolving blood clots causing the attack. Now, use of t-PA within three hours of the onset of a stroke can stop progression of clot-caused stroke and reduce chances of permanent disability by 30 percent. T-PA offers hope for an estimated 1.1 million Americans who are expected to suffer a heart attack and 450,000 at risk of a clot-caused stroke in 1998.

So Americans can continue to benefit from these types of breakthroughs, we support doubling of the NIH budget in five years. We recommend an fiscal year 1999 appropriation of $15.7 billion for the NIH as the first step toward that goal. AHA has a special interest in individual NIH institutes that relate directly to our mission. Our funding recommendations for these institutes and programs follow.

Heart research challenges and opportunities for NHLBI

These and other advances have been made possible by 50 years of AHA-sponsored research and a half-century of investment by Congress in the National Heart, Lung, and Blood Institute. Thanks to research, no longer does a heart attack or stroke necessarily mean immediate death. Now that more people are surviving, heart attack and stroke can mean permanent disability, requiring costly medical care, loss of productivity and quality of life.

The AHA urges this Committee to double the NHLBI budget in five-years. To reach this goal, we recommend an fiscal year 1999 appropriation of $1.825 billion for the NHLBI. A funding level of this amount will allow NHLBI to expand existing programs and invest in promising initiatives. Several challenges and research opportunities to advance the battle against heart disease are highlighted below.

—*Origins of atherosclerosis.*—Heart attacks and nearly half of all strokes are the end result of atherosclerosis, the disease process that causes obstructed blood vessels. About 14 million Americans live with consequences or symptoms of coronary heart disease, the cause of heart attacks. An estimated 1.1 million Americans will suffer a heart attack and about 600,000 will suffer a stroke this year. Survivors often suffer permanent heart or brain damage and are unable to return to work or to their regular lifestyle. If origins of the blockages were understood, many heart attacks and strokes may be prevented. Now, researchers are examining new theories about atherosclerosis. They include a long-lasting, low-grade inflammation in blood vessels that feed the heart and brain; a common respiratory viral infection that has been found in the blood vessel walls, and defective genes inherited from parents. More funds are needed now; because these studies may revolutionize the way we prevent or treat heart attack and stroke.

—*Congestive heart failure.*—About 5 million Americans suffer from congestive heart failure, the single most frequent cause of hospitalization for those age 65 and older. During the past 17 years, total hospitalizations for congestive heart failure more than doubled. For many, relatively simple tasks like making the bed or preparing breakfast can be so fatiguing that the rest of the day has to be spent in bed. A heart transplant is the only way to curtail suffering or postpone death for some patients. More research is essential to understand how and why the disease occurs and how it can be treated and prevented. Promising areas need more study. These include surgical techniques to remove non-functioning heart muscle; left ventricle assist devices; use of animal hearts for

transplant; transplant of healthy heart cells, and the role of programmed cell death in the development of congestive heart failure. Increased funds could lead to new methods for treatment and prevention.

—*Heart disease in infants and youth.*—Heart defects are America's most common birth defect and a key cause of childhood disability. Heart defects strike 32,000 newborns each year in the United States. About 2,300 of these infants do not live to celebrate their first birthday. Approximately 1 million Americans live with the effects of these conditions. Scientists often do not know why these defects occur. Children may also develop an acquired heart illness in infancy or childhood. Specialized Centers of Research (SCOR) in Pediatric Cardiovascular Disease have made tremendous strides in rapidly translating basic science and clinical research findings into medical care for these infants and children. Resources to renew these SCORs will allow more progress to determine underlying mechanisms and will lead to better diagnosis, treatment and prevention of heart disease that can severely restrict quality of life of too many newborns, children and grandchildren.

—*A Healthful lifestyle.*—Most Americans know smoking, physical inactivity and being overweight are unhealthful. Why then are people adopting unhealthful habits? Studies show that more teenagers than ever are smoking cigarettes. Obesity is increasing at an alarming rate among adults, teenagers and children. Obesity is a risk factor for associated disorders, including heart disease and stroke. Fatal heart attack, high blood pressure and diabetes often accompany obesity. Resources are urgently needed to determine the causes and develop effective treatments for obesity. Research is needed to develop effective educational and behavioral interventions and public health approaches that help people change their behavior and to maintain those healthful behaviors over time. More funds to study the application of current research will yield recommendations benefiting all Americans.

Stroke research challenges and opportunities for NINDS

Stroke is America's major cause of permanent disability and No. 3 cause of death. There are an estimated 4 million stroke survivors in the United States. They often face debilitating physical and mental impairment, emotional distress and overwhelming medical costs. About 20 percent required help walking and 71 percent had impaired capacity to work when examined an average of seven years later, according to the NHLBI-sponsored Framingham Heart Study. In 1998 an estimated 600,000 Americans will suffer a stroke. While stroke is considered to be a disease that strikes our grandparents, it also afflicts newborns, children and young adults. More Americans are dying from stroke than ever before.

We urge a doubling of the National Institute of Neurological Disorders and Stroke—stroke budget in five years. An fiscal year 1999 appropriation of $94.1 million for NINDS—stroke research, the first step toward the goal, will allow more rapid progress in preventing stroke, protecting the brain during stroke and enhancing rehabilitation. Some challenges and opportunities follow.

—BRAIN IMAGING.—Imaging plays a critical role in evaluating stroke patients, providing non-invasive diagnosis, treatment assessment and prediction of recovery. A wide range of imaging technologies are now available, each providing distinct information about the brain. New research is required to combine knowledge from diverse imaging techniques to enhance data on brain activity. Extra funds are needed to develop imaging to quickly diagnose some 450,000 patients a year who may benefit from t-PA. Refined imaging technology has broad application for other brain disorders.

—*Genetics of Stroke.*—Stroke often has a genetic element. Recent research has identified a gene linked to stroke caused by a blockage. Other new studies have identified genetic risk factors associated with stroke. More funds to study genetics could lead to new methods to approach stroke.

—*Stroke Clinical Trials.*—Basic research has progressed to the point where clinical studies are crucial in advancing the prevention and treatment of stroke. One fascinating trial is examining whether estrogen therapy reduces the risk of death or recurrent stroke in post-menopausal women. This study is particularly important because more than 60 percent of fatal stroke victims are women. Increased funds for clinical trials could produce cutting-edge stroke treatment and prevention.

—*New Stroke Drugs.*—Increasingly, promising new medications to treat stroke will become ready for evaluation in patients. They include drugs to restore blood flow to the brain, protect cells from dying when stroke is in progress and prevent injury when blood flow is restored. Additional resources are critically needed to test the ideal combinations of these drugs in the treatment of stroke.

—*Public and Professional Education for Stroke Treatment.*—T-PA is the first effective emergency treatment for clot-caused stroke. The AHA and eight other national organizations are working with NINDS to increase public awareness of stroke symptoms and the appropriate urgent action to take. They also are striving to develop systems to make t-PA readily available to appropriate patients. When these systems are fully implemented, stroke treatment will change from supportive care to early brain-saving intervention. More funds are urgently needed to address challenges in educating the public about stroke symptoms and the need for prompt treatment and assuring appropriate response systems are in place in communities. Health care professionals also must be educated about the new treatment and the need for rapid response.

Research in other NIH Institutes and centers benefits heart and stroke

National Institute on Aging research defines how the aging process contributes to cardiovascular diseases, a main cause of disability and No. 1 cause of death of older Americans. An fiscal year 1999 appropriation of $38.2 million for NIA cardiovascular research will allow continuation of on-going studies and expansion into innovative promising areas.

National Institute of Diabetes and Digestive and Kidney Diseases studies assist in reducing cardiovascular diseases death and disability. We advocate an fiscal year 1999 appropriation of $1 billion for NIDDK to advance research to help diabetics, 80 percent of whom will die from heart disease or stroke.

National Institute of Nursing Research studies plays a key role in promoting self-care and patient education. NINR research is critical to primary and secondary prevention of heart attack, stroke and other cardiovascular diseases. We advocate an fiscal year 1999 appropriation of $73.1 million for NINR.

Animal research is critical for heart and stroke research. AHA supports an fiscal year 1999 appropriation of $522 million for the National Center for Research Resources to help institutions and researchers obtain animals and provide humane care for them. Increased resources will fortify animal research, help correct deficiencies in research animal resources and strengthen nationwide Clinical Research Area Centers and Biomedical Technology and Infrastructure Areas.

Agency for health care policy and research

AHCPR plays an important role through establishment of practice guidelines and conduct of outcomes research. Practice guidelines and outcomes research help insure that high quality and cost effective medical services are provided. AHCPR guidelines on rehabilitation after stroke have received considerable attention from practitioners. The AHA concurs with the Friends of AHCPR's recommendation of an fiscal year 1999 appropriation of $175 million.

Centers for Disease Control and Prevention

The best way to protect the health of Americans and lessen the enormous financial burden of disease is through prevention. Your commitment as elected representatives of the public cannot stop at the laboratory door. You must fund the work that brings research into the places where heart disease and stroke live—the towns and neighborhoods that populate America.

The CDC builds the bridge between what we learn in the lab and how we live in our communities. CDC sets the pace on prevention. We recommend an fiscal year 1999 appropriation of $2.8 billion for CDC.

As a result of the efforts of this Committee, CDC's Cardiovascular Health Program will begin this year with as many as five states receiving funds to implement state-based cardiovascular disease prevention and control programs. In 1997 CDC released a report outlining what the nation's priorities should be in the area of chronic disease prevention. The report titled, "Unrealized Prevention Opportunities: Reducing the Health and Economic Burden of Chronic Disease" said "strong chronic disease prevention programs should be in place in every state to target the leading causes of death and disability in our society and their principal risk factors." Until the fiscal year 1998 appropriations for initiating a comprehensive Cardiovascular Health Program, the CDC-administered Preventive Health and Health Services Block Grant was the only source of federal funding to states for targeting the leading cause of death in every state in the nation.

The AHA is delighted by the steps taken to create the Cardiovascular Health Program. We encourage the Committee to continue reaching out to states on heart disease and stroke prevention through an fiscal year 1999 appropriation of $21 million for the Cardiovascular Health Program.

The Preventive Health and Health Services Block Grant has been a vital resource for states in their efforts to address heart disease and stroke. The Block Grant is vital in helping states with their role in preventing chronic disease. The AHA

strongly recommends an fiscal year 1999 appropriation of $255 million for the PHHSBG for fiscal year 1999. The AHA also urges the Committee to consider the importance of addressing, as the "Unrealized Prevention Opportunities" document points out, the need to target risk factors. We support CDC's effort to build the following:

—A comprehensive nutrition and physical activity program with an fiscal year 1999 appropriation of $15 million;

—A national program to prevent tobacco use, including a national public education campaign to reduce youth access to tobacco products, through the CDC's Office of Smoking and Health with an fiscal year 1999 appropriation of $150 million; and

—A comprehensive school health education program with an fiscal year 1999 appropriation of $25 million.

Coupled with a comprehensive Cardiovascular Health Program, these intervention efforts will significantly advance the fight against heart disease and stroke. We urge the Committee to make cardiovascular health a national priority through these initiatives.

Action needed

Significantly increasing resources for both research and community intervention programs will allow this nation to make great strides in the battle against heart attack, stroke and other cardiovascular diseases. Our government's response to this challenge will help define the health and well-being of our citizens—including those you love—into the next century.

PREPARED STATEMENT OF PATRICE O'TOOLE, ASSISTANT DIRECTOR, FEDERATION OF BEHAVIORAL, PSYCHOLOGICAL AND COGNITIVE SCIENCES

Mr. Chairman, members of the Subcommittee, the Federation of Behavioral, Psychological and Cognitive Sciences is a coalition of 17 scientific societies and 150 university graduate departments. The 90,000 scientists represented by the Federation conduct behavioral research. Support for their work comes, among other sources, from the Office of Educational Research and Improvement (OERI) at the Department of Education and the National Institutes of Health. The Federation's testimony is directed toward the fiscal year 1999 appropriation requests for these two agencies.

OFFICE OF EDUCATIONAL RESEARCH AND IMPROVEMENT

Any discussion of OERI funding should encompass the agency's 1995 reauthorization. That legislation was carefully crafted over the course of five years, and its aim was to make OERI one of the government's premier supporters of research and research applications. A major impediment to building a solid scientific knowledge base for educational improvement has been that OERI and its predecessor, the National Institute of Education (NIE) were buffeted by the political winds and by passing fads regarding educational interventions. NIE and OERI found themselves having to change gears to fit the current desire of those in power. That is not the right way to build a research knowledge base. The right way to do this is to look at the real problems in education and to develop research agendas to address those problems, much as the National Institutes of Health does with diseases. And so it is no happenstance that when OERI was reauthorized, it was organized into a series of research institutes, each focusing on a major problem area in education. It is also not a happenstance that an outside oversight board similar to the National Science Board of NSF or the advisory committees of the NIH was created to keep OERI on a steady course rather than to allow its programs to be whipsawed by each passing educational fad.

Under the 1995 reauthorization, OERI's Field Initiated Studies (FIS) program which supports university-based research was expanded. The basic research produced under the FIS program lays the foundation for the applied work done in the labs and centers of the institutes. Funding for the FIS program needs to increase. The fiscal year 1999 request includes a plan for 35 to 50 new field initiated studies, but does not include a request for increased funding. Reallocation of funds from expiring grants would be the method to support a new grant competition, without an increase this year. In fiscal year 1998, the OERI research budget was frozen at the fiscal year 1997 level making it impossible to sponsor a new grant competition, though the agency did maintain funding for previous FIS awards.

OERI has developed a strategic plan to assure that the elements of the reauthorization accomplish their intended purposes. As a result, the OERI has taken sub-

stantial strides toward becoming a strong research and research applications agency for education. This process is ongoing and all indications are the reinvention of OERI is going well. The Congress deserves to take pride in its handiwork with respect to the reauthorization because the reauthorization has at last established a strong framework for the support of educational research and its applications. The best framework in the world, however, cannot accomplish its purpose without adequate funding.

For OERI the Administration is requesting a 28.5 percent increase in funding levels across research, statistics and assessment. However, the bulk of this increase is slated for a new Interagency Research Institute, which is earmarked to receive a $50 million start-up budget. This new interagency research initiative is meant to be a collaborative effort between OERI, the National Science Foundation (NSF) and the National Institute of Child Health and Human Development (NICHD). An additional $25 million is expected from NSF for this project. The important point to make, however, is that this $50 million allocation is dependent upon the unresolved tobacco settlement. Without the tobacco settlement, only $15 million will be available for statistics and assessment and no increase is requested for the core research programs. The President's request for level-funding of the core research programs in fiscal year 1999 would make this the third year of a frozen budget for these programs. The Federation believes that to continue level-funding and not provide sufficient annual increases to these programs makes it impossible for OERI to meet fully the mandates of its 1995 reauthorization.

The Federation supports a $15 million increase for fiscal year 1999 for the core research programs and also supports the administration's desire to create an interagency education research program. We believe that linking the work of the Department of Education with NSF and NICHD will facilitate the passage of new knowledge from research to application.

NATIONAL INSTITUTES OF HEALTH

The Administration is requesting an unprecedented 8.4 percent increase—the largest ever—for the National Institutes of Health (NIH). This would increase NIH's budget from $13.6 billion to $14.8 billion, an increase of $1.1 billion. The Federation is joining with many other scientific organizations and key members of Congress in asking the subcommittee to recommend an even larger increase of 15 percent for NIH. This increase would be the first step toward the doubling of NIH's budget within the next five years. We base our request for this substantial increase on two observations.

The first is that the pace of discovery in the full spectrum of health sciences is accelerating, and the country needs to keep that momentum going. The second is that health care costs are at crisis proportions in this country, and one of the most important ways to control those costs is to find better ways to keep people healthy. The ultimate purpose of health research, including health research in the behavioral and social sciences, is to make the citizens of this country healthier throughout their life span.

Some of the most significant advances in science in recent years have come from research in two large fields, genetics and neuroscience. The work being done in these areas is a prime example of how basic genetic and neuroscience research is contributing to our understanding of a number of diseases, such as Parkinson's, Alzheimer's, drug addiction and diabetes. Scientific advances in the biology of brain disease have been possible because of new methods for the study of the nervous system, such as neuroimaging.

Understanding and identifying the molecules that guide the formation of the brain is allowing neurobiologists to visualize how the developing nervous system organizes itself, to explain complex behaviors, and to describe neurological and psychiatric diseases with a new level of precision.

The emergence of cross-disciplinary collaboration has been a major component in the fast paced research developments in these arenas. Across the NIH-supported sciences, the growing tendency for scientists from many disciplines to come together to solve research problems has shown significant results. AIDS has not been cured, but research has shown how a mixture of treatments can ward off the worst effects of AIDS, for many years. These treatments involve the use of a variety of drugs in combination and they involve a demanding level of discipline on the part of the patient to take the medications properly—a discipline that can be trained by application of techniques developed through behavioral research.

Similarly, recent NIH-supported behavioral research has produced useful new knowledge, including a better understanding of basic behavioral and social processes and how they interact with biological processes. This understanding is coming from

many lines of research: studies of lifestyle choices, dietary habits, the desire and ability to maintain exercise or medication regimens, psychological functioning, and influences of one's social and cultural environment on behavior. All these lines of research converge to give us a picture of the factors that can affect an individual's ability to remain healthy or to recover from disease or to function well despite a chronic condition. And that knowledge leads to treatments and other interventions to maintain health through the life span. NIH's Office of Behavioral and Social Sciences Research (OBSSR) has been pivotal in supporting these studies and translating the findings into effective prevention and treatment strategies.

OBSSR, under the purview of the Office of the Director of NIH, coordinates all the institutes and centers in marshaling their individual resources to collaborate on behavioral and social sciences research. OBSSR, for example, is overseeing a $3.7 million trans-agency research project intended to encourage the development of innovative behavior strategies for changing risk behaviors that cut across major disease categories. OBSSR chose these behaviors for collaborative research support because the diseases whose courses the research is intended to modify are among the top ten causes for premature mortality and morbidity. Sixteen NIH offices and institutes are funding this project, including NIAAA, NICHD, NIMH, and the Office of Dietary Supplements.

OBSSR was established in 1995 by Congress. This project demonstrates how OBSSR fulfills one of its primary mandates, which is fostering the development of cross-disciplinary communication and research collaboration among various behavioral and social sciences and between the behavioral and social sciences and biomedical sciences. OBSSR's efforts are assuring that development of effective behavioral interventions is keeping pace with technological advances.

OBSSR has been operating for several years now with a small staff and a small budget. The President's budget request for OBSSR for fiscal year 1999 is nominal—$2.66 million. OBSSR's current budget is $2.56 million. The Federation supports an additional $1.5 million increase for fiscal year 1999 for OBSSR. This increase combined with the President's request would bring OBSSR's total budget to $4.2 million and would significantly augment OBSSR's ability to coordinate research across institutes. This is both an efficient use of resources and a beneficial mode of operation, because it links areas of related knowledge that might otherwise remain separated.

Another prime example of the application of behavioral intervention in concert with the use of medicines has to do with deadly diseases that are reemerging after decades of dormancy in this country. Tuberculosis is the example that comes most readily to mind. A serious challenge is faced with respect to these diseases. When medications are misused, the result is not only that the patient's disease fails to be controlled, but also the bacterium that causes the disease is able to develop resistance to medication making the disease much more difficult to treat.

These diseases are cropping up in indigent populations such as the homeless—among the hardest groups in our society to treat. Research is still underway to determine what behavioral interventions can best assure that such patients will carry their treatment through to conclusion. But behavioral and social scientists are working with other scientists and with health providers to find answers to the problem. Our experience with collaboration to date leaves every reason to believe that even in this very difficult area, solutions can be found if support is maintained for the research teams that seek the answers.

NIH funding has permitted us to use research wisely, that is, in the combinations that will be most efficient in reaching solutions to typically multifaceted health problems. To continue successful biomedical and behavioral research at this level requires a major commitment by Congress to find the resources for expanding NIH's budget. With increased support, the current pace of discovery and collaboration can be sustained. The largest per person expenditures for health care occur near the end of life. One goal of research has become to understand what interventions through the life span will have the greatest promise of assuring that the period of great illness before the end of life is minimized.

Behavioral research has a large role to play here because controllable choices and behaviors in life have a heavy impact on the quality of life of the aged. Obviously, such behavioral choices as to smoke or not to smoke and what foods and quantities of food to consume are among the most important choices we make in determining our health. But each of us knows how difficult it is to do the right thing.

Behavioral researchers in cooperation with nutritional researchers, neuroscientists, epidemiologists and a host of other specialists are working to find ways to make it easier for people to make the right choices about their health. The payoff for finding solutions to these problems will be not only a healthier population, but also the shrinkage of health care costs to a manageable size without sacrificing the

well-being of the country's citizens. Through research it is becoming possible to maintain good health and keep health care costs down at the same time.

We strongly urge the Subcommittee to recommend a 15-percent increase for NIH because the investment in knowledge will result in healthier citizens and health care cost savings that far exceed the research investment. And by the same token slighting research will assure that rising health care costs will remain among our most serious national crises.

We thank the Subcommittee for the opportunity to present our views.

DEPARTMENT OF EDUCATION

PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

I. Introduction

Mr. Chairman and Members of the Subcommittee, on behalf of this nation's 30 American Indian Tribal Colleges, which comprise the American Indian Higher Education Consortium (AIHEC), we thank you for the opportunity to share our funding requests for the Department of Education's fiscal year 1999 programs.

We have four specific funding requests:

—A section is now being authorized under Title III of the Higher Education Act specifically for Tribal Colleges, and we request that this section be funded at the authorized level of $10 million.

—Funding under section 103 of the Carl D. Perkins Vocational Education and Applied Technology Act (set-aside for Indian and Hawaiian Natives) should be at a level of $15.9 million; the Tribally-controlled Postsecondary Vocational Institutions program should be funded at no less than $3.1 million; and other Vocational and Adult Education programs should be funded at the levels requested in the President's budget.

—Under Title IV, we have two priorities: (a) Funding for the Title IV campus-based assistance programs, including work-study, SEOG, and TRIO, should be fairly allocated to all institutions with documented need. (b) Funding for the Pell Grant program should be increased, over a period of five years, to the level of educational cost coverage provided in the late 1970's and early 1980's.

—The new White House Initiative on Tribal Colleges, which is housed in the Department of Education, will need support and oversight by the Congress. We support the President's request of $200,000 for this office and ask your subcommittee to build upon his budget to a level of $500,000.

Mr. Chairman, this statement will cover two topics: first, it will provide some background on the Tribal Colleges, including information on the tremendous challenges we face as we cope with the effects of welfare reform; and second, it will provide justifications for the above funding requests.

II. Background on tribal colleges

The dismal statistics concerning the American Indian experience in education brought tribal leaders to the realization that only through local, culturally-based education could many American Indians succeed in higher education and help bring desperately needed economic development to the reservations. The most remote reservation communities were heavily struggling with this problem. The Tribal College movement began more than 25 years ago as a very sound and well thought-out solution to this problem. In the late 1960's and early 1970's, the first Tribal Colleges were chartered on remote reservations by their respective tribal governments, to be governed by boards of local tribal people. These first colleges were born, with little money and a lot of determination, in abandoned and condemned government buildings and old trailers, using three-legged desks, wood crates for shelves and typewriters with missing keys. In 1972, the first six fledgling tribally-controlled institutions came together to form the American Indian Higher Education Consortium. Today, AIHEC is a cooperatively sponsored effort and integral support network for 30 member institutions in the United States and one in Canada.

Tribal Colleges now serve 26,700 students each year, offering primarily 2-year degrees, with some colleges offering 4-year and graduate degrees. Together, the colleges represent the most significant and successful development in American Indian education history, promoting achievement among students who may otherwise never know educational success. All of the Tribal Colleges are fully accredited, with the exception of the four newest institutions that are accreditation candidates.

Despite our successes, Tribal Colleges remain the most poorly funded institutions of higher education in this country, and although conditions at some have improved substantially, many of the colleges still operate in trailers, cast-off buildings, and

facilities with leaking roofs. Our core funding, which is authorized under the Tribally-Controlled Community Colleges Assistance Act of 1978 and funded through the Department of Interior appropriations bill, remains grossly inadequate. In fact, the Tribal Colleges' appropriation of $3,017 per Indian student is dramatically less than the average per student revenue of mainstream 2-year institutions. It is also far below the authorized level of funding, which is $5,820 per Indian student.

In addition to providing academic, vocational, and technical programs similar to those at mainstream institutions and cultural language and history courses unique to American Indian tribes, Tribal Colleges provide services above and beyond those provided by most other post-secondary institutions. All Tribal Colleges provide GED, basic remediation, and other college preparatory courses, probably more than any other community colleges in this country. We have done this because their missions require them to help move American Indian people toward self-sufficiency and help make American Indians productive, tax-paying members of American society.

Tribal College students are often older—the average age is 27. They are typically single parents, the majority of whom are mothers with small children, and they are extremely poor. Most are dependent on welfare, and with young families, they are unable or unwilling to leave their small reservation communities to go away to school. Yet, they want to get off welfare and provide for their families, so they turn to the Tribal Colleges.

III. The impact of welfare reform and justifications for funding requests

Fulfilling our obligation to serve Indian people will become increasingly more difficult over the next several years for two reasons: (1) federal funding resources are not keeping pace with expanding enrollments; and (2) as a result of welfare reform legislation, more and more welfare recipients are turning to Tribal Colleges for training and employment opportunities. Most Tribal Colleges are located on remote reservations in isolated communities that lack the support of basic public services available and supported by strong state and local governments with access to stable tax support systems. Given this reality, Tribal Colleges are obligated to offer a wide range of community services, such as education, job training, childcare, and community support services. They serve as community centers, providing libraries, tribal archives, career centers, economic development centers, and public meeting places. Over the next several months and years, we expect the demand for these services—along with a tremendously increased need for basic education and training services—to expand dramatically.

In the isolated Indian communities Tribal Colleges serve, current welfare recipients simply have no other place to turn. They must look to the local Tribal College for much needed—and required—education and job training. But before many can even begin the course work needed to learn a productive skill, they first must earn a GED or learn to read. According to a Carnegie Foundation survey, 20 percent of the students questioned had completed a Tribal College GED program before beginning formal classes at the Tribal College. At some schools, the percentage is even higher. For example, Lac Courte Oreilles Ojibwa Community College in Wisconsin reports that nearly one-third of its students had earned a GED through its tutoring and testing center. Clearly, the need for basic educational programs is tremendous, and it will increase as changes in the welfare laws are implemented.

Officials at Tribal Colleges agree that the old welfare system did not work. In fact, the missions of the Tribal Colleges are specifically targeted toward self-sufficiency and productivity. This has been the work of the colleges from their inception. Tribal Colleges want to continue to share in the responsibility of making the new welfare system work. The future of our people depends upon it. But Tribal Colleges cannot be successful if resources remain too inadequate to deal with the impact of the new laws. They must be fully prepared and given the appropriate resources to deal with the increases in enrollment, new program implementation, and expanded remediation services and programs.

FURTHER JUSTIFICATIONS

(1) A new part should be established under Title III of the Higher Education Act (HEA) specifically for Tribal Colleges, and this section should be fully funded at the expected authorized level of $10 million. Currently, both the House and Senate HEA reauthorization bills include the creation of a new Tribal College section for Title III, Strengthening Developing Institutions. The House Workforce Committee has authorized a $10 million competitive program, and the Senate Committee has authorized $5 million. Both measures are awaiting floor action and conference. We are hopeful that the final authority will remain at a $10 million level.

As you know, Title III of the Higher Education Act was created to assist institutions that historically have served minority and low-income students who have been denied access to postsecondary education because of race or national origin. According to the Act's findings, these institutions serve students "whose participation in the American system of higher education is in the Nation's interest so that equality of access and quality of postsecondary education opportunities may be enhanced for all students." In 1980, a specific part was created within Title III to provide assistance to Historically Black Colleges and Universities (HBCUs), and in 1992, a new section was added to provide specific funding for Hispanic Serving Institutions (HSIs). Today, we request your support for the full funding of this new part within Title III for Tribal Colleges.

A quick review of the findings of either Title III or Part B will make abundantly clear Title III's applicability to Tribal Colleges. Tribal Colleges were created specifically to serve a population that had been denied full access to America's higher education system. Our mission is to educate American Indian people and others on our reservations and to help prepare them to enter this nation's workforce. A separate section will greatly enhance the ability of Tribal Colleges to participate in Title III's programs. Over the past several years, Tribal Colleges have been nearly shut out of Title III participation. In 1991, fourteen Tribal Colleges received Title III grants. In 1994, not one Tribal Colleges received a new Title III grant. In 1995, five institutions received new funding, but in 1996, no new schools received Title III grants. Currently, only seven schools are participating in the program at all, half the number of seven years ago. The Tribal Colleges' developmental needs are overwhelming. When accessed, the Title III program has been extremely important in bringing support in areas such as faculty and curriculum development, student services, and critical community-building programs. We urge the Subcommittee to fully fund this urgently needed authority.

(2) Under Title IV, we have two priorities: (a) Funding for the campus-based assistance programs, including work-study, SEOG, and TRIO, should be fairly allocated to all institutions with documented need. (b) Funding for the Pell Grant program should be increased, over a period of five years, to the level of educational cost coverage provided in the late 1970s and early 1980s. Unfortunately, Tribal Colleges are not able to fully participate in many of the other higher education programs authorized by this Subcommittee because of existing barriers in funding formulas, laws, regulations, and grant-making procedures. Newer institutions, like the Tribal Colleges, should not be penalized solely because they have not been in existence for more than 25 or 30 years. Yet, this is exactly what happens with campus-based programs like the Supplemental Educational Opportunity Grants (SEOG) and work-study programs. A recent report by the Institute for Higher Education Policy showed that in 1994–95, students at Tribal Colleges received only an average SEOG of $326, significantly lower than the national average of $559.

Mr. Chairman, we are simply asking for parity within these programs. We do not believe that our institutions should be penalized, when documented student need is equal or greater, simply because we were not in existence when a program was originally established or modified. One suggestion is that disbursement of funds could stipulate that priority for full funding be given to institutions with high rates (85 percent or higher) of students in financial need.

In addition, we support the President's request for an increase of $100 per student award as a positive step toward this goal, and we urge the Subcommittee to supplement this amount. The importance of Pell Grants to our students cannot be overstated. Education Department figures show that half of all Tribal College students receive Pell grants, primarily because student income levels are so low, and they have far less access to other sources of aid than students at mainstream institutions. The inadequate funding Tribal Colleges receive from the federal government has forced most of the colleges into a position of increasing reliance on tuition for institutional sustainability. As a result, tuition levels at Tribal Colleges are as much as 30 percent higher than the average for mainstream public community colleges-in 1994–95, the average tuition at a Tribal College was $1,580, compared with a national average of $1,190 at community colleges.

Most Tribal Colleges are too young and too poor to have established endowments and other scholarship programs, and our students receive virtually no aid from the states. Many of our students would not be attending college and preparing to enter the workforce today if it were not for Pell grants; instead, they would be counted among the ranks of the unemployed. Within the Tribal College system, Pell grants are doing exactly what they were intended to do: they are serving the needs of the lowest income students by helping people gain access to higher education and become active, productive members of the workforce. We urge you to support and expand upon this valuable program.

(3) Funding under section 103 of the Carl D. Perkins Vocational Education and Applied Technology Act (set-aside for Indian and Hawaiian Natives) should be at a level of $15.9 million; the Tribally-controlled Postsecondary Vocational Institutions program should be funded at no less than $3.1 million; and other Vocational and Adult Education programs should be funded at the levels requested in the President's budget. Basic grants and school-to-work funding will be particularly beneficial to the Tribal Colleges as we attempt to deal with the challenges tribal communities face as a result of welfare reform, and we support adequate levels of funding for these programs. Also, it is important to note that the $3.1 million for Tribally-controlled postsecondary vocational institutions provides core funding for two of our members, United Tribes Technical College is Bismarck, North Dakota, and Crownpoint Institute of Technology in Crownpoint, New Mexico.

(4) The new White House Initiative on Tribal Colleges, which is housed in the Department of Education, will need support and oversight by the Congress. We request appropriations of $500,000 for this important office. The Subcommittee needs to be aware of this new office, which is now housed within the Department of Education's Office of Adult and Vocational Education. This office will help ensure that Tribal Colleges are not overlooked in the creation and administration of federal programs. The office was mandated by the Executive Order on Tribal Colleges and Universities (No. 13021), which the President signed in 1996 after years of advocacy by the Tribal Colleges. The Senate heavily supported the signing of the Executive Order and actively sought this long-overdue recognition through Senate Res. 264, 103rd Congress.

