S. Hrg. 107-820

# DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2003

# HEARINGS

# BEFORE A

# SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS UNITED STATES SENATE

ONE HUNDRED SEVENTH CONGRESS

SECOND SESSION

ON

# S. 2766

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, 2003, AND FOR OTHER PURPOSES

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

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# DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2003

# THURSDAY, MARCH 7, 2002

U.S. SENATE,

SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS, Washington, DC.

The subcommittee met, at 11:07 a.m., in room SD-192, Dirksen Senate Office Building, Hon. Tom Harkin (chairman) presiding. Present: Senators Harkin, Kohl, Murray, Landrieu, Specter, Stevens, Cochran, and DeWine.

# DEPARTMENT OF HEALTH AND HUMAN SERVICES

# OFFICE OF THE SECRETARY

# STATEMENT OF HON. TOMMY G. THOMPSON, SECRETARY OF HEALTH AND HUMAN SERVICES

## OPENING STATEMENT OF SENATOR TOM HARKIN

Senator HARKIN. This hearing of the Labor, Health, Human Services, and Education Appropriations Subcommittee will now come to order. I want to welcome Secretary Thompson this morning to testify about the fiscal year 2003 budget for the Department of Health and Human Services.

The fiscal year 2003 budget for the Department of Health and Human Services appropriated activities is \$312.1 billion, an increase of \$21.6 billion over fiscal year 2002. The fiscal year 2003 discretionary spending proposal includes \$59.5 billion, an increase of \$2.3 billion over fiscal year 2002. So, the bulk of the increase is in mandatory spending and not in the discretionary spending that we have jurisdiction over in this committee.

Our colleague Senator Inouye of Hawaii once said that, while the Defense Appropriations Subcommittee is the committee that defends America, this subcommittee is the committee that defines America. Each year this committee helps to define America's future by the choices it makes in education, Head Start, maternal and child health care programs, Pell grants, job training, worker safety, Medicare, and of course biomedical research.

I am very happy to see the administration's 2003 budget includes a total of \$27.3 billion for NIH, an increase of \$3.7 billion. This increase will be the fifth and final installment in our effort to double NIH funding over 5 years. I say to my friend and my colleague Senator Specter, who has helped lead this charge to double NIH funding, it has been a major part of our strong partnership on this subcommittee over the years.

I might also say that—and I will recognize him next—that the former chairman of the full committee, now the ranking member of the full committee, Senator Stevens, has also been a driving force behind ensuring that we double the NIH budget over 5 years. I look forward to the final passage of this bill and we can finally declare victory in the efforts to double funding for medical research over 5 years.

The budget also includes significant resources to combat bioterrorism, including \$940 million to upgrade State and local public health programs, \$518 million to increase the capacity of hospitals to address bioterrorism. Since September 11 this subcommittee has held a number of hearings on the threats of bioterrorism. It became clear that our Nation's hospitals and public health departments were not prepared to adequately respond to a bioterrorism event.

To address that need, we included a billion dollars in the fiscal year 2002 supplemental appropriations bill. Mr. Secretary, I am glad that your budget continues that effort and I look forward to working closely with you on this issue.

Mr. Secretary, I am pleased with the increases you have included for medical research and for bioterrorism, but I am deeply concerned about cuts in the other HHS programs, particularly cuts to HRSA. HRSA is the access agency which works to ensure health care access for all Americans, the uninsured, those with special needs, and those in rural areas. Rural health care programs are of particular interest to me because that is where I was born and raised and that is where I still live, in a town of 150 people, Cumming, Iowa. In fact, I still live in the house in which I was born.

I said that to a young person the other day and he looked at me and said: How old are you, anyway? I said: Well, let me put it this way: I was born in the last century. How about that?

While many Americans are rediscovering rural America as a place to live and work and raise a family, we have got to do more to ensure access to health care in our rural areas. Last year our subcommittee, under the leadership first of Senator Specter and then later me, included a rural health initiative in our bill. It increased support for the National Health Service Corps and Community Health Centers. It created a new Rural Hospital Improvement Program to provide regulatory relief and quality improvement for small rural hospitals, and we increased funding for our State offices of rural health.

So while I want to commend you for building on this initiative by requesting increases for the National Health Service Corps and the Community Health Centers—those are two great items, Mr. Secretary, and I really appreciate your requesting increases for that—but again, I am disappointed that we do not adequately meet some other needs in rural health areas. The budget cuts funding for the State offices of rural health. It cuts funding for rural health research. It cuts funding for telemedicine programs. Quite frankly, I think that is the wrong direction to take. While these discretionary programs can make a difference, they are not the only answer. Many problems that arise in rural areas are a result of unfair Medicare payment policies. Rural hospitals are much more dependent on public dollars and small hospitals are more likely than others to struggle. If this is not enough, people in rural areas are in poorer health.

So we need to work together to get rid of the myth that it costs less to provide health care in rural areas. There is this whole myth that somehow if you work in a rural area in a hospital they can pay you less. We now know that is not true, because if they pay you less you go to the cities and work, and then we have a vacuum. So we have to match those payments. It is just not fair to say that it is cheaper.

Smaller hospitals when they buy their pharmaceuticals and they buy their gloves and they buy their equipment, they buy in small quantities, so they pay top dollar. Large urban hospitals that are joined together, they buy in huge quantities. They get supplies and equipment at the cheaper price. So in many cases for the smaller hospital, actually it is more expensive to provide health care than in some of our larger urban hospitals.

Last year I introduced a bill with Senator Craig from Idaho called the FAIR Act, Medicare Fairness in Reimbursement Act, to change the payment system so that no State earns more than 105 percent of the national average and no State earns below 95 percent of the national per-beneficiary average. Again, during our questioning period, Mr. Secretary, I want to get into that further and point out some of these discrepancies when I get into the question and answer session.

But I know that Senator Stevens has another commitment he has to make and Senator Specter has been gracious enough to yield to Senator Stevens.

Senator SPECTER. Mr. Chairman, I do yield to our distinguished colleague Senator Stevens.

# OPENING STATEMENT OF SENATOR TED STEVENS

Senator STEVENS. You are both very kind. We do have meetings in the full committee and I am delighted to be here to welcome the Secretary.

Mr. Secretary, I do thank you for your willingness to look into the problems of rural America as the chairman has just described. We have some of the most daunting health problems in the country and I hope we will be able to arrange that you can come up and visit us again in Alaska. Unfortunately, you want to talk about statistics; we have the highest rates of child abuse, domestic violence, substance abuse, particularly alcohol, and fetal alcohol syndrome. Strangely, I believe rural America has worse health problems than the inner core city, and probably it is because of some of the things that the chairman has just discussed.

I do want you to know that we are really grateful to you for leading the charge on obesity in our country, particularly our young people. In the last year the Congress enacted a bill I introduced, the Carol White PEP, Physical Education for Progress. The concept of no child being left behind is a very important part of the education phase of the President's program. Because of the obesity problem, we want to restore physical education to children on a daily basis in our country. I would like very much to work with you on that.

My only comment is, you will find I am disturbed that the Denali Commission was——

Secretary THOMPSON. So am I.

Senator STEVENS [continuing]. Not funded properly. It is authorized. It is not a congressional add-on. It is something that the President has approved in the past, presidents have approved in the past. I do hope we can restore that funding.

As I said, Mr. Chairman, I just came by really to pay my respects to my friend the Secretary and to tell you that he has visited Alaska. As a matter of fact, he came up and worked right through the night with us literally and then moved on to the West Coast. He is a traveling Secretary and he is becoming ubiquitous. But we are delighted to know that your enthusiasm and your talents are directed towards improving our health care in the country, Mr. Secretary.

Thank you very much for allowing me to speak now.

Secretary THOMPSON. You know, Senator, we will be up there the first week in August with senior staff to travel Alaska again.

Senator STEVENS. Thank you very much.

Senator HARKIN. Thank you, Senator Stevens. Senator Specter.

# OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. Thank you, Mr. Chairman.

I join my colleagues, Mr. Secretary, in welcoming you to this hearing. The Department which you head is second to none in importance in the Federal Government. I am glad to see that the administration has recognized the importance of NIH. That is a battle which this subcommittee had initiated many years ago, could not scrape an extra dollar out of the administration, and now it has become recognized, which is very much to the country's advantage.

While there are, sir, important increases in a number of important fields, some of these cuts just cannot be accommodated. If you take a look at the CDC buildings and facilities, there is a cut of \$186 million. That was an initiative which this subcommittee undertook 2 years ago, adding \$170 million to a ramshackle operation, and last year I believe the figure was \$255 million.

You know the facilities there and I know the facilities. We both visited them. You simply cannot have people working in the quarters, distinguished scientists, and having materials which could be very dangerous, not under appropriate security precautions as they do research. So we are going to have to do a lot of juggling in this subcommittee to try to make ends meet here.

There has been a significant cut in children's graduate medical education. There is an enormous constituency for that. Community services block grants, LIHEAP—I am not exactly sure where we go, but we are going to have to make accommodations on those matters.

I see the press reports about a new head of NIH, which is long overdue. Of course, a good bit of the delay was due to the prior administration as well. It has been vacant since January of the year 2000, but more than 1 year into this administration.

The commissioner on FDA, vacant since September of 1999—a very important agency. I hear a lot of major concerns that there are matters pending there that the subordinates will not sign off on because they do not want to take the chances, and that is the job of somebody at the top. You just have to have a person.

The other directorships are vacant for the Institute of Neurological Disorders, the Institute of Biomedical Imaging, the Institute on Drug Abuse, the Institute on Mental Health, the Institute on Alcohol Abuse, the Institute on General Medical Sciences.

I am going to ask you what your progress is on moving ahead there. Then just a word or two on homeland defense—very vital. I am glad to see the increase of \$1.3 billion, up to \$4.3 billion. This subcommittee, Senator Harkin and I, held a hearing last year October 5. We had to go to the bowels of the Capitol because we could not operate over here, and we got more than \$3 billion to move ahead there and that is just indispensable because of the great concern. The President has been very blunt about the threat of some continuing risk. Any day something could happen of mammoth proportions, worse than 9/11. So that has got to be a top speed project.

Just a brief comment or two about stem cells and about the current controversy on therapeutic cloning. I am not quite sure where we go here about the ideology of the new director of NIH. I am hopeful we can keep ideology out, but I do not know that that is possible to do. We initiated here trying to get Federal funding for the stem cells and we collected 64 Senators in writing last spring who wanted to have more Federal involvement. Twelve more in reserve did not want to sign a paper.

The President acted on August 9. But on the facts I think it is insufficient and time will tell us more about that. But it has been put on the back burner by 9/11.

Now we have the issue of therapeutic cloning, which is a misnomer. It is not cloning at all. We are all against reproductive cloning. But if you do not have the process where you take a cell from a person, for example, who has Parkinson's, put it in the egg and get stem cells which will not be rejected, medical science is going to be set back tremendously.

We are going to fight that battle on the Senate floor. So perhaps it is not going to be a matter for you, and I know your constraints with all the White House directives or the NIH director to follow White House constraints to get an appointment. So it is in the lap of the Senate, and if we do the wrong thing God help America on the export of science and scientists to foreign countries and thwarting what could be really very important medical research.

So all of our hands are full. The issues which you face as the Secretary and which we face on this subcommittee level are gigantic, and we will work together to try to see to it that the public interest is carried out.

Thank you, Mr. Chairman.

Senator HARKIN. Thank you, Senator Specter. Senator Cochran.

# OPENING STATEMENT OF SENATOR THAD COCHRAN

Senator COCHRAN. Mr. Chairman, thank you. I join you in welcoming the Secretary to our hearing and I look forward to his testimony. I am very impressed with the way he is taking up the challenge of serving in the cabinet in this important position. I have been able to meet with him, as others on the committee have, talking about homeland security issues and particularly the responsibilities of the Food and Drug Administration and other agencies that he is interested in helping to supervise and direct.

I know there are big challenges in terms of personnel. We have had NIH with a vacancy. And FDA, we have a new acting director there. At CDC you are looking for a new director to run that agency. These are all very important research and administrative functions and I know that the Secretary is giving his personal attention to these challenges as well.

I want to add one comment about the stem cell research debate. I think it is really important for us to move to issuing regulations in this area to show that we are not going to shut off useful research using stem cells if it can be done without any question about leading to cloning. I think in the area of diabetes, particularly Parkinson's disease, we have two clear examples of possible beneficial uses for stem cell research.

I hope we can resolve this dilemma. I am clearly opposed to human cloning and I think we can agree on that. But we ought to be able to find a way to describe and restrict permissible research in this area without getting into the cloning activities that would trouble many in our country, and it would trouble me greatly as well.

So I hope that we can devote some attention and make this one of the highest priorities of our government at this time.

I am also worried that we are not recognizing the plight of small towns and rural communities in terms of the discriminatory reimbursement of hospitals and health care professionals in those areas. I do not know why we continue to make it impossible to have dependable medical care in the small towns and rural communities of our country because of this discriminatory policy of low reimbursements.

This is particularly true in the deep South. We have had hearings in our subcommittees of Appropriations and in other committees as well on this topic, and some changes have been made. But I think we need to take a new look at some of the deficiencies that continue to be manifested in this area. I am hopeful, Mr. Chairman, that you can help us figure out what to do to relieve those problems.

Mr. Chairman, thank you very much.

Senator HARKIN. Thank you, Senator.

Senator DeWine.

Senator DEWINE. Nothing, Mr. Chairman.

Senator HARKIN. Secretary Thompson is the 19th Secretary of the Department that oversees the health and welfare of this Nation. His career in public service began in 1966 as a representative in the Wisconsin State Assembly. Most recently he served as Governor of the State of Wisconsin from 1987 to 2000, making him the longest serving Governor in Wisconsin State history.

Secretary Thompson is well known as a leader in welfare reform and expanding access to health care for low income children. He has served as Chairman of the National Governors Association, the Education Commission of the States, and the Midwestern Governors Conference. Secretary Thompson received both his B.S. and J.D. degrees from the University of Wisconsin in Madison.

Mr. Secretary, welcome again to the committee.

#### SUMMARY STATEMENT OF HON. TOMMY G. THOMPSON

Secretary THOMPSON. Thank you and good morning, Chairman Harkin, Senator Specter. Thank you both for your hospitality and willingness to work with my Department and with me personally, and I thank you both for your leadership. Members of the subcommittee, I thank you as well.

It is an honor for me to come before you to discuss the President's fiscal year 2003 budget for the Department of Health and Human Services. Mr. Chairman, the past 13 months have witnessed some significant achievements at HHS. I will detail some of them in the course of my testimony.

As to our budget proposal itself, the total HHS request for fiscal year 2003 is \$489 billion. The discretionary component before this committee, as you indicated, is \$59.5 billion in budget authority, an increase of \$2.3 billion, or 4.1 percent over the comparable fiscal year 2000 budget.

# PROTECTING THE NATION AGAINST BIOTERRORISM

After September 11, I appointed Dr. D.A. Henderson, the physician who spearheaded the successful drive to eliminate smallpox worldwide, to head a newly created Office, in my Department, of Public Health Preparedness. About 20 feet from my office we have set up a 24-hour-a-day, 7-day-a-week, command center where we receive information from all over the world and dispense information to individuals and to communities and to States all over the country about possible bioterrorism attacks. We also dispense the pharmaceutical supplies to New York and Washington, DC, from that office.

In a word, we have been very aggressive. We have been prudent to prepare for any biological or chemical threat our enemies could use against us.

To prepare further, President Bush and I are requesting an additional \$4.3 billion, an increase of 45 percent over the current fiscal year, to support a variety of critical activities to prevent, identify, and be able to respond to incidents of bioterrorism. Right now we are providing \$1.1 billion, thanks to you and Members of both parties in this Congress that provided \$1.1 billion, to State governments to help them strengthen their capacity to respond to bioterrorism and other public health emergencies.

We are working to hook up every State and every major county health system in the Nation electronically through the Health Alert Network, and we should hope to have 90 percent of all the counties hooked up by the year 2003. In addition, we are requesting more than half a billion dollars for our hospital preparedness program, which will strengthen local hospital preparation for biological and chemical attacks and expand their surge capacity.

The NIH is researching better anthrax, plague, botulism, and the hemorrhagic fever vaccines; and we are purchasing an additional 154 million doses of smallpox vaccine so that every man, woman, and child in this Nation will be able to have a vaccine he or she needs by the end of this year.

When it comes to bioterrorism, we are growing stronger in our preparedness each and every day.

# INVESTING IN BIOMEDICAL RESEARCH

We are also advancing important biomedical research. The budget provides \$5.5 billion for research on cancer throughout NIH—I know it is a subject that both you, Senator Harkin and Senator Specter, are very interested in—and a total of \$2.8 billion for HIV– AIDS-related research.

We are also working hard to improve patient safety. As many as 98,000 Americans die annually due to medical errors. So in the 2003 budget President Bush is proposing \$10 million in new funding to improve patient safety and reduce medical errors. The increased funding will bring the total HHS budget for improving patient safety to \$84 million in fiscal year 2003. The funds will support efforts to put known safety technologies into wider use, develop new approaches, and support a stronger system for rapid reporting of adverse medical events.

# SUPPORTING HEALTH COMMUNITIES

We are also requesting \$20 million for a Healthy Communities Initiative, which is a new innovation. It is a new interdisciplinary service effort that will concentrate Department-wide expertise on the prevention of diabetes, asthma, obesity, and health disparities in minority communities. Let me note how concerned I am and how concerned all of us should be about how obesity is affecting our health as a people. Roughly three out of every five adults are overweight and approximately 300,000 U.S. deaths a year currently are associated with obesity and simply weighing too much. The total direct and indirect costs attributed to being overweight and to obesity amounted to \$117 billion in the year 2000.

We have also got a serious problem with diabetes. Nearly 16 million Americans have diabetes and 800,000 more fall victim to the disease annually. This epidemic is witnessing a terrible increase, tripling within the last 3 decades. Yet we have got solid research that shows that if you exercise just 30 minutes a day—and walking is a perfectly suitable form of exercise—and lose 10 to 15 pounds, your risk of getting diabetes falls by nearly 60 percent.

So the President and I are committed to our across the board prevention initiative. Preventive health care saves huge amounts of money, but, more importantly, it can save untold thousands of lives.

# WELFARE REFORM

We are also helping to prepare low income Americans for their future. That is why welfare reform remains so important. The good news is that since 1996, when Congress passed the TANF I bill, nearly 7 million fewer individuals are on welfare, and 2.8 million fewer children are in poverty, in large part because welfare has been transformed.

The President's budget boldly takes the next step, which requires us to work closely with States to help families that have left welfare to climb the career ladder. The foundation of welfare reform's success still remains work, for work is the only way to leave poverty and be able to become independent.

Let me also make crystal clear that the news reports yesterday about a plan to change the minimum wage law were absolutely false and incorrect. President Bush and I will insist that welfare recipients receive at least the minimum wage for the hours that they work, including community service jobs. This is an important principle that I fought for as Governor of Wisconsin and one the President and I remain committed to today as we take the next step in welfare reform.

The President's budget allocates \$16.5 billion for block grant funding, provides supplemental grants to address historical disparities in welfare spending among States, and strengthens work participation requirements. The budget provides another \$350 million in Medicaid benefits for those in the transition from welfare to work.

We are calling for a continued commitment also to child care, including \$2.7 billion for entitlement child care funding and \$2.1 billion for discretionary funding. We are giving States the flexibility they need to mix effective education and job training programs with work, as well as the money to strengthen families and reduce illegitimacy.

Strengthening Medicare is another key component of our acrossthe-board effort to broaden and strengthen our country's health care system. The 2003 budget dedicates \$190 billion over 10 years for immediate targeted improvements and comprehensive modernization.

# EXPANDED ACCESS TO HEALTH CARE

As we reach out to those still relying on welfare anywhere to strengthen Medicare, we cannot ignore the roughly 40 million Americans who lack health insurance. Since January 2001 I have been able to approve State plan amendments and Medicare and SCHIP waivers that have expanded opportunity for health coverage to 1.8 million Americans and improved existing benefits to 4.5 million individuals.

The 2003 budget also seeks \$1.5 billion to support the President's plan to impact 1,200 communities with new or expanded health centers by 2006. This is a \$114 million increase over fiscal year 2002 and would support 170 new and expanded health centers and provide services to 1 million additional patients. We will soon be issuing 27 grants totaling \$12 million under President Bush's Health Centers Initiative to help more Americans get access to quality health care. The awards are the second round of fiscal year 2002 grants under the President's initiative and will help bring needed health services to some 157,000 Americans in 17 States.

The President's budget includes \$89 billion in new health credits to help American families buy health insurance which will provide health coverage for many low income families.

# MANAGEMENT REFORMS

Finally, Mr. Chairman, I want to note that when I accepted my post at HHS, the President charged me to make significant management reforms in my Department. I have taken the President's charge seriously and have implemented reforms that will enable HHS to serve the American people even better in the coming years. To that end, we will reduce the number of HHS personnel offices from 46 to 4. We are realigning and consolidating throughout the Department, bringing better stewardship to our use of taxpayer dollars, and we have launched a regulatory reform initiative to reduce the paperwork burden on physicians, hospitals, and other health providers.

For HHS to truly be compassionate, we have to be effective. That means running our programs well and honoring the taxpayers with the best possible services that we can provide.

#### PREPARED STATEMENT

Mr. Chairman, this comprehensive, aggressive budget addresses the most pressing public health challenges that face our Nation from bioterrorism preparedness to coverage for the uninsured—in order to ensure that we have a safe and healthy America. I am confident that by working together in a bipartisan fashion we can continue to improve the health and wellbeing of our fellow citizens.

Thank you again, Mr. Chairman and members, for letting me come before you today. I look forward now to your questions.

[The statement follows:]

# PREPARED STATEMENT OF HON. TOMMY G. THOMPSON

Good Morning Chairman Harkin, Senator Specter and members of the Committee. I am honored to appear before you today to discuss the President's fiscal year 2003 budget for the Department of Health and Human Services. I am confident that a review of the full details of our budget will demonstrate that we are proposing a balanced and responsible approach to ensuring a safe and healthy America.

Before I discuss the fiscal year 2003 budget, I would like to thank the committee for its hard work and dedication to the programs at HHS. Over the past year, I have come to really appreciate your support and interest in the issues and health needs of the American people. Like you, I believe in the services HHS programs provide including our commitment to the war against bioterrorism. I look forward to furthering our relationship and building on the successes achieved during the past year.

The budget I present to you today fulfills the promises the President has made and proposes creative and innovative solutions for meeting the challenges that now face our nation. Since the September 11th attacks we have dedicated much of our efforts to ensuring that the nation is safe. HHS was one of the first agencies to respond to the September 11th attacks on New York City, and began deploying medical assistance and support within hours of the attacks. Our swift response and the overwhelming task of providing needed health related assistance made us even more aware that there is always room for improvement. The fiscal year 2003 budget for the Department of Health and Human Services builds on President Bush's commitment to ensure the health and safety of our nation. The fiscal year 2003 budget places increased emphasis on protecting our nation's citizens and ensuring safe, reliable health care for all Americans. The HHS budget also promotes scientific research, builds on our success in welfare reform, and provides support for childhood development while delivering a responsible approach for managing HHS resources. Our budget plan confronts both the challenges of today and tomorrow while protecting and supporting the well being of all Americans.

and tomorrow while protecting and supporting the well being of all Americans. Mr. Chairman, the total HHS request before this committee for fiscal year 2003 is \$312.1 billion in outlays. The discretionary component of the HHS budget totals \$59.5 billion in budget authority, which is an increase of \$2.3 billion, or +4.1 percent over fiscal year 2002. The mandatory component before this committee totals \$252.7 billion, which is an increase of \$19.4 billion or +8.3 percent. Let me now discuss some of the highlights of the HHS budget and how we hope to achieve our goals.

#### PROTECTING THE NATION AGAINST BIOTERRORISM

Mr. Chairman, as you know, the Department of Health and Human Services is the lead federal agency in countering bioterrorism. In cooperation with the States, we are responsible for preparing for, and responding to, the medical and public health needs of this nation. The fiscal year 2003 budget for HHS bioterrorism efforts is \$4.3 billion, an increase of \$1.3 billion, or 45 percent, above fiscal year 2002. The amount before this committee totals \$4.1 billion. This budget supports a variety of activities to prevent, identify, and respond to incidents of bioterrorism. These activities are administered through the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), the Office of Emergency Preparedness (OEP), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Health Resources and Services Administration (HRSA) and the Food and Drug Administration (FDA). These efforts will be directed by the newly established Office of Public Health Preparedness (OPHP).

On January 31, 2002, HHS announced plans for making \$1.1 billion available to States. This funding is available for hospital preparedness, laboratory capacity, epidemiology, and emergency medical response. Approximately 20 percent of this total either has already been provided (or will be provided within the next few weeks) for immediate expenditure to all eligible entities in base awards that will be used to establish core programs and address current needs for bioterrorism preparedness. The remaining 80 percent will be made available for expenditure once the Secretary has approved the States' work plans for their awarded funds. States will submit plans which will be reviewed by the HHS staff to ensure that funding is used wisely for bioterrorism efforts.

In order to create a blanket of preparedness against bioterrorism, the fiscal year 2003 budget provides funding to State and local organizations to improve laboratory capacity, enhance epidemiological expertise in the identification and control of diseases caused by bioterrorism, provide for better electronic communication and distance learning, and support a newly expanded focus on cooperative training between public health agencies and local hospitals.

Funding for the Laboratory Response Network enhances a system of over 80 public health labs specifically developed for identifying pathogens that could be used for bioterrorism. Funding will also support the Health Alert Network, CDC's electronic communications system that will link local public health departments in covering at least ninety percent of our nations' population. Funding will be used to support epidemiological response and outbreak control, which includes funding for the training of public health and hospital staff. This increased focus on local and state preparedness serves to provide funding where it best serves the interests of the nation.

An important part on the war against terrorism is the need to develop vaccines and maintain a National Pharmaceutical Stockpile. The National Pharmaceutical Stockpile is purchasing enough antibiotics to be able to treat up to 20 million individuals in a year for exposure to anthrax and other agents by the end of 2002. The Department is purchasing sufficient smallpox vaccines for all Americans. The fiscal year 2003 budget proposes \$650 million for the National Pharmaceutical Stockpile and costs related to stockpiling of smallpox vaccines, and next-generation anthrax vaccines currently under development.

Another important aspect of preparedness is the response capacity of our nation's hospitals. Our fiscal year 2003 budget provides \$518 million for hospital preparedness and infrastructure to enhance biological and chemical preparedness plans focused on hospitals. The fiscal year 2003 budget will provide funding to upgrade the capacity of hospitals, outpatient facilities, emergency medical services systems and poison control centers to care for victims of bioterrorism. In addition, CDC will pro-

vide support for a series of exercises to train public health and hospital workers to work together to treat and control bioterrorist outbreaks. The fiscal year 2003 budget also includes \$184 million to construct, repair and se-

The fiscal year 2003 budget also includes \$184 million to construct, repair and secure facilities at the CDC. Priorities include the construction of an infectious disease/bioterrorism laboratory in Fort Collins, Colorado, and the completion of a second infectious disease laboratory, an environmental laboratory, and a communication and training facility in Atlanta. This funding will enable the CDC to handle the most highly infectious and lethal pathogens, including potential agents of bioterrorism. Within the funds requested, \$12 million will be used to equip the Environmental Toxicology Lab, which provides core lab space for testing environmental samples for chemical terrorism. Funding will also be allocated to the ongoing maintenance of existing laboratories and support structures. The fiscal year 2003 budget also includes \$60 million for the development of new

The fiscal year 2003 budget also includes \$60 million for the development of new Educational Incentives for Curriculum Development and Training Program. The goals of this program will be the development of a health care workforce capable of recognizing indications of a bioterrorist event in their patients, that possesses the knowledge and skills to best treat their patients, and that has the competencies to rapidly and effectively inform the public health system of such an event at the community, State and national level.

#### INVESTING IN BIOMEDICAL RESEARCH

Advances in scientific knowledge have provided the foundation for improvements in public health and have led to enhanced health and quality of life for all Americans. Much of this can be attributed to the groundbreaking work carried on by, and funded by, the National Institutes of Health (NIH). Our fiscal year 2003 budget enhances support for a wide array of scientific research, while emphasizing and supporting research needed for the war against bioterrorism.

NIH is the largest and most distinguished biomedical research organization in the world. The research that is conducted and supported by the NIH offers the promise of breakthroughs in preventing and treating a number of diseases and contributes to fighting the war against bioterrorism. The fiscal year 2003 budget includes the final installment of \$3.9 billion needed to achieve the doubling of the NIH budget. The budget includes \$1.75 billion for bioterrorism research, including genomic sequencing of dangerous pathogens, development of zebra chip technology, development and procurement of an improved anthrax vaccine, and laboratory and research facilities construction and upgrades related to bioterrorism. With the commitment to bioterrorism research comes our expectation of substantial positive spin-offs for other diseases. Advancing knowledge in the arena of diagnostics, therapeutics and vaccines in general should have enormous impact on the ability to diagnose, treat, and prevent major killers-diseases such as malaria, TB, HIV/AIDS, West Nile fever, and influenza.

The fiscal year 2003 budget also provides \$5.5 billion for research on cancer throughout all of NIH. Currently, one of every two men and one of every three women in the United States will develop some type of cancer over the course of their lives. New research indicates that cancer is actually more than 200 diseases, all of which require different treatment protocols. Promising cancer research is leading to major breakthroughs in treating and curing various forms of cancer. Our budget continues to expand support for these research endeavors. The fiscal year 2003 budget also includes a total of \$2.8 billion for HIV/AIDS-related research. NIH continues to focus on prevention research, therapeutic research to treat those already infected, international research, and research targeting the disproportionate impact of AIDS on minority populations in the United States.

#### SUPPORTING HEALTHY COMMUNITIES

The fiscal year 2003 budget includes \$25 million for a Healthy Communities Innovation Initiative—a new interdisciplinary services effort that will concentrate Department-wide expertise on the prevention of diabetes and asthma, as well as obesity. Of this amount, \$20 million is available in HRSA. The purpose of the initiative is to reduce the incidence of these diseases and improve services in 5 communities through a tightly coordinated public/private partnership between medical, social, educational, business, civic and religious organizations. These chronic diseases were chosen because of their rapidly increasing prevalence within the United States. In addition there is \$5 million in CDC for a national media campaign to promote physical fitness activities, with an emphasis on families and communities.

More than 16 million Americans currently suffer from a preventable form of diabetes. Type II diabetes is increasingly prevalent in our children due to the lack of activity. In a recent study conducted by NIH, participants that were randomly assigned to intensive lifestyle intervention experienced a reduced risk of getting Type II diabetes by 58 percent. HHS plans to reach out to women and minorities to help make this initiative a success.

#### INCREASING ACCESS TO HEALTH CARE

Of all the issues confronting this Department, none has a more direct effect on the well-being of our citizens than the quality and accessibility of health care. Our budget proposes to improve the health of the American people by taking important steps to increase and expand the number of Community Health Centers, strengthen Medicaid, and ensure patient safety.

Community Health Centers provide family oriented preventive and primary health care to over 11 million patients through a network of over 3,400 health sites. The fiscal year 2003 budget will increase and expand the number of health center sites by 170, the second year of the President's initiative is to increase and expand sites by 1,200 and serve an additional 6.1 million patients by 2006. We propose to increase funding for these Community Health Centers by \$114 million in fiscal year 2003. Our long-term goal is to increase the number of people who receive high quality primary healthcare regardless of their ability to pay. With these new health centers we hope to achieve this goal.

In addition to expanding Community Health Centers, we are seeking to expand the National Health Service Corps by \$44 million. Currently, more than 2,300 health care professionals are providing service to health center patients and others in under served communities.

The Medicaid program and the State Children's Health Insurance Program (SCHIP) provide health care benefits to low-income Americans, primarily children, pregnant women, the elderly, and those with disabilities. The fiscal year 2003 budget we propose strengthens the Medicaid and SCHIP programs by implementing essential reforms in the way we pay for prescription drugs and by extending expiring SCHIP funds.

We propose to work with stakeholders to develop legislative proposals that build on the Health Insurance Flexibility and Accountability (HIFA) demonstration in order to give states the flexibility they need to design innovative ways of increasing access to health insurance coverage for the uninsured. The Administration's plan would allow at State option those who receive the President's health care tax credit to increase their purchasing power by purchasing insurance from plans that already participate in their State's Medicaid, Children's Health Insurance, or State employees' programs. This could help keep costs down and provide a more comprehensive benefit than plans in the individual market.

We also need to make an effort to narrow the drug treatment gap. As reflected in the National Drug Control Strategy, Substance Abuse and Mental Health Services Administration estimates that 4.7 million people are in need of drug abuse treatment services. However, fewer than half of those who need treatment actually receive services, leaving a treatment gap of 3.9 million individuals. Our budget supports the President's Drug Treatment initiative, and to narrow the treatment gap. We propose to increase funding for the initiative by \$127 million. These additional funds will allow States and local communities to provide treatment services to approximately 546,000 individuals, an increase of 52,000 over fiscal year 2002.

#### BUILDING UPON THE SUCCESSES OF WELFARE REFORM

President Bush has said that American families are the bedrock of American society and the primary source of strength and health for both individuals and communities. Our budget includes a number of new initiatives that support this principle by targeting resources to strengthen our nation's families. We look forward to working with Congress in considering the next phase of welfare reform and other elements of the President's proposals to help America's low-income families succeed.

#### Temporary assistance for needy families

As a former governor, I can tell you that the Temporary Assistance for Needy Families program—or TANF—has been a truly remarkable example of a successful Federal-State partnership. States were given tremendous flexibility to reform their welfare programs and as a result, millions of families have been able to end their dependency on welfare and achieve self-sufficiency.

In New York City, where we are understandably most concerned about job opportunities, the City has achieved more than 53,000 job placements for welfare recipients from September through December 2001. While the number of TANF recipients increased briefly directly because of the tragedy on September 11, by December there were about 15,000 fewer TANF recipients on the rolls than there were in August. Indeed, in December the City had its lowest number of persons on welfare since 1965.

Our reauthorization proposal embraces the needs of families by maintaining the program's overall funding and basic structure, while focusing increased efforts on building stronger families through work and job advancement and adding child wellbeing as an overarching purpose of TANF.

being as an over arching purpose of TANF. Our budget proposes \$16.5 billion each year for block grants to States and Tribes; \$319 million a year to restore supplemental grants; \$2 billion over five years for a more accessible Contingency Fund; a \$100 million a year initiative for research, demonstration and technical assistance primarily to promote family formation and healthy marriage activities; and \$100 million redirected from High Performance Bonus funds to create a competitive matching grant program to develop innovative approaches to promoting healthy marriages and reducing out-of-wedlock births. In addition, our proposal will call for modification of the bonus for high performance to reward significant achievement in promoting employment of program participants.

#### Other programs supporting TANF goals

The President's Budget also includes funding for several other programs at the State and community level that work to support the goals of TANF. The Social Services Block Grant (SSBG) provides a flexible source of funding for States to help families achieve or maintain self-sufficiency and provide an array of social services to vulnerable families. The President's Budget request for SSBG is \$1.7 billion. The President's Budget extends the Transitional Medical Assistance (TMA) pro-

The President's Budget extends the Transitional Medical Assistance (TMA) program which provides valuable health protection for former welfare recipients after they enter the workforce. This important program allows families to remain eligible for Medicaid for up to 12 months after they are no longer eligible for welfare because of earnings from their new job. TMA is an important stepping stone in helping workers and their families successfully transfer from welfare to work without fear of losing vital health coverage.

#### Child care

Child Care has played an important role in the success of welfare reform by providing parents the support they need to work. The President's Budget recognizes this critical link and maintains a high level of commitment to childcare. Continuing the substantial increase in funding that Congress has provided over the last several years, the President's Budget includes a total of \$4.8 billion in childcare funding in conjunction with our request to reauthorize the mandatory and discretionary funding provided under the Child Care and Development Block Grant and the Child Care Entitlement. States will also continue to have significant flexibility under the TANF program and under the Social Services Block Grant program to address the needs of their low-income working families. These additional funding opportunities have substantially increased the amount of resources dedicated to child care needs. For example, in fiscal year 2000 States transferred \$2.3 billion in TANF funds to the Child Care and Development Block Grant.

#### *Child support enforcement*

The Child Support Enforcement program offers another vital connection to families' ability to achieve self-sufficiency and financial stability. The President's Budget proposes to increase child support collections and direct more of the support collected to families transitioning from welfare. Under our proposal, the Federal government would share in the cost of optional expanded State efforts to pass through child support collections to families receiving TANF. States could also opt to direct all child support to families who formerly received TANF.

overall collections to families who formerly received TANF. Overall collections would be increased by expanding our successful program for denying passports to parents owing \$2,500 in past-due support, requiring States to update support awards in TANF cases every three years, and authorizing States to offset certain Social Security Administration payments when they determine such action would be appropriate to collect unpaid support. Our child support legislative package would also impose a minimal annual processing fee in any case where the State has been successful in collecting support on behalf of a family that has never received assistance.

#### Strengthening families

The fiscal year 2003 budget contains funds for four competitive grant programs, targeted at community and faith based organizations, to assist in delivering innovative services, to strengthen families and help change lives. The Compassion Capital Fund, at \$100 million, will expand the capacity of groups and organizations willing to step up and help provide these critical social services. Over 25 million children live in homes without fathers. To assist non-custodial fathers to become more involved in the lives of these children, the budget provides \$20 million in competitive grants to faith-and community-based organizations to encourage and help fathers to support their families and avoid welfare, improve fathers' ability to manage family business affairs, and encourage and support healthy marriages.

The budget also provides \$25 million for the mentoring children of prisoners initiative first proposed last year. This funding will enable public and private entities to establish or expand programs providing mentoring for children of incarcerated parents.

Finally, young pregnant mothers and their children will be provided safe environments through the \$10 million included for Maternity Group Homes. Approximately 80 grantees will provide a range of services such as childcare, education, job training, counseling and advices on parenting and life skills.

#### Promoting safe and stable families

The President's Budget would increase the funding level for this program to \$505 million, fully supporting the increased authorization included in the new law. These funds will be used to help promote and support adoption so that children can become part of a safe and stable family, as well as for increased preventive efforts to help families in crisis.

This landmark legislation also authorized a new program to provide vouchers to youth who are aging out of foster care so that they can obtain the education and training they need to lead productive lives. The President's Budget includes \$60 million for these vouchers, bringing the total request for the Foster Care Independence Program to \$200 million.

## Child welfare/foster care/adoption

Our budget framework includes resources for a number of additional programs targeted to protecting our most vulnerable and at-risk children. Foster Care, Adoption Assistance, Adoption Incentives and Child Welfare Services enhance the capacity of families to raise children in a nurturing, safe environment. The President's Budget provides resources to help States provide safe and appropriate care for children who need placement outside their homes, and to provide funds to States to assist in providing financial and medical assistance for adopted children with special needs who cannot be reunited with their families, and to reward States for increasing their number of adoptions. The budget also supports Child Welfare Services programs with the goal of keeping families together when possible and in the best interest of the child.

The budget provides \$4.9 billion for Foster Care, \$1.6 billion for Adoption Assistance, and \$43 million in Adoption Incentive funds. The President's Budget seeks almost \$300 million in funding for child welfare services and training. Together, these funds will support improvement in the healthy development, safety, and well being of the children and youth in our nation.

#### Head Start

Our budget continues to provide support for Head Start and supports early childhood education and school readiness. The President's Budget request includes \$6.7 billion for Head Start, an increase of \$130 million over fiscal year 2002. In fiscal year 2003, almost 915,000 children will receive Head Start services including 62,000 children in Early Head Start. The funding increase will maintain current enrollment levels, strengthen training and technical assistance, and support competitive salaries for Head Start teachers.

In fiscal year 2003, the Department will continue to focus on early literacy through investments in teacher quality and credentialing and, specialized efforts such as Head Start Centers of Excellence on Literacy and the Head Start Family Literacy Project. In 2003, Head Start will meet its statutory goal, assuring that 50 percent of all Head Start educators have a college degree.

#### STRENGTHENING MEDICARE

The fiscal year 2003 President's Budget dedicates \$190 billion over ten years for immediate targeted improvements and comprehensive Medicare modernization, including a subsidized prescription drug benefit, better insurance protection, and better private options for all beneficiaries. Let me assure you, the President remains committed to the framework he introduced last summer, and to bringing the Medicare program up to date by providing prescription drug coverage and other improvements. We cannot wait: it is time to act. Recognizing that there is no time to waste, the President's Budget also includes a series of targeted immediate improvements to Medicare.

- -HHS has just released a revised and improved version of the proposed drug card program, which will give beneficiaries immediate savings on the cost of their medicines and access to other valuable pharmacy services. The President is absolutely committed to providing immediate assistance to seniors who currently have to pay full price for prescription drugs, and this initiative will lay the groundwork for a comprehensive Medicare drug benefit.
- Recently, I announced a model drug waiver program-Pharmacy Plus-to allow States to reduce drug expenditures and expand drug only coverage to seniors and certain individuals with disabilities with family incomes up to 200 percent of the federal poverty level. This program is being done administratively. The recently approved Illinois initiative illustrates how states can expand coverage to Medicare beneficiaries in partnership with the federal government. The Illinois program will give an estimated 368,000 low-income seniors drug coverage.
- —This budget proposes additional federal assistance for comprehensive drug coverage to low-income Medicare beneficiaries up to 150 percent of poverty—about \$17,000 for a family of two. This policy would eventually expand drug coverage for up to 3 million beneficiaries who currently do not have prescription drug assistance, and it will be integrated with the Medicare drug benefit that is offered to all seniors once that benefit is in place. This policy also helps to establish the framework necessary for a Medicare prescription drug benefit and is essentially a provision that is in all of the major drug benefit proposals to be debated before Congress.
- —The President's budget also includes an increase in funding to stabilize and increase choice in Medicare+Choice program by aligning payment rates more closely with overall Medicare spending and paying incentives for new types of plans to participate. Over 500,000 seniors lost coverage last year because Medicare+Choice plans left the program. Today close to 5 million seniors choose to receive quality health care through the Medicare+Choice program. Because it provides access to drug coverage and other innovative benefits, it is an option many seniors like, and an option we must preserve. The President's budget also proposes the addition of two new Medigap plans to the existing 10 plans. These new plans will include prescription drug assistance and protect seniors from high out-of-pocket costs

Some of these initiatives give immediate and tangible help to seniors. But, let me make clear: these are not substitutes for comprehensive modernization and availability of a drug benefit option to all seniors in Medicare. They are immediate steps we want to take to improve the program in conjunction with comprehensive reform, so that beneficiaries will not have to wait to begin to see benefit improvements. I want to pledge today to work with each and every member of this Committee to fulfill our promise of health care security for America's seniors- now and in the future.

#### IMPROVING MANAGEMENT AND PERFORMANCE OF HHS PROGRAMS

I am committed to being proactive in preparing the nation for potential threats of bioterrorism and supporting research that will enable Americans to live healthier and safer lives. And, I am excited about beginning the next phase of Welfare reform and strengthening our Medicare and Medicaid programs. Ensuring that HHS resources are managed properly and effectively is also a challenge I take very seriously.

For any organization to succeed, it must never stop asking how it can do things better, and I am committed to supporting the President's vision for a government that is citizen-centered, results oriented, and actively promotes innovation through competition. HHS is committed to improving management within the Department and has established its own vision of a unified HHS—One Department free of unnecessary layers, collectively strong to serve the American people. The fiscal year 2003 budget supports the President's Management Agenda.

The Department will improve program performance and service delivery to our citizens by more strategically managing its human capital and ensuring that resources are directed to national priorities. HHS will reduce duplication of effort by consolidating administrative management functions and eliminating management layers to speed decision-making. The Department plans to reduce the number of personnel offices from 40 to 4 and consolidate construction funding, leasing, and other facilities management activities. These management efficiencies will result in an estimated savings of 700 full time equivalent positions, allowing the Department to redeploy staff and other resources to advance primary missions.

HHS continues working to improve budget and performance integration in support of the Government-wide effort. Although we work in a challenging environment where health outcomes may not be apparent for several years, and the Federal dollar may be just one input to complex programs, HHS is committed to demonstrating to citizens the value they receive for the tax dollars they pay.

By expanding our information technology and by establishing a single corporate Information Technology Enterprise system, HHS can build a strong foundation to re-engineer the way we do business and can provide better government services at reduced costs. By consolidating and modernizing existing financial management systems our Unified Financial Management System (UFMS) will provide a consistent, standardized system for departmental accounting and financial management. This "One Department" approach to financial management and information technology emphasizes the use of resources on an enterprise basis with a common infrastructure, thereby reducing errors and enhancing accountability. The use of cost accounting will aid in the evaluation of HHS program effectiveness, and the impacts of funding level changes on our programs.

High wind and in the contraction of time programs program choice, here the programs funding level changes on our programs. HHS is also committed to providing the highest possible standard of services and will use competitive sourcing as a management tool to study the efficiency and performance of our programs, while minimizing costs overall. The program will be linked to performance reviews to identify those programs and program components where outsourcing can have the greatest impact. Further, the incorporation of performance-based contracting will improve efficiency and performance at a savings to the taxpayer.

#### GOVERNMENT PERFORMANCE AND RESULTS ACT

HHS is committed to continual improvement in the performance and management of its programs and the Administration's efforts to provide results-oriented, citizencentered government. The budget request for fiscal year 2003 is accompanied by annual performance plans and reports required by the Government Performance and Results Act (GPRA). The performance measures cover the wide range of program activities essential to carrying out the HHS mission. Some notable fiscal year 2001 achievements include:

- -Moving Families Toward Self-sufficiency: ACF reported that 42.9 percent of adult recipients of TANF were employed by fiscal year 1999. This is a primary indicator of success in moving families toward self-sufficiency. It improves on the fiscal year 1998 baseline of 38.7 percent and exceeds the target of 42 percent.
- -Families Benefiting from Child Support Enforcement: The Child Support Enforcement program broke new records nationwide in fiscal year 2001 by collecting \$18.9 billion, one billion over fiscal year 2000 levels. In one such initiative in fiscal year 2000, the government collected a record \$1.4 billion in overdue child support from Federal income tax refunds, and more than 1.42 million families benefited from these collections.

These are just a few of the dozens of impressive success stories found in the 13 performance plans and reports. Performance measurement has been, and will continue to be, an important part of our effort to improve the management and performance of our programs.

#### WORKING TOGETHER TO ENSURE A SAFE AND HEALTHY AMERICA

Mr. Chairman, the budget I bring before you today contains many different elements of a single proposal; what binds these fundamental elements together is the desire to improve the lives of the American people. All of our proposals, from building upon the successes of welfare reform, to protecting the nation against bioterrorism; from increasing access to healthcare, to strengthening Medicare, are put forward with the simple goal of ensuring a safe and healthy America. I know this is a goal we all share, and with your support, we are committed to achieving it.

## NIH DIRECTOR

Senator HARKIN. Thank you very much, Mr. Secretary, for your statement.

Mr. Secretary, picking up a little bit on what Senator Specter talked about and what Senator Cochran mentioned also, there is an article in the newspaper this morning, the Washington Post, that basically, if it is true—I do not know if it is—I think is highly disturbing, about the new pick to be the head of the NIH. Now, as I understand it no name has come forward. This is just sort of touted. This name of this person, Elias Zerhouni, has not been submitted yet; is that correct?

Secretary THOMPSON. That is correct, Senator.

Senator HARKIN. So again I do not know whether it is true, but I am just saying if it is, it is very disturbing that a person would have to pass some philosophical test before they could be appointed the head of the NIH, that he had to agree to oppose all stem cell research that could lead to cures for things like Alzheimer's and Parkinson's and juvenile diabetes.

It is just disturbing to me that the NIH, the premier medical research agency in the world, might be led by someone with a closed mind about this promising avenue of research. As I said, I do not know if this is true or not, but it is very disturbing if it is.

Secretary THOMPSON. If it was true, I would be very disturbed, too. But it is not true, Senator.

Senator HARKIN. Oh, this story in the Post is not true?

Secretary THOMPSON. That story, the conclusions of that story are not true.

Senator HARKIN. It quoted an unknown—you always have to ask questions when it is an unknown. An unknown congressional Republican who is working to enact the anti-cloning legislation said: "He is one of us. He supports Brownback and we support him."

I guess we will have to find out if his name comes up. But are you saying that that is not true, either?

Secretary THOMPSON. I do not know his position on the Brownback bill, but I would like to point out, Senator, if I might, that there is no litmus test and I would be very disturbed if there was. There is not.

Second, the President of the United States has not chosen, has not advanced a name yet. But I know the President is reviewing the names that are over in the White House and I am very hopeful and quite confident that a name will be coming forth relatively soon.

Senator HARKIN. Mr. Secretary, I do not know-----

Secretary THOMPSON. I have had a chance to interview all of the candidates and I can assure you none of the candidates that are in the White House have a closed mind about stem cells and about research. I think once you get a chance to meet any of the three candidates that are over there you will be very satisfied after you get a chance to discuss it with them.

Senator HARKIN. Well, that is reassuring, and of course we will meet with them. They will have to come up to our committee for confirmation.

Secretary THOMPSON. That is correct.

Senator HARKIN. I just say publicly for the record that—again, you say you assure me this is not true. I am just saying, if it is, if there is substance to that and such a person were appointed to be the head of the NIH, I think you would see a mass exodus of scientists out of NIH. To think that somehow you are going to have a director of NIH that had a closed mind on a legitimate and I think promising source of research would be something that has never happened at NIH.

# CANDIDATE QUALIFICATIONS

Here we have just doubled the funding for it. We put all that money into it. We want to attract the best and the brightest minds to NIH.

Secretary THOMPSON. You do and I do as well, Senator. I can assure you that the person that will be nominated, when he is nominated by the President, will have an open mind about research and that you will feel comfortable with him. I am fairly confident about that.

Senator HARKIN. Well, I hope so. Again, there are rumors around. I can only say they are rumors. I do not know if there is any substance to them.

Secretary THOMPSON. I read the article myself this morning and I would like to point out that Dr. Varmus, who was the NIH director, spoke very highly of the individual in question.

Senator HARKIN. He said: "While Zerhouni is not widely known among basic researchers, he is a talented scientist with the ability to instill confidence in the agency."

Well, I heard a disturbing report that one of the candidates for the NIH director position was interviewed by a certain U.S. Senator, who turned thumbs down and that ended it. Now again, I do not know if that is true or not, but it was on the basis of his opposition to-or that he would not be opposed to stem cell research. I do not know if that is true.

Secretary THOMPSON. I know full well about that individual and I have the utmost confidence, as you do, in that person. He is an outstanding scientist. The question was would he give up his institute in order to take the NIH directorship and he said no. That was the question.

Senator HARKIN. But that person did not meet with a U.S. Senator regarding his position on stem cell research?

Secretary THOMPSON. I am sure he met with Senators. I do not know how many he met with, but I know he did because I requested that he do that.

Senator HARKIN. That he meet with Senators?

Secretary THOMPSON. Yes. Senator HARKIN. Well, he did not meet with me. I do not know what Senators he met with.

Secretary THOMPSON. I do not know either, sir.

Senator HARKIN. Well, there is that story out there that he met with a Senator who turned thumbs down on him because he would not commit to being opposed to stem cell research. Now again, that is just a rumor.

Secretary THOMPSON. All I know from inside information is that it was not that decision that affected his appointment. It was whether or not he would turn down-whether or not he could handle his institute and the directorship of NIH, and he wanted to do both. I thought he could and, after reviewing it, the decision was made that—well, the decision has not been made yet, but that is the question. It is not his philosophical or ideological positions. It is whether or not he could handle both positions, Senator.

Senator HARKIN. That is reassuring.

Senator Specter.

Senator SPECTER. Thank you, Mr. Chairman.

Mr. Secretary, these appointments raise very difficult considerations for Senate confirmation. It is not unexpected that the President would seek appointees who share his views on stem cells and so-called therapeutic cloning. There has even been some suggestion that you do not agree totally with the President on some of those issues, but you are following the administration policy. I am not going to ask you to comment on that, but leave that as an option for you if you want to comment on it.

Okay, the option is on the table.

Secretary THOMPSON. Sometimes discretion is the better part of valor.

# INFORMATION FLOW FROM HHS TO COMMITTEE

Senator SPECTER. Especially after you are confirmed.

Well, that is a political fact of life and it is recognized and respected. One assurance that I do want from you on the record is that when this subcommittee seeks information on these controversial subjects that we will get it in an unvarnished way. Now, you and I had a difference of opinion last year when this subcommittee wrote to the directors of all the institutes asking for their views on stem cells and their responses were edited in HHS. So that you do have directors of quite a number of the institutes who are there institutionally and they are not being appointed by the administration, which is going to ask for ideological agreement. They are there in the long haul.

The new directors may well have to pass the same sort of a test that the NIH director is, at least as reported in the media, and it has the ring of authenticity. Will you assure this subcommittee, Mr. Secretary, that when we ask for information from these directors and scientists at NIH that we will get their views without any editing or any ideological review?

Secretary THOMPSON. I can assure you without any equivocation whatsoever that will be the case, Senator.

Senator SPECTER. That is very important, so we can at least go back to the directors who have been appointed in the past. And they may have views similar to the President's, and if they do that is fine, or they may not.

Secretary THOMPSON. Everything scientifically based should be given to you in an unvarnished fashion, any way that you want it. Senator SPECTER. That is what we want to do.

Secretary THOMPSON. I can assure you that is the course of action.

Senator SPECTER. That is very important in evaluating what to do with the nominees which the President submits. Of course, he is the President of my party as well as your party.

Secretary THOMPSON. Yes.

# BUDGET FOR CDC BUILDINGS AND FACILITIES

Senator SPECTER. On to some of these items. Mr. Secretary, do you endorse a cut of \$186 million for the CDC buildings and facilities?

Secretary THOMPSON. Senator, I was faced with a difficult situation, as you are, in this budget. The first priority is the war. The second priority is bioterrorism and we have got a 45 percent increase in there. I was allocated so much money, as is the case in the budget resolution and in your house and in the House of Representatives, and I had to make the tough decisions. Those are the decisions that are in here, and some of those have been changed by OMB. But I think that the budget request of \$184 million-I would have much rather had \$250 million, which is a figure that you and I have discussed many times before at CDC.

Senator SPECTER. You are putting in \$64 million.

Secretary THOMPSON. \$184 million. It is in the budget request, Senator.

Senator SPECTER. Let me ask staff to double-check it.

Well, I am told by Senator Taylor that the \$100 million is for Fort Collins. Of all the experts in the field, Mr. Secretary, she knows more than anybody. In fact, she knows more than everybody combined.

Secretary THOMPSON. Fort Collins is part of CDC and that is part of the building program, and we put in \$184 million.

Senator SPECTER. But that is not-

Secretary THOMPSON. Fort Collins is one of the laboratories.

Senator SPECTER. Fort Collins, Colorado?

Secretary THOMPSON. That is correct.

Senator Specter. That is a long way from Atlanta, Georgia.

Secretary THOMPSON. But it is a part of the CDC building program.

Senator SPECTER. I know. But those buildings in Atlanta are crumbling, Mr. Secretary.

Secretary THOMPSON. I understand that. You have been there; I have been there. There are three campuses of CDC in Atlanta and we are renting 24 other buildings. My objective, as yours is, is to consolidate them, get all those CDC employees in rented buildings into one of those new buildings.

Senator SPECTER. Mr. Secretary, they had an award ceremony down in one of the Senate buildings, Senator SC-6, last spring and they gave you an award for the money for CDC. Now, frankly, I had some doubts as to whether they should have given you that award because all that money came from Senator Harkin. I thought he should have gotten the award. Secretary THOMPSON. He probably should have. Senator SPECTER. Do you know that if—

Senator HARKIN. You started it.

Senator SPECTER. It is easier for me to say it should have gone to you rather than to me. It would be self-serving if I said it other than to Senator Harkin.

But the point that I am making here is that if you stand by this \$64 million instead of \$250 million, you are not going to get an award next spring. Do you realize that?

Secretary THOMPSON. I probably realize that full well. I also full well realize that I had to make some tough decisions, as you will, Senator, and we had to put the money in bioterrorism and the war effort first. This is what we were able to come up with.

Senator SPECTER. But the war on bioterrorism requires a building to do the research.

Secretary THOMPSON. That is correct.

Senator SPECTER. And if you do not have a building you are not going to be able to fight the war. But as long as you factored in the consideration that you would not get an award when you put this figure on, I will let you go now, temporarily, because my time is up.

Secretary THOMPSON. Thank you, Senator. Senator HARKIN. Senator DeWine.

# OPENING STATEMENT OF SENATOR MIKE DEWINE

Senator DEWINE. Thank you, Mr. Chairman. Welcome, Mr. Secretary. Good to see you. Secretary THOMPSON. Good morning, Senator. How are you.

#### FOSTER CARE AND ADOPTION ASSISTANCE

Senator DEWINE. Good morning. Let me turn your attention to Title 4.E and I want to talk a little bit about a proposed change that you have that is causing a great deal of concern in my home State of Ohio and I imagine around the country. HHS has announced a policy change prohibiting Title 4.E reimbursement for administrative and training costs associated with the placement of children in unlicensed foster homes. It is my understanding that this policy change was made due to what your Department deemed were inconsistencies with the old policy and a law that I was very much involved in writing, the Adoption and Safe Families Act, in particular a provision that I wrote that requires that the health and safety of the child always be paramount, be the paramount concern when deciding whether to remove a child from the home and in making placement decisions.

In my home State of Ohio, this change, Mr. Chairman, is going to cost about \$22 million in funding. It cannot be replaced anyplace else. To put it in simpler terms, what we have is many times grandparents, we have aunts and uncles. These are unlicensed foster care homes. What your rule would do is it would say we can no longer count those in regard for reimbursement for administrative and training.

We are not talking about direct reimbursement for putting them in the home. We are talking about just the overall counting them for training for the caseworkers, for the training and the administrative costs.

I just would ask you to look at that. I wrote the provision of the bill that apparently has caused the problems in the bureaucracy and it was not my intention to cause that problem. I will absolutely guarantee you this was the farthest thing from my mind, that your Department would interpret it that way. So I would ask you to take a look at that. It is just not our intention. Secretary THOMPSON. Senator, it is certainly not my intention to

Secretary THOMPSON. Senator, it is certainly not my intention to in any way adversely impact your district by \$22 million, and it is not our intention to do that at all.