One of the greatest challenges that Tribal Colleges face is overcoming a surprising lack of awareness among most federal departments and agencies. Program administrators simply do not know we exist. This office will help address this fundamental problem, as similar offices have for Historically Black Colleges and Universities and Hispanic-Serving Institutions for a number of years. In addition, the office will coordinate Departmental and agency participation in the mandates of the Executive Order; assist in the development of agency 5-year plans aimed at reducing program participation barriers; and, report to the President on the inclusion of the Tribal Colleges in various departmental programs.

IV. Conclusion

In light of the justifications presented in this testimony and the even further enrollment increases that will result from welfare reform, we urge the Subcommittee to increase funding for Tribal Colleges. Fulfillment of AIHEC's fiscal year 1999 request will strengthen the mission of these colleges and the enormous, positive impact they have on their respective communities and will help ensure that they are able to properly educate and prepare thousands of American Indians for the workforce of the 21st century. Without the Tribal Colleges to serve as the means for moving from welfare to work, much of the reform accomplished by the Congress will fail throughout Indian Country. As demonstrated in this testimony, Tribal Colleges have been extremely responsible with the federal support they have received in the last 17 years. It is important that the Federal Government now capitalize on its investment. As the recent Carnegie report stated, "Now, as strongly as ever, we repeat our conviction that Tribal Colleges deserve continued support. Their value has been proven, but their vision is not yet fulfilled" (Native American Colleges: Progress and Prospects, Carnegie Foundation for the Advancement of Teaching, 1997). These institutions have proven themselves as a sound federal investment, and we ask for your continued support.

Thank you again for this opportunity to present our request before this Subcommittee. We respectfully ask the Members of this Subcommittee for their continued support and full consideration of our fiscal year 1999 appropriations request.

PREPARED STATEMENT OF JOHN S. MEGERSON, DIRECTOR OF POLICE, ON BEHALF OF THE SOUTHWEST TEXAS STATE UNIVERSITY

I appreciate the opportunity to present written testimony concerning proposed changes in the Crime Awareness and Campus Security Act of 1990 as offered in H.R. 715, Accuracy in Campus Crime Reporting Act of 1997 and request that this testimony be entered into the Record. I do so as Legislative Chair for the Texas-New Mexico Association of College and University Police Departments, as a 35-year member of the criminal justice community, and as Director of University Police for Southwest Texas State University.

You have already received a position statement from the Texas-New Mexico Association of College and University Police Departments concerning the provisions of

H.R. 715. That document deals primarily with specific provisions of the bill and difficulties inherent in compliance. I will not re-address those at this time. The purpose of my testimony is an effort to persuade you to recognize the direction you are being asked to pursue will result in the development of data which will not serve the interests or intent of those who promoted the approval of the Crime Awareness and Campus Security Act of 1990. However, I will offer a solution I believe may be acceptable to those with concerns over compliance and needed data.

In summary, you are being asked to approve legislation that would force educational institutions and their law enforcement and security organizations to produce and publish data and statistics that are incongruent with one another. In many respects the proposed legislative amendments require us to produce not what we "know" to have occurred, but what we "suspect" to have occurred. Such information is not subject to objective analysis and interpretation.

When the original Crime Awareness Act was passed it focused upon the reporting of "campus crime" and the publication and transmission of policies and services dealing with victimization and crime prevention. As the rules were developed, changes made and audits conducted, the focus began to change as well. While boundaries were set, those who set them are no longer comfortable and want them extended to streets passing through the campus, to streets patrolled by campus police on the perimeter of a campus, to public housing off campus as well as campus approved organization housing.

The quest also includes buildings and facilities leased to private enterprise for public businesses not controlled by universities anymore so than does an owner of a property leased to a university for university business. Some compliance audits have extended those boundaries to include crime occurring in other cities while a student is on an educational trip approved by the university.

The focus is no longer on crime occurring "on" a campus, but "to" a student associated with a campus and the pursuit is progressing well beyond that level of information. This is not Campus Crime data. This is Community and Student Victimization and Behavioral data. These are vastly different kinds of data and the meaning and interpretation draw entirely different pictures and conclusions. Including unsubstantiated reports of other crimes and associated infractions for which there is no criminal charge, but for which the individual might be liable (Student Justice) paints an abstract picture for which the interpretation is in the eye of the beholder. It is not objective, quantifiable or definable in any terms that are universally acceptable.

Where we were once concerned with crimes as defined by the Uniform Crime Reporting System, we are now being asked to concern ourselves with behaviors and infractions not defined by the UCR, i.e., student disciplinary violations and code of conduct violations for which an individual was not criminally charged. You have heard testimony seeking the equivalent of background checks on prospective students and annual drug screening of those receiving federal student loans. That is not campus crime data and is not germane to an act dealing with such data. You have heard testimony seeking the publication of data concerning drug, alcohol, and weapons "violations" rather than arrests. Merging violation data with "crime and arrest data" will not create a report that is subject to objective interpretation. This attempt to identify every law or university rule violated by an individual in the course of one incident for which he/she is accountable in more than one venue will obscure the true picture.

You have heard the testimony and read amendments asking for the publication of crimes reported to "other campus officials" that may, or may not, have been reported to law enforcement or campus security. You are being asked to require campus police and security departments to publish and "certify" crimes reported to others which we cannot investigate or verify; crimes which when reported to us do not contain the names of victims so that we do not record the same report several times, depending upon who heard it last.

As you think about extending the boundaries of crime reporting, please think about New York City, Los Angeles, Miami, Baltimore, every major city in this country. Each is home to a number of colleges and universities; some within a block or so of one another. In Davie, Florida, there are three institutions of higher education across the street from one another and only a mile or so from still other universities. When I sent my daughter to the University of Miami I was not nearly as interested in the campus crime rate as I was the crime rate in Dade County, Florida. I was concerned about campus burglary and theft and the quality of the campus police. I was concerned about the residence hall staff and the vigor with which they enforced their rules. I knew my daughter would not spend her every waking moment on that campus. I knew she would go with friends to a number of off-campus estab-

lishments, events, parties, and sightseeing. It was the total environment that concerned me, not just the campus.

While the University of Pennsylvania and the Department of Education are charged with having erred in terms of the spirit or intent of the law regarding what constitutes the campus, as with any law, the definitions prescribed are those that must be followed. To re-write the law and expand its prescriptions in an effort to correct this perceived "flaw" will not correct the problem. No matter what college or university is examined, at some point the boundary of the campus will end. Across the street will not be the campus and a crime occurring there will not be included. That is the nature of boundaries. However, there is a solution which should meet the intent of the original law, i.e., to allow students and parents to evaluate the crime climate of a prospective college or university.

With that as a preface, what I suggest is that the focus of crime disclosure information should be on the community as a whole in which the college or university is located. If a parent is going to look at crime data as a part of the selection process of a college or university, that is what they need to know, not just campus crime. Focus on a report that includes the "campus crime rate" as it is currently defined and a section that includes the same data for the political subdivision in which the institution is located. Both receive federal funds. Both deal with the same clientele. Both have the same statistical resources. In the vast majority of cases I am sure one will see a campus crime rate substantially lower than the surrounding community but, as other testimony has reflected, that is not the full picture that needs to be available. Hold the local community as responsible for the accuracy and disclosure of crime information as you would the university for its information, but do not hold the university accountable for the surrounding community.

Each affected institution is located in a police jurisdiction other than its own, e.g., a city, county, borough, or township which is broken into precincts, districts or some comparable police patrol and statistical area. Thus, the solution is to require those police jurisdictions to submit crime data to that institution (according to the prescriptions in the Crime Awareness Act) for their patrol area(s) in which the educational institution is located. Then, hold the educational institution responsible for publishing both the crime occurring on its own campus and that in the surrounding police jurisdiction or patrol area(s) in which it is located.

Each of those contiguous police jurisdictions receives federal funds for a variety of programs. To insure compliance with this provision, all that need be done is require all federal funding sources for local police agencies to include in their award criteria a requirement that they will comply with the provisions of the Crime Awareness and Campus Security Act; a failure to do so resulting in the withdrawal of their federal aid.

Use of this data would be an effective reference for major metropolitan areas without requiring the distribution of an entire city's crime rate, e.g., New York City, Miami, etc.; such data not being helpful to prospective students. In rural or suburban communities the patrol areas might be quite large and encompass a major portion of a community or county. In this way, you will have made the distinction between the "Campus" and the "Campus Community," a clearly important distinction in terms of crime as evidenced by the testimony and concern shown over campus boundaries.

In terms of disciplinary actions and rules violations, as previously stated, this is entirely different data. Many of these may be "crimes" in the technical sense, but they are normally not crimes for which the judicial process will take action. They are behaviors that violate codes of conduct for which there is an entirely different burden of proof for accountability and should not be included in an "Annual Crime Report." This is information that should be included in Student Services materials transmitted to all students, e.g., application materials and the Student Code of Conduct. This is information that tells the prospective students and parents the university has rules it enforces whether or not the student is accountable under criminal law.

This development of two reports draws an important distinction and creates a much clearer picture of the university environment in terms of crime and in terms of acceptable behavior within that community.

PREPARED STATEMENT OF THE NATIONAL INDIAN EDUCATION ASSOCIATION

The National Indian Education Association (NIEA), the oldest national organization representing the education concerns of over 3,000 American Indian and Alaska Native educators, school administrators, teachers, parents, and students, is pleased to submit this statement on the President's fiscal year 1999 budget as it affects In-

dian education. NIEA has an elected national board of 12 members who represent various Indian education programs and constituencies. Every year, NIEA holds an annual convention which provides our members with an opportunity to network, share information, and hear from Congressional leaders and staff as well as federal government officials on policy and legislative initiatives impacting Indian education.

We commend President Clinton for a budget that emphasizes the importance of education for all citizens of this country, including the First Americans. There are some programs such as the Office of Indian Education (OIE) in the Department of Education, Impact Aid and higher education scholarships which deserve further consideration for increases. Other issues which may arise this year, such as block granting Department of Education funding, need to be considered very carefully by the Congress. Funding for certain Indian education programs are the result of the Federal/Tribal Trust relationship and may not be conducive to these types of funding proposals.

President Clinton has proposed several new education initiatives for fiscal year1999. Some of these depend on passage of a proposed Tobacco Settlement. Administration proposals like the School Construction Tax Credit and the Class-Size Reduction Initiative are desperately needed by schools operated and funded by the Bureau of Indian Affairs (BIA) as well as many rural public schools.

The Federal responsibility for Indian education

Indian education programs are not affirmative action nor race-based educational efforts but result from the historical and legal relationship between Indian nations and the Unites States. This government-to-government relationship is a Constitutional relationship whereby the U.S. officially recognizes some 557 Indian and Alaska Native governments as separate and distinct nations. This political relationship includes broad federal authority and special trust obligations unique only to American Indians and Alaska Natives. Tribal governments are independent of State governments even though tribal lands may lie within a state's geographic boundaries. Many federal statutes provide for direct funding to tribal governments so that tribes can design and administer their own programs. Among activities undertaken by tribal governments are the administration of their own police departments, courts, schools, health facilities, social service programs, the development and enforcement of environmental codes, etc. Many programs formerly administered by the Bureau of Indian Affairs (BIA) or the Indian Health Service (IHS), are now carried out by Tribes under authority of the Indian Self-Determination and Education Assistance Act (Public Law 93–638) and the Indian Education Act of 1972 (as amended by Title IX, Public Law 103–382). Tribally chartered boards now administer more than 90 BIA-funded elementary and secondary schools and 29 tribal colleges.

Indian education executive order

For the past three years, NIEA has worked cooperatively with the National Congress of American Indians (NCAI) and the Native American Rights Fund (NARF) in developing an Executive Order on a Comprehensive Federal Indian Education Policy Statement (CFIEPS). The intent of this policy is to formally set national guidelines for Indian education programs which would be applicable to all federal agencies. The uniqueness of this document is that it is tribally-endorsed, encompasses all education levels and reflects the historical nature of federal education policy. These guidelines are broad enough to define and direct federal agency implementation of all congressional and executive branch level Indian education initiatives including budget appropriations. The CFIEPS has been forwarded to the Clinton Administration with several House and Senate Members endorsing the proposal. We urge this subcommittee's endorsement of a Presidential Executive Order on Indian Education. Below are our funding recommendations for those Indian programs under the jurisdiction of the Labor, HHS and Education Appropriations Subcommittee.

DEPARTMENT OF EDUCATION

I. Office of Indian Education (OIE)

For fiscal year 1999, the Department of Education has requested $66 million to fund formula grants to Local Education Agencies (LEAs), partially restore discretionary funding for OIE and fund certain National Center for Education Statistics (NCES) surveys. NIEA supports full funding for OIE in the amount of $83 million, $17 million more than the fiscal year 1999 President's Request. This amount, in addition to LEA grants, would permit a variety of discretionary grant programs; full funding for the National Advisory Council on Indian Education (NACIE) and partial funding for the Presidential Executive Order on Tribally Controlled Community Col-

leges (TCCC). NIEA requests partial funding for the TCC Executive Order since its implementation requires other Education Department agencies to combine resources. In 1997, budget authority for OIE transferred from Interior to this Subcommittee.

Partial funding in the amount of $3.3 million has been restored for OIE's discretionary program called Special Programs for Indian Children. NIEA requests the Committee's support for full reinstatement for other discretionary programs in adult literacy and Indian fellowships. The Department's support for Indian students throughout its other programs is well established and appreciated by the Indian community; however, few Departmental initiatives are available for Indian adults and Indian students attending postsecondary institutions. This educational gap prevents full educational access generally assured other students. NIEA's fiscal year 1999 request proposes to fill this educational inequity. The following are NIEA's recommendations regarding OIE funding by category:

—*Formula Grants to LEAs.*—For fiscal year 1999, the U.S. Department of Education has requested $62 million for its formula grant program to public schools. The Department estimates that this funding assists 405,376 Indian students attending public and 43,089 students attending Bureau of Indian Affairs (BIA) schools for a total of 448,465 students. Approximately 80 percent of BIA students receive assistance under OIE's formula grant program to LEA's.

—*Special Programs for Indian Children.*—NIEA supports the Department's effort to partially restore discretionary funding for certain OIE programs. The request includes $3.3 million for the Special Programs for Indian Children. This account, if funded, would assist two initiatives: (1) demonstration grants for early childhood and preschool education and (2) preparation of Indians to take positions in teaching and school administration. The $3.3 million increase falls far short of the amount needed to reinstate several critically needed Indian Education programs such as Indian fellowships, adult education programs and additional demonstration grant resources.

—*National Activities.*—The Administration requests $735,000 in fiscal year 1999 to augment the Year 2000 National Center for Education Statistics (NCES) Schools and Staffing Survey (SASS). The data collection effort would ensure that American Indian students are included in upcoming NCES surveys that will yield additional information on American Indian learners.

—NIEA appreciates the targeted increases for Indian education, but continues to be concerned that studies on American Indian students are not already a part of the Department's data gathering effort. Most other ethnic populations receive considerable research results without having their respective program budgets cover the cost. A 1996 report by the United States Commission on Civil Rights titled the 'Equal Educational Opportunity Project Series, Vol. 1' found that Department of Education data on student characteristics was lacking among students from American Indian, Asian and other national backgrounds. The report stated that "accurate, reliable and complete data on these ethnic groups are vital for the efforts of the education community to assess the needs of all student sub-populations." The report recommended that documents from the Department of Education's Office of Educational Research and Improvement (OERI), and other federal agencies that contain data utilized by policy and decision makers, should include information on these populations. NIEA echoes this position and recommends that the Department of Education make a concerted effort to provide accurate research data on American Indians and Alaska Natives when conducting studies and that they do so with funds requested through their own research department.

—*Tribal College Executive Order.*—When the President's budget was released, funding amounts for the Tribal Colleges Executive Order was not available. In fiscal year 1998 the funding through OIE was $200,000. NIEA has been informed by the Department that other agencies are expected to contribute to the Order's implementation. NIEA supports the tribal colleges in their request for full funding of this office.

—*The National Advisory Council on Indian Education (NACIE).*—NACIE is recommended at only $50,000 the same amount as fiscal year 1998. NIEA requests that the Committee consider full funding for NACIE in order for it to carry out its mandated under the Indian Education Act of 1972. This would require at least $400,000 additional in fiscal year 1999. NACIE currently has no permanent office and must rely on OIE staff to carry out minimal functions. NIEA has made every effort to involve NACIE in several Indian education initiatives including a proposed Indian Education Executive Order, which intends to utilize NACIE's advisory role in its implementation. NIEA also requests that NACIE

be permitted to hold hearings on Indian Education issues during the 1999 reauthorization of the "Improving America's Schools Act".

—*OIE Fellowship and Adult Education Programs.*—Another loss, from which Indian Country has yet to fully recover, is the Indian Fellowship and Adult Education Program. These programs were last funded in fiscal year 1996 and represents a broad, non-targeted approach, to ensuring Indian student participation in postsecondary education. NIEA supports a funding level of at least $3 million for the Indian Fellowship Program and $5.5 million for Adult Education. At its peak, the fellowship program funded approximately 150 students. The adult education grants served more than 30 Native communities and tribal colleges.

II. Other DoEd Indian Education-Related Programs

—*Goals 2000.*—NIEA supports the President's request for Goals 2000 in the fiscal year 1999 budget of $501 million. This represents a $10 million increase over the 1998 appropriation of $491 million. One percent of Title III funds for Territories and BIA-funded schools are used to support comprehensive, systemic education reforms to improve teaching and learning. The fiscal year 1998 budget for Bureau of Indian Affairs schools was $3.8 million with $3.6 million proposed in fiscal year 1999.

—*Safe and Drug-Free Schools.*—NIEA supports the fiscal year 1999 request for Safe and Drug-Free Schools of $606 million, or $50 million more than in 1998. State grants under this program total $526 million. BIA schools receive a one percent set-aside, which in 1998 was $5.3 million. The fiscal year 1999 request is expected to be the same with 40,000 Indian students benefitting.

—*School-To-Work.*—NIEA supports the President's request for School-To-Work funding. The President's request cuts the School-to-Work vocational education program by $75 million or 37 percent in fiscal year 1999. The fiscal year 1999 request is $125 million with an equal request from the Department of Labor bringing the total program to $250 million. This program is due to phase out in 2001, with States or other vocational education dollars continuing the program. Up to one percent of program funds are set-aside for programs to help Indian youth acquire the knowledge and skills they need to make a smooth transition from school to career-oriented work and further education and training. In fiscal year 1998 the amount available for Indian students would be $2 million with $2.4 million proposed for fiscal year 1999.

—*Title I.*—Title I, Education for the Disadvantaged, covers four programs: Title I basic grants; Title I concentration grants; Title I targeted grants; and capital expenses for private school children. The fiscal year 1999 request for Title I Basic Grants is $6.270 billion, an increase of $788,000 (less than 0.1 percent) over 1998. The BIA set-aside amount under this appropriation would be $47 million and serve 24,500 Indian students. NIEA supports the President's request.

—*Comprehensive School Reform.*—This Title I initiative was funded in fiscal year 1998 at $120 million and funds research based school-wide reform. The fiscal year 1999 request is $150 million. Under this proposal, BIA and the U.S. Territories would receive a 1 percent set-aside, estimated at approximately $2.7 million. The Department of Education notified the BIA that their portion of the set-aside would be $896,402. From this amount, $815,323 would be used for Title I comprehensive school grants and $81,079 would be used for Fund for the Improvement of Education projects. NIEA is concerned that the usual share for BIA and Territories combined funding from typical set-asides is divided according to an average 60/40 split. A ruling from the Department of Education recommends 33 percent instead of the standard 60 percent allotment. We oppose this ruling and support funding for BIA schools at no less than 60 percent.

—*Impact Aid.*—NIEA does not support the Administration request of $696 million, which is $112 million less than the 1998 amount. Impact Aid compensates school districts in areas where large numbers of children live on, or are associated with, Federal property such as Indian reservations or military bases. In 1998 the Department estimated that over 118,000 Indian children living on Indian lands would generate approximately $214.5 million for local school districts. In fiscal year 1999, American Indian students will generate approximately $270 million for local public schools. Based on 1998 funding, Impact Aid school districts would lose funding from approximately 2.7 million students (based on a total 1998 enrollment of 20 million students), should the funding not be restored. NIEA urges the Committee to support restoring the $112 million for Impact Aid school districts.

—*Education for Homeless Children and Youth.*—NIEA supports the fiscal year 1999 request of $30 million for Education of Homeless Children and Youth. Under this program, the BIA receives a one percent set-aside for homeless students served by the BIA.

—*Bilingual Education.*—NIEA supports the Bilingual Education request of $232 million. American Indians receive indirect funding for Bilingual Education programs in the amount of $30.2 million. Funding is distributed through grants to school districts to address the severe academic problems of school children who are limited English proficient. The Department estimates that 182,000 American Indian students will receive bilingual education assistance in fiscal year 1999.

—*Special Education Grants to States.*—NIEA does not support the Administration's fiscal year 1999 request for Special Education programs since it is only increased by $35 million to $4.8 billion. The Individuals with Disabilities Education Act (IDEA) was reauthorized in 1997 as Public Law 105–17. BIA schools receive 1 percent for the education of children 5–21 years with disabilities who live on reservations. An additional .25 percent is allocated for distribution to tribes and tribal organizations to provide for the coordination of assistance and related services for children aged 3–5 with disabilities on reservation schools. The set-aside amount in the fiscal year 1999 budget request is estimated at $46.7 million. Approximately 7,000 Indian students with disabilities would be served with Special Education funding. NIEA voiced its opposition during the reauthorization of IDEA as bill authors proposed to lower the Indian set-aside amount from 1.5 to 1.25 percent.

—*Special Education Grants for Infants and Families.*—NIEA supports the $4.5 million request for Grants for Infants and Families program. BIA schools receive 1.25 percent for distribution to tribes and tribal organizations for the coordination of assistance in the provision of early intervention services to children aged birth to 2 years.

—*Rehabilitation Services.*—NIEA supports the President's fiscal year 1999 request of $2.6 billion for Rehabilitation Services. The Rehabilitation Service Grants Indians in the fiscal year 1999 budget is $17.2 million, a $1.9 million increase over fiscal year 1998. Funds for this program are based on a 0.5 percent set-aside. These critical dollars provide vocational rehabilitation services to 7,000 American Indians with disabilities living on reservations.

—*Education Technology.*—The fiscal year 1999 request is $591 million, $50 million more than 1998 and includes a Technology Literacy Challenge fund, Technology Innovation Challenge Grants, and Leadership Activities. An additional $87 million goes for three new national programs: teacher training in technology, community-based technology centers, and technology leadership activities. American Indians are estimated to benefit with approximately $2.3 million in Technology Literacy Challenge funds in fiscal year 1999.

—*Alaska Native Education Equity.*—NIEA supports the fiscal year 1999 request of $8 million, the same as the previous two fiscal years. The Alaska Native Education Equity program funding request provides funding for continuation of projects that address the barriers preventing Alaska Native students from achieving to higher academic standards.

—*Vocational and Adult Education.*—The fiscal year 1999 request for Vocational Education is $1.1 billion, a $3 million increase over 1998. Under this program American Indians previously received funding under two programs the Indian and Hawaiian Native set-aside and the Tribally Controlled Postsecondary Vocational Institutions. The fiscal year 1999 request eliminates funding under the Tribally Controlled Postsecondary Vocational Institutions program, which was funded at $3.1 million in 1998, and moves it to the Indian and Native Hawaiians set-aside. Funding for the Indian and Native Hawaiians set-aside in the fiscal year 1999 request is $20.1 million, $4.5 million more than in 1998 (Tribally Controlled Postsecondary Institutions would receive $3.1 million in the 1999 request).

—*Reauthorization of the Higher Education Act.*—The reauthorization of the Higher Education Act, as proposed by the Department and passed by the House Committee on Education and the Workforce, includes a new addition to Title III, Aid for Institutional Development called the Strengthening Tribal Colleges and Universities (TCU) Program. This new initiative would create an institutional aid program designed to improve, strengthen and expand the institution's capacity to serve American Indians and other low-income students. The fiscal year 1999 request for this program is $5 million which NIEA supports. The following are some of the proposed sections of the Higher Education Act reauthorization which NIEA fully supports:

—*Title IV.*—Under Title IV, the TRIO program will remain virtually the same except for minor administrative changes. The fiscal year 1999 request is $583 million, $53 million more than in fiscal year 1998. The TRIO program benefits approximately 7,900 American Indian and Alaska Native students at an estimated $6.3 million in fiscal year 1999.

—*Title V.*—Under Title V, the Administration proposes to focus resources on recruitment of new teachers for high poverty urban and rural areas, preparing them well, and supporting them during induction, the critical stage of a teacher's career. American Indian and other minority serving institutions with teacher training programs would be given priority during the application process. Title V is currently funded at $2.2 million while the fiscal year 1999 request is $67 million, a substantial increase for teacher preparation.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

III. Administration for Children and Families

—*Head Start.*—NIEA supports the fiscal year 1999 budget request of $134.5 million for programs for American Indian children. This request is a $10 million increase over fiscal year 1998 and is needed in Indian Country. The Head Start Bureau estimates that over 21,000 American Indian children will benefit from the services provided by this program. Currently there are 130 Indian Head Start programs serving Indian communities.

—The Head Start Act is being reauthorized in 1998 and NIEA anticipates the need for few major changes to the program as it affects American Indians. NIEA is concerned, however that regulations regarding consultation with Indian Tribes are still going through the clearance process at the Department of Health and Human Services. The latest consultation requirement went into affect after the last reauthorization in 1994. NIEA requests that this be completed and made available to Indian Country as soon as possible.

IV. Indian Health Service

—*Indian Health Professions Scholarships.*—NIEA supports a funding level of $30 million, $1.3 million more than the $28.7 million requested for Indian Health Professions in fiscal year 1998. There has been no significant increase in this program since fiscal year 1996. The need for health professionals in Indian Country has far exceeded the available funding for American Indians. The Indian Health Professions is authorized by Public Law 94–437, the Indian Health Care Improvement Act (IHCIA). NIEA supports an increased appropriation to meet the rate of inflation and the higher costs of training for health-related fields that increase in cost annually.

III. Other DHHS Indian Education-Related Programs

—*Administration for Native Americans (ANA).*—NIEA requests a funding level of $38 million for ANA programs, an increase of $3.1 million over fiscal year 1998. ANA provides funding for tribes and non-profit Indian organizations to develop economic development, environmental management, and language retention and preservations projects. NIEA anticipates approximately $2 million going toward language preservation grants, which is $200,000 more than in 1998. NIEA supports the Native Language Act of 1992 which authorized a funding level of $2 million in fiscal year 1993. This provision, however, has never been appropriated. Funds have come instead through ANA.

—*Child Care Development Block Grant (CCDBG).*—NIEA supports the fiscal year 1999 request of $5.1 billion for child care activities. Included in this request are funds for child care entitlements (Mandatory Funds), and Discretionary Funds (the former CCDBG). Tribes receive a 2 percent set-aside of these funds. Included in the $5.1 billion request are funds to implement the President's Child Care Initiative which would support an Early Learning Fund, a Standards Enforcement Fund, a Child Care Provider Scholarship Fund, and a Research and Evaluation Fund. In fiscal year 1998, 243 tribal grantees were awarded over $61 million in Child Care and Development Fund (CCDF) grant funds. Through consortia arrangements, CCDF tribal grants may serve over 500 federally-recognized Indian Tribes and Alaska Native Villages.

PREPARED STATEMENT OF STEPHEN A. JANGER, PRESIDENT, CLOSE UP FOUNDATION

Mr. Chairman, distinguished members of this subcommittee, my name is Stephen A. Janger and I am President of the Close Up Foundation. I appreciate the opportunity to submit this testimony in support of the Allen J. Ellender Fellowship Pro-

gram administered by the Close Up Foundation. Please allow me to begin by expressing the sincere thanks of all of us at the Foundation for this Subcommittee's past support. Your support has enabled tens of thousands of participants to take part in our citizenship education programs.

From most accounts, today's economy is robust, unemployment rates are low, interest rates are low. There is another rate that is low, however, that is disturbing to those of us concerned with civic education. Shortly, I will discuss in more detail the recently released UCLA survey of the values and attitudes of college freshmen, but suffice it to say that the survey results demonstrate that young people entering college today are more apathetic toward politics than anytime in the history of the survey. This apathy coupled with other signs of disengagement are some of the reasons we at Close Up believe it is a critical time to address and correct the "whatever" attitudes of today's youth. Our program can help. We have spent more than 27 years working to educate young people about their citizenship responsibilities. For these and other reasons, we believe there is a critical need for our program and we respectfully request $3.0 million for fiscal year 1999.

I do not have to remind any of you that every day the news media are filled with stories about various reports or studies that contain information and statistics that are negative and troubling. In January, one of those studies was reported in media across the country. It caught our attention immediately because it is so relevant to the work Close Up has been doing for 27 years.

The results of a survey conducted by the Higher Education Research Institute at UCLA's Graduate School of Education and Information Studies are contained in a book entitled The American Freshman: National Norms for Fall 1997. The statistically-adjusted results of the 252,082 responses from college freshmen reveal record levels of academic and political disengagement. The response to the question of the importance of "keeping up to date with political affairs" was an all time low (26.7 percent) for the 32 year old annual survey. Upon reading this disturbing survey, I wrote to all of you to express my concern and to remind you that Close Up, with its commitment to educating students to be informed, responsible citizens, continues to be part of a solution for this problem.

From its inception, Close Up has had as a primary focus teaching, in a hands-on way, that informed, active citizenship is the responsibility of all Americans. Citizenship participation is a significant part of what made America strong, and it is an essential part of what will help America continue and endure. The results of the survey hopefully should awaken the country to the need to focus on trying to find ways to successfully address this problem. As a nation, we must heed the warning, and meet the challenge because the strength of our democracy lies in the civic well-being of our country.

The Close Up Foundation's programs are designed to combat the political apathy expressed by today's college freshmen. Obviously, we do not believe our program alone can correct the entire problem, particularly since our funding has been reduced by 64 percent since fiscal year 1994. We do believe, however, that our program can help to reverse the trends evidenced in the survey; and, that with an increase in Ellender Fellowship funding and a corresponding commitment to generate private sector support, we can reach a greater number of the students who need this kind of program the most.

Close Up has participants from all 50 States, the District of Columbia, Puerto Rico, and the Pacific Trust Territories. We work hard to ensure that "all kinds of kids" take part in our programs. There are students who are academically gifted and students who struggle in school; there are students from urban, rural, and suburban areas, from large and small communities; there are students who are visually-impaired, hearing impaired, or orthopedically-challenged; there are students from all economic and cultural backgrounds. All of these diverse, wonderful young people are "mixed" together on various activities in Close Up's program and the results are an eye-opening realization that they are not as different as they thought they were at the beginning of the week. They also realize that they share a common bond, they are all citizens of the United States with the same rights and responsibilities. Diversity is not America's biggest problem, it is our strongest asset.

The Ellender Fellowships are in large measure the vital key that makes this possible. With the Ellender Fellowships, Close Up can reach the most underserved student constituencies in America. We can provide fellowship assistance to economically needy students and allow them to work alongside their peers. We enable students who are recent immigrants to the United States and students whose parents are migrant workers to take part in our Program for New Americans. This encourages some of our newest citizens to work and learn with students from very different backgrounds.

Although most Close Up programs are primarily focused on students, we also are involved with educators. The Administration and several Members of Congress, from both sides of the aisle, have spoken of the need to increase the number of teachers and the quality of teaching in America. A primary objective of increasing the number of teachers is to reduce the student teacher ratios in classrooms. We believe that the Close Up experience serves to stimulate young people to enter the teaching profession. Even more importantly, our teacher professional development program significantly increases teacher retention. According to one principal, "Close Up is the strongest antidote to teacher burnout that I know."

Close Up is unique from other civic education organizations with its teacher professional development program. While the students are in Washington on their program, a separate program is conducted for teachers. This teacher program exposes educators to new teaching ideas and information presented by Close Up's trained professional staff. Teachers in this program also gain invaluable insights from their peers. Educators from across the country "swap" ideas and experiences building greater resources for all of the teachers benefiting from the program. Many veteran educators report that, "* * * participating in Close Up is the most important in-service experience of my career."