Senator DEWINE. Well, Mr. Secretary, it goes beyond—I understand budget cuts, but this decision was not made on the point of view of budget cuts. I think we also understand the philosophy that we want licensed, we want licensed homes.

Secretary THOMPSON. That is right.

Senator DEWINE. We want that. But the reality is, for any number of reasons in the real world, an aunt or an uncle or a grandparent does not go through the process to have that home licensed. What we are simply saying is those kids still have to be monitored.

Secretary THOMPSON. Absolutely.

Senator DEWINE. And the State has still got the cost of doing that.

The direct result of this, it is not money. The direct result is we are going to have fewer caseworkers out there, and that is the last thing we want to do. So if you will look at it, if you could.

Secretary THOMPSON. Senator, I will look at it the beginning of next week and I will get back and have an answer to you within 10 days.

Senator DEWINE. I appreciate that. That is fine. That is all I can ask.

# FUNDING FOR POISON CONTROL CENTERS

Let me turn to another issue and that is the poison control centers. This is something that I have worked on for a number of years. We made great progress. We now have a national 1–800 number. We have had for the last few years a small amount of money that goes into the budget that is administered to help the poison control centers around the country.

The President's budget proposes \$21.3 million, which I certainly appreciate. The question I have is, though, that I notice that in the fiscal year 2003 budget the poison control center budget line was moved to your budget for purposes of supporting our Nation's bioterrorism preparedness effort. I do not have any problem with that. I think that one of the things that we need to understand is that the poison control centers in the event of a horrible disaster would be right there in the front line. We would be using them. We have to have them and, frankly, I think we have to invest a little more. I appreciate what your budget does provide.

My question, though, is will HRSA still administer the distribution of the grant dollars and will these dollars still be used for the purposes established under our original legislation?

Secretary THOMPSON. Absolutely. It is in the bioterrorism line, Senator, so that we are able to have a more comprehensive plan for all the bioterrorism dollars and be able to bring all of our assets together. In case of a tragedy, we will be able to bring all those assets to bear.

Senator DEWINE. Which I applaud.

Secretary THOMPSON. But HRSA will still be responsible for the \$21.3 million for giving out the grants. I know this is something that is of interest to you. You fought very hard for it. They do an excellent job throughout America and I for one applaud you and applaud the job that they are doing.

applaud the job that they are doing. Senator DEWINE. I appreciate it. One last comment and question. I was disappointed—I know you have tough budget decisions, but I was disappointed to see the graduate medical education account, the children's hospital graduate medical education, reduced from \$285 million, which is where we have been able to get it the last couple years, down to \$200 million. That is really going to impact on our children's hospitals, and so I just would bring that to your attention and I hope that we are going to be able to find the money here on Capitol Hill to restore that.

Secretary THOMPSON. The reason for that decision, Senator, is that in fiscal year 2000 this budget was started with \$40 million. Then it was raised to \$200 million and last year it was raised to \$285 million. We thought that \$200 million is still a huge increase from the base year of fiscal 2000. It goes from, instead of a stipend of \$72,000 per pediatric doctor in children's hospital, to \$52,000. We think a subsidy of \$52,000 is quite adequate.

Senator DEWINE. I appreciate that. The reality is that the only reason we are having this discussion is because of a quirk, what I call at least a quirk, in the law many years ago that children's hospitals were not included under the formula to begin with. We have to fight over this every year. It is not your fault, not my fault. It is history. But we have to fight over this every year because this has to come out of the discretionary funds and does not come into some sort of entitlement that just goes through and we never have to worry about or think about and it just automatically happens.

So I know my time is up and, Mr. Secretary, I appreciate your comments.

Secretary THOMPSON. Thank you, Senator DeWine, and we will look at that administrative function on the children.

Senator DEWINE. Thank you. I appreciate it.

Secretary THOMPSON. We will get back to you. Senator HARKIN. Thank you, Senator.

Senator Kohl.

# OPENING STATEMENT OF SENATOR HERB KOHL

Senator KOHL. I thank you very much, Mr. Chairman.

Secretary THOMPSON. Senator, my friend, how are you.

Senator KOHL. Good to see you.

Secretary THOMPSON. Good seeing you.

Senator KOHL. Governor, there is no doubt that today one of the highest priorities is obviously winning the war on terrorism abroad while keeping Americans safe at home. But we also have the continuing responsibility of meeting the health and human services needs of our Nation, as you know. I am concerned that in some areas the President's HHS budget falls short in this regard and I hope that we can work together to address those problems over the coming months.

# BACKGROUND CHECKS FOR NURSING HOME WORKERS

As you know, on Monday the Aging Committee held a hearing on abuse in nursing homes. We heard, not for the first time, stories of patients being beaten, raped, and even killed by employees who are supposed to care for them. While the vast majority of nursing home workers do a great job, it only takes a few to terrorize patients.

I have introduced legislation to create a national registry of abusive workers and also to require the FBI to conduct a criminal background check before hiring an employee. The bill is supported by both patient advocates and the nursing home industry. The HHS Inspector General's Office, GAO, local prosecutors, and State officials have all called for a national background check system.

I would like to hope that you and the administration will be supportive of this legislation. I know if you will we will have an outstanding chance this year of getting it passed. I would like to solicit most respectfully your support for this legislation.

Secretary THOMPSON. Senator, first let me point out unequivocally that I personally support your legislation. I think it is needed and I think it would be a good step forward.

Short of that, what we have done through CMS is put in place the Nursing Home Compare web site where CMS will publicly report nine quality measures in six States beginning April 15. We are trying to increase the quality in nursing homes, and the consumer tool allows beneficiaries to select homes for comparison by city, State, county, or facility name. The six States participating in the pilot are Rhode Island, Colorado, Washington State, Maryland, Ohio, and Florida.

We also in January started posting and we will have this data up so that individuals will be able to look at the web site at CMS, to be able to determine nursing homes in their particular States on the information that we received, the information that we get, the kinds of quality care as well as some of the problems that you have indicated, and we are hoping that people will look to this web site when they choose the correct nursing home, because you know as well as I do there are excellent nursing homes out there and some that are not measuring up and we want to get those and, if possible, improve their quality, so that every person that goes to a nursing home receives the kind of care that you and I would like to receive.

Senator KOHL. Does that mean you would support my legislation?

Secretary THOMPSON. Yes, I said that at the beginning. But short of that, in the meantime, we are proceeding through administrative functions, while you are working on your legislation, to do other things to improve the quality.

Senator KOHL. Well, I thank you. I thank you for what I believe will be your support. I think that is great.

Secretary THOMPSON. Thank you.

# FUNDING FOR STATE SURVEY AGENCIES AND OMBUDSMEN

Senator KOHL. Governor, at last year's hearing we talked about the importance of giving State survey agencies enough funding so that they can inspect nursing homes, handle complaint investigations, and make sure residents get safe and quality care. It is also important that the State long-term care ombudsmen have enough resources to handle the increasing number of nursing home complaints. Each year I have fought to increase funding for these programs and so I was disappointed to see that the President's budget actually cuts survey funding by \$6 million and flat-lines the ombudsman funding, despite the fact that complaints have jumped quite a bit last year.

It is clear to me that we need to increase and not decrease our efforts to make sure all nursing home residents are safe. I ask the question, how can we expect States and ombudsmen to carry out these critical duties, which I know you regard as important, while at the same time decreasing their funding? Secretary THOMPSON. All I can tell you, Senator, is that, number one, we had so much money. We had a 45 percent increase in bioterrorism to \$4.3 billion. We increased NIH by \$3.7 billion. Everything else we had to make some tough decisions, and those tough decisions are reflected in this budget bill.

We are also trying to do things other than the ombudsman pro-gram and the survey program. We are putting information up on the web site so people can find nursing homes and have an opportunity to compare nursing homes and the quality of care that patients are receiving in those nursing homes.

I know that is not the answer you would like, but it is as candid as I possibly can be.

# CHILD SUPPORT PROPOSALS

Senator KOHL. Okay, I appreciate that.

The last question, Governor. I would like to thank you for what I am sure was your influence in making sure that the President's budget included child support distribution reform. You and I worked together on this issue in Wisconsin for many years and with great success.

Secretary THOMPSON. Yes, we did.

Senator KOHL. Our State of Wisconsin has had this policy due to your efforts since 1997. As you know, Wisconsin has seen great results with the program. That is why I myself sponsored legislation that would let all States follow the example that you set up in Wisconsin.

I was pleased to see that the President's budget included similar child support proposals. But even though we are all in agreement on this, we still face a tight budget this year. Can I hope that you will be able to get this program enacted on a national level this year?

Secretary THOMPSON. I am hopeful, because it is the right thing to do for the Nation. But we have a lot of things that are on our plate, Senator. All I can tell you is I will try.

Senator KOHL. I thank you so much. I thank you for being here today. I cannot help but think as I look to you how important you have always been to the State of Wisconsin, to the people of Wis-consin. Any chance you will ever return, Governor?

Secretary THOMPSON. Absolutely, Senator, without a doubt. Thank you so very much and good luck to the Bucks. Senator KOHL. Thank you.

Secretary THOMPSON. Thank you, sir.

# MEDICARE REIMBURSEMENT RATES

Senator HARKIN. Mr. Secretary, I just have a couple more questions I would like to propound to you. One, as I mentioned, one of the biggest obstacles in affecting rural States' ability to provide services is the discrepancy in Medicare payment rates. Let me draw your attention—I gave you that chart at the desk, I think; did I not?

Secretary THOMPSON. You did not give it to me. You showed it to me, Senator. I do not have it in front of me, but that is all right. Senator HARKIN. Well, here is a big one.

Secretary THOMPSON. I can see that, almost.

Senator HARKIN. It is a big one. What this is is the variation among the 50 States.

Secretary THOMPSON. I bet Iowa is down at the bottom.

Senator HARKIN. I bet you are right. That is a very good guess. Here we are.

Fifty States, from \$7,336 per beneficiary in Louisiana to \$3,053 in Iowa. Now, our people pay the same taxes exactly as the people in Florida, Louisiana, New York, Texas, Connecticut, Pennsylvania, Rhode Island, et cetera. We pay the same. Why are we penalized so much?

Just look at Iowa, and here is Nebraska. Iowa gets \$3,053 per beneficiary. Nebraska gets \$4,856 per beneficiary. What could possibly be the reason that Nebraska would get 63 percent more per beneficiary than Iowa?

This variation is simply unjustifiable and unacceptable. Now, I understand there might be some variances, there might be some reasonable differences in cost someplace. But differences of this magnitude are just unacceptable.

It has been estimated that Iowa every year, just if you took the national average, what we lose if we were just at the national average is about \$1 billion a year. We are being penalized in the State of Iowa. It is \$1 billion a year, and people wonder why we are having trouble getting doctors in our rural areas. They wonder why our small hospitals are closing. They wonder why other health care professionals like nurses and nurse practitioners and others are leaving.

Yet in Iowa we have the second highest proportion of elderly over 85 of any State in the Nation. I think we are fourth, in proportion of elderly over 65. And it is the small rural hospitals that are burdened the most with Medicare patients, the disproportionate share.

I am told that in some of these States above the national average line people get three or four times the doctor visits for the same illness, compared to low payment States. How do I tell my people in Iowa that this is somehow fair and this is equitable, and they pay the same taxes?

Secretary THOMPSON. You cannot.

Senator HARKIN. I cannot say that.

Secretary THOMPSON. You cannot.

STATUTORY CHANGES TO REIMBURSEMENT FORMULA

Senator HARKIN. My question is what are we going to do about it?

Secretary THOMPSON. Change the law. The law requires us—we are implementing the law as it is. The biggest difference, Senator—

Senator HARKIN. Has the administration proposed a change in the law?

Secretary THOMPSON. No.

Senator HARKIN. Well, will the administration propose a change in the law?

Secretary THOMPSON. I will help you.

Senator HARKIN. Well, I hope so.

Secretary THOMPSON. I will help you a lot.

What the biggest difference is, 71 percent of the difference is in the wage index. When the law was set up it was based upon the wage index, 71 percent. Twenty-four percent on top of the 71 percent is based upon utilization. So 95 percent of the rate that goes into the Medicare reimbursement is based upon the wage index and the utilization.

In Iowa, when the law was passed Iowa's wages were lower, as is Wisconsin, as is Nebraska.

Senator HARKIN. Wisconsin is right here.

Secretary THOMPSON. Wisconsin is not doing much better. Senator HARKIN. Not doing much better.

Secretary THOMPSON. Not much better, but better.

And the utilization. Your State is healthier, evidenced by the fact that it has the second highest proportion of individuals over the age of 85. The utilization—people in Iowa and Wisconsin do not go in and use the hospital and the clinics as much as other people do in the large urban areas. I guess it is one of the things that we grow up with. You know, we suffered more.

Senator HARKIN. Maybe. I do not know.

Secretary THOMPSON. I do not know what the reason is, but the utilization is down, and it has been documented that it is down. When you add 24 percent, which is part of the factor for utilization, 71 percent for the wage index, it is 95 percent and that is the difference.

The law has got to be changed. We do not have the power to change the law out there. I wish we did because I think there needs to be a look at that. Hopefully, this year on a bipartisan basis we could sit down and do something to strengthen Medicare, change the reimbursement formula, put a prescription drug in there, and come out of here with a bipartisan bill, and that is my dream. But I do not know if that is entirely possible.

Senator HARKIN. Well, we will get into prescription drugs another time. But this has gotten to the point now that we cannot just say, well, maybe next year or the year after or the year after. We have got to change this right away.

Now, as I said in my opening statement, Senator Craig and I have a bill in that would basically say no State over 105, and State under 95. So it would still leave a 10 percent variation.

Secretary THOMPSON. Yes, it would.

Senator HARKIN. For various things, but it still would not leave 100 percent variations.

Now, two things I would just respond to you. You are right on the wage and the utilization. I am doing some research to find out when these wage things were set and what was the rationale for it. But there is this myth that somehow it is cheaper in a rural area to provide the same-

Secretary THOMPSON. It is not.

Senator HARKIN. Of course. You know that. You know that from Wisconsin.

Secretary THOMPSON. I come from a big city compared to yours. My city is 1,500. Yours is 150.

Senator HARKIN. Okay, right.

Secretary THOMPSON. But we both know the needs of small rural hospitals.

Senator HARKIN. As I said, they buy in small quantities, they pay more money.

Secretary THOMPSON. Yes.

Senator HARKIN. In terms of wages, though, if they do not pay their nurses and their doctors and their administrators equivalent to what the city will pay, they lose them. So what happens is it just degenerates down, and you are losing a lot. That is the wage myth.

Now, the utilization myth is another thing. The utilization goes down because what is happening is the hospitals and the doctors are not taking any more Medicare patients. They are saying, we cannot take any more because this is charity work, it goes on our fee for pay people or managed care people or insurance people. That is where it goes and they are picking up the burden, and they cannot pick it all up.

So what happens is if the utilization rate was low at one time, it just keeps getting lower and lower and lower and lower as more and more hospitals say, we cannot take any more Medicare patients.

Secretary THOMPSON. And that impacts on the reimbursement formula.

Senator HARKIN. That impacts the reimbursement. So it just keeps spiraling down.

Secretary THOMPSON. We have to modernize it.

Senator HARKIN. I would hope that—again, I am looking forward to some legislation. We have our bill in. If you do not like that, come up with something else. I am not saying that what Larry Craig and I put in is the absolute way we have got to go. Maybe there is another way. If there is—I would like to work with you and this administration to address this inequity that we have here.

Secretary THOMPSON. Senator, I want to work with you, because when I was Governor I used to complain like you are complaining. Maybe not as eloquently as you are, but I complained vociferously the fact that Wisconsin was not getting reimbursed properly. I think that hopefully we can work together and come up with a change. But it is going to be difficult.

Senator HARKIN. Well, it may be difficult, but it is grossly unfair, grossly unfair, to the people that live in these States down in here, grossly unfair that they have this kind of discrepancies. Again, I look forward to working with you on it, but I just wanted to make that point.

Yes, you may go next, and my time is out.

Secretary THOMPSON. Thank you, Senator.

Senator HARKIN. Senator Specter.

Senator SPECTER. Mr. Secretary, just a few more questions because other of our colleagues have arrived. The budget, \$2.982 billion, almost \$3 billion, was added for homeland defense in the Department of Defense supplemental.

Secretary THOMPSON. The supplemental last year.

Senator SPECTER. Now, I do not know quite how all the arithmetic works out here, but it seems to me that in a context where the increase for HHS is only \$2.3 billion that homeland defense really ought to be a part of the Department of Defense budget as Congress legislated putting the \$3 billion in the DOD, Department of Defense, supplemental appropriation bill last year. If that money were charged to defense, which has an increase of about \$28 billion for a total budget-we had those hearings in this room last weekaround \$390 billion, we would have more leeway in the HHS budget.

That would enable us to accommodate some of these cuts, like graduate medical education. There was a real struggle to get it up to \$285 million and it is just not adequate to cut it by \$85 million. Or the community service block grants or the chronic disease prevention. I know your position is you had to make hard choices and I understand that, but I would ask for your assistance in trying to get OMB or the administration generally to acknowledge that this money for homeland defense ought not to come out of the domestic programs, which in effect it does.

Will you help us on that?

Secretary THOMPSON. Nobody has ever asked that question of me before, Senator.

Senator SPECTER. That is the first time I ever asked a question nobody else had asked.

Secretary THOMPSON. Are you talking about the \$4.3 billion that comes-

Senator Specter. Yes.

Secretary THOMPSON. The problem with it is that most of the money actually goes into research. Nine hundred million dollars of that goes into NIH for new research for vaccines for hemorrhagic viruses, botulism, plague, and a new anthrax vaccine. So that money definitely is-and \$1.1 billion, \$1 billion of that, goes back to the States through CDC to develop a really strong local and State public health system, something that we have disinvested in in the past. We have a great opportunity, Senators, to build a real vibrant, strong, local and State public health system.

Then there is \$518 million of that that goes into hospital preparedness and that is all really Health and Human Services, so I cannot imagine the administration or the Department of Defense being willing to take that as a responsibility.

Senator SPECTER. Well, I am all for that, Mr. Secretary, but not if it involves cuts in children's graduate medical education or community service block grants. Those funds are in response to 9-11 and they are an important response, but they are really a Department of Defense response, just like the money we added in in the Department of Defense supplemental last year. Well, take a look at that.

My time is about to expire and I want to cover one other subject with you.

Senator HARKIN. I just wanted to, if the Senator would just yield so I could buttress what he is saying.

Senator SPECTER. You have to stop the clock. Senator HARKIN. We will stop the clock.

Senator Specter is right on target on this. As I look at the bioterrorism overview, there are a number of items in there that rightfully should be in defense. When you are talking about anthrax for \$18 million, they are already doing that. These all add up. You may say, well, it is only \$18 million.

Secretary THOMPSON. I did not hear that, Senator. I am sorry.

Senator HARKIN. The anthrax vaccine. I am saying that the Department of Defense is already doing a lot of that.

Secretary THOMPSON. It does.

Senator HARKIN. So I think that ought to be in their purview. You have got down here command, control—

Secretary THOMPSON. I just would like to add, I argued that the \$250 million on the purchase of anthrax should be under Department of Defense. I lost that fight. I lost that battle.

Senator HARKIN. Well, let us consider that again here in our Appropriations Committee perhaps. That is where we have got to argue it again here, Mr. Secretary.

National security and early warning surveillance, \$10 million. Biological detection and assessment teams. We have got \$3 million in here for the Olympics. I really do not think that should come out when your budget proposes cutting community service block grants and child care.

Secretary THOMPSON. Well, the \$3 million for Olympics actually really rightfully was used because we had to inspect all of the food. We had a lot of our doctors and health officers out there. We had 400 personnel working during the Olympics.

Senator HARKIN. I will give you that one. But there are a lot more in here I think that we could pick out.

Secretary THOMPSON. I am more than happy to work with you, Senator.

Senator HARKIN. Thank you very much.

Senator Specter.

# NIH STEM CELL REGISTRY

Senator SPECTER. The last question I have for you, Mr. Secretary, relates to the NIH stem cell registry, which now identifies 78 stem cell lines which were purportedly in existence at 9 o'clock on August 9, the magic time line. What I would like you to provide for the record is how many stem cell lines there were on August 9 at 9 o'clock, which is the bewitching hour set by the President, and what level of development these stages are, in development and characterization, and how many of these stem cell lines are immediately available to U.S. researchers, because that issue has been put on the back burner with a lot of concern immediately after the President's speech on August 9 that there were insufficient research lines available.

I would like to see an update on that, because when our focus shifts from 9–11 we are going to come back to that question as to whether it is adequate. We had 64 Senators sign letters that there ought to be more NIH participation in research on stem cells and another 12 were in agreement but would not put it in writing, which was a factor in leading the President to make the changes he did. There are many of us who feel that, while those changes were helpful, that they are not enough.

So if you would update this so we have specific information on what are the lines now available for research, we would appreciate it.

Secretary THOMPSON. Senator, there are 78—there were 62 the night that the President made his announcement. There are 78 today that meet the requirements. But of the 78, 70 are distinct.

The additional 8 above the 70 are derivations and further characterizations of the 70. So actually I think you should really look at 70.

Senator SPECTER. Are you saying that those 70 lines are immediately available to U.S. researchers?

Secretary THOMPSON. They are all on the registry. I do not know if they are all ready for research. I think they are. I can get that information for you.

Senator SPECTER. If you get that information, I would appreciate it.

Secretary THOMPSON. I would be more than happy to. Did you want to know about the applications that we have in?

Senator SPECTER. Yes.

Secretary THOMPSON. We have right at the present time—the registry was posted November 7.

Senator SPECTER. Mr. Secretary, would you provide that for the record, because other colleagues are waiting to question.

Secretary THOMPSON. Sure, I would be more than happy to.

[The information follows:]

## STEM CELL REGISTRY

The 78 lines that are listed on the Registry are in varying states of availability. The WiCell agreement makes the lines from Wisconsin available, and one is being shipped. Infrastructure grants have been made available to help all sources increase their ability to fill requests for lines. We are making the first such awards shortly. The availability of lines other than WiCell depends to some degree on resolution of agreements between WiCell and the other sources. It appears that such negotiations are proceeding and will soon result in other lines becoming available.

Senator SPECTER. Thank you.

Senator HARKIN. Thank you, Mr. Secretary.

Senator Murray.

Senator SPECTER. Thank you.

Senator HARKIN. Senator Murray.

# OPENING STATEMENT OF SENATOR PATTY MURRAY

Senator MURRAY. Thank you very much, Mr. Chairman.

Mr. Secretary, good to have you here today.

Secretary THOMPSON. Thank you, Senator.

Senator MURRAY. I walked in as we were having the discussion on the regional inequities in the Medicare reimbursement and wholeheartedly support what Senator Harkin was showing us in terms of the regional inequities. This is not just a rural health problem or a rural reimbursement problem.

Washington State is 45th on the list and the reason we are 45th is because we had a very efficient delivery system before this was enacted and we are being penalized for that. So we are being kept down at the bottom, and seniors in my State are furious about this. They feel very strongly that their ability to have good care should not depend on where they live in this country.

But it certainly is, when you look at this chart—and if you live in one of the States on the bottom here and you are a senior citizen, you are looking at doctors leaving your State, as we are in ours, health care facilities closing. They do not think they should move to, much as they love my friend Senator Landrieu, move to Louisiana or Florida or New York in order to have better care. So we have to deal with this issue and I hope that you look at Senator Harkin's proposal and work with all of us on this very, very critical problem.

Secretary THOMPSON. Senator Murray, if I could quickly respond. I want to. I fought this fight when I was Governor. I have discussed this with you before. I have discussed it with Senator Harkin. The law is the law. We cannot change the law in the Department of Health and Human Services. The law says that you base the reimbursement on the wage index, which is 71 percent of it, and utilization, which is 24 percent.

Now, it should be upgraded, but we cannot do that without the change in the law, and I want to work with you. I think we need to do that. The problem is that when you change, increase your reimbursement, does that mean that the reimbursements for Louisiana are going to go down? I do not think Senator Landrieu is going to be too excited about voting for that.

Senator MURRAY. Well, if there is additional money it should go into the States at the bottom.

Well, let me move on and ask you about the upper payment limit.

Secretary THOMPSON. Yes.

Senator MURRAY. In Washington State that is used to provide health care services to the most vulnerable. It is not about supplanting dollars. It is not about redirecting funds. It really is about providing health care. I am very concerned that the administration is looking to roll back funding on that.

It is my understanding that the administration's efforts on UPL are intended to improve the integrity of Medicaid and to ensure that these funds are not being misused. I would just tell you, if you have any concerns about how Washington State is using this money I would be more than happy to sit down with you and my Governor and to walk through this. But what I want to remind you today, that Washington State for years has been ahead of what most of the States have in this country in expanding access for children.

In 1994 my State provided coverage up to 200 percent of the FPL. That is better than some States are providing now even with CHIPS. So we have really gone out of our way to do that, and pulling the rug out from Washington State right now when we are facing a billion dollar shortfall really is going to jeopardize the care we can provide for low income families and particularly children in the State of Washington.

So Mr. Secretary, if you could respond and just let me know how you propose States like Washington will be able to meet their obligation under this program.

Secretary THOMPSON. The upper payment limit has been something that has been a very controversial subject, that has been abused in the past, and the administration feels that 100 percent is 100 percent and you should not be reimbursing above that 100 percent. That is what the proposed rule is. Congress passed the law I think last year, or 2 years ago—it was before I came out here, 2 years ago—that has allowed for a declining period for various States. I do not know where the State of Washington is. I know the State of Illinois and California have a glide path of 8 years. I do not know where Washington is.

Senator MURRAY. Ours is as well.

Secretary THOMPSON. What?

Senator MURRAY. We are as well.

Secretary THOMPSON. You have got a glide path of 8 years as well?

Senator MURRAY. But cutting the rug out from underneath us right now is going to create a critical impact on our ability to provide—

Secretary THOMPSON. The glide path is still in the law.

Senator MURRAY. But the reimbursement is going to be pulled out from under us this year, it is my understanding.

Secretary THOMPSON. It is my understanding that the glide path is still in place.

Senator MURRAY. Mr. Secretary, what I would like to suggest is that perhaps you and my Governor and I can sit down and walk through this.

Secretary THOMPSON. Absolutely.

Senator MURRAY. Because it is really a critical challenge.

Secretary THOMPSON. Your Governor has been in and I will be more than happy to see him again. In fact, he was in I think last week and talked to me on a waiver. I think he said that you supported it.

Senator MURRAY. No, he actually said that he was going to talk to me about supporting that.

Let me ask one other quick question. I know that this is a concern I share with Senator Landrieu. She may ask about it as well. But I am concerned about the TANF proposal that seeks to expand the number of hours a week that a beneficiary must work up to 40 hours, but the President's budget does not provide any funding for child care. The biggest and most costly hurdle for women in meeting these work requirements is funding safe, affordable, dependable child care.

I am really concerned that the additional work requirements will make it almost impossible for TANF beneficiaries to provide safe, secure child care unless we increase those dollars. What is your administration going to do about that?

Secretary THOMPSON. Basically, Senator, your question is right on target because there is no question that child care has got to be appropriate and it has got to be funded in order to allow for individuals to leave welfare. This was one of the things that I argued for way back when.

But I also argued when I was the Chairman of the National Governors Conference and we negotiated the first TANF proposal that if Congress would level fund we would make do. This administration is continuing on with that promise even though there was a lot of pressure to reduce the \$16.5 billion, lowering that, because the caseload has been reduced by one-half.

There was the argument made that we should only put in \$8.5 to \$10 billion rather than the \$16.5 billion. I argued that we should maintain the commitment of \$16.5 billion so we can go to the next step.

We are also putting in the supplemental funding, which is very helpful to a State like Louisiana, \$314 million. We are putting in \$350 million for going from independence, dependence, and giving them a 1-year coverage on health care, which is extremely important, plus a contingency fund of \$2 billion.

All of these things add up to well over \$19 billion when the caseload is in half. As far as child care, we maintain level funding, \$2.7 billion in mandatory funding, \$2.1 billion in discretionary funding, for a total of \$4.9 billion. We also allowed in the TANF proposal the flexibility for States to use up to 30 percent of their TANF money for child care and then also taking money out of the SSBG, the Social Service Block Grant, for child care.

You have got an extreme lot of flexibility to develop a good program. So even though it is level funded, we think the discretion is there, and with the caseload one-half of what it was we felt that it was adequate funding, considering the overall impact to the budget where we had to put a 45 percent increase into bioterrorism out of our budget.

Senator MURRAY. Well, thank you very much, Mr. Secretary. I appreciate your response.

Mr. Chairman, my time is up, but I would just say if we are going to expand the number of hours that we are requiring beneficiaries to work we are going to have to increase the dollars for child care or we are simply putting a tremendous burden on women out there, and we are going to increase the number of kids who are in unsafe conditions in this country.

Senator HARKIN. Senator, you are absolutely right, and that is why—we have got to do something with this budget on child care. It is totally inadequate. Hopefully we can work something out on it.

Senator Landrieu.

# OPENING STATEMENT OF SENATOR MARY L. LANDRIEU

Senator LANDRIEU. Well, thank you, Mr. Chairman.

Let me begin by just following up and welcome Mr. Secretary.

Secretary THOMPSON. Thank you, Senator.

Senator LANDRIEU. I apologize for being late. I have had four meetings like this already this morning.

Secretary THOMPSON. It did not bother me that you did not come—

Senator LANDRIEU. I am going to try to ask one easy question. But let me start with the difficult and I think very appropriate one of Senator Murray. Are you suggesting, then, that because the Federal Government has lived up to its commitment of level funding, that the States will then have to find savings by their dropping caseloads to increase their block grant for child care? Is that what you are suggesting?

Secretary THOMPSON. No. We put a lot of flexibility in there for governors and for State legislatures to do. One of those was, under the previous TANF proposal it was only allocated on a year to year basis, so the States had to spend all that money or had to obligate that money 1 year at a time because they were fearful the Federal Government would pull back. We are now allowing for the States to obligate their allotment over the 5-year period, so that they will have much more flexibility.

We are also putting a waiver in here that is going to allow for the States to have an extremely lot of flexibility for developing a good program from education and so on.

The third thing is it is not 40 hours a week. It is 40 hours, 24 hours of work. Sixteen hours can go into education, can go into the job training, job seek, or into alcohol or drug treatment and rehabilitation. We think there is flexibility there for the States to meet their obligations.

Senator LANDRIEU. I appreciate that. I only suggest that flexibility without money is no flexibility at all. So I am trying to understand if your argument is that we are going to fund the welfare basically reform effort at the same level, therefore all States, as your caseloads are reduced, you are going to have to be creative in increasing your child care block grants, but you are going to have to do that on your own by efficiencies? Because if that is the message, we need to take that to the governors and to the locals and see if they buy it.

They very well may be able to. You were a Governor and a very effective leader in this area. Perhaps we can convince our States that that is the way those child care block grants are going to be funded in the future.

But I am not sure they would agree with that approach. I just do not know. I will speak to my Governor and my legislature immediately about it, because we have got to—if we want people to go to work, particularly women, we also want them to be good at raising their children and be effective and be nurturing and loving then we need to meet them more than half way and help them with these expensive child care arrangements, which I say before this committee again, Mr. Chairman, it has been a while since you have raised children. I am raising them now, one that is 10 and 5. I had quite a shock when I came to Washington to put Mary Shannon in day care and it cost me \$7,000 a year.

Luckily, I can afford that. But I can think of a lot of women that work in this building that cannot afford that, let alone women who do not have the kind of jobs, et cetera. So point made.

Let me just thank you for your help—

Secretary THOMPSON. If I could just quickly add. You are absolutely correct if the caseload was growing. But the caseload is declining, and so level funding should with the decline, should be sufficient.

Senator LANDRIEU. Should be adequate. So we will hear from our governors about their counter to that about why they are not able to increase their child care block grants by 20 or 30 or 40 percent, which would really help us.

Let me congratulate you for your focus on this new scholarship program for foster care and the help that this administration has been to the 25,000 children, a small number relative to the whole population, but I think we have a special obligation to these kids, because the system took their families, original families, away for good reason—neglect and gross abuse, and danger—but we failed to give them another family. So if we could not get them another family, we need to give them at least a chance to create a family of their own. That best chance is to give them a college education or training.

So I want to thank you and would only urge you-

Secretary THOMPSON. I want to thank you, because you have been a leader in this and I applaud you. You and I spoke together and I was amazed at your passion on this subject and your knowledge. I want to thank you.

Senator LANDRIEU. Well, I appreciate that. But I want to work with you closely to make sure that the States—and Mr. Chairman, I want us to focus because this is a new program that is standing up—to make sure that the States are not siphoning off this money even for well-intentioned middlemen and middlewomen and keeping the money, as opposed to getting it to these young people, the same age as people, young people who put on the uniform and are fighting for us in Afghanistan, 18, 19 year olds. They are responsible enough to take that money, use it for college, etcetera.

My point is there is a great idea floating that is bipartisan called IDA's, and I think you are going to be leading that, Independent, Individual Development Accounts. It is hooked to the new charity initiative, something that Senator Lieberman and Senator Santorum have championed and the President has endorsed it.

My point on this is, and for the chairman too, that there is money in the budget to set up these IDA's that is restricted to buying a home, retirement, and starting a business. I want to suggest that we expand it to allowing families or individuals that qualify to put a down payment or to purchase an automobile, the reason being that it connects to our welfare to work. People need child care and transportation to get to work, and if we link that, Mr. Secretary, by just expanding the parameters of that, you could be I think very successful in helping us to lead a more effective way, because with our policies on transportation, as much as we talk about, Mr. Chairman, mass transit, we do not have a whole lot of it.

For poor people who are living in suburbs, if they do not have access to an automobile they cannot access the jobs. There is a disconnect from where the jobs are and where they might live. We keep saying we are going to provide buses and trains. We do not do a good job of it. So since we decided automobiles is the way to go, then let us help poor people to purchase an automobile—it could be used, there could be restrictions—to get them the vehicle to get to work.

So I am going to send this to you in a letter.

Secretary THOMPSON. I would appreciate that.

Senator LANDRIEU. I have already approached Senator Lieberman on the idea and I am going to send something to the President on it.

My final point is on faces of adoption. We have a very exciting technology that was developed in the private sector, to use the technology to try to put a face and a voice now on a computer that can help a family that is looking for a child to find one that they might be willing to raise. It is very cost effective. It is the only hope that these children have that are lost in this foster care system to really try to find a family. For 4 years, Mr. Chairman, we have funded in this committee some money to help do this. Yet, while we have 100,000 children who are available for adoption, we only have 6,000 of their pictures up on the Internet. My question is why are we moving so slowly? If you need extra funding, maybe we can come up with it.

Do you have any ideas or are familiar with this?

Secretary THOMPSON. No, I am not, but I will be by next week. Senator LANDRIEU. Well, can I send this too, in writing, and be-

come familiar, because this is a great opportunity for us to do something for foster care children in this country, but show a model to the world about how using technology in appropriate ways, not exploiting children or exploiting emotions, but to help these kinds find a home.

I will end with, as Phil Gramm said, who is my advocate with me on this: "Every child that we can place out of foster care into a family willing to adopt them is not only the most wonderful thing to do for the family and the child, but it saves the taxpayers a lot of money when we do that." I know you know it.

Secretary THOMPSON. But it is the right thing to do.

Senator LANDRIEU. It is the right thing to do. So let us make the small investments that really make this work.

I thank you, Mr. Chairman.

Secretary THOMPSON. I want to work with you on both those subjects.

Senator LANDRIEU. Thank you, Mr. Secretary.

Secretary THOMPSON. Just send me the letter and I will be more than happy to respond.

Senator LANDRIEU. Thank you.

Secretary THOMPSON. Thank you.

Senator HARKIN. Thank you, Senator.

Before you leave, Mr. Secretary, I just want to respond a little bit to what Senator Landrieu pointed out about the need for the child care money and, as you pointed out, that because of the declining caseload, we will have more money in TANF to be able to do some of those things. We will have to take a close look at that because the caseload now—what we have done is we have gotten rid of the easy cases. The easy cases have gotten off welfare.

What is left are the hard ones, and these are the people that maybe in a lot of cases are not going to get off welfare. So they have got drug problems, they have got a lot of other problems. They may have medical problems, disability problems, whatever. They have got a lot of different problems.

So they are the hardest to serve. So I am not certain, just off the top of my head, I am not certain you are going to be able to find much savings there to be able to use for child care. As I said, the easy ones are gone. Now we are down to the hard cases. I think trying to look for savings there, just to make that connection, is not necessarily valid. We have to look at that.

Secretary THOMPSON. Senator, I made the same argument when I was Governor.

Senator HARKIN. Well, wait a minute. Then how come I am making this argument to you?

Secretary THOMPSON. Just history revisited. Senator HARKIN. I guess so. Well, I am glad you are where you are, Mr. Secretary. I think you are doing a great job and I really appreciate the openness and all of the work you have done with our committee, and your staff has been great and very accessible and we appreciate that very much.

Secretary THOMPSON. Thank you.

Senator HARKIN. Thank you, Mr. Secretary.

# ADDITIONAL COMMITTEE QUESTIONS

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:]

# QUESTIONS SUBMITTED BY SENATOR TOM HARKIN

#### HIV/AIDS SERVICES THROUGH RYAN WHITE

Question. This is the second year the Administration has not requested an increase of the Ryan White CARE Act Services programs. The Centers for Disease Control and Prevention (CDC) has just reported that an estimated 900,000 Americans are currently infected with HIV/AIDS. CDC further reports that about a third of these individuals do not know they are infected, and another third know their status, but are not receiving care. What is the rationale for maintaining these programs at the fiscal year 2002 level when CDC has just reported that the number of patients who require these services is higher than we expected? What is the impact of limiting these funds in light of medical inflation on each of the Ryan White CARE Act Titles?

Answer. The fiscal year 2003 budget maintains funding of the Ryan White Care Act at the historically high level of \$1.9 billion. Ryan White activities have increased by over 65 percent since fiscal year 1998. At this level, HRSA will continue in providing services to an estimated 500,000 persons. To further the Administration's comprehensive efforts to ensure services to individuals living with HIV/AIDS, the fiscal year 2003 President's Budget requests \$15 billion (more than \$950 million above fiscal year 2002 Enacted) government-wide for domestic prevention, treatment, care, and research activities.

# HEALTH PROFESSIONS REDUCTIONS

Question. The Health Professions Education programs authorized by Title VII of the Public Health Service Act have long served the Nation well in producing quality health care providers in every discipline. For almost 40 years, these programs have provided professional health training opportunities for poor and disadvantaged Americans to enter the medical and allied health fields. Over the years, specific Health Professions programs were established to meet the needs the market could not fill. These programs have been particularly effective in ensuring training opportunities for minority individuals and individuals at minority institutions. Your data has shown that these individuals have filled gaps in the supply chain in areas where other individuals have chosen not to practice.

There are still great needs throughout the country, particularly in underserved frontier and rural areas where Americans lack sufficient health providers. Why does the Administration continue to propose drastic cuts in these Health Professions Education programs? Does DHHS feel that there is no longer a need for increasing the pool of qualified health providers through these programs? Is there no longer a commitment to assuring minority access to Health Professions Education? Answer. The goal of our Health Professions programs is to increase services to the

Answer. The goal of our Health Professions programs is to increase services to the underserved. Over the past two decades, we have spent \$6 billion on Title VII health professions grants and our track record on performance is not good. Based on data reported in the HRSA Government Performance and Results Act Annual Performance Plan, only 30 percent of individuals who participate in the Title VII programs go on to practice in medically underserved areas. However, with the Health Center program and National Health Service Corps (NHSC), we know that 100 percent of these funds are going to provide services to the underserved. Of NHSC clinicians who fulfilled their service commitment in CY 2000, 75 percent chose to remain in service to the underserved. In addition to serving underserved minority populations, the NHSC provides scholarships and loans to providers from disadvantaged and racial/ethnic minority groups. In fiscal year 2001, approximately 33 percent of NHSC Scholars and 29 percent of NHSC Loan Repayment participants were from disadvantaged and racial/ethnic minority groups. The National Institutes of Health also funds medical education for students from disadvantaged backgrounds. We believe by expanding these effective programs we will increase the number of health care providers serving underserved populations, including minorities.

# SECURITY

Question. Last year this Subcommittee held several hearing regarding bioterrorism preparedness and the public health infrastructure. We heard from many witnesses who spoke about how unprepared this Nation was against a bioterrorist attack. Subsequently this Subcommittee provided over \$2 billion for bioterrorism preparedness in a supplemental appropriations bill because we felt the additional money was urgent and was needed sooner, rather than later. I'm glad to see that your budget request continues this funding.

However, some of your request is for security improvements and construction of biohazard labs at NIH and CDC. Shouldn't some of these important needs be addressed now? This appropriations bill won't be passed until later this year—could some of these things be included in this year's supplemental?

Answer. The most critical security and facilities construction needs were addressed in the fiscal year 2002 Emergency Relief Fund (ERF). The supplemental funds provided through the fiscal year 2002 ERF will allow NIH to increase support for counter-bioterrorism research, provide for the construction of a high containment BSL-4 research facility, and support upgrading current BSL-3 laboratories to handle select agents for the NIH. Additionally, the ERF will provide funding to enhance NIH security measures that are necessary for the protection of its staff and facilities. The remaining requirements are adequately addressed through the fiscal year 2003 President's Budget.

CDC will \$56 million provided in emergency supplemental funding to address the most urgent security projects. This includes \$10 million released September 21st by the Administration and planned to be used to assure on-going operation of Medicare reimbursement in the New York area. When it was determined that these funds were not needed for this purpose, they were allocated to immediate security needs at CDC, along with \$46 million that was included in the emergency supplemental appropriation. These funds will be used for the following projects:

#### [In millions of dollars]

Permanent	transshipment	building	at	the	perimeter	of	the	Roybal	
Campus .	-				-				32
Armed Secu	rity Guards at al	1 CDC loca	ition	ıs					3
Campus har	dening projects a	at all CDC	loca	tions	(fencing, lig	ghtir	ng)		6
Integrated e	mergency comm	inication s	yste	m for	the Roybal	Car	npus		5
Design and	Related Services	for New L	abor	atory	@ Fort Col	lins,	ĈΟ.		8
Security Up	grades @ Fort Co	llins, CO .							2
The \$20 1	nillion included	in the fisc	al v	ear 2	003 Preside	nt's	hudo	et request	will

extend CDC's security beyond the most immediate needs. With these funds, CDC will:

### [In millions of dollars]

<b>5</b>
7
3
E F

# BIOTERRORISM

*Question.* In one of these bioterrorism hearings, Dr. Koplan spoke about how overwhelmed the CDC was during the anthrax attacks. Many of their staff had to work around the clock and their labs were strained to capacity. If the CDC was this overwhelmed by one incident, the system could break down if multiple attacks occurred. Mr. Secretary, is there a need for CDC to have regional labs around the country, so that they have more laboratory capacity to respond to any contingency? Answer. CDC has established a network of laboratories throughout the country to respond to bioterrorism events. This Laboratory Response Network (LRN) includes 103 laboratories located in all 50 states. These are public health and federal laboratories. These laboratories have laboratory protocols and reagents for many of the BT agents of greatest concern, including anthrax, and they have been trained in laboratory diagnosis of these agents.

The anthrax attacks resulted in many hoaxes and unknown powders suspected of being anthrax being reported to law enforcement. This resulted in 122,000 specimens being tested for anthrax. About 85,000 specimens were tested in state public health LRN laboratories and CDC laboratories tested about 7500. Besides CDC, many of the LRN laboratories were also overwhelmed with testing specimens. New monies for bioterrorism preparedness and response will be used to expand the capacities of the LRN laboratories to respond to future events. CDC is also making contingency plans for responding to such events in the future.

# DOSE RECONSTRUCTION

*Question.* Can you tell me when you expect to finalize the regulations on dose reconstruction and on probability of causation?

Answer. We expect both rules to be within the next couple of months.

Question. When do you expect to start finalizing dose reconstructions?

Answer. We have begun the process of conducting dose reconstructions, and expect that we will be able to begin reporting draft results to a limited number of claimants for their review and approval in April 2002. The pace of finalized dose reconstructions will pick up substantially in the coming months, with the addition of substantial personnel through a dose reconstruction contract.

Question. Can you tell me when you expect to publish procedures for naming additional special exposure cohorts?

Answer. We expect to publish a HHS statement of policy for public comment on the procedures for designating classes of employees as members of the special exposure cohort in April 2002.

Question. When do you expect to be able to name additional cohorts if warranted? Answer. We expect to be able to publish the policy statement in April 2002 for while comment. Approximately 60 days will be required to review public comments

public comment. Approximately 60 days will be required to review public comments and finalize the policy. At that time we will be in a position to consider petitions by classes of employees. The time required to render a decision on a petition depends on the extent of effort required for full development of the factual basis for making a well-grounded decision, as well as the amount of time required for review of petitions by the Advisory Board on Radiation and Worker Health. HHS decisions on petitions become effective after a 180-day period during which Congress may review and act upon the HHS decision, as required by EEOICPA.

*Question.* How many cases have you received from DOL for dose reconstruction? Answer. As of March 20, 2002, we have received 2,605 cases from DOL which will require dose reconstruction.

*Question.* How many of those cases are from the Iowa Army Ammunition Plant and from Ames Laboratory?

Answer. Two of the cases we have received from DOL include employment at the Iowa Army Ammunition Plant; none of the cases received from DOL to date involve employment at the Ames Laboratory.

Question. I have heard that HHS has requested DOL (or some DOL centers) to limit the number of applications it passes on for dose reconstruction. Is this true, and if so, what are the requested limits?

Answer. HHS has not requested that DOL or any DOL District Office limit the number of cases it refers to HHS for dose reconstruction. We have requested that each DOL District Office forward any claims which are ready for dose reconstruction to us on a specified day each week.

*Question.* I understand that you have been proceeding with the work of dose reconstructions (without finalizing them) under the draft regulations. Can you tell me for how many cases you have attempted dose reconstructions?

Answer. We have identified approximately 70 cases where the personal radiation exposure information received from DOE appears to be adequate to initiate a dose reconstruction. We expect to complete about 20 of these in the coming month. As mentioned above, we expect the pace of finalized dose reconstructions to pick up substantially in the next few months with the addition of substantial personnel through a dose reconstruction contract.

*Question.* For how many of these cases have you been unable to do accurate dose reconstructions due to lack of available exposure data?

Answer. We have not yet reached the point in our dose reconstructions where we have identified specific cases where lack of data will not permit us to develop a reasonable estimate of an employee's radiation dose.

Question. Can you tell me the status of contracting out dose reconstructions, and how many HHS staff or contractor staff are currently working on this? Answer. We are currently in the process of evaluating proposals submitted in re-sponse to a Request for Proposal entitled "Radiation Dose Estimation, Dose Recon-struction and Evaluation of SEC Petitions under EEOICPA." We expect to have a contract awarded and in place by June 2002. The NIOSH Office of Compensation Analysis and Support europhy head a staff of 15 with 2 mere presidence aconstructions. Analysis and Support currently has a staff of 15, with 3 more positions soon ex-pected to be filled, along with 6 contractor staff. These staff all play critical roles in managing the claims, collecting the necessary data from DOE and claimants, and performing the dose reconstructions. We expect that the contract, when awarded, will bring substantial resources to bear on dose reconstructions and evaluations of special exposure cohort petitions.

*Question*. What are your plans for dealing with cases for which there is inad-equate personal exposure data (e.g. personnel who were not issued badges or who routinely did not wear them), particularly where area monitoring was also inadequate?

Answer. NIOSH will attempt to obtain a variety of types of information to esti-mate radiation doses in cases where personal exposure and area monitoring infor-mation are inadequate. Such information may include general process descriptions for the employee's work areas, characterization of the source term (i.e., the radionuclide and its quantity), extent of encapsulation, methods of containment, and other information to assess the potential for airborne dispersion. Interviews with employees, survivors and co-workers are also expected to be a valuable source of information in all cases, and particularly where other data are inadequate.

#### DISABILITY GRANTS

Question. Your budget once again zeroes out funding for two disability initiatives within the Centers for Medicare & Medicaid Services: \$40 million for Real Choice Systems Charge Grants to States and \$15 million to continue the Nursing Home Transition Initiative. What objection does the Administration have to these initiatives which are aimed at helping disabled persons live independently and avoid costly nursing home care?

Answer. We appreciate the interest and initiative of Congress to remove barriers to community living on the part of people with a disability or long-term illness. These are the very same goals articulated by the President in his New Freedom Initiative. We share a common and vital agenda.

With the recent \$55 million appropriated by Congress for the grant programs in 2002, in addition to the \$70 million we awarded in 2001, we will soon have a funding relationship with all 48 States that applied. These grants are important and they are making a difference in the ability of States to improve their systems. The Federal-State partnership that these grants exemplify is a feature that has drawn considerable praise from Governors and State legislators. We have not included further funding in the President's budget for 2003 for two reasons. First, we have permitted States up to three years to invest and spend these

reasons. First, we have permitted States up to three years to invest and spend these funds in projects that improve community services. We think it will be prudent, with 48 States already participating, to give States time to implement the projects underway and for us to assess the results. Second, we are interested in focusing fu-ture grant initiatives in ways that promote specific system improvement strategies that are coordinated with demonstration designs that go beyond just grant funds. For example, under the President's New Freedom Initiative there are specific demonstrations proposed for respite services for caregivers of either adults or children, as well as a demonstration of community services for children with a disability who may otherwise be placed in a residential treatment facility. These are high-priority issues identified by States that are included in the President's 2003 budget. I hope you can support these important initiatives.

### MEDICARE OVERPAYMENTS FOR EQUIPMENT & SUPPLIES

Question. The General Accounting Office (GAO) found that Medicare, which pays more than \$6 billion annually for medical equipment and supplies, continues to pay more than market prices for certain items. What is the status of your efforts to reduce excessive Medicare payments for medical equipment and supplies? (Background: For example, GAO found Medicare pays up to \$62 for eyeglass frames that retail for \$40 and which the Department of Veterans' Affairs purchases for less than \$33.)

Answer. The only authority that the Department has for adjusting Medicare's payment allowances for medical equipment, such as eyeglass frames, is a statutory provision referred to as "inherent reasonableness." This authority allows the Secretary or his designee to adjust Medicare Part B payment allowances, other than payments made under the physician's payment methodology, when the Secretary de-termines that the existing payment allowance is either grossly excessive or deficient. The BBRA of 1999, however, prohibits use of the inherent reasonableness author-ity until after the Department enblishes a final exclusion that the average of the secretary de-

ity until after the Department publishes a final regulation that responds to a 2000 GAO report and to comments received regarding the interim final rule published in 1998. At the current time, the final regulation is in the clearance process. CMS is currently involved in DME competitive bidding demonstrations that cover

five product categories: oxygen supplies and equipment, hospital beds and acces-sories, enteral nutrition, urological supplies, and surgical dressings. An independent evaluation of the Polk County, Florida demonstration found that the demonstration resulted in a reduction of charges of 17 percent. The Administration is proposing legislation to institute competitive bidding for all durable medical equipment and supplies to take advantage of these savings and bring down the costs of these expenditures.

# CHIEF DENTAL OFFICER AT CMS

*Question*. The Committee stated in its report last year that it was important to retain the position of Chief Dental Officer at CMS.

What steps has your department taken to fill that position? Answer. The Deputy Administrator and other senior CMS officials have met with representatives from the American Dental Association and assured them that we would give full consideration to their recommendation that we fill the position of Chief Dental Officer. Question. When do you expect to have the position filled?

Answer. While we are looking into filling this position, at this point we have no timeline for doing so

*Question.* It was the Committee's intent that the Chief Dental Officer at CMS be a full-time position at the same level as it was held through December 2001. Please tell the Committee how you intend to address those concerns.

Answer. We are aware of the language in both the House and Senate Appropriations bill urging CMS to continue the position of Chief Dental Officer, and we are exploring the possibilities for doing so.

### KDA REDUCTIONS IN SAMHSA

Question. The fiscal year 2003 budget request proposes significant reductions in services research and knowledge development and application activities at SAMHSA Centers. For example, proposed funding for Best Practices activities at the Center for Substance Abuse Prevention is more than 50 percent less than last year and the reduction proposed for the Center for Substance Abuse Treatment is almost 45 per-cent. SAMHSA's fiscal year 2003 GPRA Annual Performance Plan identifies the Agency's Mission as follows: "SAMHSA is the Federal agency charged with improving the quality and availability of prevention, treatment and rehabilitative services in order to reduce illness, death, disability and cost to society resulting from substance abuse and mental illness.

Mr. Secretary, how will SAMHSA make progress in its mission related to improv-ing the quality of prevention, treatment and rehabilitative services with these proposed reductions?

Answer. Reductions in funding have been proposed for the Best Practices or re-searched focused programs in 2003. SAMHSA will instead collaborate with NIH to ensure that services research efforts responsive to the needs of the field are continued. Most of the funding for services research was directed to the Targeted Capacity Expansion programs, which help improve the availability and quality of prevention, treatment and rehabilitative services.

# SAMHSA'S ROLE IN RESEARCH COORDINATION COUNCIL

Question. While not specifically mentioned in the SAMHSA congressional justification, it is my understanding that the Department has proposed creating a Research Coordination Council. Has your Department proposed created such a Council? If so, can you provide me with more information about the mission-of the proposed Council, how its members will be selected and the outcomes' expected to be achieved? Will SAMHSA have a role in the Council? If so, what will it be, and how does it relate to the significant reductions proposed in SAMHSA's services research budget?

Answer. SAMHSA and the other OPDIVs participate in the HHS Research Coordination Council (RCC) which is chaired by the Assistant Secretary for Planning and Evaluation (ASPE). The RCC will evaluate Department-wide research priorities to ensure that efficiencies are realized and research finding priorities are consistent with Administration priorities. SAMHSA has presented to the RCC its plans to work with the National Institutes of Health (National Institute of Mental Health, National Institute on Alcohol Abuse and Alcoholism, and the National Institute on Drug Abuse) to bring evidence-based, effective products of research to community programs nationwide. SAMHSA has already taken steps to expand our partnership with NIH to produce a "Science to Services" agenda that is responsive to the needs of the field.

### IMPLEMENTING INSTITUTE OF MEDICINE RECOMMENDATIONS

Question. Mr. Secretary, according to a recent Institute of Medicine report, the lag between discovery of more efficacious forms of treatment and their incorporation into routine patient care is unnecessarily long, in the range of about 15 to 20 years. The IOM also recommended that HHS develop a comprehensive program for aimed at making scientific evidence more useful and accessible to clinicians and patients and suggested that the Secretary should collaborate with professional and health care associations in this endeavor. What steps is SAMHSA undertaking to reduce this lag between research and translation? How is SAMHSA involving service provider professionals in implementing the IOM recommendation? In particular, how are they involved to ensure that scientific evidence is useful to them?

Answer. The President's proposed fiscal year 2003 budget reinforces the SAMHSA mission in services and in bringing evidence-based, effective products of research to community programs nationwide. It also reinforces language in our authorizing legislation that SAMHSA and the National Institutes of Health (NIH) should collaborate to promote the study, dissemination, and implementation of research findings that improve the delivery and effectiveness of substance abuse and mental health services. SAMHSA has already taken steps to expand the partnership with NIH to produce a "Science to Services" agenda that is responsive to the needs of the field. A dialogue with the Directors of the National Institute on Alcohol Abuse and Alcoholism, the National Institute on Drug Abuse, and the National Institute of Mental Health has been initiated and a common commitment to this agenda was found. Dialogue will continue with service provider professionals to ensure that their needs for useful scientific evidence guide our plans. Over the next year, SAMHSA will define and develop a "Science to Services" cycle that reduces the time between discovery of an effective treatment or intervention and its adoption as part of community-based care.

While NIH will provide appropriate focus on the development of new services-related knowledge, SAMHSA will continue its strong efforts to translate best practice information to providers nationwide. Each of SAMHSA's three Centers continues to have mechanisms in place to work with the field to implement efficacious approaches. These include programs such as the National Repository of Effective Prevention Programs; Community Action Grants; dissemination of best practice information through clearinghouses and knowledge application programs; a Decision Support System; and others. Importantly, best practice approaches will continue to be required in programs which SAMHSA supports directly. SAMHSA's continued commitment to service quality and effectiveness is expected to help reduce the lag time IOM noted in knowledge translation.

### COMMUNITY BASED SERVICES

Question. Given the President's Executive Order on Community-Based alternatives (Olmstead) to enable individuals with a disability, including those with a mental illness, to live and participate in their communities, how does SAMHSA realize that promise without additional funding for CMHS? In particular, I am concerned that the budget request does not include any funding to make new awards for the communities put evidence-based practices into use for people with mental illness and children with serious emotional disorders. Given the Administration's New Freedom Initiative and interest in fostering community-based services, why does this budget fall to request funding for this important program?

Answer. In fiscal year 2003, funds are reinvested in new programs that address the principles of the Olmstead/New Freedom Initiative. These include co-occurring disorders, substance abuse treatment, prevention and early intervention, children's services, homelessness, aging, HIV/AIDS, and criminal justice. Priority investments in Best Practices that relate to some components of the Community Action Grant program include: the development of evidence-based practice toolkits, the development of Centers of Excellence on evidence-based practices, and the Knowledge Application Initiative to disseminate findings from five multi-site studies through technical assistance and publications.

# MENTAL HEALTH

*Question.* Flat funding under the fiscal year 2003 spending plan for the Center for Mental Health Services (CMHS) is of heightened concern given an underfunded, overburdened, severely strained public mental health system, the events of September 11 and double-digit medical inflation. With no additional resources, how will the Administration address the overburdened and underfunded public mental health system? As we increase efforts to protect our nation, what efforts are being proposed in your budget to address the mental health of our citizens in a post-September 11th world?

Answer. Public mental health systems will be carefully examined by the National Commission on Mental Health which will soon be established. Commission recommendations will also consider issues such as disaster relief. It should be noted that the public mental health system is primarily funded by sources such as Medicare/Medicaid, and State revenues. SAMHSA funding is a very small portion of the total effort.

Under the Public Health Service Act Section 501(m), SAMHSA is authorized to use up to 2.5 percent of all amounts appropriated under Title V of the PHS Act, other than those appropriated under Part C, in each fiscal year to respond in emergency situations when behavioral health needs overwhelm State, Tribal or local resources, and other resources are unavailable. Applications for grants under this authority require that the mental health or substance abuse emergency be certified by the State's chief executive officer, rather than from a local government, based on the governor's experience and expertise in disaster declarations gleaned from the FEMA grants.