Through this teacher program, civic educators are reinvigorated and return to the classroom to inspire students to be good citizens and exercise the responsibilities of citizenship. An enthusiastic teacher may be the best tool to turn around the trend toward disengagement. Close Up and the Ellender Fellowships can not possibly reach all of the students we need to, but one teacher can reach 125 students or more each year. With an invigorated teacher as the messenger, high school students can begin to learn early the lessons of the importance of taking responsibility for their life-long civic literacy.

Close Up's teachers and students make other contributions to their communities. A significant number of reinvigorated Close Up teachers return to their communities and organize Close Up Local Programs. These local programs are civic education activities that focus on local or statewide governmental entities, or important policy issues facing the communities. Approximately 40,000 people take part annually in an estimated 120 local programs. All of this is done at no cost to the federal government. I am very proud of these activities, and I think they demonstrate the effectiveness of Close Up's program and message more than my words could ever express.

It is disappointing that Close Up's effectiveness and uniqueness seem not to be understood by the Department of Education. The Department of Education's (DEd) fiscal year 1999 budget justification materials include the same erroneous rationale for eliminating the Ellender Fellowship program that was presented as last year's justification. The Congress obviously did not accept the DEd's rationale last year, and nothing has changed to make that rationale any more acceptable this year.

As we stated in last year's testimony, Close Up and the Ellender Fellowship program are very distinct from other civic education organizations. Attempts to compare Close Up's fellowship program with those of other civic education organizations are not legitimate. Even with our drastically reduced funding, using an effective multiplier we have been able to provide more fellowships in any one year than some of these organizations have total participants.

More importantly, Ellender and Close Up fellowships are awarded solely on the basis of economic need. It is my understanding that other civic education organizations occasionally offer fellowships but in a very limited number. To receive a fellowship, however, the applicants are required to submit a written essay and compete for the fellowship. This can be an intimidating task for many students, and discourages students from applying for fellowships, precluding the participation of numerous students.

Additionally, I understand that some of the fellowships awarded by other organizations are designated for certain geographic areas. This prerequisite further limits the availability of fellowship assistance to students. At Close Up, we have been fortunate to receive donations from various private sources. Sometimes these donors place various restrictions on their contributions. In this vein, I can appreciate the limitations this imposes on an organization, and it is one of the reasons that the Ellender Fellowships are so critically important to Close Up's work. With the Ellender Fellowships, we can help students regardless of where a student lives or what their current abilities are with respect to essay writing or test taking.

Again this year, the DEd's budget justification includes a reference to the Department's belief that the Foundation's development efforts, especially the new alumni/ae program, will enable the Foundation to continue the Ellender Fellowship activities without federal funds. At the risk of being repetitive, I will reiterate what we said last year. Alumni/ae development programs do not generate a sustainable, sub-

stantial revenue stream for major universities or other non-profit organizations. It is very unlikely, despite our enthusiastic alumni/ae, that Close Up could expect to receive major gains from its fledgling alumni/ae program. Furthermore, Close Up's alumni/ae are a very young group of individuals. Our oldest alumni/ae are just now reaching their late forties. The vast bulk of our alumni/ae are young people who are just starting out in life and have heavy demands placed on limited financial resources. We are committed to continuing our alumni/ae program. We already have enjoyed promising results from finding old friends and developing new friends. The results, however, do not support the DEd's contention that the alumni/ae program will produce financial support sufficient to replace federal funding.

Close Up has worked hard to bring its citizenship lessons to young people. During the 1998–99 program year, Close Up will hit a noteworthy milestone. We will have had more than 500,000 participants in our programs. This is an important accomplishment, but more than the number of participants we are encouraged by the contributions our program and its participants make to the civic literacy of our country.

We hear reports all the time about Close Up participants who become engaged in the processes of good government. They return to school and become involved there as well as in their communities. Students return home and speak with their parents and family members about things like the importance of voting, or community service. The interest does not stop in the schools and homes, it continues with them to all aspects of their lives. Former Close Up participants are in all walks of life, but a recent Close Up alumni/ae search found a significant number of former participants working on Capitol Hill, in the federal government, in state and local government, and in numerous social service or policy organizations.

Fortunately, Close Up participants seem not to share the apathy of current college freshmen. Our evidence points to the fact that Close Up's program and its message are effective and working. This is a central reason why we believe Ellender Fellowship funding should be increased to allow more young people with limited economic means to have the same opportunity for civic enrichment that their more affluent peers enjoy. Providing equality of opportunity is one of the most beneficial and respected historic roles of the federal government. There are few more important educational areas where this needs to be done than in citizenship education. The Ellender Fellowships are a highly effective seed element creating widespread educational and private sector partnerships that benefit the individual, the community and the country.

Mr. Chairman, I would like to conclude by again thanking you and the members of this Subcommittee for your past support. As I believe I have demonstrated, the Ellender Fellowship funding provided by this Subcommittee is an integral part of Close Up's success in reaching thousands of students who would not be able to participate without fellowship assistance. In this time of increasing disengagement by America's youth, this relatively small amount of federal funding can be multiplied many times over to reach students who can help to change the direction of political apathy.

I will be glad to answer any questions or to provide any information. Thank you very much.

PREPARED STATEMENT OF C.M. SGT. JAMES E. LOKOVIC, USAF (RET.) DIRECTOR, MILITARY AND GOVERNMENT RELATIONS, AIR FORCE SERGEANTS ASSOCIATION

Mr. Chairman and distinguished committee members, on behalf of the members of the Air Force Sergeants Association (AFSA), thank you for this opportunity to discuss the Department of Education's (DOE) fiscal year 1999 budget. Within the DOE appropriations is a funding item of critical importance to the quality of the lives of military members and their families. Today I ask you to once again consider and, this year, to fully fund Impact Aid in support of the children of the military men and women serving our nation. AFSA's primary mission is to promote and protect the quality of the lives of all active and retired enlisted Air Force members (active duty and reserve component) and their family members and survivors.

Impact Aid is an important program for the military families we represent, as it "zeroes in" on the quality of the educational programs provided to their children. AFSA believes that full Impact Aid funding rightfully falls within the purview of this committee and the Department of Education. Impact Aid is not a "defense" program but, rather, a national program whereby the federal government reassigns these federal workers and their families from location to location then, rightfully, supplements local communities affected by their presence.

Background

Just how are local school districts impacted, and to whom does Impact Aid apply? These appropriations provide assistance to local school districts serving civil servants, Native American children, low rent housing, and, in 40 percent of the total appropriation, to school districts impacted by the presence of military children. It is on behalf of these military children that I speak today.

Since the Truman Administration, our government has recognized that it alone is responsible for placing and relocating military families. It, therefore, has accepted an obligation to compensate local school districts which provide a public education to military children. In effect, Impact Aid compensates for an "unfunded mandate." Impact Aid compensates for tax revenues (that fund local education) that are generally not paid by military members.

For military children, funding is provided at two different levels; one level (3a) if the parents of a student live and work on federal property and another level (3b) when a parent works on federal property but lives in the community as a renter or homeowner. Local educational agencies receive $2,000 for each 3a student and $200 for each 3b student. Impact Aid is an excellent example of federal funds going directly to a program with little bureaucratic red tape. The funds go directly to schools to serve the education of military children, and local boards of education decide how it is to be spent.

Certainly, the children of military members lead a unique life, fraught with challenges unlike those faced by most of the rest of this nation's youth. They typically change schools often, repeatedly being uprooted and having to readjust to new communities and friends. One very necessary annual budget action has been to recognize these young men and women by providing funding through Impact Aid to the local school districts which educate them. This federally funded program provides for the education of military children in grades K through 12.

Interestingly, for these children, the return to our government goes beyond the normal focus on an educated citizenry. They are unique in that approximately 50 percent of current active duty personnel grew up in military families. In that sense, Impact Aid directly affects the quality of our nation's future military leaders.

The all-volunteer force has had a dramatic impact on the new military and its demographics. More personnel (approximately 60 percent) are married. Approximately 65 percent of military spouses are employed, especially within enlisted families. There are more single parents in our military today. There has been a steady increase in the number of military pre-school age children. Active duty personnel have about one million children younger than 12 years of age.

Today, there are increasing pressures and anxieties for military families caused by a number of factors, including a significantly intensified operations tempo and the uncertainty of downsizing, privatization, and outsourcing. Deployment rates have been very high as our military's mission has transitioned to "peacekeeping" around the globe, and military parents must be prepared to deploy rapidly. With all of the other challenges of military life, it is important that, at the least, we are committed to provide a quality education for military children. It is a high priority for military families, and it is a readiness and a quality-of-life issue. As our military personnel are deployed, they should not have to worry about whether their children are receiving a quality education.

WHY MILITARY CHILDREN NEED THE SUPPORT OF IMPACT AID

In recent years, some districts with a large number of military children have found there is inadequate educational funding, which has required higher property tax rates (which generally fund local school systems). Clearly, localities, should not be punished because of the location of a federal facility. The administration, which ultimately assigns these families, has an obligation to support them. Accordingly, it is gratifying that this committee has stepped up to examine Impact Aid as part of the ongoing congressional and administration discussions on nationwide educational funding and expansion. The children of our military members must be considered in these plans. Impact Aid is the most proper way to reflect the need to protect their (and local community) interests.

Another potential problem would loom if Impact Aid were not fully funded. As this committee knows, there have been attempts in the past to charge"enrollment fees" to the parents of military children. Military parents expect that the federal government will act in the best interests of their families. If any group of the nation's families should earn an extra measure of governmental support, it should be those who serve our nation and are transferred at the pleasure of the government. However, we fear that continued diminishment of the program will result in other attempts by communities to charge fees to make up for educational funding short-

falls. It would be wrong to penalize military families simply because the government stations the family at a particular location.

The problem could become more severe. As the military proceeds with the privatization of military housing, and if that housing is not considered "federal property," then students would be classified as 3b students, providing only $200 per student to the local education authorities. This could create tensions between the residents of heavily affected communities and military facilities in those communities. Area civilians could reasonably question why their children's education must suffer. This is an area that requires careful congressional observation. The options are to fully fund and continue this important aid, or to underfund it (as has recently been done), hoping that Congress will remedy the situation.

During each of the past few years, the administration and the Office of Management and Budget have recommended deep cuts in the Impact Aid program and substantial increases in "nice to have" programs such as Goals 2000 and college incentives for "other than military service." Why is the basic education of military children such a low priority? If our military children don't receive the quality education they need in elementary and high schools, we won't have to worry much about college incentives.

As funding for school districts that serve military children has been reduced, one of the first areas that has been affected is new construction and upkeep of the school buildings. Continual cutting of this program has had a tremendous impact on the local schools. Also, due to the drawdown, some schools have experienced substantial increases in students and are having a difficult time accommodating the growth. Many of the school facilities used by military children are nearing a half century in use and today are in need of repair, ADA accessibility, asbestos removal, etc. The aging facilities and shortage of upkeep and maintenance has put many of the schools in dire need of attention.

In light of the cost of education and the absolute propriety of fully funding Impact Aid, what has been our government's track record? During the past 17 years, while the number of students served through Impact Aid has remained the same and the Consumer Price Index has increased by 70 percent, Impact Aid funding has remained level. In fiscal year 1998, the program received a 10 percent increase. This was definitely a step in the right direction. The fiscal year 1999 appropriation needs to continue to strive to meet the funding levels. Without question, full funding for Impact Aid would greatly assist in ensuring the children of our military personnel a quality education without endangering or compromising the budgets of local school districts.

THE REQUEST

Mr. Chairman, we believe the obligation is clear: the federal government must pay its tax bill to school districts for the education of military children. Originally instituted in 1950 and fully funded until 1970, Impact Aid is now funded at approximately 40 percent of the level originally intended. As we indicated, the result of such program proration has resulted in school districts facing many financial crisis and the prospect of possible closures.

On behalf of those that AFSA represents, I recommend a modest, 10 percent appropriation increase over last year. Based on the past few years, we expect that the Department of Defense (DOD) may once again find itself forced to supplement the Impact Aid parsed out by the Department of Education for more seriously impacted, high-need districts. This should not be the case; but in the past DOE funding shortfalls have forced the issue. If you repeat 1998's 10 percent increase, this committee would recommend an Impact Aid appropriation of $889 Million. However, if this committee is prepared to embrace the obligation to fully fund the need with education dollars (rather than requiring a DOD supplement), we would request that the full appropriation be $939 Million. Those that have tracked Impact Aid since the 1950s and the escalating costs of education have indicated that this figure will fairly supplement local school districts for situations created by the federal government.

AFSA contends that the time has come to set an automatic funding mechanism in place to avoid having to revisit this issue each year. A look at the history of Impact Aid appropriations shows a remarkable disparity between overall DOE spending and Impact Aid appropriations. Since 1950, the overall DOE budget has increased at a factor of more than 94 times; during the same period, Impact Aid appropriations have increased at a minor fraction of that. The simple, yet important, questions we need to consider in determining the right thing to do are these: "Do we, as a nation, commit to assisting local school districts who educate the children of our military?" "If so, can we arrive at a level of spending that results in quality education without endangering local budgets?" And finally, "Do we accept that in

stationing a military family there, our government also incurs an incontestable obligation to supplement local school districts for each student so educated?" If so, we urge this Congress to arrive at an annually applied formula, using $939 Million as a baseline, which would become an automatic part of every affected appropriations budget. We urge you to make the education of military children a national priority.

Mr. Chairman, we understand the difficult budget choices that you and this committee face. However, we believe that the education of military children should not suffer because their families are moved at the convenience and desire of the federal government. Military children should be held in the same high spending priority that this nation affords any other of its children. We urge this Congress to direct the Department of Education to request full funding for Impact Aid. Mr. Chairman, again I thank you for this opportunity to represent the views of enlisted members and their families on this issue. As always, the Air Force Sergeants Association is ready to support you in matters of mutual concern.

PREPARED STATEMENT OF AMERICAN COUNCIL ON EDUCATION

Mr. Chairman and members of the subcommittee: The American Council on Education is the nation's principal body representing all sectors of postsecondary education, including 1,800 two-year and four-year member colleges, universities, and education associations. We share with you the perspectives of 27 higher education organizations on the fiscal year 1999 appropriations for the Departments of Labor, Health and Human Services, and Education. Together, these associations represent the 3,700 colleges and universities across the nation that provide the teaching, research, and service essential to our economic and social well-being, as well as the students who attend them.

We begin by expressing our profound appreciation for the priority and support that members of this Subcommittee have shown for higher education, and especially for your support last year. We know well the constraints you face in the non-defense discretionary budget this year, but urge you to give a high priority to expanded investment to help individuals develop their talents to the fullest and gain access to the many options available in higher education. We continue to have a concern for those at the lowest income levels. The support provided through need-based student assistance programs helps to ensure that higher education will remain available to all. In the world in which we live, learning throughout life has become the most crucial element in the diverse fabric of American social and economic life and in the advancement of hope and opportunity for all Americans.

We especially thank this Subcommittee for last year's appropriations bill. You increased federal support for both student aid and biomedical research. The purposeful investments you made last year will pay dividends for decades to come. In particular, we commend the Subcommittee for increasing the Pell Grant maximum award to $3,000 and expanding access to Pell Grants for approximately 220,000 needy students, for increased support for the Supplemental Educational Opportunity Grant (SEOG) program, for maintaining support for the Federal Work-Study (FWS) and Perkins Loan programs, as well as increases in the TRIO program. At the same time, you also sharply increased funding for biomedical research through the National Institutes of Health (NIH).

Turning to fiscal year 1999 appropriations, we will focus predominantly on the matter of federal student financial assistance. The first session of the 105th Congress was one of the most creative and productive legislative sessions in history with regard to higher education policy. The importance of postsecondary education was evidenced by the increase in Pell Grant funding, as well as the nearly $40 billion in education-related tax cuts approved by the Congress. This effort is expected to continue as Congress completes action to reauthorize the Higher Education Act of 1965.

This Subcommittee will likely play an increasingly important and prominent role in developing good public policy, and ensuring that the interests of students and the nation are served well and effectively. Here are three reasons why we believe this to be the case:

1. Without regular increases in the Pell Grant and other forms of student grant assistance the gap in college attendance rates between low-income students and other more advantaged peers will continue to grow and crucial talent will be lost to the nation. While federal student aid has boosted the attendance rate of students from the lowest-income quartile from 45 percent in 1979 to 58 percent in 1994, the college attendance rate for high-income students has grown from 67 to 88 percent over the same period. In short, the gap has widened. Further steady increases in the Pell Grant maximum are necessary to avoid a situation in which family wealth

determines who can attend college. We must bring the attendance rates of low-income students in line with those of higher-income students and remove the financial barriers blocking access to college. The actions taken by this Subcommittee are critically important.

2. Current borrowing trends among students demonstrate clearly that students need to be given viable alternatives to debt financing as the primary means of paying for college. In 1979, Pell Grants comprised 76 percent of all federal funding for student aid, whereas today loans account for 72 percent. The maximum Pell Grant has fallen 26 percent in constant dollars since 1978. In other words, adjusted for inflation, the maximum award is worth only 74 percent of what it was in 1978. To restore the value of the 1978 Pell Grant maximum in current dollars, the maximum award today would need to be set at $4,050.

The value of the campus-based student aid programs has fared even worse over time. After adjusting for inflation, between fiscal year 1980 and fiscal year 1998, funding for the SEOG declined 17 percent; FWS dropped 25 percent; new capital contributions in the Perkins Loan program fell 76 percent; and State Student Incentive Grants (SSIG) tumbled 88 percent.

As the purchasing power of federal grants has declined, low- and middle-income students have found themselves facing an increasingly limited range of choices among institutions. Many low- and middle-income students continue to go to college, but they have had to bear the brunt of escalating indebtedness. Reducing the extent to which these students must borrow is not merely desirable education policy, it is sound national economic policy. It is this group of students for whom the highest returns on the federal dollar would be realized. The most effective remedy for lessening reliance on loans is a restoration of the value of federal grant assistance, a journey on which this Subcommittee began in fiscal year 1998. We urge you to continue that progress in fiscal year 1999.

3. Increased federal grant assistance will also help campuses reduce the pressures that increase college tuition. We share the serious concern members of this Subcommittee have with respect to college costs and prices and the rise in tuition charges over the last decade. In recent years, the rate of increase has declined significantly, but reducing the strain on institutional student aid budgets through the provision of adequate federal student aid will help greatly. Every college and university president in the country is searching for ways to contain college costs. Federal student aid helps in that important task. As the National Commission on the Cost of Higher Education noted, abundant evidence supports the assertion that the availability of student aid helps hold down the cost of college.

Data show that when federal student aid increases rapidly, tuition rises at a more modest rate than it does when student aid grows slowly. Indeed, in the 1990s, we have seen a significant moderation in the rate of increase in college tuition as federal student aid has grown.

In light of these considerations, the role of the members of the appropriations committees is more critical than ever. The issue is not merely the appropriation of funds, but, more importantly, the attainment of effective national public policy outcomes. Toward this goal, the higher education community respectfully submits the following recommendations for your consideration:

—We urge the Subcommittee to continue its strong support for the Pell Grant program. We are deeply grateful for the significant increase in the maximum grant in fiscal year 1998, which will help the neediest individuals aspiring to attend college. The Administration has proposed a $100 increase in the Pell Grant maximum in its fiscal year 1999 budget request. We urge the Subcommittee to take stronger measures to restore the lost purchasing power of the Pell Grant and provide a larger maximum. The current maximum award is still far below the authorized level, and remains insufficient to help those students with the greatest need, and to prevent students from accruing significant levels of debt.

—We urge you to provide a $70 million increase for the SEOG program, which would bring about the $100 increase proposed in 1996 by Senators Loft and Specter. SEOG funding is directed toward the most financially needy students, and until last year's modest $30 million increase, this program had been level-funded since fiscal year 1992. While this program appears to Congress to be a small one, to the most needy students, SEOG can be highly significant since it carries an allowable maximum grant of $4,000.

—In accordance with what was included in the President's budget request, we urge you to increase funding for the Federal Work-Study program by $70 million to a total of $900 million.

—We urge you to continue the federal capital contribution to the Perkins Loan program at least at the fiscal year 1998 level of $135 million. By virtue of the low interest rates the Perkins Loan offers, this program provides less expensive

loans to students with great levels of financial need. The Administration proposed a reduction in the Perkins capital contributions and we think this was a significant mistake.

—We support the continuation of the institutional-state-federal partnership in student financial assistance. We understand that this Subcommittee has raised concerns with the current SSIG program and we have heard these concerns. The authorizing committees are considering a new partnership program that will continue to use modest federal funds to leverage additional state student aid dollars. We understand that their proposal may call for an increased effort on the part of states in order to receive new money and will incorporate priorities of Members of Congress. The state role in the shared responsibility for higher education is very important. We urge you to provide at least $50 million for this new state partnership program.

—We urge the Subcommittee to provide sufficient funding in fiscal year 1999 for the Graduate Assistance in Areas of National Need (GAANN) and Javits fellowship programs to ensure that both new and continuing fellows can be supported. We appreciate the Subcommittee continuing to fund GAANN and Javits as distinct and complementary graduate programs funded within the GAANN account. The Title IX graduate education programs in your Subcommittee's jurisdiction are a critical source of federal financial assistance for academically superior students with high levels of financial need. In addition, they are the only significant source of graduate support in many academic disciplines.

—We support an increase for each of the component parts of Title III, including Strengthening Historically Black Institutions, both for the undergraduate institutions and the graduate programs in Section 326, which address the underrepresentation of African Americans in the health, scientific, and legal professions; Hispanic-Serving Institutions; and Endowment Challenge Grants. In addition, we recommend that the Subcommittee increase funding for the Strengthening Institutions program. These funds support a highly competitive program of assistance that helps developing institutions with large populations of low-income and ethnically diverse students improve the quality of their programs and services.

In conclusion, we thank the Subcommittee for your support of student aid and biomedical research in the past. The work of this Subcommittee affects the lives of all Americans, and especially those of low- and middle-income college students. Your support is essential if these students are to have the opportunity to develop their human potential in the years ahead and if our nation is to continue to prosper. We thank you for this opportunity to share the views of the higher education community.

Prepared Statement of Crystal J. Paulk, on Behalf of the Society of Professional Journalists

CAMPUS CRIME ISSUES

Mr. Chairman and members of the Committee, I appreciate the opportunity to talk with you about public access to crime records and campus judicial hearings. My name is Crystal Paulk. I am a recent graduate of the University of Georgia and worked at The Red and Black student newspaper when the university's judicial system was both closed and later opened as a result of legal action.

In recent years, Congress has shown a willingness to protect students when it passed the Student Right to Know and Campus Security Act of 1990. Congress later amended the Higher Education Act in 1992 to make clear that law enforcement records on college campuses are not beyond public scrutiny.

But this is not enough.

The U.S. Department of Education continues to allow schools to use the Family Education Rights and Privacy Act (FERPA) and its Buckley Amendment to deny access to criminal information within the campus disciplinary system. Thorough information about crimes on campuses is not available at most schools. With passage of the Accuracy in Campus Crime Reporting Act of 1997 (H.R.715), the public will be fully informed about the safety records of private and public campuses across this country.

The Society of Professional Journalists, represented by 14,000 members nationwide, feels strongly that it is the public's right to know information about such serious crimes on campus as rape, homicide and arson. Government should protect and promote the free flow of information. Without thorough and accurate crime information and the ability to report on closed disciplinary hearings, we all lose.

University communities are served by police forces and court systems that are not subject to public scrutiny. That's contrary to the way law enforcement and court systems operate. Government officials cannot filter or suppress documents or prohibit public access to criminal judicial hearings. But on campuses across the country, secret proceedings are the rule rather than the exception.

Today, campuses are experiencing increased incidents of serious crimes.

—Researchers at Cornell University and Southern Illinois recently reported that nearly one million college students may be carrying weapons

—Three students at the University of Cincinnati were recently charged with starting a dorm fire that led to the evacuation of 700 students. That single crime could cost the university $200,000.

—The University of Pennsylvania significantly increased its security measures after a rash of crimes that included 24 robberies in one month—twice the number for that month the previous year. A research associate was stabbed to death and a student was shot and wounded as he fled a holdup. Many students complained the precautions came too late.

—At Troy State University in Alabama, 13 students were arrested on various drug charges in April of 1996, and several of them lived in the same dormitory.

Despite this climate at colleges and universities—large and small, rural and metropolitan, private and public—college administrators continue to under report crime and keep the public from accessing timely and accurate information. Worse yet, they hold closed hearings on incidents involving crimes and defend the process as "educational" and necessary.

Why?

The main reason appears to be image and enrollment. Keeping the publicity at a minimum by dealing with matters internally helps recruiting. Meanwhile, parents and students become victims when they believe a campus is safe when it really isn't.

As a student, I became a member of SPJ and served as president of the University of Georgia campus chapter during the 1996–1997 school year. SPJ's members work in all media and include educators and students. One of the Society's key missions is to safeguard the public's right to records and access to meetings.

I worked for three years at The Red and Black, an independent daily newspaper. I also have been employed by the Athens Daily News and Athens Banner Herald and The Gainesville Times. I am currently an intern with Quill, the Society's national magazine. My internship is devoted to working on Freedom of Information issues. I am a student representative for the Campus Courts Task Force, a coalition of all the major organizations representing professional and student journalists and journalism educators. The Society founded the Task Force in 1993. Its 13 members support increased public access to crime information and secret campus courts.

My specific interest in this issue began during my freshman year at the University of Georgia when I began working for The Red and Black. The newspaper was successful in two cases that went before the Georgia Supreme Court in 1992 and 1993. The court granted access to disciplinary proceedings.

The first case involved a fraternity hazing ritual of paddling that left a student bleeding so badly from his rectum that he required hospitalization. The paper sued the school after reporters were denied access to the university's disciplinary hearing. In ordering that the records of this proceeding be made public, the Georgia Supreme Court aptly summarized the public's right to know:

We are mindful that openness in sensitive proceedings is sometimes unpleasant, difficult, and occasionally harmful. Nevertheless, the policy of this state is that the public's business must be open, not only to protect against potential abuse, but also to maintain the public's confidence intheir officials.

Jennifer Baker, another student, and I were assigned to cover the student judiciary beat for The Red and Black. Each week, we published a "Judicial Watch" which included information about hearings and decisions handed down during the week.

Those first few months were very difficult. Fellow students serving as student justices and defender advocates were told to have no contact with me outside the hearings, making it difficult to thoroughly report criminal incidents.

Posted notices of the hearings were also difficult to track because of a convoluted record-keeping system. On several occasions, I missed a class to attend a hearing only to discover the hearing had been canceled or moved to another room. A hearing might last 30 minutes or several hours. When I tried to speak to a student, that student was often told by a university official not to talk to me. At times, all I was seeking was the correct spelling of a name.

Despite these barriers, we persisted in the pursuit of accurate information. Accused students understood their rights and the student body overall knew the university was informing the public of criminal activity.

Unfortunately, our experience at the University of Georgia is unique. Whereas the students, faculty, staff and the general community at the University of Georgia could learn about the incidents of crime on campus—and the punishment meted out to criminal offenders—such is not the case throughout most of the nation. Instead, the vast majority of our nation's colleges and universities keep crime and its consequences hidden from public view. And despite previous efforts of the Congress to require that statistical information be publicly reported, the law as it currently stands falls woefully short in demanding that timely, thorough information about criminal information be made available.

This veil of secrecy is particularly troubling with regard to university disciplinary proceedings of students accused of criminal misconduct. The primary obstacle to access to disciplinary records is the U.S. Department of Education's interpretation of the Buckley Amendment. The Department defines disciplinary records as "education records" under the Buckley Amendment. Accordingly, it has said schools cannot release disciplinary records even when criminal activity is involved. Although the Buckley Amendment does not prohibit open hearings, university administrators are using the Buckley Amendment to close records. Thus, the conflict becomes obvious.

Frankly, the Society believes the Department of Education's definition of disciplinary records as "educational records" is wrong. Recognizing this problem, Secretary of Education Richard Riley wrote to this Committee during the 104th Congress to call attention to the fact that crime is an increasing problem in campuses, and stated that there is merit to arguments for public access for these disciplinary records. But Secretary Riley said that Congress, and not the Department, should make the necessary changes. H.R. 715 is the vehicle to make this change.

The Society and the Campus Courts Task Force strongly support public access to a daily and thorough campus police log and access to campus judicial hearings and records when the incidents stem from criminal and other non-academic misconduct. Such records should include information about how students charged with criminal behavior are disciplined. We believe the definition of law enforcement records must include disciplinary records stemming from criminal activities.

It is critical for Congress to change the definition of "educational records" to mean records only dealing with the academic life of a student. The Student Press Law Center, which provides free legal help to student journalists, offers this definition: "transcripts, teacher recommendations, test scores and other academic or financial aid records kept by the school."

My experiences as a student journalist made me understand that public access is vital to students living in the campus community for three reasons: to ensure fairness, justice and public safety. Let me explain why.

An accused student must be able to trust the judicial process.

Every school handles its disciplinary procedures differently. This also can lead to inconsistent sanctions. At the University of Georgia, the hearings resemble court proceedings. A student accused of violating a university regulation is notified by the Student Judicial Office and represented in the hearing by a student defender.

By tracking the system for The Red and Black, we discovered inconsistencies. The accused student had to choose between a formal hearing by peers or an informal hearing with an administrator. A student was seven times more likely to be suspended by his peers than by an administrator, a statistic that was reported in The Red and Black.

During the next few months, the judicial process changed. All accused students appeared before one hearing panel of two student justices and an administrator. The changes were supported by faculty and students. This inconsistent justice could not have been documented without access to disciplinary hearings.

There is no reason why campus crime and judicial proceedings should be treated differently than crime and courts off campus. Some recent examples are particularly troubling.

The University of Maryland is fighting to keep student athlete parking tickets secret. The case began after the student newspaper, The Diamondback, heard that a university basketball player had accumulated more than $8,000 in unpaid parking tickets. They also heard that the player, in violation of National Collegiate Athletic Association rules, had obtained money from a former coach to pay the fines. The newspaper sought additional information under the state's open records law. But university officials turned down the request, citing FERPA. The Diamondback sued, and a Maryland court ordered the university to turn over the records. However, the case is on appeal and both the Department of Education and the NCAA have filed supporting briefs to overturn that decision.

At Louisiana State University, a secret court was used to expel members of the student government who stole money from a campus book fair. The case was never prosecuted by the local authorities. LSU administrators informed the student body

the book fair revenue had "evaporated," but never specified who was responsible or how much money was stolen. A tenacious editor of the campus newspaper found out what had happened by interviewing two expelled students who felt their punishment was too harsh. When the editor asked LSU administrators to comment on the reported $2,700 theft, they refused. The student newspaper and the Shreveport Professional Chapter of SPJ sued for the documents, but were unsuccessful. The court ruled in the university's favor. LSU never publicly disclosed how much money was stolen, who was involved or what actions were taken to punish the violators.

Contrast the LSU example with a similar case I covered in March 1994 at the University of Georgia. During an audit of the University Bookstore, missing funds were traced to three student cashiers. The theft totaled $4,251. But in this instance, the case went to court—a real court—where the students were sentenced to 12 months probation, community service, and required to provide restitution. The students also were brought before the student judiciary in an open hearing and suspended from school for one year.

On both the LSU and Georgia campuses, students were outraged by these thefts. However, at the University of Georgia, where the case was handled openly, the public was officially informed justice had been served.

Administrators must release information for students, their parents and the community at large to know if their campuses are safe.

The Ohio Supreme Court recently recognized the necessity of open campus judicial records. In a July 9, 1997 ruling, the Court ordered Miami University to release detailed disciplinary records to the campus newspaper, The Miami Student. In words that resonate here, the Court wrote:

"Unfortunately, at present, crimes and other student misconduct are escalating at campuses across the nation. For potential students, and their parents, it is imperative that they are made aware of all campus crime statistics and other types of student misconduct in order to make an intelligent decision of which university to attend. Likewise, for students already enrolled in a university, their safety is of utmost importance. Without full public access to disciplinary proceeding records, that safety may be compromised."

The Society and the Campus Courts Task Force believe college and university crime reports are an inaccurate representation of campus crime. A story published in The Washington Post in April this year cites specific instances where violent student crimes were not included on official reports because the incidents occurred off campus. Crimes against these students are seldom included in a college's overall statistics that are reported annually to the U.S. Department of Education.

Even when the Department of Education cites a college or university for breaking the reporting requirement on annual crime reports—something it has managed to do only twice in seven years—campus administrators seem to view those federal citations as insignificant.