At the same time, SAMHSA's mental health service programs provide a key impetus for improving service quality and availability. They expand the nation's capacity to deliver mental health services and apply the knowledge gained from the outstanding services research being accomplished by NIH and others, and our legacy of developing knowledge about systems change. The Mental Health Block Grant is undergoing a transition to a performance partnership with States to increase State's flexibility in the use of funds while establishing an accountability system based on performance. This additional flexibility further supports States in increasing and improving their community-based delivery systems to better meet the treatment needs of persons who do not receive any care; receive inappropriate care; and those persons receiving care that does not lead to an effective outcome.

With respect to disaster relief, SAMHSA has initiated several programs to address the mental health of our citizens in a post September 11th world. In fiscal year 2001, the National Child Traumatic Stress Initiative established 18 treatment development and community service centers to treat children who have experienced trauma, collected clinical data to further understanding of the developmental impact of trauma on children and the success of interventions, and developed a comprehensive resource center that provides education-oriented materials for health professionals, children, and the public. In fiscal year 2002, this program increases by \$20 million from \$10 million to \$30 million. In fiscal year 2002, SAMHSA established a National Suicide Resource Center to

In fiscal year 2002, SAMHSA established a National Suicide Resource Center to provide training and field support and serve as a clearinghouse for all pertinent best practice information regarding suicide prevention. The Center promotes evaluation of suicide prevention programs to ensure that effective techniques, strategies, and recommended best practices are made available to users. In fiscal year 2003, SAMHSA will continue this program as well as the Suicide Hotline Program, begun in fiscal year 2001.

In fiscal year 2003, the President's budget includes \$10 million for Terrorism/Bioterrorism preparedness and planning program to be funded entirely from the Public Health and Social Services Emergency Fund. This program will support Federal preparation in the area of fear-induced behaviors and psychosocial consequences of bioterrorism. The focus on the program would be:

- -Technical assistance to States to assist them in incorporating bioterrorism readiness and response into their State emergency preparedness planning
- -Behavioral health triage in health care settings, bioterror crisis intervention
- —Disseminating knowledge to public officials to prepare them in averting widespread public fear and panic, fear-induced overutilization of health care facilities and loss of confidence in public institutions

—Mental health needs for first responders

-Programs that target an increase the State's emergency response capacity to provide mental health treatment and services to public safety workers affected by disasters of national significance

by disasters of national significance *Question.* Secretary, as you know, Surgeon General Satcher's 1999 mental health report called for public education efforts to combat the social stigma associated with mental illness that prevents many Americans from accessing the services they need. Last year, Congress inserted language into both the House and Senate Labor/HHS Committee report urging your department to fund a program in this area. I understand that you have responded by directing the Substance Abuse & Mental Health Services Administration (SAMHSA) to obligate \$2 million for a "barriers to treatment" public education initiative. What's the timetable for implementing this important anti-stigma initiative? Please inform the subcommittee about the focus and structure of this new program?

tant anti-stigma initiative? Please inform the subcommittee about the locus and structure of this new program? Answer. SAMHSA plans to implement the *Elimination of Barriers to Treatment*/ *Initiative* (EBI) in September 2002. This activity promotes the President's New Freedom Initiative by developing public education approaches to overcome barriers to treatment and community participation for persons with psychiatric disabilities. This program will provide targeted intensive support to eight State Mental Health Authorities and their corresponding State Mental Health Planning Councils as well as State Consumer Networks. The primary goals are to (1) enhance State and grantce social marketing/communications canacity: (2) increase awareness of and support

This program will provide targeted intensive support to eight State Mental Health Authorities and their corresponding State Mental Health Planning Councils as well as State Consumer Networks. The primary goals are to (1) enhance State and grantee social marketing/communications capacity; (2) increase awareness of and support for community support systems through partnerships with State, local and community organizations; (3) reduce stigma and discrimination in targeted communities, and; (4) increase awareness and understanding of mental health needs as well as the principle of recovery.

To support the goals of this program, a National Steering Committee will be formed of representatives of State and local officials, State Planning Councils, State consumer network grantees, providers, advocates, media, consumer and family leaders, and others. They will recommend how best to provide services to State and local efforts.

# SAMHSA DATA COLLECTION ACTIVITIES

Question. Mr. Secretary, last year the Administration proposed a \$17 million increase in budget authority for data collections activities. This investment, in combination with funding available through the block grant set aside, was intended to enable SAMHSA to make improvements in the Household Survey, Drug Abuse Warning System (DASIS). Congress appropriated an increase of \$9 million for data collection activities which is being used for improvements to the DAWN and DASIS. Why has the Administration eliminated the \$9 million required to sustain these data collection Improvements? Given the funding pressures on the block grant set aside for technical assistance to States to implement performance partnerships, how will this reduction affect SAMHSA's data collections activities?

Answer. The fiscal year 2003 request places priority on services delivery rather than data collection programs. Data collection activities are being reduced by \$9 million in fiscal year 2003. With this reduction, SAMHSA will not continue two onetime expansions within the Drug Abuse Warning Network (DAWN) and the Drug and Alcohol Services Information System (DASIS).

#### RESPONSE TO CHRONIC HOMELESSNESS

*Question.* The President's budget indicates that the Administration has developed an initiative which is designed to refocus federal homeless spending and end chronic homelessness within the next decade. This initiative includes activities at several departments including HHS, HUD, VA and Labor. Can you update the Subcommittee on SAMHSA's discussions with HUD to reform

Can you update the Subcommittee on SAMHSA's discussions with HUD to reform the federal government's response to chronic homelessness among individuals with severe mental illness and co-occurring substance abuse disorders? What information can you provide this subcommittee about the nature of discussions between SAMHSA and HUD regarding more effective targeting of federal mental health and substance abuse treatment and support services dollars to the chronic homeless population?

Answer. SAMHSA has been working with HUD to address chronic homelessness in a variety of ways. First, for over a year, SAMHSA has been working with HUD through an informal HHS-HUD staff workgroup to address various definitional and operational issues related to the integration of services and housing. For example, SAMHSA and other HHS agencies have explored developing a joint definition of chronic homelessness with HUD that would coordinate eligibility in both HHS and HUD programs. We also provided suggested definitions for the services covered by HUD's Continuum of Care programs that ensure a better fit with services supported by HHS. We have also offered to assist HUD in reviewing grant applications for this program. Second, we have also, along with other HHS agencies and HUD, devoted resources and considerable staff time to plan and hold State Policy Academies on Homelessness. These academies provide technical assistance to State teams addressing key aspects of homelessness. Particular emphasis is given to encouraging the States to extend flexibilities inherent in HHS-supported programs (e.g., block grants and Medicaid) to ensure coverage of family homelessness and chronic homelessness. The State 1Policy Academy on Chronic Homelessness will be held April 9–11 in Boston. Finally, SAMHSA is contributing at the Department level to the development of an HHS-wide plan to address this issue. An HHS-wide plan would engage resources beyond those of SAMHSA and create opportunities for a formal or targeted collaboration with HUD.

# INTEGRATED TREATMENT

Question. The Administration's fiscal year 2003 budget request highlights SAMHSA's efforts to assist states in increasing their capacity to meet the needs of individuals with co-occurring mental illness and substance abuse. As you know, in 2000 Congress directed SAMHSA develop a new knowledge bass effective clinical interventions for this difficult to serve population (Public Law 106–310). Over the past decade, NIH research has built up increasing evidence base that "integrated treatment" is the most effective approach to treating persons with co-occurring mental and addictive disorders. This research appears to demonstrate that "parallel" and "sequential" treatment generally fails this population. Further, the 1999 Surgeon General's Report on Mental Health noted the effectiveness of "combined" treatment for this population.

What steps are underway at SAMHSA to help states foster "combined" programs that follow an integrated treatment model with blended funding streams and an interdisciplinary treatment approach? Can you update the Subcommittee on SAMHSA's efforts to meet the mandate set forth by Congress on co-occurring disorders as part of Public Law 106-310?

Answer. Addressing the needs of individuals with co-occurring mental and substance abuse disorders is a SAMHSA priority. SAMHSA assists States in using integrated treatment approaches to meet the needs of individuals with co-occurring mental illness and substance abuse disorders. In fiscal year 2003, SAMHSA has requested \$6.0 million for a new Co-Occurring State Incentive Grant (SIG) program to support State integration of mental health and substance abuse services/treatment and the development of systems of care to provide more timely and efficacious treatment services.

The Youth Drug and Mental Health Services Act of 2000 (Public Law 106–310) requires SAMHSA to submit a Report to Congress (RTC) on Individuals with Co-Occurring Substance Abuse and Mental Illness by October 17, 2002. This Report is being developed with guidance and input from: (1) the Subcommittee on Co-Ccurring Disorders of SAMHSA's Advisory Council, with ad hoc representatives added to ensure comprehensive input from mental health and substance abuse researchers, States, family members, consumers, advocates, and provider, all recognized as experts on co-occurring mental and substance abuse disorders; (2) constituent organizations, including States, mental health and substance abuse researchers, treatment providers, prevention specialists, individuals receiving treatment services, family members of such individuals and representatives from criminal justice, healthcare, public health, education, housing, shelters, homeless programs, Medicaid, foundations, and cademia; (3) responses to a Federal Register request for comments on present strengths/promising developments, barriers and recommendations; and (4) a meeting with SAMHSA's HHS and non-HHS Federal partners, scheduled for mid-April, including CMS, HRSA, AoA, OCR, ACF, NIH, FDA, VA, SSA, Labor, HUD, Transportation, Agriculture, Education, and Justice. In June, 1999 SAMHSA published a policy statement that confirms that the Substance Abuse and Mental Health Block Grant funds may be utilized for the purposes

In June, 1999 SAMHSA published a policy statement that confirms that the Substance Abuse and Mental Health Block Grant funds may be utilized for the purposes of providing co-occurring services, as long as the monies can be tracked for the purpose that Congress intended them to be expended. This policy removes any perceived funding barriers to the use of Block Grant funds to support services for this population. States retain the flexibility and responsibility for making the decisions on how such funds may be utilized. Starting with fiscal year 2002, States are now describing their systems of care and inclusion of services disorders for persons with co-occurring in their Mental Health Block Grant plans.

Question. As part of his "New Freedom Initiative" President Bush has committed to form a commission to examine ways to improve public sector mental illness treatment services to promote recovery and greater independence for consumers. Can you please update the Subcommittee on progress the Administration has made in forming this commission and getting it off the ground?

Answer. The President expects to announce the New Freedom Commission on Mental Health within a few months. White House staff have been progressing with the Commission by working to identify and interview individuals who may be se-lected to serve on the Commission.

#### FEDERAL JAIL DIVERSION PROGRAM

Question. A report issued by the United States Department of Justice in 1999 revealed that 16 percent of all inmates in state and federal jails and prisons suffer schizophrenia, manic depressive illness (bipolar disorder), major depression, or another severe mental illness. This means that on any given day, there are roughly 283,000 persons with severe mental illnesses incarcerated in federal and state jails and prisons. In contrast, there are approximately 70,000 persons with severe mental illnesses in public psychiatric hospitals, and 30 percent of them are forensic pa-tients. Additionally, police are increasingly becoming front-line respondents to people with severe mental illnesses experiencing crises in the community.

n response to these trends in our criminal justice system, Congress authorized a federal jail diversion. program at CMHS. For fiscal year 2002, this Subcommittee appropriated \$4 million for this effort. Can you update the Subcommittee on efforts to make these funds available to local communities?

Answer. In April 2002, SAMHSA's Center for Mental Health Services (CMHS) will announce the availability of fiscal year 2002 funds for programs to divert indiwill announce the availability of fiscal year 2002 funds for programs to divert indi-viduals with mental illness from the criminal justice system to mental health treat-ment and appropriate support services. These grants will be made as part of the SAMHSA/CMHS' "Targeted Capacity Expansion" (TCE) program. The shortened title of this TCE program will be *Jail Diversion Programs*. It is estimated that a total of \$4 million will be available to support the program under this Guidance For Applicants (GFA). Requested funding in fiscal year 2003 will help continue support and expendent the TCE program programs will be address the foland expand this TCE program. Diversion programs will be asked to address the following objectives:

(1) Expansion of local services through implementation of required interventions for persons with a mental illness who have been diverted from the criminal justice system.

(2) Service linking between mental health, substance abuse, and criminal justice systems to coordinate assessment and treatment of persons with a mental illness who are diverted from the criminal justice system.

(3) Community outreach to ensure that services are accessible to the target population and that the community accepts use of the services as beneficial.

### EARLY CHILDHOOD DEVELOPMENT

Question. Mr. Secretary, I am concerned that the budget request does not include any additional resources for early childhood development programs. In his State of the Union Address, the President stated: "We need to prepare our children to read and succeed in school with improved Head Start and early childhood development programs." I agree with him, but I am not certain how that can be accomplished with a budget that does not enroll one additional child in Head Start-when we are serving roughly half of those eligible and less than one in 20 infants and toddlers eligible—where no additional funding is provided for high quality child care—when less than 15 percent are served and when the Early Learning Fund is eliminated.

How will the Presidents goal be achieved with millions of children not served in programs for which they are eligible? What new investments are proposed in this

budget that will help prepare our children to succeed in school? Answer. The President's proposed fiscal year 2003 Head Start budget will permit a 2 percent across-the-board cost-of-living increase. The request needs to be put in the context of the recent growth in the funding of Head Start. In fiscal year 1999, Head Start's appropriation was \$4.658 billion. In fiscal year 2002, it has increased to \$6.538 billion, an increase in just three years of nearly \$2 billion, or 40 percent. Approximately \$1.1 billion of that increase was used to maintain and improve program quality through cost-of-living and quality improvement increases awarded to local grantees.

One of the largest quality investments was made in 1999 and 2000 in which \$40 million was made available, each year on an on-going basis, to grantees to increase their number of teachers with qualifying degrees. That is, \$80 million is included in the annual funding level each year to continue efforts to increase the number of Head Start teachers with degrees in Early Childhood Education. These funds, plus other discretionary funds available to grantees for training and salary enhancement, will assure that we will be able to continue the trends of the last few years which saw the percentage of degreed teachers increase from 37 percent in 1999 to 46 percent in 2001 and also assure that Head Start will meet the statutory requirement that 50 percent of its teachers have qualifying college degrees by September 2003.

that 50 percent of its teachers have qualifying college degrees by September 2003. The President's fiscal year 2003 budget maintains a high level of commitment for the Child Care and Development Fund (CCDF), at \$4.8 billion including \$2.1 billion in discretionary funds and \$2.7 billion in mandatory funds. At this level, approximately 2.2 million children will receive child care subsidies. Funding for child care over the last several years has grown dramatically. In fact, funding under the CCDF has more than tripled in the last 10 years.

over the last several years has grown dramatically. In fact, funding under the CCDF has more than tripled in the last 10 years. Regarding child care eligibility, currently we are looking at better ways to reflect the child care services actually being provided by States and to more accurately estimate the need for child care assistance. The 12 percent figure previously used includes children served through the Child Care and Development Fund, but not those served with funds being spent directly on child care through TANF and through programs such as the Social Services Block Grant, Head Start, and State pre-kindergarten programs. It also overstates eligibility for child care by assuming all States set eligibility thresholds at the maximum level when in fact, most States set thresholds at the lower.

To maximize services to children and families, ACF promotes collaboration between child care and other early childhood programs. Child Care and Head Start have been working in partnership for a number of years to ensure that children receive the comprehensive benefits of the Head Start program and the full-day, fullyear services that parents need in order to work. We provide guidance and technical assistance to State and local grantees on ways to combine funding streams and develop innovative collaborative program models. Through partnerships, we are working to ensure that no child is left behind in critical domains of child development or in family self-sufficiency.

In addition, the President's budget includes support for a new investment geared toward helping children become ready for school: The Early Childhood Education and School Readiness Planning Initiative. Jointly funded by HHS and the Department of Education, this new initiative is designed to identify effective models for providing early childhood education and care from birth through age five.

# HEAD START

*Question.* Mr. Secretary, the budget proposal states that the ground work is being developed to transfer Head Start from your Department to the Department of Education, and also indicates that a joint task force is being developed to assess ways to improve Head Start.

What evidence is available that indicates that the Head Start program would better achieve its goals under the stewardship of the Department of Education and therefore support this proposed transfer? What specific actions are being taken by either Department related to the laying of the ground work? What activities will the joint task undertake to assess ways to improve Head Start? Answer. Head Start has, in most regards, been an excellent program that has helped America's disadvantaged children and families for over 35 years. However, the one area in which the President feels the program has not been fully successful is in helping get Head Start children ready for school by getting them "ready to

Answer. Head Start has, in most regards, been an excellent program that has helped America's disadvantaged children and families for over 35 years. However, the one area in which the President feels the program has not been fully successful is in helping get Head Start children ready for school by getting them "ready to read." To support this effort, the President has proposed to reform Head Start and return it to its original focus—getting children ready to learn. The budget provides an increase of \$130 million in fiscal year 2003 to maintain participation and program quality. HHS and the Department of Education have formed an interagency task force to assess ways to improve Head Start and lay the groundwork for the proposed transfer to the Department of Education. The task force will focus on issues including, surveying what is known about how best to encourage early literacy and developing a research plan for filling in the gaps.

### WELFARE REFORM

*Question.* Mr. Secretary, in your statement on March 6, 2002, you indicated that the ultimate goal of Welfare Reform is to help families climb the career ladder and achieve self-sufficiency, I agree with you; I have said a hand up, not a hand out.

However, when I look at the HHS budget request, I see flat funding for the TANF block grant, not one additional dollar for child care, not one child added to Head Start, flat funding for SSBG and a reduction in funding for the community services block grant program. These resources are critical to State efforts to support work and to reduce and eliminate poverty in communities throughout our nation.

Mr. Secretary, how can we ask States to put more families to work and ask families to work more without the community supports they need to succeed in their efforts to work, particularly given the current fiscal climate where States throughout the country are slashing their budgets and TANF expenditures last year, exceeded the amount of the annual TANF block grant? Isn't it true that States spent almost \$2 billion more than their annual TANF allotment in fiscal year 2001, thus proving that individuals still on the welfare roles will be more expensive to serve and help transition to work?

Answer. The President's Budget provides States with adequate and flexible resources to help families climb the career ladder. While States, indeed, had a record outlay of \$18.6 billion in TANF funds in fiscal year 2001, the upswing in fiscal year 2001 expenditures should not be construed as evidence that the dramatically reduced caseload is more expensive to serve. We know that many TANF recipients have obstacles to employment, but it does not appear that the current recipients are harder-to-employ than those who have left TANF rolls for jobs. In fact, according to research that was conducted by the Urban Institute, which compared recipients at the beginning of TANF with more recent recipients, the distribution of new entrants, cyclers (those that received TANF intermittently from 1997 to 1999), and long-term recipients has remained remarkably the same. We also know that some States needed time to determine how they could use the flexible funding available to them during the initial years of TANF implementation.

Further, we know some States may have been motivated to expend unobligated funds resting in the Federal Treasury because they believed they would be in danger of losing them. The President's TANF reauthorization proposal would allow States to count "rainy day" funds as obligated. Funds will stay in the Federal Treasury, but will be earmarked for a designated purpose and States will be assured they will not be rescinded. The \$16.5 billion in continued basic TANF grant funding is continued even though caseloads are less than half what they were five years ago and we are proposing to reauthorize a \$2 billion Contingency 1Fund as a safety net in the event of a recession, making it more accessible to the States.

Although the President's proposal for TANF contains new work requirements, our commitment to State flexibility continues, along with adequate funding for supportive services such as child care. States will have the flexibility to provide necessary services for families that need help addressing serious barriers such as substance abuse and to combine education with work to help make people employable at a higher level. States also will have time to adapt to the new work requirements, since they will receive the benefit of the full caseload reduction credit in the first fiscal year and 50 percent of the credit the following year. Further, while the Child Care and Development Fund (CCDF) itself is level-funded, the combined resources available to States to provide care includes TANF transfers to the CCDF, direct TANF spending on child care, SSBG funds some \$9 billion annually. And when you add in State TANF Maintenance of Effort Spending, this amounts to almost \$11 billion. The SSBG provides an additional flexible resource to help continue the effort to support work. All considered, we are confident that the resources are available to ginty of work.

#### CHILD CARE

*Question.* Mr. Secretary, the fiscal year 2003 budget includes no additional resources for child care, either on the mandatory or the discretionary side of the budget. Next year, this could result in a reduction in child care subsidies for 30,000 kids. Over the next five years, the number of families that could lose their child care might number more than 100,000.

Given the well documented challenges two-parent and single-parent working families face in finding and securing affordable, high quality child care, why has the Administration proposed such a reduction in child care subsidies? What options will that leave for low and middle income families trying to balance work and care of their children?

Answer. The President's fiscal year 2003 budget maintains a high level of commitment to child care. Funding for child care over the last several years has grown dramatically. In fact funding under the Child Care and Development Fund has more than tripled in the last 10 years. In addition, States continue to have significant flexibility under the TANF program and the Social Services Block Grant program to address the needs of their low income working families.

The combined resources available to States to provide child care, including TANF transfers to CCDF, direct TANF spending on child care, and SSBG funds, amounts to some \$9 billion annually. And when you add in State TANF MOE Spending and State CCDF spending, this amounts to almost \$11 billion.

In addition, I would add that States have a tremendous amount of flexibility to target their funds strategically (e.g., by adjusting eligibility, co-payments, and/or provider reimbursement), develop innovative ways to serve families, and increase their collaboration with other programs.

#### BARRIERS TO FAITH AND COMMUNITY BASED ORGANIZATIONS

Question. The White House Faith Based report identified Limited Accessibility of Federal Grants Information as one of the barriers that faith and community based organizations face. In fact, the report stated: "Federal discretionary grant programs typically announce the availability of funds in the Federal Register and on the program's or the respective Department's Website. These sources are not everyday reading for small faith-based and community groups; these places are regular information sources only for organizations that have already decided that they might have a chance to win Federal funds and that can dedicate staff attention to monitoring funding announcements." Yet the Department's response to this barrier was to create links on the HHS Center for Faith-Based and Community Initiatives website to the Catalog of Federal Discretionary Assistance, Federal Register and funding opportunities listed by agency within the Department.

How will this action reduce the barrier of limited accessibility to information? What other steps has the Department taken—within current law—to reduce barriers identified in the White House report?

What other steps has the Department taken—within current law—to reduce barriers identified in the White House report? Answer. The first step to expanding access was to create a more user friendly and centralized website which has helped introduce small novice and potential applicants to the Department, the overall initiative, and available grant opportunities. The news about this website and initiative has begun to expand beyond the Beltway, not only through our individual staff speeches and contact with community and faith leaders, but through the various organizations and leaders promoting it in their newsletters and existing networks. Further, we are working within each Agency to look at new ways to reach out, for example, by expanding existing mailing lists and e-mail list serves, conducting pre-application workshops with enough advance notification, and by sponsoring conferences and workshops geared for training smaller faith and community-based organizations. This is an on-going process, and the Department will continue to seek new and creative ways to increase communication and opportunities for new faith and community partners.

### COMPASSION CAPITAL FUND

*Question.* Congress provided \$30 million for fiscal year 2002 for the Compassion Capital Fund for grants to public/private partnerships that help small faith-based and community-based organizations replicate or expand model social services programs. Funds also were intended to support and promote rigorous evaluations on the "best practices" among charitable organizations so that successful models can be emulated and expanded by other entities. Please provide an update on your plans for developing a competition for these funds, as well as your plans for awarding these funds.

Answer. Since the inception of the faith and community based offices throughout the federal government, we have seen a tremendous need for technical assistance, capacity building and research for the non-traditional provider community. On Feb. 26th, a request for comment went out to the public to gain insight from the provider community on how to design the Fund. Comments are due back to the Department March 29th. We plan to award the first round of grants in the Fall of 2002. *Question.* The President's message accompanying the fiscal year 2003 budget

Question. The President's message accompanying the fiscal year 2003 budget states: "Where government programs are succeeding, their efforts should be reinforced—and the 2003 Budget provides resources to do that. And when objective measures reveal that government programs are not succeeding, those programs should be reinvented, redirected, or retired." Mr. Secretary, the fiscal year 2003 request for the Compassion Capital Fund includes an increase of 233 percent, when non-defense and homeland security programs on average received an increase of 2 percent. What justifies such a dramatic increase in this program? When will information be available about how funds are used, and whether they are being spent effectively to meet the goals and objectives of this program? Answer. Successful support for those in need comes from many sources and we must broaden our efforts to work with faith-based and community-based organization. These organizations are closest to the people in need; they have a stake in the community and have a history of providing services to those in need. The Administration is committed to ensuring that the Federal government plays a larger role in providing support to charitable organizations because as indicated in response to the previous question, there is a tremendous need for technical assistance, capacity building and research for faith and community based providers. The Compassion Capital Fund is intended to support this partnership. With respect to when information will be available, the first grant awards will be issued this fall. At that time we will be better able to estimate when measurable results will be available.

# LIHEAP

Question. Given the significant growth in LIHEAP caseloads (a 38 percent increase since fiscal year 2000) and the unknown of next winter's energy prices, how will States continue to serve the more than 5 million current LIHEAP recipients with a \$300 million reduction in regular funding if prices are higher next winter than currently assumed in the budget request? In the current condition of state budget deficits, won't they be forced to choose between reducing eligibility and/or cutting benefits?

Answer. Each year, States make decisions in setting eligibility and benefit levels for energy programs that target those households that are most vulnerable and have the most need, and determining how to make efficient use of the resources available to them.

The Low Income Home Energy Assistance Program (LIHEAP) provides assistance to the States and is targeted to those low-income households that have the highest energy costs or needs, taking into account family size, and responds to emergency situations such as extreme weather conditions, supply disruptions, or price spikes.

A number of States have been successful in negotiating reduced utility rates for households that receive LIHEAP assistance. For instance, Massachusetts and Connecticut have very sophisticated pricing mechanisms that allow them to realize substantial savings for their clients. Minnesota negotiates specific discount rates with each of its fuel vendors. Many States take advantage of the opportunity to use as much as 15 percent of their LIHEAP funds for weatherization and other low-cost energy repairs. Under certain circumstances, a State can ask for a waiver to use up to 25 percent for weatherization. The flexibility to use a small portion of LIHEAP funs in this way allows States to help households make their energy bills more affordable.

Additionally, the Personal Responsibility and Work Opportunity Reconciliation Act (Public Law 104–193) provides that States may use both Federal Temporary Assistance for Needy Families (TANF) dollars and State funds used for the TANF "maintenance of effort" (MOE) requirement to provide energy assistance and services to financially eligible or needy families. In using these funds for energy assistance, States establish their own financial eligibility criteria—i.e., the income and resource standard to determine whether the family is eligible for the particular energy benefit the State might offer.

For fiscal year 2003, the President's budget includes \$1.4 billion in regular block grant appropriations and an additional \$300 million in emergency contingency funds for the unanticipated home energy needs. This request is consistent with the level Congress appropriated in fiscal year 2001, prior to the temporary and unprecedented increases in fuel prices. With the \$300 million in fiscal year 2001 carry-over contingency funds, there should be sufficient funding available to address severe and unanticipated needs. The Department of Energy forecasts fuel prices to remain constant through the remainder of the year.

Question. Mr. Secretary, payroll employment fell by 1.2 million from August 2001 to February 2002, as 12 states exhausted all of their LIHEAP funding for the current year. Another four states expect to be out of money by the end of March. Do you believe these conditions warrant release some or all of \$600 million currently available to the Administration in the LIHEAP contingency fund? If not, why not? Answer. As you know, LIHEAP contingency funds are generally released in the

Answer. As you know, LIHEAP contingency funds are generally released in the event of an energy emergency, such as unusually severe weather or high home energy prices. This year, relatively mild winter weather across the nation has produced lower fuel costs. In addition, we must also be prepared in the event that there is a need for contingency funds resulting from a heat wave or some other unexpected cooling emergency this summer.

The full \$1.7 billion in fiscal year 2002 LIHEAP formula block grant funds are available to the States. States are usually limited to 90 percent of their funds

through the second quarter. However, the Administration granted waivers to states that requested to receive 100 percent of their funds to meet their needs this winter. To date, the Administration has retained the Supplemental Contingency Funds.

We are continuously monitoring conditions to determine how to best allocate the Contingency Funds, and the President is prepared to respond by releasing the funds should the determination of a qualified emergency be made.

#### NUTRITION SERVICES INCENTIVE PROGRAM

*Question.* Please clarify how the funds for the Nutrition Services Incentive Program (NSIP) that the Administration proposed to transfer from the United States Department of Agriculture to AoA will be distributed to the States. How will this proposal better serve seniors?

Answer. Instead of funding nutrition programs through two separate agency ap-propriations, The President's Budget requests that the funding previously provided for the USDA Nutrition Services Incentive Program (NSIP) be combined with AoA nutrition program funding. To ensure that each State continues to receive the same level of funding, the current formula used to distribute USDA funds, contained in section 311 of the Older Americans Act, would continue to be applied to \$150 million of the combined funding appropriated to AoA for nutrition programs. No older person will be adversely effected by this transfer. States and localities

will benefit from the increase in management efficiency, streamlining and reduction in duplication especially in reporting that will result from implementation of this proposal.

# INTERAGENCY TASK FORCE ON AGING PROGRAMS

Question. Last year, the Senate Committee report included language directing the Department to form an Interagency Task Force on Aging Programs. The purpose of this task force was to maximize the positive impact of existing programs, reduce and eliminate duplication in service provision and minimize regulatory burdens and costs at the local level. What is the current status of complying with this directive? What role will AoA assume in the HHS Interagency Task Force on Aging? How is the development and the work of the task force progressing within HHS

Answer. HHS is already involved in a number of efforts related to building an Interagency Task Force on Aging. We operate HHS as "one Department" just as the President operates this Administration as "one government." We are working first within HHS and secondly across other Cabinet level agencies in the areas of regulatory reform, removal of barriers to accessing services, enhancing consumer focus, and developing an integrated system for linking health care systems and commu-

and developing an integrated system for finking heath care systems and commu-nity-based services that serve older individuals and their families and caregivers. Within HHS we have sought greater partnerships and coordination of activities across HHS agencies such as CMS, the CDC, the FDA, HRSA, the Indian Health Service (IHS) and a number of other agencies. These activities include: —CMS—working together to help States and local providers coordinate Older Americans Act funded programs with Medicare and Medicaid CDC, working to develop on integrated curves of health promotion and disease

- Americans Act funded programs with Medicare and Medicaid -CDC—working to develop an integrated system of health promotion and disease prevention services for older adults through the "Aging States Project" -FDA—partnering in the current diabetes awareness campaign by enlisting the assistance of the aging network as a vital and effective partner in this effort -HRSA—working together on issues related to the current shortage of profes-sional and paraprofessional health care workers.

IHS-working together on home and community-based long-term care issues in Indian communities.

These partnerships are also being expanded to other Departments. For instance, under the New Freedom Initiative, we are working to remove barriers to services across government. HHS is also working with the Department of Transportation on issues of better coordination of transportation, especially in rural areas. AoA has also received a number of comments through its community listening sessions across the country as part of its development of regulations. AoA has met with staff from other Departments, including Labor, the Department of Veterans Affairs, the Department of Housing and Urban Development, the Social Security Administration, and a number of other cabinet agencies, and will continue these efforts in the future.

The Administration on Aging has provided leadership in these efforts and will continue to do so. As an example, AoA has had a leading role in the "New Freedom Initiative" that focuses on health, social services, transportation, housing and labor issues for the disabled. AoA has led efforts to receive and analyze comments and input from consumers and advocates reflecting aging concerns.

# NUTRITION PROGRAM FUNDING

Question. Last year, this subcommittee provided historic investments in the Aging Network, including additional investments in elderly nutrition programs, family caregiving activities, senior centers and critical support services like transportation and adult day care. In a press statement on March 1, 2002 celebrating the 30th Anniversary of the Older Americans Act Nutrition Program, Mr. Secretary, you referred to the Nutrition Program as one of the most successful community-based programs for seniors in America. Yet this budget request essentially level funds funding for Older American Act programs, including an increase of less than 1 percent for the Nutrition Program. In a budget request that provides an average increase of 2 percent for non-defense and non-homeland security programs, why has one of the most successful programs for the elderly received what amounts to a reduction in funding?

Answer. AoA has a solid budget request that maintains and builds on the historic investments in the network that the Congress provided in fiscal year 2002. Notwithstanding the hard choices that the President had to make this year, including decisions on funding for the war on terrorism, bioterrorism and homeland security, the AoA request provides increases for home-delivered meals and preventive health activities, two areas especially important for the growing population of older, frail elderly.

Federal funds constitute a portion (30 percent) of the total spending by the Network on Older Americans Act programs. Older Americans Act nutrition programs leverage additional State, local, and private funds which reflect the efficiency of these programs. These programs will continue to target those most in need. Of the clients served by the aging network (1999 data) 32 percent were poor, 19 percent were of minority origins, and 34 percent lived in rural areas.

Working with our partners in the aging network, we expect to maintain the fiscal year 2002 level of meals served, 300 million meals to 2.6 million older adults. Historically, when appropriated funds have not increased over the previous year, the aging network has been able to maintain services and meals provided to seniors.

### QUESTIONS SUBMITTED BY SENATOR ARLEN SPECTER

# NATIONWIDE HEALTH TRACKING NETWORK

Question. We have heard some concerns that CDC is not giving the Nationwide Health Tracking Network program a high enough profile. Building upon earlier reports that there is duplication and inefficiency within CDC, how can you assure us that a nationwide health tracking network will take full advantage of existing programs and build a coordinated system? (Specifically, the National Center for Environmental Health has established a new branch, its Division of Environmental Hazards and Health Effects. We are concerned that burying the tracking network this deep in an individual center will continue the silo mentality and lead to duplication rather than coordination as the tracking network is developed.)

ards and Health Effects. We are concerned that burying the tracking network this deep in an individual center will continue the silo mentality and lead to duplication rather than coordination as the tracking network is developed.) Answer. Building the nationwide health tracking network efficiently and cost-effectively will require supplementing, not supplanting or duplicating existing programs associated with this tracking effort. CDC's National Center for Environmental Health (NCEH) has worked closely with the various programs throughout the Agency to gather input and lay the groundwork for continued collaboration. In fact, NCEH has made it a priority to assure that collaboration extends beyond CDC to include other relevant federal and state government agencies, and non-governmental organizations. The NCEH staff is in the process of establishing "linkages" across Centers and programs such as the National Electronic Disease Surveillance System (NEDSS), the Data web, the National Program of Cancer Registries, the Behavioral Risk Factor Surveillance System, and the State Birth Defects and Surveilance communications between various existing activities. CDC's environmental health tracking program will build upon the lessons learned from existing systems and nork closely with those programs that will be essential in building a strong national network.

Within CDC's organizational structure, many major public health programs have been designed, implemented, and have flourished under the division and branch structure. Programs such as the National Breast and Cervical Cancer Early Detection Program, the National Childhood Lead Poisoning Program, the National Asthma Control Program, and the National Cancer Registries Programs, just to name a few, are successfully managed out of branches. Question. The CDC received \$1 billion to develop a public health infrastructure that is responsive to the shortcomings that were highlighted by September 11 and the anthrax attacks. As you are developing the tracking network, how is it connected to all the activities of rebuilding surveillance and infrastructure for bio-terrorism? Is it part of the planning and implementation? To what degree?

Answer. Using the supplemental funds provided under the "Public Health Preparedness and Response for Bioterrorism" cooperative agreement, grantees will be required to develop and/or enhance existing surveillance systems to monitor key bioterrorism and infectious disease indicators. Information Technology guidelines have been provided to assist the grantees in creating electronic systems that can be easily integrated into databases of not only possible bioterrorism agents, but infectious diseases.

In addition, Congress has provided funds in the fiscal year 2002 budget to begin the development of a nationwide, environmental health tracking network that will integrate data on environmental exposure with data on the occurrences of diseases that have possible links to the environment. These funds will be used to assure development of environmental and chronic disease surveillance systems and linkage to EPA and state environmental department data and information systems. This is unique to the development of this network and will complement the development of bioterrorism surveillance systems for environmental hazards.

This system will allow on-going monitoring and dissemination of information on levels of environmental contaminants, trends in disease occurrences, facilitate research on possible linkages, and measure the impact of regulatory and prevention strategies. Funding will be made available for pilot projects to develop strategies and mechanisms for building statewide or regional systems that will provide the foundation and architecture for linking, integrating and displaying health and environmental data.

Real time assessment of environmental hazard data will provide states with capability for early detection of emerging hazards, threats or intentional releases of dangerous chemicals. This can initiate a response on the part of state and local environment management teams to mitigate the potential for exposure to the public. Additional public health action may be needed to prevent or respond to associated disease occurrences.

Question. How are you using the \$17.5 million appropriated for Nationwide Health Tracking in fiscal year 2002 budget?

Answer. The goal of environmental health tracking is to develop a surveillance network, which can integrate data on environmental exposure with data on the occurrences of diseases that have possible links to the environment. This system will allow on-going monitoring and dissemination of information on levels of environmental contaminants, trends in disease occurrences, facilitate research on possible linkages, and measure the impact of regulatory and prevention strategies. With this information, federal, state and local agencies will be better prepared to develop and evaluate effective public health action to prevent or control diseases across our nation.

tion. Funding will be made available for up to 15 state and/or local pilot projects to develop strategies and mechanisms for building statewide or regional systems that will provide the foundation and architecture for linking, integrating and displaying health and environmental data. Funding will also be provided to several Schools of Public Health/Centers of Excellence to coordinate and translate research needs/activities between academia and the pilot projects/state grantees. The Centers of Excellence will assist with the development and understanding of public health surveillance practices and methodologies.

Question. More and more, it appears that CDC is trying to become more of a research organization than a community-based public health organization. It appears that very valuable data is sitting on desks until it can be released in a peer-reviewed journal, which might look good on the CV of your staff but doesn't help bring the information to the communities where it is most needed. How are you insuring the communities in the process of developing the network? Are you engaging communities in the process of developing the network? How will you assure that citizens will be able to access information about exposures and health outcomes in their community? We know about the work groups and I assure you that these workgroups do not reflect the community nor do they adequately represent community concerns.

Ånswer. The CDC has always played a major role in assisting state and local public health officials in developing and implementing programs that will improve the health of communities. CDC is committed to disseminating information learned from disease surveillance to drive public health action and to conduct essential research that translates into improved public health practices. The CDC is looking very carefully at how right-to-know issues relating to environmental health surveillance can be balanced with right-to-privacy and confidentiality issues. Guidelines and procedures for making aggregated data available to the public at a community level, in an easily accessible and readily available format will be developed as part of the standard operations for the Environmental Health Tracking Program. It is too early in program development to outline exactly what that data will look like.

Each state grantee will be asked to develop community-based coalitions to ensure local community input in identifying environmental public health priorities and needs. Additionally, CDC will identify Network stakeholders, assess their needs, and determine effective communication in order to fully understand how national and statewide systems can best serve communities.

Plans being developed for statewide and national networks will address access and dissemination issues. A public access web site which provides both the environmental and health outcome data in an easy to understand format and which assures the protection of individual privacy is a logical model to consider. However, because many members of the public do not have access to the web or are not comfortable with electronic systems, written reports and fact sheets will be developed and shared. Other methods for providing communities access to information will be explored.

### OFFICE OF THE SECRETARY CONSOLIDATIONS

Question. You are proposing to consolidate the management of construction funds under your office. You are also planning a major consolidation of the Department's communications, legislative and public affairs offices and placing them directly under your control. How will this sudden centralization of decision-making and information dissemination affect the ability of Congressional staff to receive fast and accurate information? Could you explain your reasons for these plans?

Answer. Our intention is to improve the flow of information to both Congress and the public by avoiding the confusion and delays that are sometimes caused by the present separation of information offices within the Department. This change does not represent any alteration in our policy regarding the ready availability and active dissemination of information; instead, it represents an administrative change intended to overcome bureaucratic gaps that can negatively impact the flow of information. Furthermore, by consolidating efforts throughout the Department, we expect to achieve more effective and less duplicative dissemination of information than at present. Members of Congress and their staffs will still be able to contact individual Operating Divisions directly; however, it might be more efficient and effective for them to contact the consolidated legislative or public affairs office in Washington instead, as those offices will be able to pull the pertinent pieces together from all of the Operating Divisions, and deliver a comprehensive and clear answer to a Member.

I have decided to implement these changes in administrative structure because consolidation offers HHS the opportunity to achieve economies of scale, and to redeploy resources from administrative support to mission-critical areas. Following are additional details regarding these consolidations.

Health Facilities Construction and Management Fund.—HHS will provide the oversight of all construction projects from a centralized office in the Office of the Secretary. The intent is to inject more accountability into the construction process, by centralizing the financial management of construction projects and continuously monitoring the progress being made in relationship to the dollars being spent. In summary, the concept is centralized oversight with decentralized execution.

summary, the concept is centralized oversight with decentralized execution. Personnel Offices.—In September 2001, HHS had 40 personnel offices providing human resource services to HHS employees. This represents tremendous duplication of effort—e.g., more than 20 separate personnel offices on the NIH campus, six personnel offices at FDA, multiple personnel offices in one building (the Parklawn Building in Rockville)—as well as wide variation in the quality and timeliness of the services provided. By the end of fiscal year 2003, we plan to move from these 40 separate offices to four consolidated service sites. These consolidated sites will be co-located with large employee concentrations in Atlanta, Baltimore, Bethesda, and Rockville.

The first phase of our current consolidation effort has begun. The personnel offices for SAMHSA and AHRQ were consolidated with the PSC personnel office in October 2001. By the end of this fiscal year, NIH will consolidate its current 27 personnel offices into one, and FDA will consolidate its 6 personnel offices into one. Planning is well underway for both of these consolidations, and we expect the NIH and FDA consolidated sites to operate with fewer FTE than are now dedicated to personnel services in those Operating Divisions. As with SAMHSA and AHRQ, this will provide the opportunity to shift resources to front-line operations.

To achieve our goal of further consolidating to four sites by the end of fiscal year 2003, the Department will soon convene a workgroup of Operating Division representatives to design the new structure, recommend service and resource levels, and address staffing issues. While our objectives include more efficient service delivery and more effective use of resources, my commitment is that no employee will lose a job as a result of consolidation, although they will not necessarily stay in the same job they now have. Nor do we expect our consolidation efforts to result in wholesale employee geographic relocation.

wholesale employee geographic relocation. Public Affairs and Legislative Affairs.—HHS is currently in the process of developing a detailed plan for executing these consolidation. This effort entails working closely with each Operating Division to determine the positions involved, the job duties involved, and how best to restructure the operations within each agency into a coordinated effort. The goal is to create a cohesive structure that supports the development and execution of clear, timely and fact-based communication with both Congress and the public.

Specific individuals to be transferred to the consolidated Public Affairs and Legislative Affairs offices have not yet been identified. Below is a table outlining the number of FTE to be transferred from each HHS Operating Division, and the cost associated with those FTE.

IIIIS Operating Division	Tot	tal	Public	Affairs	Legislation	
HHS Operating Division	FTE	Dollars	FTE	Dollars	FTE	Dollars
FDA	80	\$7,317	46	\$4,623	34	\$2,694
HRSA	31	3,354	18	1,947	13	1,407
IHS	8	838	5	599	3	239
CDC	60	7,870	44	5,415	16	2,455
SAMHSA	12	1,610	11	1,476	1	134
CMS	63	5,714	17	1,551	46	4,163
ACF	10	1,090	7	753	3	337
NIH	381	51,106	372	49,899	9	1,207
AHRQ	12	1,610	10	1,342	2	268
Total	657	80,509	530	67,605	127	12,904

# LIHEAP

*Question.* The Administration has not released \$600 million in emergency LIHEAP funds, despite high energy prices and cold temperatures. Why haven't these funds been released and why is there a request to cut \$300 million from LIHEAP in fiscal year 2003?

Answer. The fiscal year 2003 President's budget includes \$1.4 billion in regular block grant appropriations and an additional \$300 million emergency contingency funds for the unanticipated home energy needs. Given the reduction in fuel prices from last year, we believe these funds will be sufficient. The Department of Energy forecasts fuel prices to remain constant through the remainder of the year into next winter absent any unforeseen energy emergencies.

Additionally, the \$300 million in funds appropriated under LIHEAP's emergency contingency provision in the July 2001 Supplemental Appropriations Act remains available. Since this amount is considered to be "no-year" funding, it can be carried over into subsequent fiscal years. Therefore, if part or all of these monies are not released this year, these funds would be available for LIHEAP in fiscal year 2003 to meet any unexpected demands.

### HEALTHY COMMUNITIES INNOVATION INITIATIVE

*Question*. Could you explain more about your Healthy Communities Innovation Initiative? Given the focus on reducing diabetes, obesity, and asthma, can you explain how this new program does not duplicate similar programs that have been funded for years through CDC?

Answer. HHS has been working hard to treat and prevent asthma, diabetes, and obesity. However, I believe their rapidly increasing prevalence calls for an initiative to target resources on a new interdisciplinary services demonstration to focus our efforts at the community level. The Healthy Communities Innovation Initiative will be modeled on the successful Healthy Start community-based demonstration project to enhance access to services and change health outcomes.

HRSA's expertise is in working with communities to develop and implement tailored services programs through a variety of activities and programs. HRSA cur-rently partners with other agencies, including CMS and CDC, and will use its expertise to enhance the effectiveness of other existing programs to reduce the preva-lence of diabetes, asthma, and obesity. HRSA will forge a tightly coordinated public/ private partnership between prevention, medical, social, educational, business, civic, and religious organizations to enhance access to services and change health outcomes, while avoiding duplication of existing efforts.

Another critical element of this initiative will be based upon HRSA experiences gained in the successful Maternal and Child Health Block Grant performance meas-urement agreements worked out in collaboration with all 59 States and territories, and in place and working well for three years now. This HRSA experience will be used to effectively develop and utilize requirements for each grantee to define achievable health outcome goals and measures for which it will be held accountable.

# COMMUNITY HEALTH CENTERS

Question. The budget request includes a \$114 million increase to expand commu-nity health centers to serve poor, migrant, and homeless individuals. Will this increase result in additional health centers, or the expansion of existing health cen-ters? With this increase, how many more people will be served? What additional areas of the country will be served?

Answer. The President's Budget for fiscal year 2003 proposes a \$114 million increase to fund the second year of the Presidential Initiative to increase and expand health center access points by 1,200 and increase the number of people served by 6 million in five years. These funds will support the establishment of approximately 90 new access points and the expansion of service capacity at 80 existing sites. Thirty of the 90 new access points are projected to be new sites of new grantee organizations, with the remaining 60 new access points projected to be new satellite sites of existing grantee organizations.

These new and expanded sites will increase services to an additional 1 million in-dividuals, for a total of 12.8 million persons. This will include an additional 60,000 migrant farm workers and their family members, and 64,000 special population clients including homeless persons and residents of public housing facilities. Due to the competitive nature of the grant application and review process, the Health Center program is unable to predict the geographic distribution of grant awards. However, the Program is expected to continue to maintain an appropriate balance between rural and urban grant awards, and to continue to give special consideration to sparsely populated areas of the country.

### CHILDREN'S GRADUATE MEDICAL EDUCATION

Question. The Children's Hospitals Graduate Medical Education (GME) has been

Question. The Children's Hospitals Graduate Medical Education (GME) has been essential to supporting medical education in free-standing children's hospitals be-cause these hospitals serve few, if any, Medicare patients and, therefore, do not re-ceive medical education funding from Medicare as do other teaching hospitals. The President's budget cuts Children's GME \$85 million. Could you explain the reasons for this cut and how you believe this will affect children's hospitals? Answer. Since fiscal year 2000 when this program was initiated, it has expanded seven fold, going from \$40 million to \$285 million in only three years. Our proposal for fiscal year 2003 is a modest effort to restrain spending, holding funding at \$200 million. We have made a few priority determinations in developing the overall Presi-dent's Budget and this is one place where we suggest that the funding level could be pared back. Even with the \$85 million reduction in GME payments, the approxi-mately 60 Children's Hospitals in the country would receive an estimated per resi-dent payment of \$51,200. dent payment of \$51,200.

#### HEALTH PROFESSIONS

Question. The Administration has zeroed out funding for Public Health Workforce Development in the Health Resources and Services Administration. Could you explain the cut in that area, as well as cuts in funding for other health professions?

Answer. The goal of our Health Professions programs is to increase services to the underserved. Over the past two decades, we have spent \$6 billion on Title VII health professions grants and our track record on performance is not good. Based on data reported in the HRSA Government Performance and Results Act Annual Performance Plan, only 30 percent of individuals who participate in the Title VII programs go on to practice in medically underserved areas. However, with the Health Center program and National Health Service Corps, we know that 100 per-cent of these funds are going to provide services to the underserved. Title VII pro-

grams were enacted to correct an overall shortage of physicians. Today, there is no shortage of physicians. In fact, the number of physicians have increased by 21 per-cent in the last 10 years and 64 percent over the last 20 years.

We have provided increases in two areas where we do have shortages nursing and ensuring our health professionals are adequately trained to diagnose and treat bioterrorism illnesses. It is also important to note that we make substantial invest-ments in training health care workers, particularly doctors, through Medicare reimbursements \$8 billion estimated in fiscal year 2003 through Graduate Medical Education.

# NURSING SHORTAGE

Question. We continue to face an ever-increasing shortage of nurses in this country. Unless we focus our attention on this problem, the nursing shortage will only worsen as our population ages. What short-term, mid-term, and long-range strategies are you instituting to deal with this crisis?

Answer. HRSA administers programs authorized under Title VIII of the Public Health Service Act, often referred to as the Nurse Education Act. Specific activities helping to mitigate the shortage of nurses include support for (1) basic and advanced nursing education programs, (2) diversity programs targeting minority and disadvantaged students, (3) scholarship, traineeships and loans, and (4) nursing workforce analysis.

- -The Advanced Education Nursing Program supports projects educating nurses for faculty positions in nursing schools, public health nurses, nurse administra-tors and advanced practice nurses which include nurse practitioners, clinical nurse specialists, nurse anesthetists, and nurse midwives. Funds from this program support advanced education projects enrolling approximately 4,550 students and provide traineeship support for 5,800 graduate level students. -The Nursing Workforce Diversity Program provides support to projects targeting
- 1,800 minority and disadvantaged students in elementary and secondary schools, pre-nursing programs, and nursing schools. This program provides re-medial and support services necessary to assure successful completion of those students enrolled in nursing programs
- -The Basic Nurse Education and Practice Program supports academic and continuing education projects designed to recruit and retain a strong nursing workforce. Funds are used to support basic entry-level career ladder programs for licensed practical nurses, innovative academic distance learning projects for rural RNs, and projects to expand enrollments in baccalaureate nursing programs. Support is provided for retention strategies through continuing education projects to enhance the skills of the existing nursing workforce for prac-tice in existing and emerging health care systems. In addition, support for fac-ulty-run nurse managed centers provides educational settings for nursing students and clinical practice sites for faculty providing care to underserved populations
- -The Nursing Education Loan Repayment Program assist registered nurses by repaying up to 85 percent of their qualified educational loans over 3 years in return for their commitment to provided services at health facilities in shortage areas.
- -Other student scholarship and loan support available under the following HRSA programs for fiscal year 2001 provided the following:
- The Scholarships for Disadvantaged Students Program Assistance
- -The revolving Nursing Student Loan Program -The National Health Service Corp Scholarship and Loan Repayment Programs

### BIOTERRORISM

Question. What is the status of the applications from the States for the remaining 80 percent of funds appropriated for bioterrorism preparedness? Has the Depart-ment received much feedback from the States? Does it appear that the timeline the Department has set for review of applications is realistic?

Answer. Recently awarded cooperative agreements from the Centers for Disease Control and Prevention and the Health Resources and Services Administration, respectively, allocated over \$1 billion by formula to health departments of states and other eligible entities to enhance public health preparedness. Twenty percent (20 percent) of the allocated funds are available for immediate expenditure. The remaining eighty percent (80 percent) will become available as soon as the Secretary has approved the awardees' work plans for expenditure of the funds. These work plans are due on or before April 15, 2002. To help the awardees prepare their work plans, the Department offered detailed guidance and conducted four regional workshops (Atlanta, Denver, San Francisco, and Boston). Based on this first hand contact, we find the awardees enthusiastic at the prospect of this major infusion of funds to enhance bioterrorism preparedness in general and the public health infrastructure in particular.

in general and the public health infrastructure in particular. We believe that the timeline is realistic. A few states may request a short extension of the deadline for submitting the work plans. However, the Department remains committed to reviewing and approving the workplans within 30 business days following determination that the plans are complete. Both the Department and the awardees share a sense of urgency about enhancing public health preparedness. *Question.* How are bioterrorism funds, which are spread out among several agen-

*Question.* How are bioterrorism funds, which are spread out among several agencies within the department, being coordinated? Answer. I have commissioned Dr. D.A. Henderson and the new Office of Public

Answer. I have commissioned Dr. D.A. Henderson and the new Office of Public Health Preparedness (OPHP) he heads to direct and coordinate our efforts across HHS. He is overseeing all parts of our preparedness planning efforts. We created this office precisely because our bioterrorism functions are diverse. We engage a wide array of experts throughout the Department and strive to ensure that their efforts are effectively channeled to meet growing demands for preparedness.

Most of our bioterrorism funding was appropriated to a single unified account the Public Health and Social Services Emergency Fund in the Office of the Secretary. We are making these monies available to the operating organizations—the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA), and the Office of Emergency Preparedness (OEP)—as soon as plans for their use have been approved by Dr. Henderson and the Assistant Secretary for Budget, Technology, and Finance.

In particular, we have moved aggressively to allocate more than \$1 billion for improving State and local preparedness for bioterrorism and other public health emergencies. This involved close collaboration among CDC, HRSA, OEP, and the Office of the Secretary.

CDC issued cooperative agreements totaling \$918 million using a formula-based allocation. The awardees (primarily states) can use up to 20 percent of their awards immediately and will be able to access the remaining 80 percent once the Secretary has approved their work plans for use of the funds. Among the objectives are enhancements of infectious disease surveillance and epidemic response and planning for receipt and distribution of material from the National Pharmaceutical Stockpile.

HRSA allocated \$125 million to States and other eligible entities for hospital preparedness using a formula based approach similar to that used by CDC. Further, the HRSA awardees also can use 20 percent of their allocated funds immediately and will have access to the rest once the Secretary has approved their work plans.

Although NIH and FDA received direct appropriations, both are coordinating their plans closely with OPHP. FDA's funding was highly targeted- much of it directed to adding new inspectors/compliance officers that FDA is actively recruiting and hiring.

### STEM CELL RESEARCH

*Question.* The NIH Stem Cell Registry now identifies 78 stem cell lines. It is my understanding that these lines are at various stages of development and characterization. How many of these stem cell lines are immediately available to U.S. researchers?

Answer. The 78 lines that are listed on the Registry are in varying states of availability. The WiCell agreement makes the lines from Wisconsin available, and one is being shipped. Infrastructure grants have been made available to help all sources increase their ability to fill requests for lines. The notices have been issued for the first 3 of these awards. The availability of lines other than WiCell depends to some degree on resolution of agreements between WiCell and the other sources. It appears that such negotiations are proceeding and will soon result in other lines becoming available.

### QUESTION SUBMITTED BY SENATOR KAY BAILEY HUTCHINSON

# RESPONSE TO TROPICAL STORM ALLISON

*Question*. Secretary Thompson, I want to commend you and your Department for your concern and responsiveness to my state after the disastrous flooding we encountered from Tropical Storm Allison last summer. The total losses in Houston alone were over \$5 billion, and the medical institutions at the Texas Medical Center alone suffered \$2 billion worth of this damage. More importantly, as I'm sure you

are aware, the losses to our entire country, in fact to the world, of critical research in areas such as breast cancer, a flu vaccine and AIDS research will likely take years to replace. I understand that many of these losses will never be reimbursed because FEMA reimburses property loss and even NIH takes a pretty narrow view of what it is actually able to reimburse.

A significant portion of the Texas Medical Center's losses were incurred because of business loss. I understand that following September 11, the New York City hospitals also suffered enormous business losses. Mr. Secretary, you now have the authority in recent disaster relief legislation to reimburse the New York City hospitals from your Public Health and Emergency Assistance Fund for their business losses and the Congress has earmarked \$140 million specifically for this purpose.

May I have your commitment that you will review the situation with the Houston hospital and research facility business losses and do your best to find a way to provide similar relief for these losses in my state?

Answer. I personally visited the Texas Medical Center last year to observe firsthand the devastation caused by the floods. NIH officials have also made numerous visits to offer technical assistance in applying for supplemental research grants from NIH and in working through FEMA's rules for compensation. NIH has assigned a case-manager to work with the affected research institutions. NIH has awarded over \$12 million in supplemental grants for research and research equipment at Baylor College of Medicine and more than \$1 million to the University of Texas-Houston. NIH also has about 8-10 more such administrative supplements in the review queue. Each of these institutions have also received about \$3 million in extramural construction funds from NIH to help rebuild the research labs that were lost. As an example of the close and effective collaboration we have had with FEMA on the research side, FEMA has agreed to support the costs of technicians needed to regenerate knock-out mouse strains. It is my understanding that the research institutions have been pleased with NIH's efforts on their behalf and have sent NIH letters of thanks. The fiscal year 2002 Emergency Supplemental provided \$140 million to reimburse only those entities with health care-related expenses or lost revenues directly attributable to the September 11, 2001, terrorist attacks. Further Congressional guidance states that funds are to be allocated based on the applicants' proximity to the attack zone, the number of patients served, or the provision of specialized services such as trauma care which participated most directly in disaster response efforts. These funds are not available for costs that have otherwise been reimbursed or are eligible for reimbursement from other sources.

# QUESTIONS SUBMITTED BY SENATOR TED STEVENS

# COMMUNITY HEALTH CENTERS

Question. The budget request includes a \$114 million increase to expand community health centers to serve poor, migrant, and homeless individuals. Will this increase result in additional health centers, or the expansion of existing health centers? With this increase, how many more people will be served? What additional areas of the country will be served?