In March 1997, the U.S. General Accounting Office reported on the difficulties that colleges have faced in meeting federal reporting requirements about campus crime. See U.S. General Accounting Office Report to Congressional Requesters, Campus Crime: Difficulties Meeting Federal Reporting Requirements, Report No. GAO/HEHS–97–52, March 1997. The GAO concluded that the Department of Education was "slow" in monitoring compliance with the reporting requirements and was late in issuing a report to Congress. The colleges faced problems as well. The GAO concluded that because colleges handle their data differently, it is difficult to compare one school to another. The GAO also noted that considerable confusion still exists among colleges about what and how they should report incidents of campus crime. For example, most of the colleges studied omitted hate crimes from their statistics, while others excluded crimes reported to local police.

One of the most sensitive areas of concern when dealing with campus crime is sexual assault. Administrators say they fear victims of sexual assault may be reluctant to report the crime if hearings are open. Journalists usually do not disclose the identity of sexual assault victims even when covering open criminal trials. However, reporters may contact a victim. In those instances, a victim may choose to go public and deference is given to the victim to make that choice. The Society's Code of Ethics directs all journalists to "show compassion for those who may be affected adversely by news coverage" and to "be cautious about identifying—victims of sex crimes." Ethical journalists treat sources, subjects and colleagues as human beings deserving of respect.

While every effort should be made to ensure victims' rights, public safety issues cannot be ignored. If so, it will only result in more victims. Consider, for instance, the warm spring Sunday morning in 1995, when a female student was jogging alone on the sidewalk behind the University of Georgia football stadium. Music from her portable stereo prevented her from hearing a man slip behind her. The woman was

dragged into a wooded area, brutally raped and beaten with a rock. Left for dead, she managed to haul her battered body to the street. A passing motorist mistook the woman for a hit-and-run and called an ambulance.

Several hours after the attack was reported, University of Georgia police issued a press release with specific information about the time and location of the assault. It also included a description of the woman's assailant. This immediate response most likely prevented another assault because the campus community was an informed community.

There is no logical reason for officials to deny access to crime reports or disciplinary records. Protection of a school's reputation is not adequate justification. Nor is the protection of an individual worth endangering other lives within a college or university community. Only when fully informed of the nature and extent of crime on campuses can students, faculty and the community at large take measures to protect themselves and make their collegiate environment safe for all.

On behalf of the Society of Professional Journalists, the Campus Courts Task Force and students throughout the nation, I thank you for your time.

PREPARED STATEMENT OF MARTHA JEAN LORENZO

RE: COMMONWEALTH OF MASSACHUSETTS V. BRENDAN D. GARVEY

Dear Committee Members: On March 4, 1998, 18 months after Brendan Garvey raped our daughter, Angela M. Lorenzo, as she slept in her college dormitory bedroom, Garvey (age 19 and paroled on September 4) pled guilty to a lesser charge of sexual assault and battery on a person 14 years or older. While this was not the charge Angela truly sought (as she expressed to the judge), reasonable doubt was a serious factor she considered after the defense attorney portrayed Angela as an alcoholic and immoral young woman.

Angela endured 2 days of painful testimony. She is one of the few women who decide to press charges; she flew to Massachusetts from her home in Florida three times, at her own expense, to seek justice.

Angela was a freshman student at Wheaton College in Norton, Massachusetts. She was thrilled at having been accepted to the college of her choice and was to play on the softball team. But, only 14 days into her first semester, one of her roommates invited three ex-convicts to visit the campus. On the second occasion, after a few attempts to remove herself from a very unsafe situation, Angela and a third roommate fell asleep. Angela awoke to Garvey raping her.

And so began a nightmare. Angela and her family have only begun to heal now following the trial and Garvey's conviction. Hearing Garvey admit he had touched her without her consent was music to Angela's ears. She felt vindicated, but only momentarily, because post-rape traumatic stress syndrome is now dominating her life. Her future is uncertain.

As her mother, I prepared my daughter as to avoid roofies, date rape, and other dangerous scenarios. But the thought of a convicted felon, the boyfriend of a new roommate, being in her bedroom never entered my mind. Well, perhaps her tragic story will help others.

Angela is here to hug and hold and talk to. She did not become a murder statistic; the Lorenzo family is grateful for that. But the system of trying to obtain justice was grueling, especially at the actual trial. The assistant district attorney was not impressed with her case. But Angela never wavered in her quest for justice. The dean of students at Wheaton has always been supportive of Angela's case. There has never been the slightest hint to hush it up.

Our family has been turned inside-out and thus we are willing to share this personal, sensitive story with you to try to make our college campuses safer places. Our 18-year-old daughter arrived at college full of hope and anticipation. Now, sadly, a lot of confusion, fear and pain have replaced her dream.

Thank you for accepting Angela's story. We hope you remember these words from a mother, from a family devoted to its daughter and sister.

PREPARED STATEMENT OF STANLEY HERRERA, PRESIDENT, ALAMO NAVAJO SCHOOL BOARD

The Alamo reservation is a ten-square-mile non-contiguous part of the Navajo Nation in east-central New Mexico, about 250 miles from the Nation's headquarters in Window Rock, Arizona and near the small town of Magdalena. Because of our reservation's physical isolation from the "Big Navajo" reservation, the Alamo School

Board is the primary source of most governmental services to our 1,800 community members.

Since 1983, the Alamo Navajo School Board has successfully operated a Head Start program, first as a sub-grantee of the Navajo Nation Head Start program and, since 1997, as a direct grantee under the American Indian Programs Branch of the Head Start Bureau.

In the fiscal year 1999 Labor, Health and Human Services, and Education appropriations bill and report, we urge the Subcommittee to take the following critical actions regarding Head Start:

—Fully fund the Administration's fiscal year 1999 budget request of $4.66 billion for the Head Start program;
—Prioritize the construction of badly-needed new Head Start facilities; and
—Encourage the Department of Health and Human Services (HHS) to allow tribal organizations to administer Head Start programs under Public Law 93–638 self-determination contracts.

BUDGET REQUEST WOULD IMPROVE HEAD START ACCESS FOR NEEDY KIDS

Head Start works. For this simple reason, the Head Start program has historically enjoyed strong bipartisan support in Congress and the White House and from the general public. Even as pressure has mounted to control the federal budget deficit and cut domestic discretionary spending, Congress has increased Head Start appropriations dramatically. Unfortunately, even the current funding level of approximately $4.36 billion leaves far too many eligible children out in the cold.

Children who live in poverty and near-poverty conditions have a high risk of educational failure, but studies show that such high quality early education programs as Head Start give these kids the lift they need to succeed later in life. At Alamo, we have found that our Head Start children enter kindergarten much more prepared to learn than their classmates whom our program was unable to serve.

By fully funding the Administration's fiscal year 1999 budget request of $4.66 billion, you will give another 30,000 children the hope and opportunity Head Start provides.

FACILITY CONSTRUCTION MUST BE A HIGH PRIORITY

The Administration's goal is to increase Head Start enrollment to one million. This will intensify what is already in many areas a critical facilities shortage.

Congress has repeatedly recognized the pressing need to safe Head Start facilities. The House Committee on Education and Labor stated in H. Rept. 102–763, the report accompanying the Head Start Improvement Act of 1992 that "of primary importance to the Head Start community, and an important focus in the attempt to serve families in need, is ensuring that the infrastructure for Head Start programs is in place before increases in funding are undertaken."

Because adequate facilities were still not available in many low-income communities when Head Start was reauthorized in 1994, the statute was amended to give the Secretary the authority to use funds for capital expenditures for Head Start construction if she determines that suitable facilities are not otherwise available to tribes, rural communities and other low-income communities, that the lack of these facilities will hurt program operations, and that construction is less expensive than purchasing or renovating an existing facility.

We urgently request the Subcommittee to go one step further and designate a specific portion of the fiscal year 1999 Head Start appropriation for facility needs. The problems we face at the Alamo Navajo facility—which we are proposing to replace using a cooperative funding agreement using federal, state and tribal resources—illustrate why additional facility funding is necessary to preserving the overall quality of the Head Start program.

Our current facility is a two-room school constructed in 1972. Settling of the foundation has created large cracks in the exterior block walls and the floors. The building's poor structural condition has been documented by the Indian Health Service Office of Environmental Health in its annual health and safety survey. Furthermore, space limitations prevent Alamo Navajo from serving all of our Head Start-eligible children. We can only serve 35 children at one time. So that we could increase the number of eligible children served, we applied for and received expansion funds to serve 55 children. To accommodate these extra kids, we have had to institute double shifts. Even so, we have a waiting list every year of 10 to 20 children and have to limit the children served to 4-year-olds.

Our reservation birth rate continues to grow. In 1995, 52 children were born in our community, and nearly all of them meet Head Start eligibility criteria. We ex-

pect to have approximately 95 Head Start-eligible children in two years—but we do not have the space to provide them with the services they should receive.

ALLOW TRIBES TO ADMINISTER LOCAL HEAD START PROGRAMS

Section 102 of the Indian Self-Determination Act (Public Law 93–638) directs the Secretary of Health and Human Services (HHS) to contract with tribes to operate federal-funded programs for their members.

Administering a tribal Head Start program through a self-determination contract would be an attractive option for many tribes and tribal organizations, including the Alamo School Board. It would decrease the amount of federal red tape and paperwork that we must go through by allowing us to receive all of our funds directly from Head Start using one funding document, reduce micromanagement by bureaucrats in Washington, and—most importantly—allow us to better tailor our local programs to meet local needs.

Unfortunately, HHS has discouraged tribal contracting for Head Start and has restricted self-determination contracts with tribes to Indian Health Service programs. Frankly, self-determination contracts for Head Start would be a "win-win" situation for both tribes and HHS.

Therefore, we request that you include fiscal year 1999 report language that would encourage the Secretary to work with tribes to fully implement the Indian Self-Determination Act so that tribal organizations may contract for such HHS programs as Head Start.

CONCLUSION

Thank you for your past support of the Head Start program. We are confident that you will give the same thoughtful consideration to our concerns and to the current needs of children in Indian country.

PREPARED STATEMENT OF CAROL C. HENDERSON, EXECUTIVE DIRECTOR, WASHINGTON OFFICE, THE AMERICAN LIBRARY ASSOCIATION

The American Library Association appreciates the opportunity to provide this statement for review and inclusion in the hearing record for fiscal year 1999 Appropriations. The 58,000 members of ALA, including public, school, state, academic and special librarians, library supporters, trustees, and friends of libraries, thank the Labor, Health and Human Services and Education Subcommittee for your support in the past and request a funding level of $160 million for the second year of the Library Services and Technology Act.

In addition, we ask that you fund the Improving America's Schools Act existing Title VI block grant at as high a level as possible above the fiscal year 1998 level of $350 million. This Title is the only funding possibility for school libraries and the Department of Education estimated last year that at least 40 percent of the funding goes for school library materials and resources.

Library Services and Technology Act

The Library Services and Technology Act was passed and signed into law on September 30, 1996. The purpose of the legislation is to consolidate Federal library programs while stimulating excellence and promoting access to learning and information resources in all types of libraries for individuals of all ages.

The provisions of the Library Services and Technology Act promote library services that provide all users access to information through State, regional, national and international electronic networks and provide electronic linkages among and between libraries. The law promotes targeted library services to people of diverse geographic, cultural and socioeconomic backgrounds, to individuals with disabilities and to people with limited functional literacy or information skills.

Most funds are allocated through state library agencies, which administer programs and develop cooperative plans for use of the funds; 3¾ percent of the funds are to be used for national leadership purposes and 1½ percent for tribal library services.

The Library Services and Technology Act builds on the strengths of previous federal library programs but has some major advantages and differences. It retains the state-based approach, but sharpens the focus to two key priorities: information access through technology; and information empowerment through special services.

New technology and a multitude of community needs will shape the way we seek and obtain information. The Library Services and Technology Act encourages interlibrary cooperation, emphasizes libraries as change agents and implementers of eq-

uity, extends libraries' reach as self-help institutions and community partners in lifelong learning and literacy, economic development, jobs information, health information, etc.

Public libraries of today are vastly different from the libraries of thirty years ago and the libraries of the next millennium will be different as well. The new LSTA gives states the flexibility to determine state needs and shape library programs to address those needs.

The following examples illustrate the kinds of innovative projects libraries are conducting with the use of federal funds to connect people to information that can help to change lives, advance education and contribute towards the productivity of the nation:

Student needs.—The Houston Public Library system has established ASPIRE, after school programs for students which provide assistance from tutors with homework, a rich supply of books and other materials to support that homework, access and training on resources on the Internet, and special programs and activities along with library instruction. Three branch libraries have the program underway with two more to be implemented soon. The success stories of student improvement have brought rewards to librarians and volunteer tutors as well as the students who have made great strides academically.

Literacy.—Springfield's Lincoln Library in Illinois has a collaborative family literacy project which coordinates activities at the library with the local literacy program. Families attend a family fun night at the library where library services are presented and reading activities occur. The librarian also visits the local school as part of this coordinated effort to reach low-literacy families.

The Ela Area Public Library District in Lake Zurich, Illinois, has an outreach program for senior citizens in nursing homes where trained volunteers conduct a Read-Aloud group. The reading and discussion group encourages older adults to continue their love of reading and enjoyment of books.

Technology.—The 1997 National Survey of U.S. Public Libraries and the Internet sponsored by the ALA and the U.S. National Commission on Libraries and Information Science found that fewer than 1 in 7 library branches offer World Wide Web access (see attachment for the latest data on public library connectivity).

States are making major strides in improving and upgrading access to new technology in libraries. The Library Services and Technology Act is critical to progress. For example, South Carolina expects all 184 public library sites to have Internet access this year. Florida has used LSTA funds to enhance library connectivity to the Internet through its statewide FloriNet program. FloriNet has assisted public libraries in providing graphical Internet access to their users. More than 200 Florida public library outlets have connected through FloriNet grants, and by September 1998, there will be public Internet access in at least one public library in every one of the state's 67 counties. Other states have similar initiatives underway, using LSTA and other sources of assistance to help with the major investment libraries must make to ensure that all Americans have access to advanced information technologies.

The federal role in support of libraries helps to ensure that the existing information infrastructure of libraries is technologically equipped to perform governmental functions cost effectively. Examples include supporting literacy and lifelong learning, organizing and providing access to federal, state, and local government information and other community information, undergirding economic development by providing jobs information and supporting small businesses and providing access to consumer health information.

Past library funding was administered by the Department of Education library programs through the Library Services and Construction Act. With the new law, the Library Services and Technology Act, administration of the program moved to the Institute of Museum and Library Services (IMLS). The new home for library programs in IMLS is working out well, and the IMLS leadership has established good working relationships with the library community. In addition, cooperative interaction between libraries and museums is increasing in very innovative ways. The Federal investment in the former Library Services and Construction Act and the new Library Services and Technology Act has acted and will act as a stimulant to local and state investment because of matching requirements, and because the E-rate discounts are requiring libraries to make the additional investment required to support advanced telecommunications.

The Administration's budget requests level funding for library programs. In this second year of funding of the new Library Services and Technology Act, it is particularly important for Congress to continue increasing resources to improve library programs to realize the goals of the new legislation. For fiscal year 1999, ALA recommends an appropriation for LSTA of $160 million.

A strong investment will connect more libraries to the Internet and support in-depth training on the nature and use of the Internet for the public at the one community institution available to all. It will continue to support literacy and education, help libraries provide job and consumer health information, serve small businesses, provide information for lifelong learning, and allow for effective leadership projects. (See attached examples of Internet training in libraries).

IASA title VI

The reauthorization of the Elementary and Secondary Education Act (the Improving America's Schools Act), included renewal of the Title VI (formerly Chapter 2) block grant. This block grant allows funding of school library resources and materials among its uses of funding. Our children deserve not only technological resources but the resources for in-depth research as well. We ask the Subcommittee to fund IASA Title VI at as high a level as possible above the fiscal year 1998 level of $350 million. The Administration's budget did not request funding for this program.

Other initiatives

The Administration's fiscal year 1998 budget proposed increased funding for IASA Title III Educational Technology. We ask the Subcommittee to fund IASA Title III at the requested level. We recommend funding of children's literacy initiatives such as the President's America Reads Challenge or the House-passed Reading Excellence Act. We also ask that you fund other programs under your jurisdiction that improve reading skills, literacy and lifelong learning, technological literacy, the National Library of Education, and educational research and statistics. We also urge support of the budget request of the U.S. National Commission on Libraries and Information Science.

We thank the Subcommittee for the consideration you have shown for libraries in the past, and particularly for your part in accomplishing the reauthorization of the Library Services and Technology Act in the Fall of 1996.

PREPARED STATEMENT OF ROCK POINT COMMUNITY SCHOOL BOARD, ROCK POINT, AZ

Mr. Chairman and Members of the Committee: The Rock Point Community School Board urges the Subcommittee to take the following actions regarding Head Start in the fiscal year 1999 Labor, Health and Human Services, and Education appropriations bill and report:

—Fully fund the Administration's fiscal year 1999 budget request of $4.66 billion for the Head Start program;
—Prioritize the allocation of facilities maintenance funds within the Head Start appropriation;
—Prioritize the construction of badly-needed tribal Head Start facilities;
—Address the transportation needs of Head Start-eligible children; and,
—Encourage the Department of Health and Human Services (HHS) to allow tribal organizations to administer Head Start programs under Public Law 93–638 self-determination contracts.

BACKGROUND

The Rock Point community is located in an especially isolated area of the Navajo Nation reservation. The community's Head Start program, which is one of 180 Head Start centers operated by the Navajo Nation through a direct grant from the Head Start Bureau American Indian Programs Branch, serves a total of 30 children. Twenty are served at the Head Start center and ten who live in particularly remote areas receive 1.5 hours of weekly home-based instruction.

The Rock Point Community School Board currently is in the process of applying for direct grantee status to operate the Head Start program. By becoming a direct grantee, we will be able to run a Head Start program which best suits the unique needs of our small community.

BUDGET REQUEST WOULD ALLOW US TO SERVE MORE ELIGIBLE CHILDREN

Because of its successful track record, Members of Congress from both sides of the aisle have supported Head Start. In fact, even while Congress and the Administration has worked to cut deficit spending and balance the budget, Head Start spending has grown.

At the Rock Point Community School, we see that children who have attended Head Start are more ready to learn. Unfortunately, the current $4.36 billion funding

level does not allow us to serve all of our Head Start-eligible children. The Head Start program serves 20 children ages three through five, four days per week for six hours per day, plus another ten children through extremely limited home-based instruction. That said, at least 50 children are eligible for comprehensive Head Start services, based on the kindergarten enrollment statistics for the Rock Point Community School—but we lack the funding to expand our program.

That is why we strongly support the Administration's long-range goal of increasing Head Start enrollment to one million. If the Subcommittee fully funds the Administration's fiscal year 1999 budget request of $4.66 billion, another 30,000 children will reap the benefits of Head Start and we will be one step closer to reaching this important goal.

MAINTENANCE DOLLARS ARE NEEDED

Our Head Start facility is a two-room building consisting of a kitchen area and a classroom. It was built approximately 37 years ago and currently has numerous health and safety deficiencies, a number of which were documented in a March 9, 1998 Indian Health Service/American Indian Programs Branch Head Start Health and Safety Report. The following lists some of the most frightening of 23 critical violations cited in the report.

—Lead was detected at harmful levels in the drinking water.
—On-site wastewater system was not properly operated or maintained. This facility experienced a back-up of sewage recently that resulted in a closure of school operations for a week.
—Gas, sewer and water piping fixtures and appurtenances were not free of leaks or defects, namely the wall coverings above most all wall-mounted gas heaters were peeled.
—Exterior gas shut-off was not accessible.
—Fuel gas storage tanks were not properly installed or maintained.
—The facility did not meet minimum fire safety standards for educational occupancies.
—Electrical wiring did not meet the minimum safety requirements.
—Plumbing and fixtures were not constructed or maintained in a sanitary manner.
—Handwashing sinks were not provided with hot and cold running water, namely one bathroom lacked cold water and another lacked hot water.
—The playground fence was not adequate to provide separation from vehicle traffic, restrict children from leaving the premises, or restrict animals from the play area.
—Playground equipment was not free of sharp edges, protruding parts, or defects that could injure a child.
—Excessive amounts of potentially harmful radon gas were found within the facility.

Clearly, in order to protect the health of those children currently served through the Head Start program, we must ensure that there are adequate maintenance dollars to correct these grievous conditions immediately. If additional dollars are not provided for this critically needed maintenance, we will be forced to use funds that should be used to increase enrollment of eligible children and we will experience continued deterioration of our existing facility.

REPLACEMENT FACILITY CONSTRUCTION SHOULD BE PRIORITIZED

Without funding to build new—and safe—facilities, the goal of increasing Head Start enrollment to one million will be meaningless to Rock Point. In order to expand services to the 50 children who are eligible for Head Start, we will need an additional building, which we also would like to use as a central facility for early education services.

Because adequate facilities were not available in many low-income communities when the Head Start program was reauthorized in 1994, the Secretary was authorized to use funds for capital expenditures for Head Start construction if she determines that suitable facilities are not otherwise available to tribes, rural communities and other low-income communities, that the lack of these facilities will hurt program operations, and that construction is less expensive than purchasing or renovating an existing facility.

At Rock Point and in many other locations around the country, we are still waiting for these funds. Therefore, we ask you to allocate a specific portion of the fiscal year 1999 Head Start appropriation for facility needs.

CHILDREN NEED BUSES, TOO

Access to our community, which is scattered over a radius of 15 miles, is primarily by dirt roads. Because these roads become extremely muddy and icy during the winter, extra funds are needed to maintain and repair our one Head Start bus, which is old and in poor condition. Even worse, the closest bus maintenance and service location is a 250-mile round trip.

Compounding this situation is the fact that GSA rental and mileage rates are escalating, which means we have to pay more and more out of our limited transportation budget.

We request that additional bus maintenance and replacement funds be provided through the Head Start appropriation.

ALLOW TRIBES TO ADMINISTER LOCAL HEAD START PROGRAMS

Section 102 of the Indian Self-Determination Act (Public Law 93–638) directs the Secretary of Health and Human Services (HHS) to contract with tribes to operate federally-funded programs for their members.

The Rock Point Community School Board has successfully contracted education programs since 1972 and has continually improved student services during this time period. As such, the Board believes that administering a tribal Head Start program through a self- determination contract would be beneficial. It would decrease the amount of federal bureaucracy that we deal with by allowing us to receive all of our funds directly from Head Start using one funding document and would let us to run our local programs to meet local needs.

Unfortunately, HHS has discouraged tribal contracting for Head Start and has restricted self-determination contracts with tribes to Indian Health Service programs. Frankly, self- determination contracts for Head Start would be a "win-win" situation for both tribes and HHS.

Therefore, we request that you include fiscal year 1999 report language that would encourage the Secretary to work with tribes to fully implement the Indian Self-Determination Act so that tribal organizations may contract for such HHS programs as Head Start.

CONCLUSION

Thank you for your past support of the Head Start program. We are confident that you will give the same consideration to our concerns.

PREPARED STATEMENT OF DAVID M. GIPP, PRESIDENT, AND RUSSELL MASON, BOARD PRESIDENT AND CHAIRMAN, THREE AFFILIATED TRIBES OF NORTH DAKOTA

UNITED TRIBES TECHNICAL COLLEGE: MAKING A DIFFERENCE

Summary of Request. For thirty years United Tribes Technical College (UTTC) has been providing postsecondary vocational education, job training and family services to Indian students from the Great Plains and throughout the nation. An intertribally controlled educational institution,[1] UTTC was assisting Indian people in moving from public assistance to economic self-sufficiency long before the 1996 welfare reform act. Our placement rate in 1997 was 96 percent. The request of United Tribes Technical College for fiscal year 1999 Department of Education funding for tribally controlled postsecondary vocational institutions as authorized under Title III, Part H of the Carl Perkins Vocational and Applied Technology Act is $4 million. This is $900,000 over the fiscal year 1998 enacted amount and the same as the authorized level.

This funding is essential to our survival as we receive no state-appropriated vocational education monies.

The Administration's Request. Title III, Part H of the Carl Perkins Act currently provides support to UTTC and one other tribally controlled postsecondary vocational institution, the Crownpoint Institute of Technology. The Administration's request is for $3.1 million, the same as the fiscal year 1998 enacted level. The Department of Education's budget justification is misleading, however, in that it states that fund-

[1] The college is owned and operated by five federally-recognized tribes situated wholly or in part in North Dakota. These Tribes are the Spirit Lake Sioux Tribe, the Sisseton-Wahpeton Sioux Tribe, the Standing Rock Sioux Tribe, the Three Affiliated Tribes of the Fort Berthold Reservation, and the Turtle Mountain Band of Chippewa. Control of the institution is vested in a ten-member board of directors comprised of elected Tribal Chairpersons and Tribal council members.

ing for the tribally controlled postsecondary vocational institutions will be consolidated with the 1.25 percent tribal allocation under the Perkins Act. While the Administration's proposed vocational education reauthorization bill would have consolidated these programs, both the House-passed and the Senate committee-approved vocational education bills (H.R. 1853/S. 1186) maintain our program separate from the tribal allocation. We opposed the Administration's proposal in this regard and are pleased that the pending authorization bills would maintain a tribal postsecondary vocational education program.

United Tribes Technical College: A Unique Inter-Tribal Educational Organization. United Tribes Technical College is the only inter-tribally controlled, campus-based, postsecondary vocational institution for Indian people. Our campus is the site of the Fort Lincoln Amy Post, an 110-acre area near Bismarck, North Dakota. We currently enroll 310 students from 36 tribes and 17 states. In addition, we serve 110 children in our pre-school programs and 115 children in our elementary school, bringing the population for whom we provide direct services to 535. In some years our students come from as many as 45 tribes.

Educating Students and Placing Them in Jobs. We are proud of the education, skills and services provided by UTTC for our students and their families over the past thirty years. And we are proud that this education is taking placing in a tribal setting, where our students and their families can maintain and strengthen their tribal heritage. We have had a placement rate exceeding 80 percent sustained over the last 10 years, and in 1997 had a placement rate of 96 percent. This success is all the more gratifying in light of the background of our students, most of whom come from tribal areas where poverty and unemployment are the norm. A large proportion of our students are from the fourteen tribes in the Dakotas, where unemployment among Indian people is chronic. BIA Labor Force data reports the percentage of potential Indian labor force on and near reservations in the Aberdeen Area (North Dakota, South Dakota, Nebraska) who are jobless is 75 percent.

UTTC Course Offerings and Coordination with Other Educational Institutions. UTTC offers 8 Certificate and 12 Associate of Applied Science degree programs.[2] Entrepreneurship and new technology skills are being integrated into appropriate curricula. All programs are accredited through the North Central Association of Colleges and Schools at both the certificate and two-year degree granting levels. During the last re-accreditation process (1996), the NCACS authorized UTTC to begin developing curricula for 4-year degrees.

UTTC has transfer and articulation agreements with other colleges so our graduates can transfer to four-year schools from areas including Licensed Practical Nursing, Criminal Justice, Business and Entrepreneurship and Health Instruction. We provide academic instruction which provides our graduates the background to pursue additional college work.

UTTC has been a member of the Interactive Video Network of North Dakota's colleges, universities and tribal colleges since 1994. This is expanding the educational opportunities for our students.

Job Training and Economic Development. UTTC is a designated Indian Minority Business Center serving Montana, South Dakota and North Dakota. We also administer a Job Training Partnership Act program and an internship program with private employers. And, thanks to a grant from the Kellogg Foundation, we are assisting tribes and tribal members in the Aberdeen Area with rebuilding buffalo herds.

Coordination with State Welfare-to-Work Efforts. UTTC is working in cooperation with the state of North Dakota on welfare reform. We are serving state-referred Temporary Assistance for Need Families (TANF) recipients who are able to participate in our Cooperative Education internship program with private employers. By attending UTTC, these TANF recipients can meet their work, training and volunteer requirements. And we are providing child care for 60 children of state-referred TANF recipients.

We take exception to the 12-month statutory limit on the length of time a TANF recipient can be enrolled in a vocational education course and still be eligible for TANF. This limits TANF recipients to taking one-year certificate courses at UTTC.

---

[2]The following one-year certificates are offered: Office Technology, Automotive Service Technician; Construction Trades Technology with options in Carpentry, Electrical, Plumbing, and Welding, Early Childhood Education; Criminal Justice; Hospitality Management: Food & Beverage Specialization; Medical Secretary.; and Welding Technician.

The following two-year Associate of Applied Science (A.A.S.) degrees are offered: Arts/Marketing; Automotive Service Technology; Construction Trades Technology with options in Carpentry, Electrical Plumbing and Welding; Criminal Justice; Early Childhood Education; Health Information Technology; Hospitality Management: Food and Beverage Specialization, Office Technology with emphasis in computer applications or accounting; Practical Nursing; Small Business Management; Welding Technology; and Dietetic Technician.

Our experience shows that the students who graduate from a two-year, rather than a one-year, course have significantly higher earning power. Many of our students come to UTTC planning to take a one-year course, and then, finding themselves in a supportive environment and seeing the economic benefit of the longer course, decide to work for the two-year degree.

Serving Families Contributes to Education and Job Placement. We believe that a primary reason for UTTC student success is that we serve the students' social, academic and cultural needs. Many of our students are the first generation in their family to attend college and for many it is their first experience in living away from home. Many students are on public assistance and many have families of their own. Some of our services are:

—Early childhood services for 110 children, ages 8 weeks to five years;
—The Theodore Jamerson Elementary School (grades K–8) serving 115 Indian students;
—A health clinic which, among others services, provides immunization, health education, eye and dental exams, and referrals to other health care providers;
—Family housing and dormitories for solo parents and for students without children;
—A local transportation system for students for school activities and necessary appointments e.g., (doctor appointments) outside the campus. Most UTTC students do not have cars.

UTTC Seeks Other Funds. UTTC is aggressive in seeking funding outside the Perkins Act for special needs. For example, we combined Department of Agriculture, Economic Development Administration and state Community Development Block Grant funds and replaced our aging water, sewer and gas systems in 1997. However, we still need $350,000 for replacement and repair of roads damaged as a result of this project.

Our elementary school received a competitive Department of Education grant for computer technology, and was one five Indian schools to receive this funding. We also received a Kellogg Foundation grant to develop buffalo management skills for the tribes and their members throughout the Aberdeen Area, as they attempt to rebuild herds of buffalo decimated more than 100 years ago.

The above mentioned grants are highly competitive, restrictive, one-time grants, and they cannot provide for day-to-day operations. We cannot survive without the basic operating funds which come through the Department of Education's tribally controlled postsecondary vocational institutions program.

Current Needs. We certainly appreciate the $200,000 increase provided by Congress in fiscal year 1998 for the tribally controlled postsecondary vocational program (from $2.9 million to $3.1 million). The increase is important, not only for the unmet needs of the current grantees, but because other institutions may become eligible for funding under this program.

The operating and purchasing strength of our budget has diminished by some 20 percent since 1990. Utility costs are especially difficult. Electricity expenses have risen about 20 percent per unit and the per unit gas costs have increases approximately 113 percent during this decade. We have been able to partially offset utility rate increases by implementing stringent conservation measures such as improved weatherization and reductions in building temperatures. However, energy consumption cannot be further reduced because of our location and the harsh winters in the northern plains.

While even a $4 million appropriation for the Tribally Controlled Postsecondary Institutions program would leave us with enormous needs, it would allow us to make improvements in key areas including course offerings, student services, and technology. Below are some of our financial needs of which we want you to be aware:

—Housing We need new and rehabilitated campus housing so that we can increase student enrollment. Many of our buildindgs are of historic importance. The College occupies the old Fort Lincoln Army Post, and many people visit our campus to see these buildings. Other than the more recently constructed skills center and the community center, UTTC's core facilities are 90 years old. Estimates for new facilities total over $12 million, according to a 1993 U.S. Department of Education report to Congress. Continuing a course of non-repair will ultimately prove more costly as the repairs will be greater. Fire and safety reports document our repair needs.
—Salaries. We were able to provide a cost-of-living increase for our employees this year. However, our faculty still receive salaries that are lower than in any state college system. North Dakota salaries for higher education faculty are the low-

est in the nation—but the average faculty salaries at UTTC are even lower than those in the North Dakota state system.[3]

—Emergency Repair. Our needs for emergency repair on both single and family student housing, instructional facilities and support facilities exceeds $100,000. This amount will obviously not cover major renovations or new facilities. Funding is also needed for maintenance and repair related to damaged caused by inclement weather, including blizzards and extremely low temperatures.