Answer. The President's Budget for fiscal year 2003 proposes a \$114 million increase to fund the second year of the Presidential Initiative to increase and expand health center access points by 1,200 and increase the number of people served by 6 million in five years. These funds will support the establishment of approximately 90 new access points and the expansion of service capacity at 80 existing sites. Thirty of the 90 new access points are projected to be new sites of new grantee organizations, with the remaining 60 new access points projected to be new satellite sites of existing grantee organizations.

These new and expanded sites will increase services to an additional 1 million individuals, for a total of 12.8 million persons. This will include an additional 60,000 migrant farm workers and their family members, and 64,000 special population clients including homeless persons and residents of public housing facilities. Due to the competitive nature of the grant application and review process, the Health Center program is unable to predict the geographic distribution of grant awards. However, the Program is expected to continue to maintain an appropriate balance between rural and urban grant awards, and to continue to give special consideration to sparsely populated areas of the country.

#### COMMUNITY SERVICES BLOCK GRANT

*Question.* The budget documents mention a focus on strengthening families and supporting communities through faith- and community-based initiatives. However,

given this focus, why does the request cut the community services block grant by \$80 million? These funds help provide housing and employment assistance, education and training services, and nutrition and substance abuse treatment. Could you explain the reasons for this cut?

you explain the reasons for this cut? Answer. The fiscal year 2003 budget includes \$570 million for the Community Services Block Grant. While a reduction from the fiscal year 2002 level, the President's budget makes significant investments in similar programs which focus services at the community based level.

#### SUBSTANCE ABUSE TREATMENT

Question. Unfortunately, my State has one of the highest rates of substance abuse. I support the President's request for an increase in funding for drug treatment; however, I am concerned and disappointed that the request includes a \$45 million cut in drug prevention programs. These programs focus on children and teens to attempt to prevent what can be life-long addictions. Could you explain the rationale for this drastic cut in these important programs?

Answer. The President's budget focuses on increasing the availability of drug treatment. The budget totals \$2.1 billion, an increase of \$127 million to fund the second year of the President's multi-year Drug Treatment Initiative. SAMHSA will be able to provide treatment services to an additional 52,000 individuals, for a total of 546,000 people receiving treatment services. Within the increased amount, \$67 million will fund activities which provide direct treatment services to individuals and community-based organizations and \$60 million is for the Substance Abuse Prevention and Treatment Block Grant. It should be noted that 20 percent of the block grant funds are used for prevention activities.

Prevention activities are an important element in reducing drug abuse problems in this country. SAMHSA will continue its efforts in providing substance abuse prevention services that focus on children and teens, however they will be de-emphasizing the Best Practices applied research activity—relying instead on NIH to accomplish this work. The Budget requests continued level funding for prevention services such as through the State Incentive Grants. In addition, I have tasked the Office of the Assistant Secretary for Planning and Evaluation with coordinating all non-biomedical research across the Department. Specifically, the Department's strategy will be to streamline research through its Research Coordinating Council (RCC). The RCC will evaluate Department-wide research priorities to ensure that efficiencies are realized and research funding priorities are consistent with the Administration's priorities.

#### NURSING SHORTAGE

Question. We continue to face an ever-increasing shortage of nurses in this country. Unless we focus our attention on this problem, the nursing shortage will only worsen as our population ages. What short-term, mid-term, and long-range strategies are you instituting to deal with this crisis? Answer. HRSA administers programs authorized under Title VIII of the Public

Answer. HRSA administers programs authorized under Title VIII of the Public Health Service Act, often referred to as the Nurse Education Act. Specific activities helping to mitigate the shortage of nurses include support for (1) basic and advanced nursing education programs, (2) diversity programs targeting minority and disadvantaged students, (3) scholarship, traineeships and loans, and (4) nursing workforce analysis.

- The Advanced Education Nursing Program supports projects educating nurses for faculty positions in nursing schools, public health nurses, nurse administrators and advanced practice nurses which include nurse practitioners, clinical nurse specialists, nurse anesthetists, and nurse midwives. Funds from this program support advanced education projects enrolling approximately 4,550 students and provide traineeship support for 5,800 graduate level students.
   —The Nursing Workforce Diversity Program provides support to projects targeting
- —The Nursing Workforce Diversity Program provides support to projects targeting 1,800 minority and disadvantaged students in elementary and secondary schools, pre-nursing programs, and nursing schools. This program provides remedial and support services necessary to assure successful completion of those students enrolled in nursing programs.
- -The Basic Nurse Education and Practice Program supports academic and continuing education projects designed to recruit and retain a strong nursing workforce. Funds are used to support basic entry-level career ladder programs for licensed practical nurses, innovative academic distance learning projects for rural RNs, and projects to expand enrollments in baccalaureate nursing programs. Support is provided for retention strategies through continuing education projects to enhance the skills of the existing nursing workforce for prac-

tice in existing and emerging health care systems. In addition, support for fac-ulty-run nurse managed centers provides educational settings for nursing stu-dents and clinical practice sites for faculty providing care to underserved populations.

- -The Nursing Education Loan Repayment Program assist registered nurses by repaying up to 85 percent of their qualified educational loans over 3 years in return for their commitment to provided services at health facilities in shortage areas.
- -Other student scholarship and loan support available under the following HRSA programs for fiscal year 2001 provided the following: —The Scholarships for Disadvantaged Students Program Assistance

  - -The revolving Nursing Student Loan Program
  - -The National Health Service Corp Scholarship and Loan Repayment Programs

# SUBCOMMITTEE RECESS

Senator HARKIN. Thank you all very much. The subcommittee will stand in recess to reconvene at 2:30 p.m., Thursday, March 14, in room SD-138. At that time we will hear testimony from the Honorable Roderick Paige, Secretary, Department of Education. [Whereupon, at 12:41 a.m., Thursday, March 7, the subcom-mittee was recessed, to reconvene at 2:30 p.m., Thursday, March 14.1

14.]

# DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2003

# THURSDAY, MARCH 14, 2002

U.S. SENATE,

SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS, Washington, DC.

The subcommittee met at 2:39 p.m., in room SD-138, Dirksen Senate Office Building, Hon. Tom Harkin (chairman) presiding. Present: Senators Harkin, Gregg, Murray, Stevens, Cochran, and

Specter.

# DEPARTMENT OF EDUCATION

# OFFICE OF THE SECRETARY

# STATEMENT OF HON. RODERICK PAIGE, SECRETARY OF EDUCATION

# ACCOMPANIED BY:

# WILLIAM HANSEN, DEPUTY SECRETARY

# THOMAS SKELLY, DIRECTOR, BUDGET SERVICE

# OPENING STATEMENT OF SENATOR TOM HARKIN

Senator HARKIN. Good morning. The Labor, Health and Human Services and Education Subcommittee will now come to order.

Mr. Secretary, I apologize for being a little late, and I thank you for joining us today to talk about the fiscal year 2003 budget for the Department of Education. This is our first education hearing since the passage of the No Child Left Behind Act of last year.

# EDUCATION FUNDING INCREASES OF PREVIOUS YEARS

Over the past 6 years, Congress has increased the Federal investment in education by an average of 13.5 percent per year. Instead of building on that progress, the President has proposed an increase for education of just 2.8 percent next year, and that barely keeps up with inflation.

The budget would cut teacher-quality programs. It would freeze funding for after-school programs, bilingual education, and State assessments. It will eliminate all funding for over 40 other programs, including rural education, school counseling, dropout prevention, teacher training and technology, and civic education.

# NO CHILD LEFT BEHIND ACT OF 2001

I guess the reason I am so disappointed in this budget is it came right after we signed the No Child Left Behind Act, which we supported, and which I supported. The administration actually cuts funding for the programs in that act by \$90 million.

If we fail to invest in education reform, then Leave No Child Behind becomes another unfunded mandate for States that are already strapped for cash. According to the National Governor's Association, at least 40 States are now experiencing budget shortfalls totaling more than \$40 billion.

In Iowa, the last year, a budget shortfall forced schools to cut spending by 4.3 percent in the middle of the school year. If we really want reform, we have to provide schools with the resources to get the job done right, and it will be a test to whether we keep our promise of opportunity to all.

# TEACHER QUALITY MANDATES IN NO CHILD LEFT BEHIND

Now, where are my charts?

This is a list of all of the new teacher quality mandates that are in the bill that we signed. They are mandates. Those are mandates.

Let us look at the budget. Last year, we appropriated \$3.232 billion before all those mandates, and now with all the mandates, your budget has us at \$3.077 billion. So we have the mandates, and we have the funding.

# PELL GRANTS AND AFFORDABLE COLLEGE TUITION

Now, the President's proposal for higher education is also a concern. More than ever before, what workers earn is tied to what they learn. For example, the average salary of someone whose education ends after high school is almost 55 percent less than someone with a bachelor's degree. If we are going to invest in America's economic future, we have to invest in the workforce of the future, and that means making a college education more affordable and accessible for every American. Unfortunately, students and families throughout the country are finding it harder to make ends meet when it comes to a college education.

Last week, I had a meeting in Des Moines with a number of students, teachers, and others about their college education expenses. Rae Taylor, whom I met last Friday, is a junior at my alma mater, Iowa State. She comes from a background much like my own, a working-class family. Rae and her parents work hard, but like a lot of Americans they cannot afford the high cost of higher education, but Rae has not let that stand in her way. She works three jobs, 40 hours a week, and carries a courseload of 17 credits. Even though she receives the maximum Pell Grant award, she has already accumulated \$20,000 in loans before she graduates.

Mr. Secretary, I simply could not explain to Rae that this administration cannot give her a hand by increasing the maximum Pell Grant. She is willing to work hard, she has proven that. She has taken on debt, she wants to go to school, but your budget will not increase her Pell Grant by even one penny. So where does that leave Rae? Well, her tuition is going to in-

So where does that leave Rae? Well, her tuition is going to increase by 19 percent next year. She has a choice. She can either work more hours than 40 hours a week, or she can delay her graduation. I do not think that is a fair choice for her to make. She has done her part. It is time for us here in the Congress, and for the President, to do ours, and I hope that we will work together to make college more affordable for Rae and students like her.

# LOAN FORGIVENESS FOR TEACHERS AND NURSES

One positive step in that direction is the President's proposal to increase the limit on loan forgiveness for highly qualified math, science, and special education educators serving in high-needs schools. That is a good step, but we should go further, and that is why I announced this morning that I will introduce legislation providing additional loan forgiveness for all teachers serving in highneeds schools, and for all nurses providing direct medical care. There are thousands of young people in America who want to go into teaching or nursing, but when they look at the debts that they will pile up, and what that job pays them, they opt into other fields of endeavor. I hope that we can work together to make it better and easier, more affordable, for these kids to go to college and become teachers and nurses.

A great deal, I know, has changed since the Secretary first came before us last year. The tragedy of September 11th has forced us to adjust our priorities, as well it should, but we cannot allow terror from abroad to paralyze us here at home. We need to take a hard look at this education budget. I believe it comes up well short of where we need to be, but I do want to work with you, Mr. Secretary, and with the President, first, to make education reform work. I supported the No Child Left Behind bill, and I believe those reforms are good, but if we do not have the money to back it, then I think we are setting up schools for failure. So I think we have to increase our investment there and in higher education.

# PREPARED STATEMENT

Again, Mr. Secretary, I look forward to hearing your testimony and working with you to insure a better opportunity for all of our kids in school. I will leave the record open for an opening statement by my ranking member, Senator Specter, and I would yield and recognize the distinguished ranking member of the entire committee, Senator Stevens.

### PREPARED STATEMENT OF SENATOR TOM HARKIN

This hearing of the Labor, Health and Human Services, and Education Appropriations Subcommittee will now come to order.

Mr. Secretary, thank you for joining us today to talk about the fiscal year 2003 budget for the Department of Education. This is our first education hearing since the passage of the No Child Left Behind Act last year, and I'd like to congratulate you for your work on that important piece of legislation.

The passage of that bill was a victory for public education, and I was proud to support it. But my belief in education reform is why I am so deeply disappointed by the president's education budget for the coming year.

Over the past 6 years, Congress has increased the federal investment in education by an average of 13.5 percent a year. Instead of building on that progress, the president has proposed an increase for education of just 2.8 percent. That barely keeps up with inflation.

This budget would cut teacher quality programs. It would freeze funding for after school programs, bilingual education and state assessments. And it would eliminate

ALL funding for over 40 other programs, including rural education, school counselors, dropout prevention, teacher training in technology, and civic education.

I guess the reason I'm so disappointed in this budget is that it came right after President Bush signed the No Child Left Behind Act. The Administration actually cuts funding for the programs in that bill by \$90 million. If we fail to invest in education reform, 'Leave No Child Behind' becomes another

If we fail to invest in education reform, 'Leave No Child Behind' becomes another unfunded mandate for states that are already strapped for cash. According to the National Governors Association, at least 40 states are now experiencing budget shortfalls totaling more than \$40 billion. In Iowa last year, a budget shortfall forced schools to cut spending by 4.3 percent in the middle of the school year.

If we really want reform, we've got to provide schools with the resources to get the job done right. It will be the test of whether we keep our promise of opportunity to all of America's children.

The president's proposal for higher education is also cause for concern. More than ever before, what workers earn is tied to what they learn. For example, the average salary of someone whose education ends after high school is almost 55 percent less than someone with a Bachelor's Degree. If we're going to invest in America's economic future we have to invest in the workforce of the future. That means making a college education more affordable and accessible for every American.

Unfortunately, students and families throughout the country are finding it harder to make ends meet when it comes to a college education. Raye Taylor, who I met last Friday in Des Moines, is, a junior at my alma mater, Iowa State. She comes from a background much like my own. Raye and her parents work hard, but like a lot of Americans they simply can't afford the high cost of higher education.

But Raye hasn't let that stand in her way. She works three jobs for a total of 40 hours a week while carrying a course load of 17 credits. Even though she receives a maximum Pell Grant award, she's already accumulated \$20,000 in loans.

Mr. Secretary, I simply couldn't explain to Raye that this Administration, for all of its talk about education, can't give her a hand by increasing the maximum Pell grant. She's willing to work hard, she's taken on debt, she wants to go to school and become a veterinarian. Yet your budget won't increase her Pell Grant by even one penny.

So where does that leave Raye? Well, her tuition is going to increase by 19 percent next year. She's got a choice—she can either work more hours, or she can delay her graduation. I don't think that's a choice Raye or any other hard working kid should be forced to make. She's done her part, Mr. Secretary. It's time for you and the president to do yours. I hope you'll work with us to make college affordable for Raye and students like her.

One positive step in that direction is the president's proposal to increase the limit on loan forgiveness for highly qualified math, science and special education educators serving in high need schools. It's a good step, but we should go further.

That's why I announced this morning that I will introduce legislation providing additional loan forgiveness for ALL teachers serving in high-need schools and for all nurses providing direct medical care. There are thousands of young people in America who want to go into teaching or nursing, but they've got so much student loan debt they just can't afford it. I hope I can work with you and the president to help them serve America in these important professions.

A great deal has changed in America since the Secretary first came before us last year. The tragedy of September 11 has forced us to adjust our priorities, as well it should. But we cannot allow terror from abroad to paralyze us here at home. We need to take a hard look at this education budget. It comes up well short of where we need to be. But I want to work with you, Mr. Secretary, and with the president, to make education reform work and to increase our investment in higher education.

I look forward to hearing your testimony, Mr. Secretary, but first I'll yield to my friend, Senator Arlen Specter, for an opening statement.

# OPENING STATEMENT OF SENATOR TED STEVENS

Senator STEVENS. Thank you for your courtesy. I do have to go to another meeting. I am pleased to see you here, Secretary Paige, and welcome you to the committee.

Secretary PAIGE. Thank you.

# NO CHILD LEFT BEHIND ACT OF 2001

Senator STEVENS. You have a great challenge before you, I think, wide-ranging concepts of secondary and elementary education, and in the No Child Left Behind Act, which the President signed in January, which we all support very strongly. But, I wonder if you know that in many places, as a matter of fact, I think outside of the major school districts, in what we call the unorganized borough of our State, I am informed that not one child could pass the tests that are now required by Federal law.

## ALASKAN NATIVE EDUCATION EQUITY ACT

We are in a situation where we funded last year an Alaskan Native Education Equity Act at \$24 million. Your budget proposes to reduce that program to \$14.2 million below what we provided for 2001 and for 2002.

We hope you will come up and see our State and go out to those native areas. I think maybe you can come up with Secretary Thompson sometime, because you have joint responsibilities in many things. Sixty percent of those children do not graduate from high school. In some of the schools, as I said, not a single child has passed the exams.

Last year, out of 227 villages, there were 80 teacher spots in rural Alaska that were vacant that we could not fill. Now, the Alaskan Education Equity Act provided the extra funds to help bridge those gaps and try to get some increased quality of education in rural Alaska. I would hope that you would help us and proceed. There is some indication that the Department wants to wait 3 years to get the results from the national tests before you proceed, is that correct?

Secretary PAIGE. I do not believe that is correct, Senator.

Senator STEVENS. I hope it is not. I am just going with the hope that you would not do that. Our State is one-fifth the size of the whole United States, and the population is just slightly higher than that of North Dakota. We have areas that I want to take you to that have no roads, they are accessible only by plane, and as a matter of fact, you have to go in the daylight, because those runways do not even have lights on them. We are dealing with an area that is rampant with high rates of abuse of substances, that have basically no running water or sewer, and they have increasing population rates that is astounding, about eight children per family.

We need to find somebody to follow through on the act that we passed, that the President requested, and we passed, in an area that really it will help. It does not really fit, but it will help, if we recognize the need to bring those children up to where they, too, can have a quality education.

## CAROLYN WHITE PHYSICAL EDUCATION FOR PROGRESS ACT

I am also concerned about the funding for a program we call the Carolyn M. White Physical Education for Progress, the PEP Act, which is part of that No Child Left Behind Act. Mr. Secretary, that is named after my chief of staff, who is on her way to Duke right now for about her tenth session in radiation and other treatment, because of a brain tumor. She conceived that act, and on a bipartisan basis, the committee decided to name it after her. She has a very fine edge in terms of whether she survives or not. We all pray for her.

This budget eliminates that funding, and we authorized it, and we had hoped that it would be funded as part of the process. I hope that you will take a look at that. I have long been an advocate of physical exercise for the focus of health. In our State—well, as a matter of fact, the Surgeon General issued a report that we have an epidemic of obesity, he said, the other day.

In Alaska, I checked this morning, since 1991, obesity in our State has risen 50 percent. Obesity-related diseases, like diabetes and heart disease, outstrip, for instance, smoking-related illnesses now, and I think physical activity ought to be a major portion of the educational system. Of course, I am old enough to remember that we had to do it 1 hour a day whether we liked it or not, and it was tough, and the toughest part of the whole education program was the coaches, and you played whether you were good or not, and you exercised. As a matter of fact, we got most of our hygiene education, and even the differences between the birds and the bees from the coaches. I do not want to elaborate on that.

Secretary PAIGE. I do not know if that is good or bad, Senator. Senator STEVENS. As a father of six, I have had to follow through and take their places a few times.

I do ask that you take a look at the PEP Act. It was designed to have some examples throughout the country that school districts would take on the duty of restoring daily physical education in grades one through twelve, and if they did, they got assistance in modernization of their facilities to provide that physical education opportunity.

# JUVENILE DIABETES CONNECTED TO LOW EXERCISE LEVELS

I have one other comment to you, Mr. Secretary. I will not ask questions at this time. I am taking too much time already. The diabetes problem in this whole equation, it bothers me, because the diabetes people tell me that with just a little bit of exercise every day, and we could hold back juvenile diabetes. Did you know that? It really retards growth. Yet, the education program neglects physical education totally.

What is your feeling about that? Can I ask one question? What is your feeling about physical education, as far as the education curriculum?

Secretary PAIGE. I think it is a very important part of the curriculum, Senator. In fact, I have a background in physical education—

Senator STEVENS. Good.

Secretary PAIGE [continuing]. And I would think that physical education is imperative, in fact, along the lines of which you have just spoken about.

Senator STEVENS. I want you to meet my chief of staff when she recovers, God willing, and she will give you a few lessons about physical education.

Secretary PAIGE. Please indicate our blessings to her.

Senator STEVENS. Thank you very much. Thank you for your courtesy.

# Senator HARKIN. Thank you, Senator Stevens. Senator Murray.

# OPENING STATEMENT OF SENATOR PATTY MURRAY

#### Senator MURRAY. Thank you very much, Mr. Chairman.

I will submit my opening statement and my questions for answers, since I will not be able to stay for that part, but let me just echo what the chairman said about my deep disappointment about the President's budget that has been sent to us. We worked very hard last year to come to a consensus on an education reform bill that was called No Child Left Behind.

# NO CHILD LEFT BEHIND ACT OF 2001

There were two parts of that bill. It called for higher standards and accountability, but it also promised more investments so schools could make progress. So I was very deeply disappointed just a few months after that bill was signed, and everybody went around the country touting it, that the budget does not reflect the reality of the need in the numbers that came to us. Freezing programs like after school, and safe and drug-free schools, and Pell Grants, and not fully funding our share of special education costs, that was a huge part of the debate over ESEA reauthorization, cutting all funds for dropout prevention and smaller schools, training teachers to use technology, rural student achievement, mentoring disadvantaged students. It just is a real disappointment to see the numbers after we heard such rhetoric out there, and I echo the chairman's comments about that.

I am especially surprised to see in the budget a proposal for a massive expenditure on a backdoor voucher scheme through tax cuts, when the Committee, and Congress rejected vouchers in the No Child Left Behind Act. So it seems to me that we have made a decision against vouchers. Yet the President has made a decision to go ahead and fund that at the expense of a lot of things we all worked together on and agreed on with the President in terms of leaving no child behind.

I also just want to mention rural education. Senator Stevens talked about the tremendous challenges rural education faces, from severe teacher shortages, to transportation costs, lack of resources, or lack of access to advanced classes, I was really surprised to see the President's budget zero out funding for the Rural Education Advancement Progam, and I want to know how we plan to overcome these barriers, if we do not provide additional funds.

# PELL GRANT FUNDING

Finally, Mr. Chairman, let me just mention that I was really disappointed to see \$1.3 billion in cuts to other education investments to pay for last year's Pell Grant increase. That is unnecessary. The program has frequently run a deficit in the past. It has always been corrected. What the President did was really cut all of the investments that we identified as needs in our local communities. I know that you as a former superintendent know, that we know the needs out in our local districts far better than somebody here in Washington, DC. Those programs were ones that we identified and then as a Congress, agreed on in the appropriations bill. I think the needs of Washington State to fund investments that we know are needed, like early childhood education programs, after-school programs, and Internet connections for our rural districts, should not be played off against very needed Pell Grant increases.

Mr. Chairman, I just came to express my real frustration with the budget request that we have been given, and I want to work with you and Secretary Paige as well, because I think we are doing our kids a disservice if we fund education in this manner. Thank you very much.

Senator HARKIN. Thank you, Senator Murray.

I know Senator Specter has obligations on another committee, and I would turn to our ranking member, Senator Specter at this time.

## OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. Well, thank you, Mr. Chairman.

Senator SPECTER [continuing]. And thanking you for your service in the administration, and for coming from Houston. I think you are doing an outstanding job.

Secretary PAIGE. Thank you.

## NO CHILD LEFT BEHING ACT OF 2001

Senator SPECTER. There is no higher priority than education. I think last year was a very good year for education in America, with the increase in funding, and with the enactment of the No Child Left Behind Act, an important education bill. The bill provides accountability and testing on a bipartisan basis, I think it was a very, very significant piece of legislation.

The budget which has been submitted candidly looks a little spare to me, considering as much as we really ought to be doing in education, but I know that the administration faces difficult priorities, and OMB has a very important, if not decisive, hand in the budgets which are proposed. But, Senator Harkin and I will be working through it, and trying to find a way to expand it to the extent that we can.

I am presently involved in the Judiciary Committee hearing on Judge Pickering, and statements are being made at this time. I was able to leave, because Senator Hatch was speaking. It is very important to have the proper inflexion on that, not to have any suggestion at all, but I do have to return. I will be submitting some questions in writing.

#### CAMPUS CRIME

One item I would comment on, Mr. Secretary, is the campus crime issue, something that I have been working on for a long time. The constituents, the Clary's, are the parents of a young girl who was brutally murdered, and they have been an inspirational force. We passed legislation, and we need to have a look by you Mr. Secretary, personally, at the way that the laws are being enforced. There is a great deal more that I would like to say, but I do have to return to the Pickering hearing.

Thank you, Mr. Chairman.

Secretary PAIGE. Thank you for coming, Senator.

Senator HARKIN. Thank you, Senator Specter.

Senator Gregg.

# OPENING STATEMENT OF SENATOR JUDD GREGG

Senator GREGG. Thank you, Mr. Chairman. Mr. Secretary, it is a pleasure to be here with you today, and to have a chance to have you present testimony to this committee relative to the President's proposal on education.

Let me just say, I have to disagree with the characterization of the chairman and the Senator from Washington as to the President's initiatives here on education. Let us put it in some perspective.

## EDUCATION FUNDING INCREASES OF PREVIOUS YEARS

First off, I congratulate the chairman of this committee and the other members of this committee for the extraordinary commitment they have had to education over the last few years, and the significant increase in funding, as the chairman mentioned, a 13.7 percent increase I think is what he said.

## NO CHILD LEFT BEHIND ACT OF 2001

We have to remember that when we did the No Child Left Behind bill, basically, we looked at all the programmatic activity that was out there. In the context of those increases, we made some very significant decisions as to how we should reorganize the delivery of education dollars from the Federal level.

## INCREASES IN CLASS SIZE AND SCHOOL CONSTRUCTION

One of the decisions we made was that in those 13 percent increases, the majority of those increases came in two categorical programs, class size and building construction, along with a variety of smaller categorical programs.

We decided as an authorizing committee, of which everyone on this committee seems to be a member, that we will change the focus of those programs. We reduced the number of categorical programs out there, and we took specifically the class-size money and the school construction money and changed the way it was to be allocated.

# TEACHER QUALITY PROGRAMS—FUNDING INCREASES

Education quality funding, as noted in the charts by the chairman, is a reflection of a huge increase in spending for teachers. Last year, under this committee's leadership, the teacher dollars went up, I think, something like \$780 million, something like that. Essentially, what we did with those new dollars, which were then class-size dollars mostly, was we joined them together with the Eisenhower fund, and we turned them back to the local communities, and said, "Here, these dollars are now going to be given to you with great flexibility. You can hire more teachers, if you need them, for class size, you can educate your teachers better, you can give them more support, or you can pay your teachers better." We did this in an attempt to get more for those dollars, and to leave it to the local communities to get more for those dollars, and to recognize the fact that we had put a huge amount of money into this account, and that we weren't getting more for those dollars, because we weren't seeing an increase in educational efforts.

So I think that account and its new structure, under the funding mechanism that has been proposed, is properly funded, because actually these communities are going to end up with more bang for the buck, a lot more bang for the buck, and because of this committee's commitment earlier in the prior years to significantly increase those dollars, there are a lot of dollars in the pipeline.

## TITLE I AND IDEA FUNDING INCREASES

Where the President did significantly increase education funding, and it was regrettably not mentioned here earlier, is on the accounts that have not been adequately funded over the last 8 years. Over the last 8 years, the prior administration simply did not pay attention to Title I. Title I, or IDEA, for that matter, this committee paid attention to IDEA, but the President did not, the prior President.

So what this President has said is, "I want to focus the new dollars on the programmatic activity that is directly the responsibility of the Federal Government, which is helping low-income kids and helping kids who are disabled. So he has increased, the most significant increase in history, Title I, by \$1 billion, more than \$1 billion, and he has, for the second year in a row—in fact, he increased that last year, too, for the second year in a row—sent up \$1 billion increase in IDEA, which makes the 2 most significant years of increase in IDEA ever proposed by the administration. However, I will note, under the leadership of Senator Harkin, this committee has managed to beat the administration in the last 2 years, and I congratulate them for that.

## NO CHILD LEFT BEHIND ACT

The point here is this. The No Child Left Behind bill set up a new structure to approaching education, which was essentially that we were going to focus on getting money into the Title I system, and we were going to decide to get the Title I system to be more responsive to benefitting the low-income child, and the President recognizes that with his funding punch, significant funding punch, and he has also recognized the need for IDEA funding.

So I think if you put the dollar increases in that context, you can recognize that the President has fulfilled his commitments, he has lived up to what he said he would do under the No Child Left Behind bill. A lot of miscellaneous programs, which have not necessarily been proven to work that well, have been reduced, and most of them are small programs, and some of the budget has been level funded, because it had received such large increases in the prior years.

# PELL GRANT FUNDING DEFICIT

Pell Grants is another issue. Pell Grants has been running a deficit for 2 or 3 years now, a \$900 million deficit 2 years ago, an \$800 million deficit this year. Trying to correct that is something that we as a Congress are going to have to figure out how to do, and the President has set up a supplemental to try to do that, and he has committed to try to get the backlog of people at the \$4,000 Pell Grant award level, but we haven't even covered the \$4,000. I don't know how we can even go higher.

## TITLE I AND IDEA FUNDING INCREASES

So I do believe this President has made the type of commitment that is appropriate to living up to the understanding under No Child Left Behind. There is a strong commitment, and it is especially strong in the context of the fact that when we started this exercise, there was a huge surplus, and we were not at war. Today, we are at war, and we are in deficit, and the President has still stood by his commitment to dramatically increase funding, the largest increase in history in Title I, and to maintain the continued strong funding stream of increases in IDEA.