—Technology. We need funding for computers and hardware to increase our capabilities for distance learning programs for our campus-based students and students at other locations. We are working with the Denver Indian Center to provide UTTC classes, via distance learning. to the Indian population in the Denver area. We also need to complete our local area computer network and to provide more staff training.

—Course Offerings/Student Services. We would like to change some of our courses to better meet new market demands. For example, we want to expand the allied health professions program and also to expand the business clerical program into the business administration area. We also need to expand our diagnostic capabilities in tribal-specific areas and also in the areas of literacy and math-science background. This would allow us to improve student remediation services. Finally, we want to make improvements in our student follow up, career development, and job market research efforts.

Thank you for your consideration of our request. We need your assistance to ensure that the unique educational opportunities offered by United Tribes Technical College will be available for what we hope will be an increasing number of Indian and Alaska Native students and their families next year and in the future.

PREPARED STATEMENT OF PETER BELLETTO, PRESIDENT, NATIONAL INDIAN IMPACTED SCHOOLS ASSOCIATION, GANADO UNIFIED SCHOOL DISTRICT, GANADO, AZ

The National Indian Impacted Schools Association (NIISA) is an association of public schools in Indian country dedicated to quality education and assuring that the United States' obligation to provide resources for educating Indian and Alaska Native students is fulfilled. Our membership consists of public school districts which receive federal Impact Aid funds because of the presence of students from Indian trust lands and Alaska Native lands. Approximately 90 percent of Indian and Alaska Native students nationwide attend public schools.

Summary of Request. We ask the Subcommittee to recommend the following with regard to the fiscal year 1999 Department of Education budget:

—*Impact Aid Basic Support Payments*.—$700 million for Impact Aid Basic Support payments. This is the same as the request of the National Association of Federally Impacted Schools and is $38 million over the fiscal year 1998 enacted level. This amount would allow the schools to be paid at 100 percent of LOT.

—*Impact Aid Construction*.—$25 million under the authority of the Impact Aid statute for payments for Construction. This compares to the fiscal year 1998 enacted level of $7 million and the President's request of no funding. While this is termed a "construction" account, the funds can be used only for repair and renovations, not new construction.

—*Education Technology*.—$475 million for million for the Technology Literacy Challenge Fund as requested by the Administration to help schools integrate technology into school curricula. This is $50 million over the fiscal year 1998 enacted level. We also support the President's request of an additional $75 million for technology training for new teachers.

Importance of the Impact Aid Program to Indian Country. For Indian country, the Impact Aid program is a vital element of the public policy of providing every child a free public education. Signed into law in 1950, the Impact Aid program is one of the oldest federal education programs. Simply put, it provides federal funds for public school operations that would have otherwise been provided by local tax revenues but for the presence of federal property—in our case, lands held in trust by the federal government for Indian tribes. The Impact Aid program is an example of the U.S. government carrying out its trust responsibility—in this case, for education—for Indian and Alaska Native peoples. Some facts about the importance of the Impact Aid Program to Indian Country:

—There are over 600 school districts throughout the country which receive Impact Aid funds for Indian lands schools.

---

[3] Source: Integrated Postsecondary Education Data Systems (IPEDS) Report of the U.S. Bureau of the Census and the Department of Education Office of Education Statistics.

—Funds for Indian lands students represent nearly 50 percent of the federal Impact Aid appropriation.
—The Indian Country land base that generates Impact Aid funds consist of 53 million acres of Indian trust land in the lower 48 states and 44 million acres included in the Alaska Native Claims Settlement Act.

Additionally, the Impact Aid law provides a formal link between tribal governments and the public schools, providing for school district consultation with Indian tribes and tribal communities. This is especially important because public schools are State institutions, but located on tribal lands. School districts must consult with tribes and the Indian community to develop Indian Policies and Procedures (IPP). Tribes and parents of Indian students are able to comment on whether Indian students are equal participants in educational programs and school activities, and to request modifications in school programs and materials. Tribes also have administrative appeal rights under the statute.

Attached is a booklet prepared by the Department of Education regarding the implementation of the Impact Aid program in Indian country.

School Facilities.—School facilities construction and renovation, including making facilities ready for education technology, is a high priority for our organization. We are dismayed by the Administration's fiscal year 1999 proposal of zero funding for under section 8007 of the Impact Aid program—the authority for school repair and renovation. At the same time, the Administration requested $10 million for the school facilities which the Department of Education owns (section 8008). We support the proposed funding for maintenance of DOE-owned school facilities, and ask for similar consideration for our school districts.

The Administration's budget justifies a request of zero funding for the section 8007 school construction account by noting that the President is proposing legislation which would help school districts build schools by paying the interest on school construction bonds. This is putting the cart before the horse. Even if such legislation is enacted, it would not be an immediately available benefit for those schools fortunate enough to avail themselves of the program. It certainly would not be available in fiscal year 1999. In the meantime, our schools are crumbling.

NIISA has and will continue to work with Congress on pending school construction proposals to make them responsive to the needs of our schools—Indian lands public schools. School construction bills have been introduced in a steady stream during the 104th and 105th Congresses. We have seen in these bills a growing recognition that there needs to be accommodation for public school districts which have little, if any, bonding capacity (including those schools in the Bureau of Indian Affairs system). To the extent that a school district has limited ability to generate revenues because of a federal presence (e.g., the existence of Indian trust land or federal property in the school district), there is a clear federal responsibility toward the education of the children attending those schools.

For instance, S. 12, introduced early in the 105th Congress, would have allowed for a waiver on amount of interest which could be paid on a school construction bond if "the local area contains a significant percentage of Federally-owned land that is not subject to local taxation." However, S. 12 did not address the fact that due to the presence of federally held lands—e.g., trust lands on Indian reservations—there is little, and sometimes, no, bonding capacity. S. 1705 and S. 1708, introduced on March 4, 1998, have the advantage of paying, via a federal tax credit, 100 percent of interest on school construction bonds. This credit allocation would be available to both local school districts and to states. Importantly, the bills would require the state, in order to receive a federal tax credit allocation, to explain how it will use its allocation to assist localities that lack the fiscal capacity to issue bonds on their own. Should states opt to issue bonds for their school districts which lack bonding capacity, it would benefit public school districts with large amount of Indian trust lands.

The condition of public and Bureau of Indian Affairs school facilities has been documented in General Accounting Office (GAO) surveys. In October, 1996, our organization undertook a survey of school districts which receive Indian lands Impact Aid funding. Our survey went further than bricks and mortar. It also asked questions regarding the ability of the school district to raise revenue for facility construction—something not done by the GAO surveys. Finally, the survey contained a series of questions regarding each school district's readiness for computers, the internet and other education technology. We reported some of the findings from the survey in our appropriations statement last year, and repeat them here:

—65 percent of buildings are over 20 years old, including 38.2 percent over 30 years old;
—$6,872,000 is the average estimated costs necessary for repairs, renovations, modernization and construction to put schools in overall good condition;

—The average cost per student to make school buildings meet health and safety standards is $1,947;
—To accommodate expected increased enrollment over the next 5 years, the schools responding to the survey will need 13.1 percent more space. Within 10 years, the space needs are expected to increase by 27.9 percent;
—71 percent of school districts have had no school construction bond issued since 1985, and 23 percent of school districts have never had a bond issued;
—Of schools with 70 percent LOT MOD and higher, the need for construction, renovation, and repair funding is two thirds higher per pupil than in the other respondents to the NIISA survey. (Note: LOT MOD is a Department of Education measure of need of school districts affected by the presence of federal property);
—42 percent of respondents have unhoused students;
—59 percent of school buildings have inadequate laboratory science space;
—63 percent of schools are not well served for before/after school care.

Education Technology.—NIISA thanks Congress for providing a significant increase in education technology in the fiscal year 1998 Education Department budget, and supports the President's request for $475 million for Technology Literacy Challenge Fund to help schools integrate technology into the curriculum. We also support the Administration's request of $75 million for technology education for new teachers. Although there is considerable public discussion about linking schools to the internet, NIISA's survey results show that many, many schools lack the electrical, telephone and other infrastructure necessary to utilize modern educational technology. The NIISA survey responses show:

—75 percent of school buildings need funding for infrastructure to support education technology—this compares to the 60 percent figure in the GAO surveys;
—56 percent of school buildings have significant needs for computers for instructional use;
—61 percent of school buildings have significant needs for modems;
—81 percent of school buildings need telephone lines for instruction areas;
—79 percent of school buildings need fiber optic cable; and
—62 percent of school buildings need for electrical wiring for computers.

Thank you for your interest in the need of our public schools which educate children from Indian country. We ask you to always keep in mind the trust responsibility for the education of Indian and Alaska Native children and the federal responsibility regarding school districts which contain Indian and federal property.

PREPARED STATEMENT OF THE NATIONAL MILITARY FAMILY ASSOCIATION

The National Military Family Association (NMFA) is the only national organization whose sole focus is the military family and whose goal is to influence the development and implementation of policies which will improve the lives of those family members. Our mission is to serve the families of the Seven Uniformed Services through education, information and advocacy.

Founded in 1969 as the Military Wives Association, NMFA is a non-profit 501 (c)(3) primarily volunteer organization. NMFA today represents the interests of family members and the active duty, reserve components and retired personnel of the seven uniformed services: Army, Navy, Air Force, Marine Corps, Coast Guard, Public Health Service and the National Oceanic and Atmospheric Administration.

NMFA Representatives in military communities worldwide provide a direct link between military families and NMFA staff in the nation's capital. Representatives are the "eyes and ears" of NMFA, bringing shared local concerns to national attention.

NMFA receives no federal grants and has no federal contracts.

NMFA has been the recipient of the following awards: Military Impacted Schools Association "Champions for Children" Award (1998) Defense Commissary Agency Award for Outstanding Support as Customer Advocates (1993) Department of the Army Commander Award for Public Service (1988) Association of the United States Army Citation for Exceptional Service in Support of National Defense (1988)

Various members of NMFA's staff have also received personal awards for their support of military families.

NMFA's web site is located at: http://www.nmfa.org

NMFA and the families we represent are grateful to this Subcommittee and the Senate for its efforts on behalf of military children and the Impact Aid Program. We commend all Congressional supporters of Impact Aid, including the members of the House and Senate Impact Aid Coalitions, for securing the fiscal year 1998 appropriation of $808 million—an increase of $78 million over fiscal year 1997 and

$150 million over the Administration's proposal. We are a small, but wide-spread constituency and it is important that all Members of Congress understand the importance of the Impact Aid program to approximately 500,000 military children and several million of their civilian classmates in school districts across the country. NMFA appreciates this opportunity to express its views.

THE MILITARY FAMILY AND CHILD

NMFA presents this statement on behalf of military families, or more specifically on behalf of military children. These children move every 2 to 4 years and attend an average of five different schools. Since the drawdown overseas, those schools are more likely to be in stateside systems dependent on Impact Aid rather than in Department of Defense Schools. Military children bring a rich experience gained from travel and learning in other parts of the United States and the world to the schools they attend. But they also bring the apprehension and insecurities faced by any child who must not only adjust to a new teacher and new classmates each year, but to different school systems. They are ahead of the class in some schools or performing below grade level in others. They lose credits needed for graduation because of different course standards. They enter school too late to win a spot on the school paper or cheerleading squad. They must adjust to different curricula and standardized tests. Sometimes the military child's transition into a new school is further complicated by the absence of the military parent.

Military families want to be involved in their children's education. They serve as room parents, vote for school board members, and raise money for playground equipment and computers that might not be installed until after they've moved away. Military families list education as one of their most important Quality of Life concerns. Military commanders know that worries over the education of their children affect the morale and retention of personnel. And, in this age of increased accountability, military families hold their children's schools to a higher standard than any state does. They insist that schools prepare their children to enter school at their next assignment, no matter where in the world that might be, with the skills and knowledge necessary to succeed. They expect their children's schools to have the necessary resources to orient families, process records, provide counseling, evaluate students' strengths and weaknesses, and place them in the right programs.

Military families understand that the Impact Aid program supports basic education services provided by their local school districts. They hold the government, and the citizens they have sworn to serve and protect, accountable for living up to their promise to provide a quality education for their children. The districts have accepted the responsibility to educate our children; the Federal government must provide the resources it has promised to support that education.

FEDERAL RESPONSIBILITY

The Federal Government's responsibility, originally defined in Public Law 81–874 in 1950 and restated in Public Law 103–382 in 1994, is ''to provide financial assistance for those local educational agencies upon which the United States has placed financial burden.'' The original intent of Public Law 81–874 was to establish a mechanism for consistent funding of the Government's obligation to these districts and the children they serve. It provided a payment equal to the local per-pupil costs for students whose military parent both lived and worked on a federal installation (these students were designated A students) and one-half of the local per-pupil cost for students whose military parent worked on a federal installation but lived in the civilian community (B students). Under the current law, revenue for a B student is 10 percent of that for an A student. It costs roughly $6,000 to educate a child in the United States today. But the current average Impact Aid payment for an A child is $2,000; the average payment for a B child is $200, nowhere near the original intent or the cost to educate a child.

Although the Federal Government has acknowledged its responsibility to provide Impact Aid, the program has not been fully funded since 1970. Even with much-appreciated Department of Defense supplemental funding for the most heavily-impacted districts, Impact Aid does not cover many districts' basic needs (A DOD Supplement of $35 million was authorized for fiscal year 1998, but not appropriated.). Local and state taxpayers continue to bear part of the burden for federal students. In the State of Washington, for example, Impact Aid funds only 23 percent of the cost of educating a federal student. The citizens of Washington fund the remaining 77 percent through local and state taxes.

The fiscal year 1998 Impact Aid appropriation of $808 million was generous by the standards of previous years. We know that the increase will enable districts to serve military children more effectively. Continued consistent funding at or near the

authorized level will help these districts wrestle with increased salaries and benefits for quality teachers, rising special education and transportation costs, and the demands of equipping schools and classrooms with the latest technology. Impact Aid funds help these districts approach the level of educational opportunity available in neighboring, non-impacted school districts even though they do not have access to the same kind of tax base.

The Central Union School District in California, with 1,850 students in four schools, provides a wonderful example of how districts use Impact Aid funds to keep pace with others in their state. The district earmarks its DOD Supplemental funds for technology. Internet access in all schools has enabled military students living on base at the Lemoore Naval Air Station to communicate with their parents on sea duty.

NEEDS OF HEAVILY-IMPACTED DISTRICTS

One of the greatest needs faced by heavily-impacted districts is for construction funds. The photos in Attachment A of this statement illustrate some typical construction needs, caused by the influx of new students, postponed maintenance, the demands for new technology, and normal wear-and-tear in buildings long-overdue for renewal and renovation. The reduced tax base caused by the presence of a large military installation often makes it difficult for these districts to float construction bond issues or take advantage of states' offers of matching funds.

South Kitsap (WA) High School serves children of military members stationed at Bangor Submarine Base. Overcrowded and with the largest enrollment in the state, South Kitsap cannot get a bond issue for a new school or pass a levy to help pay for portables.

The State of California recently allocated $1.6 million to cover one-half of the Central Union School District's costs of modernizing the two on-base schools. But how could the district ask the parents of the six hundred students who live off-base to pass a bond issue raising their own property taxes to modernize schools for children whose parents do not pay property tax? Central instead used its Impact Aid funds—"property taxes" from the Federal government for the land it owns—to create a special reserve so that the district's 50 percent share would be available when the state funds were released.

Routine repairs and maintenance are often deferred when districts need to buy textbooks or pay teachers. But safe, structurally-sound buildings are essential for education. Listen to a student's description of lunch at Vandan High School in the Travis Unified School District in California:

When it rains at Vanden, the driving winds and stinging rains are unbearable; and I have nowhere to eat. For every student that can find space to sit in the cafeteria, there are three of us who must suffer the tumultuous elements. And because of El Niño this year the rains will come harder and longer; and the winds will be more fierce. I should like to invite you to have lunch with me on a day with torrential rains and 30 mile an hour winds. I guarantee that you will have an enlightening experience. If you can't make it for lunch, perhaps you'd send your 15 year old daughter. ("A Voice for the Unheard," by Trecia Pottinger, Student Board Representative, Travis Unified School District, speech given at meeting of National Association of Federally Impacted Schools, October 1997)

WHAT'S AHEAD FOR FISCAL YEAR 1999?

The Administration has requested $696 million dollars for Impact Aid in fiscal year 1999, $112 million dollars less than Congress appropriated for fiscal year 1998. We are concerned that the Administration has not requested any money to help heavily impacted districts such as the Travis United School District with construction, repairs, and maintenance. And, once again, the Administration proposes to cut funding for the military B students, the children of military members living in the local civilian community. The authors of the first Impact Aid legislation recognized that the greatest burden for school districts serving military children would be when the military parent both lived and worked on a federal installation. However, they understood that the military B children also created costs to the district beyond what it would collect from the payment of some taxes. Local property taxes fund a declining share of a district's education expenses. States contribute more than ever to elementary and secondary education. In many states, local governments receive state allocations based on local property taxes, putting districts with large areas of nontaxable federal land at further disadvantage. Many other taxes used by state and local governments to support schools, such as personal property taxes, license fees, and state or local income taxes, are not paid by military members unless they happen to be residing at their legal domicile. Every time military families shop

at exchanges and commissaries on the installation, states and localities lose sales tax revenue which could have gone to support schools.

The notion that only children living on base pose a financial burden on school districts is disconcerting to NMFA and its members who have witnessed the impact large numbers of transient military children can have on a district even when their parents pay real estate taxes. NMFA believes that continued funding for B students is even more essential now that the Department of Defense is privatizing military family housing at many installations. As this Subcommittee considers the funding needs of federally-impacted school districts this year, we ask that you continue to recognize this Federal responsibility, as first articulated in P. L. 81–874, to provide funding for the military children living off the federal installation.

We note that, in its fiscal year 1999 education proposals, the Administration is requesting several new programs to the long list of current federal education programs. Most of these programs target funds to specific needs or to supplement basic education in school districts which meet the eligibility requirements for that program. Impact Aid is different. Impact Aid dollars are targeted to districts where the Federal responsibility is the greatest under the law. The dollars go directly to school districts with no strings attached. The Newport News (VA) school district uses Impact Aid funds as part of its general operating fund. Other districts focus on reducing class size, upgrading technology, making building repairs, or continuing special programs. In each of these districts the local community, the people who have the greatest stake in the quality of education in their schools, decides how Impact Aid funds will best serve the basic education needs of all students.

SERVING THE MILITARY CHILD

Until recently, local districts generally made decisions about how to use their Impact Aid funds and what programs and policies to adopt based on purely local needs. When the school officials responsible for educating military children got together, they talked of how to secure better Impact Aid or DOD funding or how to educate public officials about the importance of Impact Aid. Gradually, however, these educators began to acknowledge that educational issues affecting military children often transcend local needs. Military children are everybody's children! The quality of education a military child receives in the California school she attends in 1st grade, for example, will affect the education she and her classmates receive in the North Carolina school she attends in 4th grade. Children whose schools are unable to provide the necessary educational services could easily fall behind their peers in other districts. A smooth transition into their next school, whether across the state or across the country, benefits military children and their new classmates.

In June 1997, some of the people who educate "everybody's children" participated in the First Annual Supporting the Military Child Conference sponsored by the Killeen (TX) Independent School District and Fort Hood. Participants identified critical issues involved in the transitioning of military students such as emotional and social support for the child, records transfer and proper placement, parental involvement, and communication. They offered recommendations on how districts could address these issues through technology, the sharing of information, the formation of partnerships between districts and military installations. They especially emphasized the need for continued communication between all school systems serving military children.

To build on the foundation begun at the Killeen/Fort Hood conference, the Groton (CT) Public School district began plans for a national conference on "Serving the Military Child" to be held October 1998 in Arlington, VA. In order to involve even more districts educating military children, members of the planning committee for this conference come from several states and represent all branches of the Armed Services. The conference has already attracted support from the Departments of Defense, Education and Transportation and Members of Congress. General Henry H. Shelton, Chairman of the Joint Chiefs of Staff, has indicated that he will participate in the opening session of the conference.

Organizers of the upcoming conference have agreed that one of their goals is to establish a new Military Child Education Coalition, whose mission is "to promote partnerships and provide for networking of military installations and their supporting schools for the purpose of establishing systems and developing processes which address transition and other educational issues related to the military child." Convinced of the necessity for an organization focused on the educational needs of military children, the Killeen School Board recently voted to fund start- up costs for the coalition. The coalition would be open to all school systems serving military children, from the Department of Defense Schools, to the heavily impacted, to those with just a few on a small installation.

To military parents, the idea of a coalition dedicated to the education and transition needs of military children is a wonderful thing. It is exciting to imagine that all the school systems which might ever educate our children are talking to each other about how they can do a better job. The educational focus of the Military Child conferences and Coalition demonstrates the effectiveness of the Impact Aid program. When the Federal government fulfills its responsibility to provide funding for basic education to districts serving military children, the districts can concentrate on creating a high-quality educational program for all students. They can create partnerships with other school systems and military commanders to look out for the educational needs of the military children they serve. We urge you, the Members of this Subcommittee, to be active partners in the education of military children and their civilian classmates and fully fund Impact Aid.

RELATED AGENCIES

PREPARED STATEMENT OF HOWARD K. AMMERMAN, PH.D., ON BEHALF OF THE U.S. INSTITUTE OF PEACE

Thank you for the opportunity to present this testimony. These views are expressed as those of an interested citizen with a background in economics who has supported the United States Institute of Peace [USIP] since its inception and who is very apprehensive concerning the scourge of war.

With a budget of slightly more than $11 million for the current year, the United States Institute of Peace is asking for an increase to $12.6 million for fiscal year 1999. To me, the total budget of the Institute is too small anyway, so I certainly support this increase. With the additional funds its present program in Bosnia could be pursued more intensively.

At this point in time, perhaps we need to be reminded that the Institute of Peace is a unique agency with its creation being the culmination of about two hundred years of effort. The very persistence of efforts to bring this about indicates a perceived gap in our dealing with the matter of conflicts among nations and a belief in the possibility of improving our performance. One figure observed recently for world deaths due to wars in the present century was 110 million and of these figures, 2 million were children killed in the past decade. Another total figure cited was considerably higher, and casualties among children seem to have increased rapidly in recent decades. Do we need to be reminded that drastic changes need to be made in our patterns of human behavior, and in this case, particularly in international relations or domestic conflicts that threaten to spill over into the international realm?

In Bosnia at the present time the Peace Institute finds itself involved in a post-conflict situation and directing its efforts toward helping those affected to follow through with an existing peace agreement. Matters of concern include such problems as transitional justice, political restructuring, the role of religion in conflict, and conflict resolution training. The work of the Institute serves to augment the work of other government agencies, but is some cases the Institute is doing work no other agency has the competency to do. This has been a natural extension of the work the Institute has been doing over the years. The Institute Board charged the staff to explore ways that its past work might contribute to peace building in Bosnia once the Dayton Accords had been signed. And it might be well to remember that on that Board are representatives of the Department of State and the Department of Defense.

Yet it seems to me that there is still great resistance to even the acceptance of the idea of an Institute of Peace. It may be gaining more attention abroad than in the U.S. One way to give more credence to the Institute is to increase its appropriations. In perspective, I consider its budget figure to be trivial. So, let's not stop at its requested $12.6 million, but add at least another million, for the Institute has built a base on which it can expand readily into other promising endeavors. Personally, I am disappointed Congress did not appropriate funds for construction of a headquarters building for the Institute; however, in raising the funds by public subscription the Institute will become better known to the general public. But in anticipation of having its own home, a budget figure such as it now has to me would be ridiculously low.

Because of this lack of attention to the Institute of Peace it may be well to consider the background for justifying the creation of such an agency even when this means repetition of previously submitted testimony. The Institute must spend at least 25 percent of its budget for research, but it is also greatly committed to the application of knowledge to specific problems of social relations and in the process

of such applications gaining useful experience and insights transferable to other cases. The President of the Institute, a former Foreign Service Officer, pointed out the need in Bosnia to move beyond the research and the academic to application. In Bosnia the Institute may well be doing some pioneering in this complex situation.

Recently the Hubble Space Telescope was described as, "The most expensive and complex scientific instrument ever". Without in any way deprecating this effort to learn more about the universe we may ask when are we going to make a comparable effort to learn more about the problems of human behavior on our planet? Rightfully, we make great efforts to learn more about that scourge of the human body, cancer. What about that cancer of the body politic, war? Perhaps the words of Thomas Jefferson may be of some help in this context—

"I am not an advocate for frequent changes in laws and constitutions, but laws and institutions must go hand in hand with the progress of the human mind. As that becomes more developed, more enlightened, as new discoveries are made, new truths discovered, and manners and opinions change, institutions must advance also to keep pace with the time. We might as well require a man to wear still the coat which fitted him as a boy as a civilized society to remain ever under the regimen of their barbarous ancestors."

Along with our ability to create, we human beings have the capacity to destroy, or shall we say, to engage in creativity for destructive purposes. Aren't there good reasons to be appalled by the danger of nuclear weapons and the disservice to humankind in strewing landmines over some 70 countries? At the same time, there are grounds for dismay at the comparative timidity of our efforts toward constructive creativity in developing a science of peach and a technology for achieving and maintaining such in international relations.

Rather, we tend to underestimate the dangers of our weapons of violence and destruction and to belittle our potentials for, and the urgency to develop, effective methods of nonviolent resolution of conflicts. This is not to overlook the great contributions made by scholars in the study of the causes of war and the avenues to peace but to emphasize the relative efforts made as compared to that given to the development of instruments and tactics for war. Furthermore, there are estimates that the lag between the appearance of an article in a professional journal and the possible uses of some of the ideas presented in policy determination may be as long as 30–40 years. But it has been said that, "The world can not long continue to wage war like physical giants and seek peace like intellectual pygmies".

On a broader basis, technological developments growing out of the physical and natural sciences are moving rapidly ahead and are not waiting for the behavioral sciences to catch up. International economic interdependence is also increasing. So the global village concept is becoming more and more of a reality. It is within this context that the need for peaceful resolution of conflicts become all the more important. And it seems to me the challenge lies in developing a science of peace. As remarkable as the contributions of the physical and natural sciences have been, and probably will be, to the betterment of human life, in my opinion our ultimate fate lies in the area of the behavioral.

The USIP is a unique institution in our national history and congressionally was the outgrowth of what was intended to be a National Peace Academy. The commission set up to consider the possible creation of such an academy stated in its report, "The Commission uses 'peace' forthrightly in its discussion the Commission rejects emphatically any insinuation that peace—any more than love, church, justice, family, or flag—is soft or naive. The commission believes that timorous attitudes toward peace do not advance the national interest or reflect the American Character. Peace is neither utopian nor a sign of weakness or cowardice. Peace is not simply to be measured by an absence of tension or a quietude of complaint. Peace is not only a desired state; it is a process that is vigorous. The Commission finds that peace is a legitimate field of learning that encompasses rigorous interdisciplinary research, education, and training directed toward peacemaking expertise". In pursuing such learning can we assume that despite our being such complex and diverse creatures we still have more in common than we have differences? Isn't there a contradiction in directing some of our best minds toward the creation of more "efficient" weapons of violence? Can we do less than give our best efforts to achieve more effective ways to resolve our conflicts peacefully?

Psychiatrist Vamik D. Volkan, in his "The Need to Have Enemies and Allies," sees the need for enemies as the embodiment of what we do not wish to become. They are standards by which we can measure our own "higher level" goals. It has been speculated that were our planet to be invaded from Mars, for example, we would quickly put aside our differences to engage the common enemy. But isn't it possible we on earth already have common enemies? After all, national boundaries are often very artificial limits. What about problems of the environment, greenhouse

effect, poverty, and hunger? Can these be said to constitute common enemies? And wouldn't common efforts to ameliorate these conditions do much to make us allies? Without succumbing to self conceit can we say as human beings we have plumbed the depths of our combined and coordinated potentials for dealing effectively with these common problems?

Looking hard for alternatives to violence in human relations at any level is intellectually stimulating. And all the more so because it involves a comprehensive effort to achieve positive and lasting results. In conflict resolution terms, this is a striving for "win-win" solutions. The extent of our funding for the USIP raises questions as to how seriously we take the efforts to achieve peace. There seems to be a very limited value placed on what some of the best minds in our country, and others, might accomplish. Isn't there a contradiction in directing some of our most talented toward the creation of ever more "efficient" weapons of violence? Can we do less than give our best efforts to achieve more effective ways to resolve our conflicts peacefully? Put another way, the relative amounts appropriated for the USIP as compared to those for instruments of violence tell a story. Is this a story with which we can or should be comfortable? To be sure, programs of research, education, training, and dissemination of information pertinent to peace-making can be done at much less cost than developing some of our most sophisticated weapons of violence, but can we expect sheer miracles?

In conclusion, isn't there an element of escapism, if not irresponsibility, in the "always has been and always will be" generalization? Would we not be in default in the application of our collective mental capacities if we take this view. But to avoid this will require much more widespread and intensive efforts on our part than we have made in the past. It would be shortsighted to look at the dangers and difficulties in human relations today without also recognizing the opportunities for good. The United States Institute of Peace, in one of its publications, has made this stimulating comment, "We are not looking for a revolution in human nature, we are looking for an evolution in human institutions."

Prepared Statement of Harris Wofford, Chief Executive Officer, Corporation for National Service

Mr. Chairman and Members of the Subcommittee, I appreciate the opportunity to review the achievements of national service over the last year and inform you about our programs and proposed budget.

I want to express my appreciation to the Subcommittee for the increases it provided last year. I know that you must sort between competing claims and make tough decisions with scarce resources. I believe that AmeriCorps*VISTA and Senior Corps have always been good investments, and I am firmly convinced that they merit your support today, more than ever. The Senior Corps and VISTA have a long tradition of involvement in our communities, improving education, bettering the health of children, promoting independent living and economic self-sufficiency, and harnessing the power of people in communities in every state in America.

The total fiscal year 1999 budget request to the Subcommittee for programs authorized under the Domestic Volunteer Service Act is $278.4 million, an increase of $21.8 million over the fiscal year 1998 appropriated level of $256.6 million. The request for the National Senior Service Corps programs is $173.9 million, including $43.3 million for the RSVP, an increase of $3 million, $94.1 million for the Foster Grandparent program, an increase of $6.6 million and $35.4 million for the Senior Companion program, level funding from last year. The request for AmeriCorps*VISTA is $73 million, an increase of $7.8 million.

These funds would provide program support for 5,500 AmeriCorps*VISTA member service years and almost 500,000 in the National Senior Service Corps—including approximately 462,500 in the Retired and Senior Volunteer Program (RSVP), 23,450 Foster Grandparents, and 8,600 Senior Companions. The requested budget for fiscal year 1999 would provide for an increase of 620 AmeriCorps*VISTA member service years and 8,800 Senior Corps service years. (The other programs of the Corporation for National Service, including AmeriCorps grants, the National Civilian Community Corps, and Learn and Serve America, and the Corporation's Office of the Inspector General are funded through the Subcommittee on VA, HUD, and Independent Agencies.)

COST EFFECTIVENESS

After three decades and the service of over 120,000 men and women at 15,000 local projects, VISTA (Volunteers in Service to America) today remains vibrant and vital. Now a part of the AmeriCorps network of national service programs, VISTA

continues its mission of building community capacity, breaking the bonds of dependency, and creating self-reliance among low-income people.

AmeriCorps*VISTA strengthens community-based organizations by expanding the capacity of local organizations to recruit, train, and coordinate local volunteers whose efforts continue in communities long after the VISTA members leave. Through these capacity-building partnerships, AmeriCorps*VISTA members help to expand affordable housing, create job opportunities, make health care more accessible, develop literacy activities and enable local citizens to live in safer neighborhoods.

AmeriCorps*VISTA is cost-effective. The living allowance and other support costs provided for each AmeriCorps*VISTA member total less than $13,400 per year. For every appropriated dollar spent on AmeriCorps*VISTA, $3.33 is returned to the community in the form of financial and in-kind resources and local volunteers generated by AmeriCorps*VISTA members for their projects. According to the most recent accomplishments study conducted by WESTAT Inc. and completed in April, 1998, AmeriCorps*VISTA members raised $82 million in cash and in-kind resources for their projects, and recruited and coordinated 140,600 local volunteers who provided more than four million hours of service. On average, each AmeriCorps*VISTA member recruited 42 community volunteers and generated $24,350 worth of resources.

In 1997, 25,300 Foster Grandparents served through 305 projects in all 50 states, the District of Columbia, Puerto Rico and the Virgin Islands. These Foster Grandparents served more than 175,000 children. Foster Grandparent projects are jointly funded by Federal, state, and local governments, with significant support from the private sector.

In 1997, the 24 million hours of service provided by Foster Grandparents were valued at more than $315 million based on an assessment service conducted by the Independent Sector and the Gallup Organization that assumes $13.24 an hour to calculate the value of volunteer. This represents more than a four-fold return on the Federal dollars invested in these projects.

The majority of children served by Foster Grandparents are young—ages birth through 12. Almost 14,000 Foster Grandparents help children with physical and mental impairments, about 4,000 help children who have been abused, abandoned, neglected, or are homeless, and some 2,000 help juvenile offenders or children with substance abuse problems.

RSVP volunteers provide hundreds of community services. They tutor at-risk youth, computerize information systems for community health organizations, get children immunized, teach parenting skills to teen parents, provide respite for caregivers of Alzheimer's victims, establish neighborhood watch groups, plan community gardens, and perform a myriad of other community services. Through such efforts, RSVP is meeting community needs that strained local budgets cannot afford to address.

In 1997, approximately 450,000 RSVP volunteers served in 751 projects sponsored by local public and private nonprofit agencies. RSVP volunteers contributed over 74 million hours of service to their communities in approximately 1,400 counties nationwide. These projects are jointly funded by the Federal Government, state and local governments, and the private sector. The 74 million hours of service provided annually by RSVP volunteers have an estimated value of over $1 billion; approximately a 30-fold return on the Federal dollars invested in RSVP.

In 1997, almost 14,000 Senior Companions served approximately 37,000 frail adults through 191 projects sponsored by local public and private nonprofit agencies. These projects are jointly funded by the Federal Government, state and local governments, and the private sector.

In 1997, the 12 million hours of service provided by Senior Companions were valued at $156 million; representing more than a five-fold return on the Federal dollars invested in Senior Companion Program projects.

GETTING THINGS DONE IN EDUCATION

Education has long been a central focus of the Senior Corps and AmeriCorps*VISTA programs. The challenge to have all children reading well and independently by the end of the third grade requires a mobilization of appropriately-trained reading tutors and partners from all walks of life, working closely with teachers and schools to enhance children's learning. AmeriCorps*VISTA has already begun to meet this challenge by committing members to recruit, screen, train, and place community volunteers—students, members of the business community, teachers, administrators, parents, PTA members—as reading tutors and mentors.

RSVP and the Foster Grandparent Program have been involved in children's literacy efforts since their inception. In the 1980s this focus was solidified in a multi-year partnership with B. Dalton Booksellers, Laubach Literacy, and the National Association of RSVP Directors to fund, train, and provide the technical assistance necessary to establish the RSVP Literacy Network. The Network eventually included over 75 percent of the local RSVP projects. In 1996, more than 35,000 RSVP volunteers provided over 1.8 million hours of education-related services to children and youth. By 1997, the Foster Grandparent Program was serving in over 3,100 schools and 1,200 Head Start programs. RSVPs served over 5,400 schools, 2,200 libraries, 1,100 Head Start/pre-schools, and 4,500 other educational settings. In 1997, the Corporation funded 265 local RSVP and FGP projects to support an additional 3,300 volunteers providing reading assistance to children in Head Start, schools, out of school tutoring programs, family literacy programs such as Even Start.

In 1997, the Corporation funded 25 new Foster Grandparent Program local projects with a strong child literacy component. These new Foster Grandparent projects are expected to increase the level of effort in child literacy by 1,055 volunteers, reaching an estimated 3,700 children nationwide.

In 1997, the Corporation also launched a new national demonstration program, Seniors for Schools, to mobilize the talent, experience, and resources of senior volunteers as literacy and reading resources to public school children in kindergarten through third grade. Two-year grants were awarded to projects in Florida, Massachusetts, Minnesota, Missouri, New York, Ohio, Oregon, Pennsylvania, and Texas. As of December 1997, more than 200 Seniors for Schools volunteers were tutoring, strengthening reading skills, increasing parental involvement, and planning special projects with more than 1,100 children from 23 public schools.

The Southeast Foster Grandparent Program of Monticello, Arkansas, began participating in child literacy activities with four public elementary schools in the fall of 1997. Sixteen Foster Grandparents received training as literacy tutors and were placed in the schools. Mid-year teacher evaluations, collected in January 1998, showed 77 percent are making noticeable progress.

In Durham, North Carolina, 73 RSVP volunteers served in elementary schools as reading tutors to 146 students who were reading below grade level. At the close of the 1996–1997 school year, five schools being served by RSVP volunteers met their reading goals, while six schools using RSVP volunteers exceeded their goals. An annual state reading test for third graders found that in 1996–1997, 65.2 percent of the tutored students were reading on grade level, a 33.3 percent increase from the previous year.

In Laurens, South Carolina, the County Family Education Center is a collaborative effort of the local literacy council and the public schools to provide an education program for disadvantaged parents and their pre-school children. Parents attend classes on adult literacy and parenting skills, and participate in PACT (Parent and Child Together) time in which teachers and Foster Grandparents model positive discipline techniques, language enrichment, and appropriate feeding/diapering techniques to the parents. Three Foster Grandparents are assigned to assist two preschool teachers using developmentally and age appropriate materials and practices for nurturing growth and development of 23 individual children. The Foster Grandparents served the children and their parents 20 hours per week for a total of 1980 hours of direct service. The Center staff indicated that objectives of the Center were met in that 91 percent (goal 80 percent) of the children assessed have indicated growth in age-appropriate development tasks and 82 percent (goal 75 percent) attended parenting sessions.

In Buhl, Idaho, Foster Grandparents provide literacy services to the children of Popplewell Elementary School where 40 percent of the students read below their grade level. Foster Grandparents help kindergarten and first grade students with word recognition and writing; serve in the library, assisting students of all grades to read aloud; help fifth graders whose first language is not English with reading comprehension; and engage students in all grades in creative writing and storytelling.

Foster Grandparents served 16 River Valley School, Iowa students with disabilities. As part of a summer reading program, Foster Grandparents and students were paired for 30 minutes and took turns reading aloud to each other. The group cumulatively read 112 books over the course of the summer. Students were assessed at the beginning of the summer to determine their abilities and interests, then weekly records monitored their attentiveness, enjoyment and attitude during the reading program. The weekly assessments demonstrated that 79 percent of the students rated excellent in attentiveness; 84 percent rated excellent in attitude and behavior; and 100 percent wanted to continue in the summer reading program next year.

In Springfield, Missouri, 90 percent of students at Fairbanks Elementary School are eligible for free or reduced lunches. Students' scores on standardized tests and attendance are consistently below the district average. The school also has one of the highest percentages of single parent families, with very low parental involvement. Twenty-one RSVP volunteers were recruited to work one-on-one with a specific child in first or second grade for approximately 45 minutes per week at breakfast or lunch for the entire school year. The reading teacher prepares packets with suggested books and activities specific for each child each week. According to reading teachers and the principal, children served by volunteers are already beginning to showing improved reading skills and attitudes towards reading.

In 1997, AmeriCorps*VISTA members serving in more than 300 education projects established or expanded adult and child literacy programs; conducted outreach campaigns to enroll individuals in GED or high school diploma equivalency programs; recruited, trained, and coordinated volunteer tutors; gathered books, supplies, and cash donations to sustain programs; and built school and community partnerships that will continue long after the VISTA members leave. Over the past two decades, AmeriCorps*VISTA has provided support for adult, family, and child literacy programs conducted by organizations such as the Literacy Volunteers of America, Laubach Literacy Action, and Communities in Schools. In all of these cases, VISTA members provide support to enable these organizations to more effectively carry out their education model.

In Pennsylvania, AmeriCorps*VISTA members recruited volunteers and raised the funds necessary to allow the Adams County Literacy Council to survive financially and provide effective one-to-one tutoring to adult nonreaders. VISTA members have established interactive programs with local school districts, Harrisburg Area Community college, and Gettysburg College. One VISTA member single-handedly conducted the first "Buck a Book" campaign in which area children enlisted sponsors for each book they read in a one week period. The campaign brought in $19,500 to the program.

The Oregon Children's Foundation's SMART programs encourage and support reading among children in kindergarten through second grade. Thirty-two AmeriCorps*VISTA members have recruited and trained more than 4,000 local volunteers in 78 schools to read to children, educate the public about volunteering, develop public-private partnerships and mobilize community resources. Private sector support comes from over 350 companies including Nike, Intel Corporation, Smith Barney and Wal-Mart.

In Kentucky, the Laurel County Literacy Council expanded its VISTA project activities to include five nearby counties. Since then, VISTA members have concentrated their efforts on resource mobilization. For example, the counties received a $17,500 grant from the KY Department of Adult Education and Literacy to purchase laptop computers in each of the five counties. A VISTA member in Bell County created "Little Bird", a new program that will distribute books to each parent of a newborn upon their release from the local hospital. As a result of the VISTA members, the Literacy Council received a $10,000 grant from NY Life Foundation to support student transportation and an additional instructor.

IMPROVING HEALTH AND NUTRITION

Senior Corps and AmeriCorps*VISTA programs also focus heavily on the health and nutrition needs of Americans of all ages. AmeriCorps*VISTA members assigned to nearly 150 projects have established or expanded 170 immunization programs which have immunized more than 47,000 children and adults, provided 155,000 individuals or families with health information or educational materials, and established or expanded 90 food banks. The Senior Companion program focuses on the needs of the frail elderly, while Foster Grandparents work with children who have physical, educational, or emotional disabilities.

In 1996, almost 300,000 families and 108,000 individuals received health care services from RSVP volunteers. RSVP volunteers assisted in serving more than 23 million meals. In 1997, Foster Grandparents provided service to 5,600 children with developmental disabilities, 2,700 children with emotional impairments and 4,500 children with a variety of physical disabilities. RSVP serves 4,300 hospitals and clinics, 6,000 nursing homes, 2,500 other long-term care facilities, and 900 home health care agencies.

In Pennsylvania, AmeriCorps*VISTA members serving the Greater Philadelphia Food Bank, raised over $150,000 through the Check Out Hunger Program. VISTA members also helped establish "The Greater Philadelphia Anti-Hunger Coalition," a self-sustaining network of agencies to enable feeding charities to function more efficiently. As a result of VISTA efforts, over 500,000 pounds of food annually is made

available to those in need. By helping to develop the resources to obtain a delivery vehicle, VISTA members have enabled the Food Bank to extend its delivery to include a 150 mile radius of the city.

The Northwest Arkansas Free Health and Dental Clinic in Fayetteville serves the needs of a low-income population. AmeriCorps*VISTA members designed and implemented a dental education program for children. Members recruited six dentists to work in the dental clinic, implemented an appointment system, secured donations of supplies and pharmaceuticals and recruited community volunteers to assist in the dental clinic's operations. One member secured a $40,000 grant from the Foundation of the Mid South that will sustain the operations of the children's dental program.

According to statistics from the Alzheimer's Association, an estimated 1 in 10 persons over 65 and nearly one-half of those over 85 have Alzheimer's disease. Most of those people live at home. Almost 75 percent of the home care is provided by family and friends; however, the remainder is paid care costing an average of $12,500 per year—to many, a prohibitively expensive amount. To help meet these care giver needs, volunteers from the Senior Companion Program of Harrison County provided almost 10,000 hours of in- home services to Alzheimer's patients in Ellisville, MS. Senior Companions assist with daily living activities, provide companionship to their client, and respite assistance to the caregiver. By helping people to live independently, Senior Companions help seniors avoid the $38,000 average annual nursing home costs.

In Hawaii, the Senior Companion Program expanded to Oahu's Leeward Coast to address the health needs of the homebound elderly. This remote area of the island is economically depressed and public transportation is poor. Senior Companions were assigned to a health care agency to provide personal care, home management, and social support for in-home caregivers. Five Senior Companions provided over 3,000 hours of service to 10 clients. As a result, the State has saved a minimum of $16,800 in nursing care for one year for each of the ten clients.

CREATING ECONOMIC OPPORTUNITY

AmeriCorps*VISTA is helping to move people from welfare to work. VISTA members assigned to 200 community economic development projects are providing training for many welfare recipients. In 1997, AmeriCorps*VISTA members identified more than 150 businesses across the country which agreed to hire welfare recipients and other unemployed people. AmeriCorps*VISTA members are also expanding microenterprise opportunities for aspiring entrepreneurs in low-income communities. In 1997, members helped 430 individuals or businesses obtain development capital and helped establish or expand nearly 800 microenterprises.

In Seattle, Washington, an AmeriCorps*VISTA member is assisting "Washington Works," an organization which places welfare recipients in paid employment. The VISTA member is assisting women who have succeeded initially confront child-care and transportation needs, skill training, and other potential obstacles which often prevent them from achieving long-term success on the job. Other AmeriCorps*VISTA members in Washington are working with the International Association of Machinists-CARES program to launch an employment program for people with AIDS.

AmeriCorps*VISTA members serving with Working Capital—a community based organization in Massachusetts—are assisting micro and small business development in 20 economically distressed communities throughout the State. The project utilizes a unique peer lending model to provide loans, training, and support to microentrepreneurs.

Through the work of the VISTAs in 1997, more than 1,000 businesses participated in and invested over $1 million dollars in the peer lending process. More than 200 microbusinesses have been created. The VISTAs play a vital role in recruiting potential business owners and assisting in the development of marketing strategies for Working Capital.

In New Haven, Connecticut, two AmeriCorps*VISTA members with the Greater New Haven Opportunities Industrialization Center assisted in the creation of a "Youth Mall" to give young adults the experience of entrepreneurship and to create jobs for young people moving from school to work. At-risk youth participated in the training program in order to establish, own, operate, and manage a snack shop and clothing store. The snack shop is now fully operational with program participants running the shop. The initial phase of developing the clothing store is also underway.

In Beloit, Wisconsin, AmeriCorps*VISTA members working for the Neighborhood Housing Services helped develop Homebuyers Clubs, developing a manual, creating and implementing working, and recruiting participants for this program to assist

families in buying homes. Because of the VISTA members' help, the Housing Services has been able to continue and maintain this program. Currently, the Clubs meet on a monthly basis to work through the process of becoming homeowners.

Thirty-two AmeriCorps*VISTA members are serving with 28 credit unions throughout the country through National Federation of Community Development Credit Unions. Members are developing Individual Development Account (IDA) programs, providing home ownership counseling and small and micro-business training. In the past 6 months, VISTA members have recruited 2,500 new credit union members and established eight youth credit union programs. Members have also helped to market, design, and implement 27 new programs or products to expand financial services to low income people such as IDAs, mortgage loans, small business lending, direct deposit, share accounts, and financial education seminars.

RSVP has a long history of providing assistance to older people, and low income families and individuals. In 1996, almost 270,000 volunteers contributed 9.8 million hours of professional or technical support services such as tax preparation or retirement planning. Approximately 528,000 families received assistance to alleviate problems related to homelessness.

In St. Louis, Missouri, Senior Companions team with younger home care workers who are welfare-to-work transition single mothers placed through the Near South Side Empowerment Coalition to provide services to Medicaid recipients. The young workers allow the Senior Companions to better attend to the emotional and relationship needs of the isolated and elderly clients, while the young workers handle chore services and other needs.

EXPANDING EFFECTIVE AND EFFICIENT SERVICE

A major goal of both the Senior Corps and AmeriCorps*VISTA is to expand service opportunities while maintaining high-quality. We are achieving this goal through Programming for Impact, cost-share agreements, public/private partnerships, serving in Enterprise and Empowerment zones, and helping community-based organizations obtain the resources they need to sustain their operations after Federal support has ended.

Programming for impact

After three decades of service, the Senior Corps is bringing a new vision into focus, shifting from a single focus on creating volunteer opportunities to a two dimensional approach of Senior and Service. This dual approach, which we call Programming for Impact, will position us to meet the challenges of the future and to establish existing programs as vehicles to harness the tremendous resource that the growing population of older persons can bring to addressing critical community needs. Senior Corps programs have proved that older volunteers are interested in serving and willing to serve, and that they do so impressively. We are now exercising leadership focusing on measurable benefits and outcomes realized from the efforts of the volunteers. This approach allows us to retain the best of the past while meeting the needs of the future.

Programming for Impact is the implementation vehicle to help change the way the Senior Corps does business. It was developed to enhance the "service" side of "senior service" by allowing projects to effectively assess community needs, engage volunteers in activities that relate directly to meeting the need, identify inputs and resources necessary, and set a basis for measuring accomplishments and changes that occur in the community as a result of the efforts of the volunteers.

The Senior Corps is engaged in a thoughtful, deliberate and incremental implementation of Programming for Impact. The impact goals are reflected in the Corporation's Government Performance and Results Act plan, budget request, and program evaluation plan.

In July 1996, the Senior Corps held a national conference, "Renewing America Through Senior Service," attended by all project directors who manage the more than 1,200 local Senior Corps projects. The directors were introduced to the nuts and bolts and rationale for these changes.

From July 1996 through 1997, the Senior Corps developed pilot test sites, and held state impact training conferences as incremental steps to reinforce Programming for Impact, to experiment with implementation, and to develop state-specific State Programming for Impact Implementation Plans. These locally-driven plans, designed to engage a wide base of Senior Corps stakeholders, defined how states will phase in the application of Programming for Impact to all projects over a 15 month period, during the period from July 1, 1997 through September 30, 1998.

In 1998, the Corporation worked to modify tools and systems needed to manage and guide Programming for Impact including the Senior Corps Grant Application

and the Project Progress Report (to include reporting on Government Performance and Review Act). We are currently field testing a set of Accomplishment Surveys that will capture both the "inputs" and "accomplishments" of Senior Corps projects in fiscal year 1999. As of July 1, 1998, Programming for Impact becomes the official approach for all Senior Corps projects with renewal dates of July 1, 1998, or later using the revised Grant Application.

SUSTAINABILITY

A recent evaluation conducted by People Works, Inc. found that nearly 73 percent of AmeriCorps*VISTA supported programs continued to operate years after the VISTAs had completed their assignments. This reflects the self-help philosophy of AmeriCorps*VISTA whose goal is to increase the capacity of the communities to solve their own problems. Each sponsoring organization plans from the beginning to phase out AmeriCorps*VISTA resources after three to five years and to have the community take over and sustain those activities. AmeriCorps*VISTA has proven that it works.

AmeriCorps*VISTA members who served with the Southern Development Foundation in Opelousas, Louisiana, introduced 75 farmers to sequential vegetable farming techniques and goat production. With the VISTAs' assistance, the farmers were able to realize a $3,000 to $5,000 per year increase in income with no significant increases in investment. The members established a Farmer's Market for the sale of participating farmers' produce which remains operational after AmeriCorps*VISTA resources have been removed.

AmeriCorps*VISTA members who served with the Arkansas Disability Coalition organized 20 parent support groups in rural areas with high levels of poverty throughout Southeast and Northeast Arkansas. These groups advocate on behalf of children with disabilities to ensure that they get the services and support they need. VISTAs developed and institutionalized the "Arkansas Meeting Plan," a listserve with over 100 members ranging from individuals with disabilities and their family members to professionals in the disability field. This listserve provides information on changes in special education policy, notices for opportunities to participate in social activities, information on the changes to Medicaid, and other important issues. VISTAs were also able to secure computers for 40 families and ongoing training for interested persons.

When Project VIDA AmeriCorps*VISTA in El Paso, TX, ended in 1996, it left a strong VISTA legacy in the community. Members developed an institutionalized reading development project as a piece of the after-school component that has succeeded in increasing standardized reading scores in each of its last three years. The VISTA health education component spun out into a community health clinic with a thousand visits a year. The housing component continues to conduct the environmental clean sweeps, graffiti suppression, and a tenant rights education program. According to the program director, "If it were not for the VISTA members, there would be no after school programs.* * * In housing, maybe the community would have been served another way, but we would be at least three years behind where we are today."

Cost-share programming

The AmeriCorps*VISTA program model has proven so successful that demand for AmeriCorps*VISTA members around the country exceeds the ability of federally appropriated dollars to provide them. However, as sponsoring organizations recognize the value of the VISTA resource they use their own resources on a cost-share basis to pay for basic member support costs while the Corporation provides the education award, training, and recruitment support. The number of members funded in this manner has risen from 560 in 1994 to more than 1,300 in fiscal year 1998. More than 200 sponsoring organizations contribute $13 million to this effort.

One example of a cost-share project making a difference is the State of Oregon's Health Division which has agreed to pay the basic expenses for 45 AmeriCorps*VISTA members. The members are located in almost every county in the state referring WIC and immunization clients to the Oregon Health Plan and publicizing the need for complete immunization. Because of the program, immunization rates in Lake County have increased from 57 percent in 1995 to 87 percent today; Lincoln County now has a new immunization clinic that is open in the evenings; the AmeriCorps*VISTA in Waso-Sherman County has regular monthly WIC/Immunization features on local radio stations and monthly spots in local newspapers; and, in Baker County, there are only 22 children under age two with incomplete immunizations.

Non-Federal funds also provide critical support to Senior Corps programs. In fiscal year 1997, the non-Federal local contribution to Foster Grandparent programs exceeded $32 million or 42 cents for every Federal dollar invested—well above the 10 percent matching share required by law. The non-Federal local contribution to RSVP projects of over $42 million, exceeding the Federal contribution, demonstrates broad support for RSVP across the country. For Senior Companion programs, the non-Federal local contribution was over $19 million. This non-Federal contribution represented a match of 61 percent, well above the 10-percent matching share required by law.

Public/private partnerships

—AmeriCorps*VISTA is partnering with over twenty national organizations including Big Brothers/Big Sisters, Communities in Schools, Habitat for Humanity, Save the Children, Literacy Volunteers of America, Laubach Literacy Action, National Alliance to End Homelessness, and United Way of America to make an impact on communities in the areas of adult and children's literacy, education, technology, housing and homelessness, among other issues.

AmeriCorps*VISTA has a long history of service with Habitat for Humanity which shares VISTA's mission to help low-income individuals help themselves. There are more than 200 AmeriCorps*VISTA members throughout the country recruiting volunteers and garnering donations at 40 Habitat for Humanity project sites. In Phelps, Kentucky, three AmeriCorps*VISTA members working with Phelps Habitat for Humanity mobilized tens of thousands of dollars in land, labor, and machinery. Members also recruited local volunteers and assisted the local communities in site plan development and family selection. Because of VISTA's involvement, Phelps Area Habitat now starts to build a new home every 6 weeks.

AmeriCorps*VISTA has collaborated with IBM and United Way of America to create Team TECH. Through this partnership 55 AmeriCorps*VISTA members are placed in 11 communities throughout the country to develop strong leadership and technological skills among nonprofit organizations serving the poor. They provide technology planning assistance, obtain funding for hardware and software, and provide computer training. During the past eight months, the Team TECH project has affected nearly 300,000 children providing $1.8 million in technology and technical services in the 11 communities served. These services provide children with direct access to new computers and software through after-school programs, daycare programs, education workshops, and mentoring programs.

In Burlington, Vermont, AmeriCorps*VISTA members serving with Team TECH have brought technology and technology assistance to more than 650 children in the Burlington Boys and Girls Club. The computers allowed the Vermont Job Bank to install education software, access to the Internet, and educational software, and set up a database of employment opportunities.

AmeriCorps*VISTA has also partnered with Rural LISC (Local Initiative Support Corporation), an organization which provides support and easier access to technology services in rural America. Eight members are serving with four community development corporations in New York, Wisconsin, California, and Oklahoma. The purpose of the project is to develop websites to provide low-income individuals in rural areas access to public and private support in order to obtain decent housing and a range of services intended to help them remain in housing. Thanks to the Internet, more than 60 community development corporations affiliated with Rural LISC will ultimately benefit from this project. Rural communities will have a significant new tool to prevent homelessness and improve services to the rural homeless.

MANAGEMENT ISSUES

Program administration

Program administration is authorized under Title IV of the Domestic Volunteer Service Act of 1973, as amended. For fiscal year 1999, the Corporation is requesting $31,512,000 for Program Administration. The requested funding will maintain necessary staffing for effective program oversight and to improve our financial control and reporting. Of the total, $22,231,000 will fully support 332 full-time equivalent workyears by staff providing direction, oversight, technical assistance and administrative services to programs nationwide. The remaining $9,281,000 will cover the cost of rents, supplies, communications, printing, contractual services, travel, transportation, and equipment.

Auditability

Last year, I indicated that we expected to have 97 of the 99 items cited in the Corporation's 1996 auditability study completed and appropriately addressed by the time the Inspector General conducted her review during the spring and early summer of 1997. That auditability review showed that the Corporation had fully addressed 72 items. However, we fell short of the goal I stated last year. The auditability review found 21 material weaknesses and reportable conditions that had not been fully cleared. Since that report, we have successfully addressed 10 of these 21, have made significant and sustained progress on seven others, and have begun to address the remaining four. In the review, both the Office of the Inspector General and Arthur Andersen stated that the Corporation had demonstrated a commitment to correct the deficiencies and weaknesses.

Our efforts on these auditability issues and our activities to establish strong financial management focus on five areas: (1) the maintenance of the growing number of paper records related to enrollments in the National Service Trust; (2) the timely reconciliation of cash; (3) improvement of controls over grants management; (4) improvement of budget and funds control; and (5) improvement of general financial control. We have had much success in each area. With important assistance from the Office of Management and Budget (OMB), we have developed a specific action plan with a timeline to remedy the remaining weaknesses identified in the July, 1997, review and to provide the basis for obtaining an unqualified opinion on the Corporation's Financial Statements for fiscal year 1998.

The first area is the maintenance of the growing number of paper records related to enrollments in the National Service Trust. We will use digital imaging technology, which we expect to have in place in the current fiscal year, to enter new enrollments and aid in the resolution of any historical problems related to older records. This use of imaging technology will ensure the accuracy of AmeriCorps members' records for the future and facilitate the prompt correction of past errors.

The second area of major effort is the timely reconciliation of cash. In our plan, remaining auditability items related to cash reconciliation will be successfully addressed by the end of August of this year. Interagency charges represent a special challenge. The timely posting of interagency charges is being addressed by OMB as part of a government-wide solution to the problem of an antiquated system for such charges. We will be among the first agencies to take advantage of new capabilities when OMB and the Department of the Treasury bring on-line the new capacity to identify sub-elements of interagency transfers.

In the third area, grants management, we are improving the accuracy of Trust records by enhancing our oversight program. In addition, we are establishing practices to strengthen our record-keeping regarding grant receivables and payables, such as better recording and tracking of funds owed the Corporation following audits.

With regard to the fourth area, budget and funds control, we will purchase and implement a new financial management system that will provide the capability to record commitments and obligations, thereby substantially increasing the effectiveness of controls. Meanwhile, we have adopted new procedures that protect against the over-obligation of grant funds.

Improvement of other financial controls is the fifth element in our plan. This includes, among other things, strengthening procedures for ensuring the accuracy of VISTA stipend payments and improving financial reporting.

While we continue to address these items, we have also made other important changes. Enhancements to our accounting and Trust systems have improved system security and data. We have issued policies and procedures for various financial management activities. New job descriptions have been written. Job duties have been segregated across our major financial functions. The staff supporting the operational activities of the National Service Trust have been consolidated into a single organization to improve management control.

The Government Performance and Results Act

The Corporation is complying with the requirement of the Government Performance and Results Act (GPRA). We have met, and are meeting, all of the requirements of GPRA. Our strategic plan was submitted on time and in full compliance with the Act. We have distributed copies of the plan widely, throughout the national service community, and it is available on our Internet website at www.nationalservice.org. Our fiscal 1999 performance plan was sent to the Congress on February 20 and soon it will be available through the Internet.

The strategic plan and the performance plan lay out in clear terms our vision and goals, and the practical steps we will follow to get there.

In addition, standards of program quality will be set for every area of national service. We will be creating indexes that can be used to rate objectively the quality of our programs. These indexes will combine data from many sources, including customer satisfaction and community impact ratings, into an overall assessment of quality. Every program area will be subject to what we call community impact ratings. In a national survey, we will be asking key community representatives, who are expected to have first-hand knowledge of national service programs, to rate the impact and quality of the services provided by our programs.

Every program area sponsored by the Corporation will have some form of customer satisfaction survey. We intend to know and report how well national service participants are addressing the unmet needs of the American people.

To implement the plan and measure our performance against its goals, we have in place, or are in the process of establishing, the systems needed to get the job done. We are on schedule to implement fully the data collection and analysis plans needed so that we can report to the Congress and the public in March 2000 how well we have done in meeting our goals.

Reauthorization

After two years of work with national service sponsors, partners and participants, as well as Governors, Mayors, and other local elected officials, the Corporation for National Service's reauthorization proposal has been transmitted by the President to the Congress, and introduced in the House on March 26. The bill, entitled the "National and Community Service Amendments Act of 1998," was introduced with bipartisan co-sponsorship. The legislation proposes significant steps to improve national service, based on the lessons learned over the last several years and the careful analysis the programs have received from within and outside of the Corporation. Specifically, the proposed legislation:

—Strengthens partnerships with traditional volunteer organizations;
—Codifies agreements with Congress and others to reduce costs and streamline national service;
—Provides States additional flexibility to administer national service programs; and
—Expands opportunities for Americans to serve.

I want to emphasize that the Administration's proposal is a starting point for—not the end of—discussions on what a reauthorization bill should include. I look forward to working with the Members of the Subcommittee on this important matter.

CONCLUSION

This is an exciting time to be engaged in service. The activities of millions of Americans on Dr. Martin Luther King, Jr., Day and in the wake of Presidents' Summit for America's Future evidence the growing awareness in this country of the importance of community service.

The Martin Luther King Day of Service

Pursuant to the 1994 Act of Congress, the Corporation works in partnership with the Martin Luther King Center for Non-Violent Social Change to make the national holiday in honor of Martin Luther King, Jr., a "Day On, Not a Day Off" in which Americans, across the lines that divide us, join in service to their communities. In this, the third year of promoting this observance of Dr. King's birthday in a way that reflects his life and teachings, we had a breakthrough in focusing national attention on this day as a day of service. Our other national partners included the United Way of America, the Points of Light Foundation and Do Something—a youth service organization. With national media attention in almost every major media market and almost 300 local projects reported in 48 States, the District of Columbia, Puerto Rico and the Virgin Islands, we gained significant momentum toward our goal and legislative responsibility to promote service in honor of Dr. King.

Follow-up to the Presidents' Summit For America's Future

The Presidents' Summit For America's Future held last April in Philadelphia was an opportunity for the public sector to join with the private sector and the nonprofit sector to focus attention on the need for a new level of concerted citizen action to turn the tide for millions of young people. The goal of the Summit and of America's Promise, the post-Summit campaign led by General Colin Powell, is to mobilize millions of citizens and thousands of organizations—including Government, corporations, foundations, faith-based and community service organizations—to help children who lack the conditions for success in life.

At the Summit, the Presidents signed a declaration setting five goals—five fundamental resources for a young person's success:

—An ongoing relationship with a caring adult—as a mentor, tutor, or coach;
—Safe places with structured activities to learn and grow during non-school hours;
—A healthy start and a healthy future;
—An effective education providing a marketable skill, including the ability to read well; and
—An opportunity to serve, not just be served.

National service is already playing an active role in achieving each of these goals. The fifth goal—service by young people—is at the heart of our mission. Goal Five seeks a large-scale expansion of youth service and service-learning opportunities. The Corporation is helping to shape and promote Goal Five in collaboration with a growing alliance of organizations committed to that effort, including the nation's great civic and youth service organizations such as the Y.M.C.A, Boys and Girls Clubs, the Lions Clubs, and Big Brothers Big Sisters of America; philanthropic organizations such as the W.K. Kellogg Foundation and the James Irvine Foundation; corporations with an interest in youth such as Viacom's MTV Networks; and faith-based organizations such as the Council of Religious Volunteer Agencies.

Since last April, scores of States and communities have held their own follow-up summits to gather local partners and secure local commitments to pursue the summit goals. The national service network is actively assisting America's Promise in planning and carrying out these follow-up summits along with our original Summit partners—the Points of Light Foundation's Volunteer Centers and the United Way of America. State Commissions, Corporation State Offices, national service sponsors, and national service participants have worked with Governors, Mayors, corporate leaders, and nonprofit organizations to develop their own plans of action.

Consistent with the activities of the Summit, on January 1, 1998, President Clinton and former President Bush reintroduced the Daily Points of Light. Initially awarded during the Bush Administration, the Daily Points of Light are designed to honor volunteers and volunteer organizations that demonstrate unique and innovative approaches to community volunteering and citizen action, with a strong emphasis on service focused on the goals for children and young people set by the Presidents' Summit for America's Future. The Daily Points of Light program is co-sponsored by the Points of Light Foundation, the Corporation for National Service, and the Knights of Columbus. The Knights of Columbus Supreme Council provides full funding for the awards.

While the examples and initiatives described above represent only a fraction of the overall activities and accomplishments of the national service programs authorized by the Domestic Volunteer Service Act, they provide a glimpse into the remarkable diversity, ingenuity and cost-effectiveness of national service. These programs share a proud history, a long tradition of success, and have evolved to meet our nation's challenges. As we move into the next century, AmeriCorps*VISTA and the National Senior Service Corps will continue to help local communities develop and implement solutions to their problems. The programs have thrived through seven administrations, Democratic and Republican alike, with strong bipartisan support along the way.

I look forward to working with the Subcommittee to continue this tradition.

PREPARED STATEMENT OF THE ASSOCIATION OF AMERICA'S PUBLIC TELEVISION STATIONS

OVERVIEW

The Association of America's Public Television Stations (APTS) submits this testimony to the Senate Appropriations Subcommittee for Labor, Health and Human Services, Education and Related Agencies on behalf of the nation's 179 local public television licensees. America's public television stations reach 99 percent of television households through a public broadcasting system that is in place and working now.

APTS is requesting that the subcommittee provide the Corporation for Public Broadcasting (CPB) $340 million in annual appropriations for fiscal year 2001. This is the same amount requested by the Administration in its fiscal year 1999 budget. In addition, APTS is requesting an appropriation of $75 million for CPB in fiscal year 1999 to establish a matching grant program that will assist public broadcasting stations in the conversion to digital broadcasting.

We are pleased that the Administration has established a Public Broadcasting Digital Transition Fund in the fiscal year 1999 budget request to Congress. That

request is for $450 million over 5 years to be administered by CPB and the Public Telecommunications Facilities Program (PTFP) at the Department of Commerce.

Public broadcasters estimate that the costs to convert public radio and television to digital technology will be $1.7 billion. Unlike commercial broadcasters, public broadcasters are nonprofit or state and local government entities that rely on a grassroots funding structure. Public broadcasting's support comes from a combination of Federal and non-Federal sources, including individual viewers and listeners, foundations and businesses, colleges and universities and State and local governments.

Unfunded Federal mandate

Public broadcasting is asking the Federal Government for a total of $600 million over 4 years for digital transition. America's public television stations concur with the Administration's support of $375 million for the CPB portion of the fund. Public television stations cannot wait, however, until 2003 for the final payout as proposed by the Administration. The FCC has mandated that all public television stations be on the air with a digital signal by May 2003. Public television stations support the division of the CPB portion of the fund in an equitable manner among all stations, similar to the community services grant (CSG) process currently in place, beginning with $75 million in fiscal year 1999.

The remainder of the funds-$225 million over four years, $56.25 million per year-would be administered by PTFP to meet the needs of rural or hardship sole-service stations and to meet the continuing analog equipment needs of public television and radio stations.

Stations' fundraising abilities

Because of their nonprofit status and grassroots funding structure, stations are constrained in their ability to finance major capital expenditures such as the digital investment. Unlike their commercial counterparts, public stations are unable to pass along their costs to their customers. Most public broadcast stations cannot take out capital loans, and many, by law, must have balanced budgets on an annual basis and may not maintain cash reserves. Given these constraints, stations cannot use the typical mechanisms available to commercial entities to fund a major capital expenditure.

An additional Federal investment is critical to ensure that all citizens of the United States have access to public telecommunications services through digital technology. The clarity of high definition and the multicasting capability of digital technology will allow public television to enhance the educational value of its programming and to multiply educational services. With digital, public television can serve more diverse, unserved and underserved audiences on a single channel.

Public broadcasting will raise the rest of the necessary funds, roughly $1 billion, from other sources: individual contributions, corporate underwriting, State funding, foundation grants, and through new efficiencies and cost savings. The noncommercial nature of public broadcasting makes raising these funds from private sources even more challenging than for the commercial networks, and thus requires a public investment to meet the new technological standard.

Critical Federal participation

Since 1968, the Federal Government has provided financial support to the public broadcasting system through an annual appropriation. CPB will continue to need an annual Federal appropriation in order to distribute funds (75 percent) to local public television and radio stations for station operations and programming. These community service grants (CSGs) provide, on average, one sixth of the revenue for a public television station. This figure varies widely, however. Many small rural stations depend on Federal support for 30 percent of their operating budgets.

This Federal support will enable public broadcasting to continue to serve the nation and maintain its core principles. These principles are:

—Noncommercial character with an educational mission;
—Creation and delivery of programming of unequaled quality and excellence;
—Editorial integrity and independence;
—PTV's adaptation of new technologies to educational and public service purposes;
—Universal access to our services; and
—Local ownership, control and focus of public television stations.

With, by and for local constituents

The goal of each local station is to serve its community. Stations are governed by boards composed of people who live and have a personal investment in their community; decisions are made at the local level to determine the special needs of that

community. Public broadcasting is the only broadcasting entity that is totally committed to ensuring that all Americans have access to free, locally based, enriching programs and education services in the digital age.

TECHNICAL LEADERSHIP

Public broadcasters have always been leaders in making use of new technologies for public service. We developed closed captioning and descriptive video services and pioneered satellite delivery of broadcast television. Public broadcasters once again have a vision of what new digital technology can deliver. We look forward to developing further applications of new technology to educate and enlighten all Americans.

Community service leadership

We will provide the following services through these new digital technologies:

—Multicasting will enable public broadcasting to extend the reach of its educational services by enabling stations to broadcast four or more separate, but simultaneous, program streams. Potential channels might include: a preschool Ready to Learn service; K–12 instructional programming; GED and college credit telecourses; workforce training; local public affairs; or popular how-to shows.

—The DTV signal will give public television the ability to transmit computer information and data over-the-air, providing another powerful tool for public television stations to expand their educational missions. Stations will have the capacity to deliver course-related materials to teachers and students, program guide information, and selected portions of the World Wide Web over-the-air to homes and schools. End users will be able to download this information instantaneously, using a television set converter, computer or a digital television receiver.

—High Definition Television (HDTV) will significantly enhance the beauty and detail of public broadcasting's signature programming in science and nature, performing arts, science, drama and travel.

Highlighted below are some of our current services that can be enhanced in the digital age. Public television will be able to multicast more quality programs simultaneously with information and data available to download immediately. Science and technical programs, through high definition television, will have the same aesthetic quality as major motion pictures.

Serving local schools

Public television stations work directly with local schools. They broadcast an average of five and a half hours per day of instructional programming for classroom use, enabling 2 million teachers to use quality instructional programming to reach 30 million students in 63,000 K–12 schools. Local stations broadcast overnight so that teachers can record and build a library of programs. Stations encourage this and many publish special guides for teachers as well as supplementary materials to facilitate the use of public television programs in the classroom. Public television stations work with teachers to enable them to use video most effectively; we also offer access to program information on the World Wide Web.

Serving children

Our educational programming remains the first choice of children, parents and teachers. Research does prove that children raised on Sesame Street and other public television programs perform better in school. The Ready to Learn project undertaken by public television is centered around a daytime block of children's programming. Local stations have expanded the value of these programs by providing outreach services to children and their parents and caregivers to help them use public television as an effective learning tool. Over 450 workshops for parents and caregivers and benefiting over 70,000 children have been sponsored by local stations.

Serving the local economy

GED ON TV is an excellent example of what public television does best. Produced by the Kentucky Network and currently offered by 54 percent of public television stations, GED ON TV has enabled nearly 2 million adults to acquire a high school equivalency certificate. Recent figures from the Bureau of Labor Statistics indicate that citizens with a high school diploma or equivalency contribute $4980 more per year to their state's economy than do high school dropouts. That's almost $10 billion added to our nation's economy annually. Multiply that by the 30 or more years American's spend in the workforce.

Bringing the world into schools

Electronic field trips, produced by Kentucky Education Television have allowed an average of 550 classrooms across the state to visit Mammoth Cave, a working horse farm, a newspaper and an underground Kentucky coal mine. Other electronic field trips, produced by public television, have taken students to such exciting locales as the South Pole and Colonial Williamsburg.

Serving working adults

Two thousand colleges and universities are using public television's Adult Learning Service (ALS). Local public television stations enable 400,000 tuition-paying students a chance to earn a college degree through television. In the last 15 years, over 3.5 million adults have participated in public television's ALS. These generally older students often live off campus, are employed and have adult responsibilities. Public television helps them move ahead by making a college degree accessible.

Funding the mandate

Congress has mandated the conversion to digital and the Federal Communications Commission has set a deadline of 2003 for public television stations to broadcast in the digital format. Digital technology is not a frill; it's a technological imperative. Since the FCC is requiring all television stations to convert to digital programming by 2003, public broadcasters are obliged to make unprecedented investments in new transmission and production equipment.

Public broadcasters simply will not be able to make the transition to digital without Federal support. Almost half of all public television licensees (86 out of 177) will incur transition costs that alone exceed their projected annual revenues. Federal funds provide the critical seed money that stimulates private contributions.

For a one-time charge of $2.28 per American-less than the cost of a video rental-every viewer will gain a lifetime of unlimited access to public broadcasting's enriched and expanded programs and education services in the digital era. That's a high value for a relatively low cost. The alternative-a future of 500 digital channels with no safe harbor of noncommercial educational channels-puts this investment into perspective. At a time when the education needs of this nation are so great, it should be one of the government's highest priorities.

A model of efficiency

Public television stations are already exploring the challenges and opportunities of digital transition to achieve efficiencies and cost savings. Many stations are participating in CPB's Future Fund projects to experiment, on a micro basis, with the activities that all of public broadcasting may have to undertake in the digital future. The transition to digital gives public broadcasters an opportunity to undertake collaborative activities that will yield a more efficient broadcasting operation while reducing costs.

Congressional leadership

You have made a very wise investment in public broadcasting. You have helped us improve millions of Americans lives every day. We hope that you will continue this support by assisting the industry into the digital age.

Thank you. On behalf of the nation's public television stations, we look forward to working with you to ensure that we have the financial resources to continue to provide the American people free access to quality, noncommercial educational television.

PREPARED STATEMENT OF THE NATIONAL FEDERATION OF COMMUNITY BROADCASTERS

Thank you for the opportunity to submit testimony on behalf of the National Federation of Community Broadcasters, or NFCB, which is the sole national organization of community oriented non-commercial radio stations.

Community radio fully supports $340 million in funding for the Corporation for Public Broadcasting in fiscal year 2001. Federal support distributed through the CPB is an unreplaceable resource for rural stations and for those stations serving minority communities. In the case of the rural and minority stations, CPB support may not ever be replaced and the goal of universal, local, non-commercial radio service will never be achieved.

In larger towns and cities, sustaining grants from CPB enable community radio stations to provide a reliable source of noncommercial programming—about the communities themselves. Local programming is an increasingly rare commodity in a nation that can hear and view news from around in the world every thirty minutes.

The NFCB has two requests we submit to the Subcommittee. First, we ask that the Subcommittee recommend to the CPB to continue its funding priority for rural radio, especially sole service providers, stations with minimal donor bases or service areas with limited programming alternatives, and community radio stations. Second, we recommend that funds for the transition to digital broadcasting allocated to the CPB include support for both public radio and public television.

I. Maintain funding to sole service, rural, and stations reaching underserved audiences

The NFCB requests that the Subcommittee include with its fiscal year 2001 CPB appropriation report a recommendation that CPB give funding priority to public radio stations that serve rural and unserved areas, sole service stations and stations reaching underserved audiences. Our request echoes language included in reports from House and Senate subcommittees on CPB appropriations in recent years.

In the Senate Report 105–58 for fiscal year 1998 Labor, Health and Human Services, Education and Related Agencies Appropriations, (fiscal year 2000 CPB funding) CPB grant programs for the stations described above were encouraged with the language: The Committee intends that CPB foster services for unserved or underserved audiences focusing on entities whose primary services are directed at audiences in rural areas and Native American audiences. The Committee is concerned about the erosion of grants for radio stations serving these communities.

The Committee recognizes that stations serving rural and underserved audiences have limited local potential for fundraising because of sparse populations serviced, limited number of local businesses, and low-income level. In rural areas, while many stations receive per capita support far greater than that contributed in urban areas, they receive relatively few matching dollars because the populations served are small.

The Committee directs CPB to explore new methodologies for distribution of Federal matching dollars which take into account measures such as per capita support and other factors that would serve to level the playing field between urban and rural stations in the distribution of matching funds.

Similar language has been included House reports on the CPB appropriations for fiscal year 1998 and fiscal year 1999. We are asking that the Subcommittee consider including such a recommendation with the fiscal year 2001 appropriation report.

II. Funds appropriated to the CPB for the transition to digital broadcasting should support both public radio and public television

The NFCB fully supports the maximum funding for CPB to assist public radio and television to transition to digital broadcasting. While the NFCB understands that television is under a strict deadline for the digital conversion, and we support the greatest amount possible in Federal funding to assist public television, we want to advise the Committee that public radio is already planning for its own digital conversion.

Federal funds distributed by the CPB should be available to the all public radio stations eligible for Federal equipment support through the Public Telecommunications Facilities Program (PTFP) of the National Telecommunications and Information Agency of the Department of Commerce. In previous years, Federal support for public radio and television equipment has been distributed through the PTFP grant program. The PTFP criteria for funding are exacting, but allow for wider participation among public broadcasters. Stations eligible for PTFP funding and not for CPB funding include small budget, rural and minority controlled stations.

Thank you for your consideration of our testimony.

The NFCB is a twenty year old grassroots organization which was established by, and continues to be supported by our member stations. Large and small, rural and urban, the NFCB member stations are distinguished by their commitment to local programming and community participation and support. NFCB's 90 Participant members and 136 Associates come from across the United States, from Alaska to Florida; from every major market to the smallest Native American reservation. While the urban member stations serve communities that include New York, Minneapolis, San Francisco and other major markets, the rural members are often the sole source of local and national daily news and information in their communities. NFCB's membership reflects the true diversity of the American population: 40 percent of the members serve rural communities and 34 percent are minority radio services.

On community radio stations' airwaves examples of localism abound: on KILI in Porcupine, South Dakota you will hear morning drive programs in their Native Lakota language; throughout the California farming areas around Fresno, Radio Bilingue programs five stations targeting low-income farm workers; in Barrow Alas-

ka, on KBRW you will hear the local news and fishing reports in English, and Yupik Eskimo; in Dunmore, West Virginia, you will hear coverage of the local school board and county commission meetings; KABR in Alamo, New Mexico serves its small isolated Native American population with programming almost exclusively in Navajo; and on WWOZ you can hear the sounds and culture of New Orleans throughout the day.

In 1949 the first community radio station went on the air. From that day forward, community radio stations were reliant on their local community for support through listener contributions. Today, many stations are partially funded through the Corporation for Public Broadcasting grant programs. CPB funds represent about 15 percent of the larger stations' budgets, but often can represent up to 40 percent of the budget of the smallest rural stations.

PREPARED STATEMENT OF DELANO E. LEWIS, PRESIDENT AND CEO, NATIONAL PUBLIC RADIO

On behalf of National Public Radio (NPR) and the more than 590 public radio stations it represents, I respectfully submit this statement for the hearing record. For 30 years, the public broadcasting system has provided a noncommercial, educational programming alternative for parents, children and others. The Senate Labor/HHS Appropriations Subcommittee has made a commitment to helping public broadcasting fulfill this public service mission. Your efforts are greatly appreciated. Looking ahead, public broadcasting plans to better serve Americans through new technology. I urge members of the Subcommittee to reinvest the resources necessary to revolutionize the way public broadcasting delivers its unique programming and services.

Public broadcasters are seeking two appropriations for the Corporation for Public Broadcasting (CPB). The first funding request is for a $340 million appropriation for the traditional, annual CPB appropriation for fiscal year 2001. As you know, CPB is forward funded by two years. Second, we request your support of a $375 million appropriation over four years for the conversion to digital broadcasting. For fiscal year 1999, public broadcasters urge the Subcommittee to appropriate $75 million for digital broadcasting.

Annual CPB appropriation A Public/Private Partnership

Public broadcasters support the recommended $340 million for CPB in fiscal year 2001. Public broadcasters are part of a successful public-private partnership. According to the latest CPB "Public Broadcasting Revenue Report for fiscal year 1996", Federal money accounts for 17 percent of public broadcasting's revenue, a small but important piece of the funding pie. The largest single portion of public broadcasting's revenue is derived from listeners and viewers, accounting for 23 percent. Business support accounts for 15 percent, universities and colleges 10 percent and foundations eight percent. Support also comes from state and local governments (15 percent and three percent, respectively). For public radio, every Federal dollar leverages over $5 from non-Federal sources. That is a five to one return on the Federal investment in quality programs and services. Federal money is crucial because it helps public radio stations plan, produce and acquire programs that attract non-Federal funding sources.

When Federal public broadcasting funding was challenged in 1995, the American public aggressively supported its continuation. In fact, when given a choice of 20 services, Americans judged public radio and television the second and third best value in return for tax dollars spent. Military defense ranked first. This information comes through a poll conducted last summer by Roper Starch Worldwide, Inc. The American people consider Federal funding for public broadcasting to be a wise use of their tax dollars because they value the programming and services provided by their local public station. For fiscal years 1998 and 1999, public broadcasting cost each American 93 cents per year. For public radio alone, this figure is merely 23 cents per American each year. Currently, CPB funding is at its lowest level since 1992. This funding increase will help keep pace with rising programming costs. The majority of Federal money is directed to local stations. After CPB administrative costs, public radio receives 25 percent of the Federal appropriation and public television receives 75 percent. Of radio's portion, 93 percent goes directly to public radio stations. The other seven percent of radio funds remain at CPB to support national programming through a competitive grant process. CPB funding assists public broadcasting stations to produce local programming and to purchase national programs.

Public Radio Is A Source Of Educational, Cultural and Informational Programming

Americans rely on public broadcasting for diverse, long-form educational, cultural and informational programming. In some cases, these programs may not be commercially viable because they do not attract a mass audience. Nevertheless, these programs are intrinsically valuable because they examine important issues that may not otherwise receive necessary attention.

Public radio stations are treasure-troves of quality local programming. This programming, on average, accounts for 48 percent of stations' formats. For instance, KUAF–FM in Fayetteville, AR is partnering with Washington Regional Medical Center Hospice Program (WRMC) to bring listeners information on life and death decisionmaking—a special outreach program and broadcast series exploring end-of-life issues. KUAF–FM and WRMC will sponsor a series of community forums to stimulate dialogue on these topics.

In addition to shows featuring big band, folk and country music, KCMW–FM in Warrensburg, MO offers daily jazz programming which regularly features local jazz artists, both past and present, who have helped frame and define the jazz genre. In addition, KCMW–FM broadcasts the concerts performed at the Scott Joplin Ragtime Festival in Sedalia, MO each June. WRTI–FM in Philadelphia, PA produces a classical music program titled, Notes from Philadelphia. This program highlights local classical musicians and performance groups through their music and interviews. These artist are not as well known as some musicians in professional orchestras, but they are committed, talented artists who perform and give voice to the community. In San Antonio, TX, KSTX–FM's Community Forum are monthly public forums which foster lively discussion on topics of local interest with experts and the community. The April forum will focus on teenage pregnancy, a problem in San Antonio. In addition, KSTX–FM has received a grant from Sound Partners to produce a 6-month awareness series on teen pregnancy. The station is partnering with the Metropolitan Health District as well as co-sponsoring awareness projects and events with local organizations including local schools and a museum.

Four times a year KPBX–FM in Spokane, WA produces free public forums on subjects that are important to the communities of the inland northwest region such as education, health care, the environment and timber issues. The station brings together groups of up to 250 citizens for moderated, face to face discussions with expert panelists. The meetings are later broadcast. Hawaii Public Radio produces and broadcasts several public affairs programs that are extremely important to the ethnically diverse population of Hawaii. A Second Glance is a weekly program about native Hawaiian issues. Pacific Island News airs three times daily, Monday through Saturday, and collects news from all of the Pacific Island communities. Asia Report airs two times daily and features news from China, Japan, Korea, and the Philippines. Also, KTEP–FM in El Paso, TX produces a senior citizens program, Senior Junction, which provides information to the elderly and their care givers.

Public radio is a unique educational resource for local communities. KXCV–FM in Maryville, MO is involved in a project with teachers from schools in the five-county area to assist them in developing lesson plans for developing communication skills. KXCV–FM also helps coordinate an industry/education partnership where teachers spend a day with various businesses to learn the skills that students are expected to need to develop for the world of work. Music educators throughout Mississippi integrate Public Radio Mississippi's music and arts programs into their teaching plans. Each week over 100,000 Mississippians tune into PRM. WFDD-FM in Wintson-Salem, NC produces Neighborhood News for the Blind. This is a one-hour weekly reading service program providing synopses of neighborhood news reported in local newspapers.

Public radio stations also support local artists, musicians and cultural opportunities for children. For example, WUSF–FM in Tampa, Florida records and broadcasts performances by the Florida Orchestra, the Naples Philharmonic and the Sarasota Music Festival. Performances by the music faculty at the University of South Florida in Tampa are also recorded and aired. WJHU–FM in Baltimore, MD, produces music programs that prepare students to better understand and enjoy their first symphony concert. The station is under contract with the Chicago Symphony Orchestra to replicate this project in Chicago, IL.

National programs such as All Things Considered , Performance Today and Marketplace help draw listeners to public radio. These national offerings complement local productions by providing quality educational, cultural and informational programs to local communities. For instance, in May, NPR's Talk of the Nation will broadcast a four part series chronicling the history of America's disabled community. Beyond Affliction will examine this powerful issue that other media often ignores. Locally, stations may develop their own programming and outreach activities to complement national special programs. Over 50 disability organizations and their

local chapters have agreed to provide NPR stations with experts for local programming and assistance in organizing or sponsoring community events.

National cultural programs such as Performance Today provide listeners with thoughtful, helpful insights into the world of classical music together with great concert performances. Wynton Marsalis: Making the Music is a series designed to explore an American art-form, jazz. The program is hosted by Wynton Marsalis who engages and educates listeners about the history and sound of this music.

Public radio's news programs present in-depth reports which furnish the full particulars of a story. For instance, Marketplace is a national series detailing the world's news through a business, economic and financial perspective. NPR's Morning Edition and All Things Considered are two award-winning news magazines that cover in-depth politics, international affairs, education, arts, sports and music. Stations rely on Federal funding to purchase these national treasures, providing public radio stations with a balance of local, national and international programming.

Americans Value Public Broadcasting

In addition to the polling results discussed earlier, there are other obvious ways listeners show their support. They donate their time and money. In 1995, people volunteered over 2.5 million hours at their local public radio and television stations. Nearly 7 million people supported public radio and television financially.[1] Millions of other people who listen and view public broadcasting value the programs and services. For instance, WJAZ–FM and WITF–FM in the Harrisburg, PA area have 22,000 weekly listeners. Meanwhile, WOI–AM/FM in the Des Moines, IA area have 65,700 listeners weekly, and in Mississippi WMAB–FM and WMAE–FM in the Columbus-Tupelo area have 15,700 listeners.[2]

There are also many Americans abroad that listen to public radio through the Internet or Armed Forces Radio. U.S. Army Sergeant Tom Daniels had this to say about public radio while stationed in Bosnia-Hercegovina, "I found Armed Forces Radio playing All Things Considered at 11 p.m., each night, and I was thrilled. I just wanted to say thank you! I listen every night, and as you are my greatest contact with America, I can keep that feeling of home." Dennis Keeton wrote, "I am a soldier on active duty and have listened to NPR through Armed Forces Network while serving in Germany and while living in a tent in Zagreb, Croatia with UNPROFOR. Weekend Edition, All Things Considered, Car Talk and many others have all been treasured links with America and HOME. Thank you for all of the listening enjoyment." A $340 million CPB appropriation for fiscal year 2001 will assist public radio with continuing to deliver this quality, educational programming that Americans everywhere rely on and expect.

Digital CPB appropriation: An investment in the future

Reinvesting in the future of public broadcasting is an investment in education, culture and an informed public. Public broadcasting is requesting a $75 million CPB digital appropriation for fiscal year 1999, $100 million in fiscal year 2000, $100 million in fiscal year 2001, and $100 million in fiscal year 2002, for a grand total of $375 million. Public broadcasters are also requesting $225 million over four years for the Public Telecommunications Facilities Program (PTFP), a matching grants program, to fund both the system's current equipment replacement needs and digital broadcasting. Together, the Federal digital funding appropriation is $600 million over four years. Public broadcasters estimate that the digital conversion will cost $1.7 billion.

There are two known scenarios where public radio stations will be impacted by the transition to digital television (DTV)—tower relocation and signal interference. Access to Federal money will be vital to public radio stations incurring these additional costs. Congress' mandate to convert television stations to DTV will result in many radio stations currently co-located on a television tower having to move from these leased towers. DTV technology requires that more transmission equipment be placed on towers, creating a weight and a load problem. Thus, these public radio stations would have to build new towers, an expensive prospect. Or, if space is available, a dislocated public radio station would have to move to another tower and may incur interference problems. There is also a possibility that after the DTV transition, public radio stations would have to move a second time. Forty-eight public radio stations have been identified as candidates for antenna or tower relocation as a result of planned installations of DTV facilities. NPR is working to identify other stations with translators that may also be affected by DTV.

---

[1] CPB. "Frequently asked questions about Public Broadcasting 1997", page 9.
[2] National Public Radio. Strategic Planning and Audience Research [SPAR].

There are also other significant costs associated with the transition to DTV. For instance, there is a possibility of greater interference involving adjacent television and reserved FM band stations. Federal assistance can help ease the severity of these expensive disruptions. Public radio must be included in digital funding legislation. Public radio estimates that its portion of the overall digital transmission conversion cost is $50 million. While public television is operating under a mandate to convert to digital broadcasting by 2003, public radio has no similar directive. Currently, the U.S. is without a technical standard for digital radio, but one is expected. Conversion to digital transmission, however, is only a part of the imminent digital revolution. As the communications marketplace experiences even greater growth, public radio must be poised to take advantage of new and emerging digital production, transmission and distribution technologies that can offer programming to listeners in ways not imagined.

The transmission technology currently emerging is called Digital Audio Broadcasting (DAB) which delivers compact disc-quality sound free of interference and noise to listeners. DAB will allow radio stations to upgrade their delivery of audio programming. For example, digital radio will provide more reliable AM and FM transmissions, less subject to the effects of geography and terrain. This is particularly important in rural areas, where there would be little or no broadcast service without public broadcasting. Digital will also permit public stations to transmit "smart radio" signals that deliver text messages along with the audio program. This digital text may be used to locally provide continuous specialized information, such as weather, traffic, music titles, program or emergency information on a local basis.

Digital radio also offers spectrum efficiency. It is touted as being of equal or greater efficiency as its analog FM counterpart. Tests have shown when operating at the same transmitting frequency as the current FM band it can also be more power efficient than FM, requiring around one one-thousandths the amount of transmitted power to cover the same area.

The investment in digital broadcasting will allow public broadcasting stations to participate in the sweeping technological revolution, resulting in a more dynamic and valuable public broadcasting system. Please support a $375 million digital CPB funding level over four years.

Conclusion

Public broadcasting is poised to deliver bold new services through new technologies. Public broadcasting's goals cannot be realized without significant funding increases. Again, public broadcasters urge the Subcommittee to support a $340 million annual CPB appropriation and a $375 million appropriation for digital over four years. With your help, public radio and television can better fulfill its mission to advance education, to support culture and to foster an active citizenship through an informed public.

Prepared Statement of the National Minority Public Broadcasting Consortia

The National Minority Public Broadcasting Consortia (Minority Consortia) submits this statement on the fiscal year 2001 appropriation for the Corporation for Public Broadcasting (CPB). Our primary missions are to bring a significant amount of programming by and about our communities into the mainstream of public broadcasting. And our primary message today is that we want to get back on course with CPB in our working partnership to increase the diversity of programming available through public broadcasting. Below are our recommendations:

—Principles of Partnership. We requst a minimum of $5 million for the Principles of Partnership initiative as agreed to by CPB in 1994 in addition to the current funding provided to the Minority Consortia. We request that any funding increase up to $5 million over the fiscal year 2000 level be provided for this farsighted initiative. The House Appropriations Committee Report from last year (H. Rpt. 105–205) stated:

  —The committee supports the CPB's commitment to maximize resources with the goal of increasing multicultural programming for public television by formalizing partnerships among the Minority Consortia organizations, the CPB, the Public Broadcasting System, America's Public Television Stations, and individual television stations.

  —We ask that this Subcommittee and Congress follow through on the its stated support for CPB implementing the Principles of Partnership agreement.

—Funding. We support $340 million in fiscal year 2001 CPB funding for programming and system support as requested by the Administration.

—Digital Conversion. Two requests with regard to the provisoin of digital conversion funding for the public broadcast system: (1) We ask that some digital conversion funds be used to assist producers with the increased costs of producing programming for digital broadcast, and (2) We also ask for Congressional support for prime-time digital broadcasts of a broad range of programming.

—CPB Plans for Multicultural Programming. We request Congressional support for the creation of a CPB draft plan regarding its vision for continued mission and support of the Minority Consortia and increased multicultural programming.

We are operating under two handicaps in submitting this statement. First, we submit this statement knowing only the funding level recommended by the Administration for fiscal year 2001 for CPB; the detailed CPB budget justification is not yet available. After we have seen the budget justification, we may want to file supplemental comments to the Subcommittee. Second, CPB is in a state of flux and reorganization. Its policies with regard to the Minority Consortia are undergoing review—evidence of this is that it was nearly seven months into fiscal year 1998 before any of the Minority Consortia organizations received our fiscal year 1998 administrative contracts from CPB. While we appreciate that CPB is undertaking a system-wide review of its contracts and other financial management issues, and will continue to cooperate with those efforts, it has been a hardship on our organizations.

A commitment of $340 million by the Federal Government to public television and public radio is a wholly reasonable contribution toward this national treasure. If there is one thing that the past few years debate on public broadcasting has shown is how highly people in this nation value it.

Public broadcasting is particularly important for minority and ethnic communities. While there is a niche in the commercial broadcast and cable world for quality programming about our communities and our concerns, it is in the public broadcasting industry where minority communities and producers are more able to bring you quality programming for national audiences. In 1994, CPB initiated research among Asian American and Native American communities documenting that respondents felt their communities were negatively stereotyped on commercial television but that public television had more realistic portrayals.[1] This survey also revealed that both groups wanted increased visibility in public television and further recommended that there be expanded promotion of public broadcast programming utilizing Asian-American community groups and tribal organizations. Earlier CPB surveys of the Latino and African American communities showed similar findings.

It is clear that we and our communities and CPB need each other to address the Congressional mandate regarding minority communities and multicultural programming in the CPB authorizing statute. CPB, the Public Broadcasting System (PBS) and America's Public Television Stations (APTS) and the stations want and need the culturally diverse programming for public broadcasting that the five Minority Consortia organizations can help develop, produce and distribute. We, on the other hand, need continued financial and in-kind resources from CPB and public broadcasting to increase our programming production capacity and to facilitate business planing toward financial self-sufficiency. We have had some promising negotiations with CPB, PBS and APTS over the past several years on both of these counts, but neither effort has yet carried through to fruition.

Principles of Partnership Initiative. Below is a brief description of partnership effort between the Minority Consortia, CPB, APTS and PBS which we urge Congress to support:

In 1994, after protracted discussions, CPB publicly announced funding to formalize partnerships between the Minority Consortia organizations with CPB, PBS, APTS and television stations to maximize all our resources in an effort to increase multicultural educational programming for television. The funding for this Principles of Partnership initiative, $5 million, was to begin October 1, 1995. Concurrent with this funding, the Minority Consortia agreed on a joint plan of distribution methodology, allocating funds for production, community capacity-building, and program support functions. This agreement between the Minority Consortia and CPB was announced with considerable fanfare in a CPB newsrelease and reported in the public broadcast press in June 1994. There is also a lengthy section on the Principles of Partnership agreement in the CPB report presented to the 103rd Congress, Reaching Common Ground: Public Broadcasting's Services to Minorities and Other Groups, July 1, 1994.

The Principles of Partnership included:

---

[1] Reaching Common Ground: Public Broadcasting's Services to Minorities and Other Groups, July 1, 1994, pages 41–42 of the Appendix.

—Establishment of an annual $5 million Minority Program Fund for development, production and capacity-building, including promotion and outreach;
—Each Consortia organization would enter into a partnership with a public television station;
—Producers of all races and backgrounds and from consortia, stations, and regional networks would be eligible to submit proposals and receive grants;
—Grants would be available to national and regional programs as well as audience-building and outreach services and "capacity building" activities;
—CPB would create system advisory panels including top CPB , PBS and APTS programmers, station executive and independent producers;
—Programming supported by the Minority Program Fund would be available to all PTV stations;
—After five years, the arrangement would be evaluated and changed if advisable.

Unfortunately CPB, citing budget cuts, decided not to provide the $5 million funding for the partnership initiative. However, CPB did create an $11 million "Futures Fund" which contained no specific initiatives for the work of the Minority Consortia. Because the Principles of Partnership funding was to be in lieu of funding increases (as supported by Congress) for infrastructure and program development, we feel strongly that CPB, despite budget pressures, should have committed funding for the Principles of Partnership—the timing was optimum. By the end of 1994, we had been working with CPB, APTS, and PBS, and others in the public broadcast field for over a year to reach this agreement. Understanding and good will was at an all time high among the "principals" of this partnership.

Digital Conversion. CPB is requesting funding for an initial installment of funds for the required conversion to digital broadcast. As you know, there are costs involved in the conversion which go beyond the significant equipment and hardware needs of television and radio stations. It will also take additional money to produce programming for digital broadcast. All producers will face these new, higher costs. Film producers will need to use equipment that is high definition quality, and that is an expensive proposition. For instance, producers will need to use 35 mm or super 16 film. Producers will need new, and expensive, field equipment and cameras in order to shoot in wide screen format. Most of the producers with whom we work do not have the finances for this new equipment.

Our understanding is that public television will air prime time programming on digital broadcast. In non-prime time, the signal will be split so that four programs can be accessed at any one time. These non-prime time programs will be in the analog format. The National Minority Public Broadcasting Consortia organizations, a major producer of multicultural programming for public television, believes that the programs which are broadcast in digital format should include the whole range of what is available on public television. Digital broadcast should not be limited to big musical events or those programs which feature beautiful landscapes. For the full range of programming to be digitally broadcast, independent producers , including those who multicultural programming, will need to be able to meet the higher production costs.

We ask that Congress, in appropriating funds for digital conversion for the public broadcast system: (1) provide assistance to producers for the conversion, and (2) support prime-time digital broadcasts of a broad range of programming, including multicultural programming.

Congressional Support. Since 1988, nine House and Senate authorizing and appropriations reports have expressed support for CPB funding of the Minority Consortia [2] and multicultural programming.

---

[2] House Report 100–825, report of the House Committee on Energy and Commerce on the Public Telecommunications Act of 1988.
Senate Report 100–444, report of the Senate Commerce, Science and Transportation Committee, on the Public Telecommunications Act of 1988
House Report 102–363, report of the House Committee on Energy and Commerce on the Public Telecommunications Act of 1991
Senate Report 102–221, report of the Senate Commerce, Science and Transportation Committee report on the Public Telecommunications Act of 1991
House Report 102–708, report of the House Appropriations Committee on the fiscal year 1993 Labor, HHS, Education Appropriations Act (fiscal year 1995 CPB funding)
House Report 103–156 report of the House Appropriations Committee on the fiscal year 1994 Labor, HHS, Education Appropriations Act (fiscal year 1996 CPB funding)
House Report 103–553, report of the House Appropriations Committee on the fiscal year 1995 Labor, HHS, Education Appropriations Act (fiscal year 1997 CPB funding)
House Report 104–659, report of the House Appropriations Committee on the fiscal year 1997 Labor, HHS, Education Appropriations Act (fiscal year 1999 CPB funding)
House Report 105–205, report of the House Appropriations Committee on the fiscal year 1998 Labor, HHS, Education Appropriations Act (fiscal year 2000 CPB funding)

Despite good Congressional interest, funding for the work of the Minority Consortia has remained extremely modest and has certainly not matched the overall increases for CPB since the 80's. In fiscal year 1997 we received 1.7 percent of the CPB budget in combined organizational support program funds ($1.45 million in organization support and $3.3 million in Multicultural Program funds for the five organizations combined). Despite ups and downs in annual appropriations, funding for CPB grew 72 percent from fiscal year 1985 through 1997. During this same time CPB funding for the minority consortia organizational support went from $663,500 (0.44 percent of the CPB budget) to $1.4 million (0.55 percent of the CPB budget).

The Minority Consortia, along with many others who receive funding through CPB, expect to receive reductions in fiscal year 1998 and fiscal year 1999 because of the cut in Federal appropriations.

Common Concerns. When we say that we want increased programming by and about our communities, we do not mean that our programming is limited in its value to members of our communities. Nothing could be further from the truth. The notion that minority producers cannot produce programming of interest to the general viewing audience has permeated the system for too long. Our concerns are common to all of America—crime, drugs, literacy, education, teenage pregnancy. Examples of minority programming well received by the general viewing audiences include Stand and Deliver, Maya Lin, Daughters of the Dust, Storytellers of the Pacific, and in the White Man's Image. The list is very long.

It is true that we are extremely interested in bringing to the general public our histories—histories which include family traditions, educating our youth, the civil rights movement—which have for have for too long been unreported and misreported. It is in the national interest that the many peoples who form the mosaic of the United States better understand and appreciate each others history, culture, and contributions to today's society.

Thank you for consideration of our requests. Congress has the power to help public broadcasting renew its commitment to the work of the Minority Consortia in expanding the diversity of public programming and attractingnew audiences to the public broadcasting system.

Summary of the Work of the Minority Consortia Organizations. The programming one sees and hears on public television and radio are the end products of a long, long road. The work of the Minority Consortia organizations is largely on the front end of the production process, and thus our programming image is not always visible in national distribution. The Minority Consortia organizations have close ties with our communities and are a bridge between public broadcasters and the general public. We have in the last five years provided to Public Broadcasting's program schedule hundreds of hours of programming addressing the cultural, social and economic issues of the country's racial and ethnic communities. Additionally, each organization has been engaged in cultivating ongoing relationships with the independent minority producers community by providing program funding, programming support and distribution assistance. We also provide numerous hours of programming to individual public television and radio stations.

Individually, each organization plays an increasingly effective role in interfacing with a broad spectrum of their constituent groups. Training projects, community outreach—including youth employment opportunities, school support programs, and community festivals are ongoing activities of each organization. Some of these projects have generated new, non-Federal revenue streams. We have also developed unique operational competencies. For example:

—The National Asian American Telecommunications Association has an 8-year investment in the sales of its video library, serving over one-thousand institutions annually, and has turned this endeavor into a potentially-rich source of new income.

—Native American Public Telecommunications has gained substantial experience technology initiatives through its relationships with the American Indian Radio on Satellite (AIROS) project, the Tribal Infrastructure Information Highway Project (TIIP) and generating co-productions between national producers and public broadcast stations.

—The National Black Programming Consortium's highly-successful "Prized Pieces" international film and video competition brings together a broad cross-section of the independent production community, the international film community, and public broadcasting. The Heritage Video and Learning Center provides an invaluable resource to the community with an extensive array of quality programming. The video and learning center enables our audience to access hundreds of programs which highlight the works of independent and commercial filmmakers.

—The National Latino Communications Center has leveraged its long history of positive relationships within the Latino community at large, and with the Latino producing community to build a new pledge model aimed at focusing the reach of public television's fundraising activity into the Hispanic community. NLCC has leveraged its programming dollars very successfully, with a rate of five dollars to one.

—Pacific Islanders in Communications, the newest Consortia member, is already developing a production expertise having served as executive producer for two national series. One of those series, done in conjunction with Native American Public Telecommunications, Storytellers of the Pacific, received the awards for Best Documentary, Best Global Indigenous Production, and Outstanding Series Award of the Dreamspeakers Film Festival.

PREPARED STATEMENT OF RON NIESING, PRESIDENT, THE NATIONAL COUNCIL OF SOCIAL SECURITY MANAGEMENT ASSOCIATIONS, INC.

The National Council of Social Security Management Associations (NCSSMA), of which I am President, has for twenty-nine years been the voice of Social Security's field office and teleservice center management. Each day we directly serve the American public in person and over the phone. For many of those we serve, we provide the only face-to-face contact they have with the Federal Government. When the Vice President met recently with the heads of what he has named "High Impact Agencies," including SSA, he said: "Yours are the agencies that shape the public's opinion of government and can redeem the promise of self-government. Public cynicism about government is a cancer on democracy. Reinvention isn't just about fixing processes, it's about redefining priorities and focusing on the things that matter." The Government Performance and Results Act similarly asks agencies to focus on performance measures which reflect outcomes valued by the public.

We who live and work in the same communities as those we serve across the country are the ones accountable in the eyes of the public for proper administration of all of SSA's programs. Our greatest concern is to serve the American public well by providing not only timely, accurate payment of their Social Security benefits but also dignified, courteous service. The public deserves—and has paid for—no less.

NCSSMA urges Congress to provide SSA with sufficient fiscal year 1999 funding to permit infusion of resources into community-based field offices and teleservice centers, including earmarked funds for an effective and ongoing public education effort. Following are the views of our members across the country on some of SSA's most serious resource problems and needs.

Public education

As this Committee begins work to determine fiscal year 1999 funding levels for the administration of Social Security programs, the country has embarked on a crucial debate about the long-term future of Social Security. While Congress and the President grapple with the challenges of Social Security reform, the question of how to quickly and effectively involve the public in that debate is paramount. Without public education and consensus-building, without public confidence and trust in the future of Social Security, successful reform cannot happen.

Like politics, all education is "local." The 3,200 members of the National Council of Social Security Management Associations, representing Social Security managers and supervisors working in SSA's 1,300 field offices across the country have learned this through firsthand experience. Our experience also teaches that community-based service is the most effective and most trusted way to serve the public.

Public education about Social Security—through speeches, seminars, workshops, local radio and television, press releases, and school presentations—was historically one of the cornerstone's of SSA's field services. Yet, as the Social Security Advisory Board points out in its recent report, "Increasing Public Understanding of Social Security," reduced SSA staffing since the 1980s, combined with increasing workloads, results in conflicting demands which significantly diminish critical public information activities at the local level. Reductions in supervisory ranks in recent years, aimed at an arbitrary "supervisory ratio" target, have even further reduced local managers' ability to be active in community activities outside the office.

Community involvement and education in the past not only helped those who live and work in our communities but also helped the agency retain the trust and support of those communities. The erosion of time for community activities among Social Security field managers, driven by budget exigencies, is in part responsible for the nationwide loss of public faith in the future of Social Security programs and in the Federal Government itself.

At the local level, we can facilitate public engagement in the question of how to proceed with modifications to the Social Security system. Our ongoing presence and involvement in communities across the country then must continue if Social Security is to regain and maintain public trust. As the Social Security Advisory Board states: "The agency's many knowledgeable employees in communities throughout the Nation constitute a valuable resource for increasing the public's understanding of Social Security. The agency should make greater use of this resource." Recent SSA initiatives to train staff and managers on the history, philosophy, and mission of Social Security will begin to address this need.

Fraud and misuse of social security numbers

Social Security field office managers and supervisors take our responsibilities as stewards of the public monies very seriously. As SSA and its independent IG have both testified, we are well positioned and well qualified to identify fraud and abuse, another critical factor in garnering public trust and confidence. Any significant success SSA might have in combating fraud and abuse of Social Security numbers will depend on the efforts of local managers working directly with employers and employee groups within their respective communities.

For example, a number of years ago, Social Security received wage reports for employees who were using incorrect Social Security numbers. Discrepancies were resolved with face-to-face contacts by local offices with employers and employees. Since SSA began downsizing its staff and management resources, these types of routine contacts were eliminated. It would be interesting to note any statistical differences in fraudulent use of Social Security numbers now compared to those times when the agency processed these wage reports. Proper posting of Social Security earnings records and frequent issuance of duplicate SSNs are other workloads with fraud and abuse implications confronted in the field.

As long as field offices are handicapped by inadequate staff, our ability to focus on identification and prosecution of all types of fraud is compromised. Problems such as the one uncovered in Georgia, where 181 members of an extended family were receiving SSI benefits, could be avoided if sufficient management and staff were in place in field offices to work with local medical providers.

Overall staffing levels

In 1993, the National Performance Review (NPR) called upon agencies government to reduce the number of supervisors, headquarters staff, and management control positions by half. Despite the intent of these mandates to reshape the face of government and to put the resources on the front-lines, only slightly more than 50 percent of SSA's employees work in field office and teleservice centers to provide direct services to the American people. Headquarters staffing and management control functions have not been reduced by 50 percent, as directed by the NPR.

Field offices are given staffing justified through the measurement of some of the work we produce. However, there is no justification or method in place to measure the work—or the value of that work to the mission of SSA—produced by staffing resources in headquarters and other components which are supposed to support the work that is done in the field.

Long-range plans call for the SSA to reduce overall staffing levels from approximately 65,000 currently in place to 62,000 by the end of fiscal year 1999. It is our understanding that more than half of these cuts will be absorbed by the field and TSC components—the very facilities that are visited or called by your constituents every day. These cuts will be made despite the unmet directives of the NPR to reduce headquarters staffing; despite the increasing workloads processed in field offices to combat fraud and abuse, such as more Continuing Disability Reviews and SSI reviews; despite the modernization of SSA systems that will allow more work to be processed directly in field offices and less in program service centers; and despite the fact that the public has shown on numerous occasions that it prefers dealing with SSA on a face-to-face basis, especially in their initial contact with the agency when filing for benefits

Span of supervision

SSA has relentlessly pursued the NPR mandate to reduce the number of supervisors to employees to a 1:15 ratio, despite the fact that SSA, as an independent agency, cannot be required to do so under the Executive Order directive.

Reductions in SSA's supervisory ranks are being done without any analysis of the impact on our ability to serve the American public. Every time a supervisor is cut in the field, the level and quality of service suffers. SSA has not recognized the unique role that managers and supervisors play in carrying out the mission of this agency. In addition to negative impacts on the working environment for employees and the increased demands on remaining supervisors and office managers, SSA suf-

fers potentially increased costs because there are fewer quality reviews and declining technical support for its employees in the field offices and teleservice centers. There are fewer resources available to conduct community outreach and education on program solvency. There are fewer resources available to ensure that employers and employees are doing their part to reduce fraud and abuse in the use of Social Security numbers or in the initial receipt of or continuing payment of Social Security or SSI benefits.

A dramatically increasing number of field offices have only one management person, placing an almost impossible burden on them. How does one individual manage a facility, supervise employees working in different jobs, educate the public, and combat potential fraud and abuse? The overall cuts in front line employees preclude the assignment of some of these responsibilities to non-supervisory staff.

Local telephone service

Probably the single biggest complaint your home offices receive about Social Security is the inability of your constituents to get their telephone calls through to their local Social Security office. Significant improvements have been noted in SSA's toll-free 800 number service, but many people still prefer to deal with the people that they know—their local Social Security office.

A recent NCSSMA survey revealed that nearly all field office managers feel their offices provide inadequate phone service to your constituents. SSA has not measured the impact or volume of local telephone calls, but many individual field office studies of local telephone service have revealed busy rates of upwards of 75 percent. This means that three out of four callers to some Social Security offices are not getting through.

To some extent, new technology, such as voice mail and automated attendant, has enabled local offices to offer better services to the calling public. However, this new technology has not allowed for significantly more of the public to get through on our telephone lines. We still have the same number of incoming lines and the same, if not a declining number, of individuals available to answer those calls. It is time for SSA's commitment to improved telephone service to be expanded to include the services to the millions of Americans who are calling their local Social Security offices each day.

Disability workloads/disability reengineering

SSA is moving forward with various disability initiatives. Pilot projects around the country are aimed at finding better ways to process initial disability claims. In fiscal year 1999, local offices will process over 2.1 million initial disability claims and will help process a record number of CDR's—over 1,600,000. The real problem, however, is not in the initial claims process, but rather in the appeals process. Adequate resources need to be directed toward the appeals process to ensure that staff have modernized, up-to-date equipment to handle their work. We hope this Committee will work with SSA to secure more accountability from the Office of Hearings and Appeals in reducing overall appeals times.

Overdependence on the promise of automation

Social Security offices have and are undergoing significant changes, especially as related to the continued automation of our programs and the installation of new computer systems or IWS/LAN. All of us appreciate the support and efforts of this committee, in particular, in getting these tools to us on the front lines. However, automation alone has not been the panacea for all SSA's workload problems.

The agency's Strategic Plan repeatedly points to productivity gains from automation initiatives as solutions to workload management problems. This is doubly dangerous. Experience of the past teaches that productivity increases from automation have been attained much further in the future than projected. In addition, a focus on services such as the PEBES website and public information made available through the Internet ignores the demographic realities of a large portion of the population we serve. For example, while less than 35 percent of American homes currently have computers, 25 to 35 percent of the U.S. population is functionally illiterate. Although growing numbers of Americans have home computers and Internet access, the numbers of individuals without these tools is also growing. Many people for many reasons will continue to walk in the doors of Social Security offices and telephone our teleservice center representatives across the country. The ability of these facilities to handle these workloads, and the level of resources given to them to do the job right, will be crucial to the success of SSA and will influence heavily the impression many Americans have of their government.

Training and development

SSA is set to embark on one of its most ambitious training initiatives for managers and supervisors. It would be in the best long-term interest of the agency if this training were focused on management skills for the changing environment in today's workplace, management of budget and procurement processes, and public education initiatives related to solvency and reform of Social Security. A well-trained management corps ensures that we will most effectively meet the needs of the public we serve. SSA will be able to more effectively educate the public now that it is once again training employees on the history and mission of Social Security, but SSA must also focus its attention on the development of future leaders that will be necessary due to the retirement of many of its senior managers in the next 5 to 10 years. SSA recently announced a management development program, restricted to only 10 people, which will not begin to meet the long-term needs of SSA.

Conclusion

NCSSMA strongly advocates full funding of SSA's fiscal year 1999 budget request and enhancement of all locally-delivered services nationwide to meet the variety of needs of beneficiaries, claimants and the general public. To maximize efficient use of taxpayer dollars, locally-delivered services can be effectively coordinated with services provided by SSA's more centralized teleservice centers. Only through a balanced approach to provision of all services, including re-invigoration of efforts to effectively educate the public about Social Security through community activities at the local level, can SSA fulfill its mandate and help restore trust in government. We recommend that funding be earmarked to ensure sufficient staffing resources and monies for public information materials in the field to facilitate a successful public discourse on Social Security reform.

Focusing on provision of better public service, NCSSMA is developing recommendations regarding SSA's claims-taking initiatives, telephone service, disability process, labor-management partnership and performance measures. We are updating our recommendations for development of a comprehensive plan for efficient service-delivery across the entire range of services and facilities within SSA. As we develop these projects, we will share our ideas with the members of this committee in the hope of garnering your support and guidance.

It is also our hope that any future performance commitments made by SSA to this Committee will better reflect the diversity and inter-dependence of the services we provide within the context of a balanced plan, rather than focus on a narrow set of measures which result in erosion of our ability to fulfill all of our responsibilities to the public. A stable Social Security Administration which delivers quality, community-based service throughout the country is our primary goal, and we urge SSA administrative funding for fiscal year 1999 which is supportive of that goal. Thank you for considering our views.

PREPARED STATEMENT OF JANE WATKINS, PRESIDENT, NATIONAL ASSOCIATION OF FOSTER GRANDPARENT PROGRAM DIRECTORS; DWIGHT RASMUSSEN, PRESIDENT, NATIONAL ASSOCIATION OF SENIOR COMPANION PROJECT DIRECTORS; AND NAN YORK, PRESIDENT, NATIONAL ASSOCIATION OF RETIRED AND SENIOR VOLUNTEER PROGRAM DIRECTORS

We are pleased to testify in support of fiscal year 1999 appropriations for the Foster Grandparent Program (FGP), Senior Companion Program (SCP), and Retired and Senior Volunteer Program (RSVP), known collectively as the National Senior Service Corps (NSSC) authorized by the Domestic Volunteer Service Act and administered by the Corporation for National and Community Service.

The National Directors Associations are membership-supported professional organizations whose rosters include the majority of more than 1,200 directors who administer NSSC programs across the nation, as well as local sponsoring agencies and others who value and support the work of NSSC programs.

While we support the aggregate funding levels set forth in the President's fiscal year 1999 budget request for the Senior Corps, we request that the subcommittee approve a fiscal year 1999 allocation for our programs in a slightly different manner from that proposed by the President. Specifically, we request that the Subcommittee appropriation a funding level of $173.910 million for the National Senior Service Corps in the aggregate: $43.001 million for the Retired and Senior Volunteer Program (RSVP), $37.653 million for the Senior Companion Program (SCP), and $93.256 for the Foster Grandparent Program (FGP).

Where the President proposes to earmark all funding increases for national service programs administered by the Corporation for National Service to the Adminis-

tration's "America Reads" initiative, we urge the Subcommittee to recognize that our senior volunteer programs address many community needs beyond children's literacy. In fact, children's literacy services is not within the scope of the Senior Companion Program—a fact evidenced by the President's proposed freeze in Senior Companion simply because the program answers community needs other than children's literacy.

Accordingly, we urge the Subcommittee to embrace funding priorities for the additional funds requested as follows:

—Foster Grandparents and Senior Companions will receive a $.05/hour increase in their volunteer stipend;

—Each senior volunteer program will receive a 3-percent increase to cover administrative costs, including those resulting from new activities under the Programming For Impact initiative;

—Each program will receive expansion funding to support Programs of National Significance not limited to the America Reads initiative, consistent with current law; and

—The Retired and Senior Volunteer Program will receive additional funding to start new programs in unserved communities.

We believe this funding allocation plan maximizes the number of additional volunteers and volunteer service hours which can be generated for each Federal dollar invested, supports existing programs in maintaining their volunteer efforts, and allows for expansion of volunteer efforts in areas of highest community need and in areas currently unserved by FGP, SCP, and RSVP. All told, the funding levels and allocations we request would support more than 14,000 more senior volunteers, contributing in excess of 3 million hours annually.

We ask that language be included in the committee report accompanying the fiscal year 1999 funding measure which supports and specifies the above allocation priorities for funds requested for fiscal year 1999 and directs the Corporation for National and Community Service to disburse funds for fiscal year 1999 in this manner.

With Federal resources under increasing pressure as Congress moves toward a balanced budget by fiscal year 2002, it is critical that we act smart with tax dollars—drawing the best return on our investments in Federal programs. Since 1965, FGP, SCP, and RSVP have represented the best in the Federal partnership with local communities, with Federal dollars flowing directly to local sponsoring agencies, which in turn determine how the funds are used. Together, these three programs have proven themselves cost-effective and economical in leveraging Federal funds to secure a total of $93.9 million in local community support—an impressive $.65 for every Federal dollar invested—toward underwriting a total of 108 million hours of service annually in communities across the country. The evidence supports this claim:

—The Foster Grandparent Program fiscal year 1997 budget of $77.812 million was matched with $32.0 million in cash and inkind donations from states and local communities in which Foster Grandparents volunteer. This represents a non-Federal match of 41 percent—well over the 10 percent local match required by law.

—The Retired and Senior Volunteer Program saw its fiscal year 1997 Federal budget of $35.708 million matched with $42 million in contributions by states and local communities, demonstrating broad support for RSVP across the country. This represents a non-Federal match of 118 percent—well over the 30 percent required by law.

—And, the Senior Companion Program, with a Federal appropriation of $31.244 million in fiscal year 1997, was supplemented by $19.9 million in cash and inkind contributions from states and local communities in which Companions volunteer. This represents a match of 64 percent—far in excess of the 10 percent match required by law.

Independent Sector has estimated the per hour value of volunteer service in 1997 to be $13.24 per hour. The 109+ million hours of service provided by the nearly 500,000 volunteers serving through RSVP, FGP, and SCP is valued at more than $1.4 billion, a 10-fold return on the Federal investment of $144.764 million in 1997. Obviously, however, the work of our senior volunteers means much more than money. The programs are a lifeline to communities and Americans of all ages.

In 1997, 25,300 Foster Grandparent volunteers contributed 23.8 million hours of service through 8,400 local agencies, working with children and teenagers who have special needs as well as their families. Every year, 80,000 children, teenagers, and their families are supported by the services of Foster Grandparents in all 50 states, the District of Columbia, Puerto Rico, and the Virgin Islands. Over 14,000 Foster Grandparents serve 39,200 children in settings connected to the health care system.

Foster Grandparents help young people achieve personal independence and self-confidence so that they can learn to overcome their problems and become productive members of society. The annual Federal cost for one Foster Grandparent is $3,761—less than $4.00 per hour.

In 1997, RSVP volunteers provided over 74 million hours of service in a variety of settings throughout their communities across the country. The total cost of fielding one RSVP volunteer is 48 per hour of service. All told, 453,300 RSVP volunteers serve annually through more than 57,000 public and non-profit local volunteer stations. Sixty-nine percent of RSVP volunteers are over age 70. Volunteers serve through 758 projects sponsored and managed by local nonprofit agencies in all 50 States, the District of Columbia, Puerto Rico, and the Virgin Islands. RSVP volunteers provide services that utilize their own talents and interests; they present their communities with a rich array of options for addressing the full spectrum of community needs.

In 1997, Senior Companion volunteers contributed 11.4 million hours of service to their frail older clients—giving assistance to other adults with physical, mental, or emotional impairments. In one year, 13,300 Senior Companions serve nearly 48,000 clients, primarily in in-home settings. SCP volunteers serve through 185 programs sponsored and managed by local nonprofit agencies in all 50 states, the District of Columbia, Puerto Rico, and the Virgin Islands. Senior Companions help frail older people achieve and maintain the highest possible level of independent living and avoid institutionalization. The average annual cost of nursing home care in the United States exceeds $30,000. The annual Federal cost for one Senior Companion is $3,831—less than $4.00 per hour.

For more than three decades, Federally-supported senior volunteers have been touching lives and helping communities in a variety of ways.

Statistics show that FGP, RSVP and SCP focus their resources where they will have the largest impact: FGP on early intervention and literacy activities, SCP on in-home assignments with frail older people at risk of institutionalization, and RSVP on helping their peers, children, and their communities in significant ways. Nationally, 82 percent of the children served by Foster Grandparents are under the age of 12. Recognizing that children's needs are more effectively addressed as early in their lives as possible, 50 percent of these children are age 5 and under. Foster Grandparents work intensively with these very young children to address their problems at as early an age as possible, before they enter school. One-third of FGP volunteers serve over 8 million hours annually addressing literacy and pre-literacy problems with children who have special needs. Sixty-seven percent of FGP volunteers serve in public and private schools as well as sites which provide early childhood pre-literacy services to very young children, including Head Start.

Twenty-six thousand of the clients served by SCP are 75 or older, and 74 percent of SCP volunteers serve in the homes of clients. It is the 75+ elder population which most often experiences health problems which require institutionalization; SCP prevents institutionalization for these people by focusing on providing one-to-one in-home daily service and companionship to this population. Thirty percent of SCP volunteers provide respite care to families serving as primary care-givers for an elder loved one. Fifty percent of volunteers address chronic care disabilities. Over ten percent of RSVP volunteers serve in sites which focus on school-age and preschool age literacy activities, as well as adult literacy. Sixty-four percent of RSVP volunteers provide service to their fellow seniors through congregate meal programs, food banks and kitchens, senior centers, and long term care residential facilities.

We appreciate the goals of the Subcommittee in exercising its best judgment to effect the best use of scarce Federal resources, and as American taxpayers, we endorse your efforts to ensure that tax dollars yield significant impact. We have much evidence that FGP, SCP, and RSVP produce results: numerous and anecdotal stories of lives changed, dollars saved, and lasting good works accomplished in communities across the country.

This evidence is compelling, but we believe that much more is necessary to show that investing Federal dollars in FGP, SCP, and RSVP volunteers produces quantifiable, concrete results that significantly impact communities in measurable ways. That is why project directors nationwide, in cooperation with NSSC staff from the Corporation for National Service and with the wholehearted support of the three national Directors Associations, have begun to participate in a new effort, Programming for Impact (PFI).

Through PFI, projects and sites where volunteers serve will cooperate to collect and report data which support the impact our volunteers are having in addressing pressing local community needs. We hope that you will agree that the impact data now coming in truly does document the incredible effect our volunteers are having

in their communities, and supports your past Federal investment in our programs as well as our request for increased funds for fiscal year 1999.

—In Clay County, Iowa, members of the Retired and Senior Volunteer Program (RSVP) spearheaded a project to protect their community's ground water. Working with students from Spencer Middle School and youth of the Iowa Rural Water Association (IRWA), 14 RSVP volunteers learned about groundwater and sources of contamination, divided into work groups and surveyed their community—identifying possible contaminants, collecting data, and putting together an education program to get the entire community involved in wellhead protection—thus ensuring for future generations that the water quality in the Clay County Water District remains the top quality that residents enjoy now. RSVP volunteers were critical to the program, not only for providing intergenerational mentoring guidance to their student partners, but also for their extensive knowledge of the are and its history. Their lifetime experiences have proven an invaluable community resource in the program.

—The human story of the Foster Grandparent Program is about Pennsylvanian's like Ryan and his Foster Grandmother Ann Creevy. If it hadn't been for Foster Grandparent Ann Creevy, young Ryan might still be a statistic in a class for special needs children. It was Grandma Ann who first saw the cigarette burns on Ryan's arms and immediately took action when she recognized these signs of abuse. During the course of working with Ryan, it was Grandma Ann who identified Ryan's hearing loss as the reason for his inability to learn. Several years later Ryan is a thriving 12-year-old living on his new adoptive home, earning excellent grades in a regular classroom. Grandma Ann serves with the Union/Snyder Foster Grandparent Program in Central Pennsylvania. AARP, in cooperation with Centrum Silver, awarded her a Legacy Award in recognition of her efforts on behalf of Ryan, whose life she saved and changed forever, and the other children she serves.

—Mr. W.H. of Belleville, Illinois, who will be 76 in May, had a severe stroke in 1994. It left him unable to speak other than a few words. His wife, who is the primary caregiver, has had a Senior Companion two days a week since 1995. Because of the Senior Companion, Mrs. H is now able to cope with the situation. She can leave her husband to run errands, get groceries, keep doctors' appointments, and more, without the constant worry about his well-being. The respite care provided by the Senior Companion allows Mrs. H. to satisfy the full time care giving responsibilities she has assumed for her husband of many years. However, there is a waiting list for this service and the center operates at capacity each day. Senior Companions allow fewer staff to serve more clients by providing one on one support to the clients in the most need. They assist with activities of daily living such as helping with clothing and personal tasks and assisting at meal times. Additionally, the Senior Companions are watchful for client concerns and safety issues that can be relayed to appropriate staff. This support for families caring for their elders helps avoid the annual cost of nursing home care and keeps loved one together.

As baby boomers age, the "graying of America" is progressing at a phenomenal rate. Yet, only 5 percent of those over 65 years of age live in institutions, and a full 81 percent of the non-institutionalized 65+ population has no limitation in their activities of daily living. According to a U.S. Administration on Aging/Marriott Senior Living Services volunteerism survey, over 41 percent (15.1 million) of the 37.7 million Americans 60 years of age and older performed some sort of volunteer work in the previous year. An additional 37.5 percent (14 million) indicated they would volunteer if they were asked. The message is clear: in spite of the general public's conception of older people as frail and dependent, the aging process is, for most people, a time of wellness when they have both the time and the desire to serve others.

We need more funds to engage more seniors in meeting the pressing needs being expressed by our communities. Your enhanced investment in all three senior volunteer programs now will pay off in the short and long term—savings realized by the value of service rendered to communities across America by senior volunteers; savings realized as additional avenues are provided for more older Americans to be involved in meaningful service opportunities; and savings realized as that involvement keeps older people healthy and independent. Our goal is to expand the Foster Grandparent Program, the Senior Companion Program, and the Retired and Senior Volunteer Program so that they can provide the opportunity for one million Americans to serve by the turn of the century.

Please help us to tap the nation's fastest growing natural resource—our seniors—by supporting a total fiscal year 1999 appropriation of $173.910 for the programs of the National Senior Service Corps: $93.256 million for the Foster Grandparent

Program; $37.653 million for the Senior Companion Program; and $43.001 million for the Retired and Senior Volunteer Program.

LIST OF WITNESSES, COMMUNICATIONS, AND PREPARED STATEMENTS

SUBJECT INDEX

DEPARTMENT OF EDUCATION

OFFICE OF THE SECRETARY OF EDUCATION

○