So that is the way I perceive this. I recognize that it is a little different than the way the chairman perceives it, but that is why we have two parties. Thank you, Mr. Chairman.

Senator HARKIN. Thank you, Senator Gregg.

Senator Cochran.

## OPENING STATEMENT OF SENATOR THAD COCHRAN

Senator COCHRAN. Mr. Chairman, thank you. I join you in welcoming the distinguished Secretary of Education to our committee. It is good to see you, Mr. Secretary.

Secretary PAIGE. Thank you, Senator.

# TEACHER RECRUITMENT AND TRAINING

Senator COCHRAN. I congratulate you on the work you are doing as the Secretary. We appreciate you coming to our State, and visiting schools, and colleges. I was just with the president of Jackson State University over at my office, and they were pretty excited about some support that they were receiving under a discretionary program for teacher recruitment and training, trying to do something about the teacher shortage, and the like. I want to congratulate you on the effort you are making to help deal with that problem at the national level.

## DIGITAL EDUCATIONAL PROGRAMMING GRANTS

One other area that I want to specifically mention is that last year the education authorization bill included a competitive grant program for local public television stations who were faced with inordinate expenses in converting to digital programming for education programs. Twelve million dollars were actually appropriated to fund the program, and there is no information, though, on the Department's web site about the grant process, or how to apply and compete, and it makes us wonder what point we are at in getting this program functioning, and getting people up to speed as to what they ought to do to compete for these funds.

I bring that to your attention just by way of expressing the hope that the local public television stations will know soon how they can compete for these funds.

Secretary PAIGE. Thank you.

Senator COCHRAN. There is a very important program that you are requesting funds for. There were some categorical programs that we argued over, here in the Congress, about whether to authorize them in the reauthorization bill, but things like character education, Reading is Fundamental, you've requested funds for these programs, and I want to congratulate you there, and many others, such as tech prep, which is important. It shows that the administration is willing to work with the Congress, and I think that is a very important step to identify these areas of special interest, and to provide the funds for them.

## READY TO LEARN TELEVISION

The Ready to Learn Television program, for example, has a request in your budget for \$22 million for that program. I have seen for myself at some demonstrations back in my State how students are reacting, parents and preschool children are reacting to these programs. I really think we are on to something here, and I think you realize that, and I congratulate you and the people in your department for working to make these programs a success. Thank you, Mr. Chairman.

Senator HARKIN. Thank you, Senator Cochran.

Secretary Paige, you have been very kind and generous to hear us all out on our thoughts on the budget, and now, it is your turn.

So, Mr. Secretary, again, we welcome you here, and your entire statement will be made a part of the record, and please proceed as you so desire.

## SUMMARY STATEMENT OF HON. RODERICK PAIGE

Secretary PAIGE. Well, thank you. Thank you, Mr. Chairman.

Members of the committee, thank you for this opportunity to testify on behalf of President Bush's 2003 budget for the Department of Education. I want to begin by once again thanking the members of this committee, along with your colleagues in the full Senate, for your hard work and many contributions to securing the passage of the No Child Left Behind Act of 2001, which President Bush signed into law in January.

# NO CHILD LEFT BEHIND ACT OF 2001

I take it as a vote of confidence—in the new law and in the Department of Education's ability to carry out the law—that the Congress followed up its approval of the No Child Left Behind Act by providing the \$6.7 billion increase for the Department in fiscal year 2002. This was the largest in a series of increases that have more than doubled the Department's discretionary budget since fiscal year 1996. These new resources, which will be available for the school year beginning this fall, will help States, school districts, and schools implement the No Child Left Behind Act as quickly as possible.

For fiscal year 2003, the President's budget was driven by the overriding concern of defending our Nation and people from the threat of terrorism following the terrible events of September 11. Most of the new resources in the President's proposal for 2003 are dedicated to the Defense Department, which continues to wage war against terrorism outside our borders, and to Homeland Security, for efforts to keep our States and communities safe, and to prevent attacks.

## NO CHILD LEFT BEHIND FUNDING

Nevertheless, our 2003 budget for education builds on the major increases provided in recent years. It gives States and school districts the resources they need to implement the changes called for in the No Child Left Behind Act. The request would provide \$50.3 billion in discretionary appropriations, an increase of \$1.4 billion, or 2.8 percent, over the 2002 enacted level.

With this increase, the Federal investment in education will have climbed nearly \$15 billion, or 41 percent, over the past 3 years. I emphasize the very significant increase provided by this committee for the Department in recent years to make the larger point about President Bush's strategy for investing in education.

With this administration, No Child Left Behind was not just about how we spend Federal funds on education, but rather about how we increase the return on that investment. We have very little to show, for example, for the nearly \$190 billion we have invested in the Elementary and Secondary Education Act since 1965. Dramatic growth in State and local funding for elementary and

Dramatic growth in State and local funding for elementary and secondary education of the past decade also has failed to significantly close the achievement gap for poor and minority students, or even raise the overall student achievement in any meaningful way. Increased funding may be one answer, but it is clearly not the only answer for our education problems.

In addition, while we all agree on the importance and the promise of programs like Title I Grants to Local Education Agencies, that is simply not the case for every program reauthorized by the No Child Left Behind Act. Many of the smaller ESEA programs are redundant, serving the same purposes and populations as larger, more flexible programs, while others do not appear to actually work, and still others have already achieved their original purpose, or are just too small to have a national impact on our schools. These realities gave us some clear guidelines for responding to the dramatically different budget perspectives resulting from the combination of September 11 and declines in economic performance.

#### PRINCIPLES UNDERLYING NO CHILD LEFT BEHIND

First, we believe that the No Child Left Behind Act provides a real opportunity to leverage existing Federal education resources already in the pipeline following the large increases of recent years. Funding decisions will be based on the principles that drove the No Child Left Behind Act, including increased accountability, greater choice for parents and students, particularly those from low-income backgrounds who attend low-performing schools, more flexibility for States and school districts, and stronger emphasis on teaching methods grounded in scientifically based research, especially in teaching our children to read.

# TARGETING FEDERAL EDUCATION DOLLARS

Second, we remain committed to targeting Federal education dollars to poor and minority students, and others who are more likely to be left behind by our education system. One way to do this would be to redirect resources from narrow categorical programs to more flexible formula grant programs that better focus on the students in schools with the greatest need for assistance.

The results of these guidelines is a fair and straightforward 2003 budget request that we believe provides effective support for turning the vision reflected in the No Child Left Behind Act into a reality of better schools and improved student achievement.

## PROPOSED FUNDING INCREASE

We are proposing significant increases for Title I Grants to Local Education Agencies, Special Education Grants to States, and Pell Grants. Other priorities include major increases for the researchbased Reading First program, and for further research, development, and dissemination of proven educational practices.

## TEACHER QUALITY STATE GRANTS

We would maintain funding for large, flexible State grant programs, most of which, like Improving Teacher Quality State Grants, have received big increases in recent years. The request would consolidate and eliminate some smaller and less flexible categorical programs, which in nearly every case could be continued at the discretion of State and local authorities under other authorities.

## PREPARED STATEMENT

These are rough times for those charged with preparing a responsible Federal budget, and they demand rough choices. I believe the President's 2003 budget makes these rough choices in a way that is fully consistent with the No Child Left Behind Act. I hope you will seriously consider our proposals, and I would be happy to answer any questions that you might have. Thank you for this opportunity.

[The statement follows:]

## PREPARED STATEMENT OF HON. RODERICK PAIGE

Mr. Chairman and Members of the Committee: Thank you for this opportunity to testify on behalf of President Bush's 2003 budget for the Department of Education. I want to begin by once again thanking the Members of this Committee, along with your colleagues in the full Senate, for your hard work and many contributions to securing passage of the No Child Left Behind Act of 2001, which the President signed into law in early January.

#### NO CHILD LEFT BEHIND ACT

This new law, which reauthorized the Elementary and Secondary Education Act, promises to greatly improve Federal support for the changes we need to raise student achievement and ensure that no child is left behind by our education system. In particular, the stronger accountability found throughout the No Child Left Behind Act (NCLB) will help ensure that the investments this Committee makes in education bring real improvement to our schools.

I take it as a vote of confidence—in the new law and in the Department of Education's ability to carry out that law—that the Congress followed up its approval of the No Child Left Behind Act by providing a \$6.7 billion increase for education for fiscal year 2002. This was the largest of a series of increases that have more than doubled the Department's discretionary budget since fiscal year 1996. We are working hard to help States, school districts, and schools to use these new resources effectively, through rapid implementation of the reforms in the new law, to help all students meet high standards.

#### FISCAL YEAR 2003 BUDGET REQUEST

For fiscal year 2003, I think all of you know that the President's budget was driven by the overriding concern of defending our Nation and people from the threat of terrorism following the terrible events of September 11. Most of the new resources in the President's proposal for 2003 are dedicated to the Defense Department, which continues to wage the war against terrorism outside our borders, and to Homeland Security for efforts to help our States and community prevent and prepare for new attacks on our freedom.

Nevertheless, I believe we are proposing a strong budget for education in 2003. It builds on the major increases provided in recent years, and gives States and school districts the resources they need to implement the changes called for in the No Child Left Behind Act.

The request would provide \$50.3 billion in discretionary appropriations for the Department of Education in fiscal year 2003, an increase of \$1.4 billion, or 2.8 percent, over the 2002 enacted level. With this increase, the Federal investment in education will have climbed nearly \$15 billion, or 41 percent, over the past three years.

I want to emphasize two points about our investment in education. First, as most of you know, Federal education dollars are closely targeted to poor and minority students, those students who are most likely to be left behind by our education system. Our 2003 budget would do an even better job of targeting, by redirecting resources from narrow, categorical programs to more flexible formula grant programs that better focus on students and schools with the greatest need for assistance.

Second, we want to make sure this new investment in education produces results, in terms of improved student achievement. Unfortunately, this has not been the case in recent years, which have witnessed growing Federal budgets for education but flat or even declining student achievement. For this reason, our budget targets the same principles that drove the No Child Left Behind Act, which reauthorized the Elementary and Secondary Education Act.

These principles include increased accountability for States, school districts, and schools; greater choice for parents and students, particularly those from low-income backgrounds who attend low-performing schools; more flexibility for States and school districts in the use of Federal education dollars; and a stronger emphasis on teaching methods grounded in scientifically based research, especially in teaching our children to read.

#### IMPLEMENTING NO CHILD LEFT BEHIND

For example, our request includes \$11.4 billion for Title I Grants to Local Educational Agencies, an increase of \$1 billion, or 9.7 percent, to give States and school districts additional resources to turn around low-performing schools, improve teacher quality, and ensure that no child is trapped in a failing school. The \$1 billion increase would be allocated through the Targeted Grants formula, which directs a greater share of funds to the highest-poverty schools than the other Grants to LEAs formulas.

We also are asking for a \$100 million increase for Reading First State Grants, for a total of \$1 billion to support comprehensive reading instruction, grounded in scientifically based research, for children in grades K-3. The budget would continue to provide \$75 million for Early Reading First, the new competitive grant program that helps to develop the school readiness of preschool-aged children in high-poverty communities.

To help increase the availability of evidence-based research and knowledge of proven educational practices, the request includes \$175 million for Research and Dissemination, an increase of \$53.2 million, or almost 44 percent. And to support State efforts in measuring the progress of all students toward proficiency in reading and mathematics, we would provide \$387 million for State Assessments and Enhanced Assessment Instruments. These funds would pay the Federal share of developing and implementing—by the 2005–2006 school year—the expanded annual assessments in grades 3 through 8 that are integral to the strong State accountability systems required by the NCLB Act.

#### EXPANDING OPTIONS FOR PARENTS

A key principle of the No Child Left Behind Act is that when parents have the information and options they need to make the right choices for their children's education, our schools and our children will succeed. The NCLB Act requires States and school districts to report annually on how their schools and students are performing, and the new assessments will provide diagnostic information that will help parents and teachers to identify the strengths and weaknesses of individual students. Parents of students in failing schools will have the option of transferring them to a better public school or obtaining supplemental educational services from the provider of their choice. Our 2003 budget would help to ensure that parents have meaningful options for providing their children a high-quality education.

options for providing their children a high-quality education. For example, the President is proposing a new refundable tax credit for parents transferring a child from a failing public school. If a student's regular public school fails to make adequate yearly progress, parents would be able to transfer the student to another public or private school and receive a credit of 50 percent of the first \$5,000 in tuition, fees, and transportation costs.

The request also includes \$50 million for a new Choice Demonstration Fund, which would support research projects that develop, implement, and evaluate innovative approaches to providing parents with expanded school choice options, including both private- and public-school choice. We also would continue to support Voluntary Public School Choice through \$25 million in grants to establish or expand public school choice programs across States or districts. Grants would support planning, transportation, tuition transfer payments, and efforts to increase the capacity of schools to accept students exercising a choice option.

Another key part of the Administration's efforts to increase choice for students and parents is continuing support for Charter Schools, which would receive \$200 million in 2003. In addition, we are proposing a new, \$100 million Credit Enhancement for Charter School Facilities program. A major obstacle to the creation of charter schools is their limited ability to obtain suitable academic facilities. Our proposal would support competitive grants to public and nonprofit entities to help charter schools finance their facilities through such means as providing loan guarantees, insuring debt, and other activities to encourage private lending.

#### INCREASING FLEXIBILITY FOR STATES AND SCHOOL DISTRICTS

The NCLB Act provides unprecedented flexibility for States and school districts to combine resources from selected State formula grant programs to pursue their own strategies for raising student achievement and ensuring that no child is left behind. For example, States and LEAs may transfer up to 50 percent of the funding they receive under four major formula grant programs to any one of the programs, or to Title I. The covered programs are Improving Teacher Quality State Grants, Educational Technology, Innovative Programs, and Safe and Drug-Free Schools and Communities.

The President's budget includes substantial funding for these flexible programs, including \$2.85 billion for Improving Teacher Quality State Grants, \$700.5 million for Educational Technology State Grants, \$385 million for State Grants for Innovative Programs, and \$472 million for Safe and Drug-Free Schools and Communities State Grants.

In addition, the request provides \$665 million for English Language Acquisition State Grants, which replace a complex series of categorical grants with a flexible program that will enable States to design and implement statewide strategies, grounded in scientifically based research, for meeting the educational needs of limited English proficient and immigrant students. The request also provides \$1 billion for 21st Century Community Learning Centers to provide before- and after-school academic enrichment opportunities, particularly for children who attend high-poverty or low-performing schools.

## SPECIAL EDUCATION AND VOCATIONAL REHABILITATION

Special education is another area that we will be focusing on over the next year. President Bush's commitment to leave no child behind specifically includes children with disabilities. This is why he believes it is important for the Federal Government to continue providing additional support, through the Individuals with Disabilities Education Act (IDEA), for State and local efforts to help children with disabilities meet the same challenging State standards as other children. For 2003, the President is proposing a \$1 billion, or 13.3 percent, increase for Special Education Grants to States. In addition, the President has established a Commission on Excellence in Special Education which, as part of the reauthorization process, will assist the Administration in a comprehensive, evidence-based review of the IDEA.

The 2003 request also supports the President's *New Freedom Initiative*, which is aimed in part at promoting the integration of individuals with disabilities into the workforce. Although many people with disabilities are obtaining and retaining jobs, the unemployment rate for people with disabilities remains unacceptably high. To help individuals with disabilities prepare for, obtain, or retain employment, the budget provides \$2.6 billion for the Vocational Rehabilitation (VR) State Grants program, an increase of \$134.9 million, or 5.4 percent. The request for VR State Grants reflects the mandatory inflation increase, an additional \$20 million to improve employment outcomes, and a consolidation of funding from smaller, overlapping categorical programs under a multi-year Administration effort to reform the Federal Government's training and employment programs.

#### POSTSECONDARY EDUCATION

The President emphasized reform of elementary and secondary education during his first year in office, but he fully recognizes the critical role of postsecondary education in securing the American Dream of success and prosperity. This is why, for example, our budget includes \$10.9 billion for the Pell Grant program, an increase of \$549 million, or 5.3 percent, to help ensure access to postsecondary education for low-income students and families and to maintain the maximum Pell award level at \$4,000. This increase does not include the \$1.3 billion supplemental for Pell Grants that the President is proposing for fiscal year 2002 in order to address the shortfall created by the 2002 appropriations act.

-Overall student financial aid available would expand to \$54.9 billion under the President's budget for 2003, an increase of \$2.8 billion, or 5 percent, over 2002, with the number of recipients of grant, loan, and work-study assistance growing by 339,000 to 8.4 million students and parents.

In addition to traditional student aid, our request would encourage highly qualified math, science, and special education teachers to teach in low-income communities by expanding loan forgiveness for such teachers from \$5,000 to a maximum of \$17,500. Too often, schools in such communities are forced to hire uncertified teachers or assign teachers who are teaching "out-of-field."

—The budget also increases support for institutions that enroll a large proportion of minority and disadvantaged students, including Historically Black Colleges and Universities, Historically Black Graduate Institutions, Hispanic-Serving Institutions, and other colleges serving underrepresented populations. The request includes a total increase of \$15.8 million for these institutions to help close achievement and attainment gaps between minority students and other students. The budget also includes \$802.5 million for the Federal TRIO Programs, and \$285 million for Gaining Early Awareness and Readiness for Undergraduate Programs (GEAR UP), to provide educational outreach and support services to help more than 2 million disadvantaged students to enter and complete college.

#### DEPARTMENT MANAGEMENT

Finally, I want to mention part of our budget that is very important to me personally, and that is our effort to improve Department Management. As most of you know, I am determined to carry out the President's Management Agenda and make the Department a model Federal agency. To help reach this goal, our 2003 request supports my *Blueprint for Management Excellence*, a long-term action plan for improving Department management. This plan includes efforts to ensure financial integrity, strengthen management of the student financial aid programs, improve the Department's use of its human capital, use technology to better meet customer needs, and create an accountability-for-results culture within the Department.

#### CONCLUSION

The President's 2003 budget for education supports the vision reflected in the No Child Left Behind Act for closing the achievement gap and improving the quality of education for all Americans. I urge you to give these proposals careful consideration, and I stand ready to answer any questions you may have.

# RURAL EDUCATION PROGRAM

Senator HARKIN. Mr. Secretary, thank you very much, and I can assure you that we will. This committee will seriously look at the budget requests and proposals, but as you have heard from some of the people on the committee before they left, there may be some adjustments made in some of the programs.

One that I just wanted to pick up on, Mr. Secretary, is sort of closely tied to what Senator Stevens was talking about, and that has to do with rural education. Rural school districts have many unique needs. I know. I came from one. I went to a two-room school in a small rural district in Iowa. Small schools in these rural areas, when they try to attract good teachers, they have a problem. They have a problem in offering any kind of advanced classes. They have a problem in providing up-to-date technology.

Now, when you are talking about formula grants, they are so small sometimes that the money they get from a formula grant is not really much—they cannot do much of anything with it. So last year, Congress created a new rural education program, and funded it at \$162 million. As a result—I can only talk about my State more than 80 small districts in my State of Iowa will each receive an additional \$20,000 to \$60,000, as well as greater flexibility to pull together the funds they get from a variety of programs.

I have heard from some of them. They are very excited about using this money to make some significant changes in their schools, but now they learn that the President's budget completely eliminates the program.

I will tell you about one that I heard from. This is a 340-student Preston School District in Iowa. The superintendent, Paul Tobin, says that under the President's budget his district would get about \$1,200 for technology, \$2,000 for Safe and Drug-Free Schools, \$2,000 for an innovative program grant, \$1,500 for professional development.

Now, even if you pool all that money together, as you suggest, Mr. Tobin says it is not that much to work with, but if you add another \$30,000, which is what he would get under the Rural Education Program, then he would have enough to do something significant, like add some up-to-date technology, hire another teacher. So that is the difference that he is looking at. So how would you explain this to Mr. Tobin, and what he should do, Mr. Secretary?

Secretary PAIGE. I would begin by saying the administration proposed no funding for rural education in fiscal year 2003, and this is because the administration believes that changes made in the reauthorization of the Elementary and Secondary Education Act of 1965 eliminates the needs for categorical programs like the two rural education programs. The reauthorized ESEA programs, target dollars in broader categories that can be used to cover those needs, so the dollars are not taken away, they are just in different places in the budget. Title I would be a specific reference that I would make.

Senator HARKIN. Well, by the elimination of this program, Superintendent Paul Tobin loses \$30,000. Now, you say there is another \$30,000 someplace for him. He loses \$30,000. Tell me where he is going to—you say he is going to get some more money someplace. Tell me where he is going to get it.

## RURAL EDUCATION FUNDING

Secretary PAIGE. Mr. Chairman, it may be different from district to district, but in the aggregate, the total money is increased, so when we look at the increases in the technology monies, and the Title I monies, the teacher quality monies, those are the activities that we believe would be better vehicles to drive those funds to rural districts.

We know that the numbers may be different from district to district, but in the aggregate, the numbers we have would actually hopefully drive more money to rural education activities.

Senator HARKIN. Did you mention technology?

Secretary PAIGE. Yes.

Senator HARKIN. I guess there is no increase in technology money.

Secretary PAIGE. I am talking about the increases from 2001 to 2003, total.

Senator HARKIN. Well, he says his district is going to get about \$1,200 for technology. I mean he admits that. I told you what he's going to get. He had had the \$30,000. Now he is not going to get it.

Secretary PAIGE. Did he indicate what he was getting in 2001, by any chance?

Senator HARKIN. Well, I do not know. The figures I read to you were for 2002.

Secretary PAIGE. Okay.

Senator HARKIN. I guess you are saying that there are not going to be any cuts out there, but Mr. Tobin tells me that he is losing \$30,000. I understand aggregates. That is wonderful. Mr. Tobin, he does not care about aggregates. He cares about his school district.

There are about 80 districts in my State that are going to be cut, and these are rural districts, and they have no other place to go. I just want some help here. What am I supposed to tell him?

Mr. HANSEN. Again, as the Secretary said in his opening statement, the priority programs in our budget were for Title I and IDEA, and that is where \$3.5 billion of increases were proposed in our budget.

Secretary PAIGE. What is happening here is that the core programs of the ESEA are experiencing significant increases in terms of the President's request. Title I would be such a program. We consider this a core program. There are other small programs inside the ESEA that have been reduced, reasoning that the larger increase in Title I will offset that, and they can draw funds from Title I, with the flexibility that is provided there, to cover the costs of the \$30,000 that you are speaking of.

The difference is we are not categorically specifying where these dollars go, because we are providing the kind of flexibility to the States and local districts to make those decisions. So where he has found a loss there, he will find an increase in Title I.

Senator HARKIN. Well, I will check into that. Now, he did not list Title I, but I am told that any increases in Title I will not replace the money lost to the Preston School District by eliminating the rural education money. I will look at it further, I do not know, but that is what I am told.

Secretary PAIGE. We will do so as well, Senator, but I can assure you of one thing, and that is, we have no interest in making matters worse for our rural educators, or our urban educators. We want all education to experience an increase in productivity. We will have some discussions with you about that.

Senator HARKIN. I just think that a number of us on this committee recognizes that some of these small rural districts, when it all falls out, and you get all these programs, and grants, and all that kind of stuff, they just do not get much, and so we wanted to get a targeted program out to help them, and that is what this was for, but we will work with you on it, and see if we can-

Secretary PAIGE. Thank you.

Senator HARKIN [continuing]. Figure something out.

Secretary PAIGE. As we will as well. Senator HARKIN. Thank you. Thank you, Mr. Secretary.

Senator COCHRAN. Mr. Chairman?

Senator HARKIN. Senator Cochran.

# FLEXIBILITY IN EDUCATION FUNDING

Senator COCHRAN. Thank you very much. I can remember when I was running for Congress in 1972, and I talked to my parents first about it, and my wife, and her parents. And after having decided to run, when I was in the process of figuring out things that I wanted to accomplish, I asked my father, who was a county superintendent of education, what I ought to say to the teachers and the school principals that I would run into in the congressional dis-trict. He said, "We need more flexibility in how we use the Federal funds that come to us, and we need to know earlier in the year, rather than later in the year, how much we are going to get." Those were the two things that have stuck with me over the years that I remember from that initial campaign.

## TITLE I INCREASE

I think this budget, like you pointed out, carries that into the language of the budget request, because Title I is increased by \$1 billion over the last year's level of funding, and we are providing that information to school districts earlier rather than later, as to what the budget request is, so they can make plans more coherent and consistent with the availability of the funds that they will need to administer the programs. So I want to congratulate you for that, and for using as a centerpiece of education reform the flexibility that you have given to local school administrators and teachers.

I had a hearing back in my State last year with the State board of education, and some of the administrators of these Title I funds in Mississippi to gauge how important they were, were they useful, how we could change the program to improve the effectiveness of it, and many of those suggestions that we got were included in the legislation that we passed last year, and that the President supported and recommended, to some extent.

So I think we are headed in the right direction. I know there are some programs that we asked to be included in the reauthorization bill that are not a part of the budget request, but that is part of the give and take, and as we go through our process of the hearings, and analyzing the budget in more detail, we will have to compromise on some of those things, and I think that is what the chairman is suggesting here, too, that we are going to probably have some differences of opinion, but in my view, they are not going to be very serious.

I think we really are on the same wavelength now, and a lot of that has to do with the President's attitude and your attitude as well.

Secretary PAIGE. Thank you.

Senator COCHRAN. I am very pleased overall, and I think you are going to find that kind of response throughout the country as well. Secretary PAIGE. Thank you.

Senator HARKIN. Thank you, Senator Cochran.

# TEACHER QUALITY MANDATES

I just have a couple more things that I would like to go over with you, Mr. Secretary. Would you put that chart back up there, that one with all the mandates on it. I wanted to go over this with you again, because I think it—not only for my own benefit, but for everyone else's.

Here are the new teacher quality mandates. "Beginning in 2002 and 2003, all teachers newly hired in a program supported by Title I funds must be highly qualified. They must be fully licensed or certified, have a bachelor's degree, and demonstrate they are competent to teach the subject or subjects they are teaching."

Number two, "All current teachers, not just those in Title I schools, must meet this new standard by the end of the 2005–2006 school year."

The third, "States must monitor annual progress of the LEAs," local education agencies—"in reaching the requirement of having all teachers highly qualified." Fourth, "At the beginning of each school year, school districts

Fourth, "At the beginning of each school year, school districts must make available to parents, upon request, the following information about their child's classroom teacher, whether the teacher has met State qualifications and licensing criteria for the grade levels and subject areas taught, whether the teacher is teaching under emergency or provisional status, the baccalaureate degree of the teacher, and any other graduate certification or degree held by the teacher, and the subject area of the certification or degree, or if the child is provided a service by paraprofessionals, and if so, the paraprofessional's qualifications."

[The information follows:]

## NEW TEACHER QUALITY MANDATES

Beginning in 2002–03, all teachers newly hired in a program supported with Title I funds must be "highly qualified." They must be fully licensed or certified, have a bachelor's degree and demonstrate they are competent to teach the subject or subjects they are teaching.

All current teachers (not just in Title I schools) must meet this new standard by the end of the 2005–06 school year.

States must monitor annual progress of LEAs in reaching the requirement of having all teachers highly qualified.

At the beginning of each school year, school districts must make available to parents, upon request, the following information about their child's classroom teacher:

- -Whether the teacher has met state qualification and licensing criteria for the grade levels and subject areas taught. Whether the teacher is teaching under emergency or other provisional status.
- -The baccalaureate degree of the teacher and any other graduate certification or
- degree held by the teacher, and the subject area of the cereification or degree. -Whether the child is provided service by paraprofessionals and, if so, the paraprofessional's qualifications.

## TEACHER QUALITY FUNDING-FISCAL YEAR 2002 AND FISCAL YEAR 2003

Senator HARKIN. Well, that is quite a bit that they have to do, and I guess that was all part of the thought process in the Leave No Child Behind Act, of putting some standards out, and getting standards out there. Well, then we look at what we did on the teacher quality funding for the same group of teachers. This is all the teacher quality State grants. These are basically catch-all grants. School leadership, National Board for Professional Teaching Standards, which, by the way, was zeroed out in your budget.

Early childhood education, professional development, left the same, math and science partnerships, left the same, which is a cut, if you include inflation. Math and science consortia, from \$15 million to zero. Transition to teaching, that went up by \$4 million. National writing project, from \$14 million to zero.

The teaching of American history, from \$100 million to \$50 million. I think you are going to find a lot of people here on this committee concerned about that, dropping the teaching of American history. But how about this, technology training, \$62.5 million to zero for technology training. Teacher quality enhancement left at \$90 million.

These are all of the items that we have before us on our plate as an appropriations committee to deal with. This deals with teacher quality funding. The previous chart I had showed all of the mandates for teacher quality, and yet we now see this as about \$155 million less for teacher quality training, so, again, you can see our concern on where we are going to find this money, Mr. Secretary. May I have your response, please?

[The information follows:]

## TEACHER QUALITY FUNDING

	Fiscal year	
	2002	2003 (Bush)
Teacher Quality State Grants	10 million 15 million 12.5 million 15 million	12.5 million
	14 million 100 million 62.5 million 90 million	50 million 90 million
Total	3.232 billion	3.077 billior

Secretary PAIGE. Yes. Thank you for the opportunity, Senator, to respond. This budget is based on prioritizing the expenditures of the dollars that we have available to us. I would like to use the teacher quality one, with the \$2.85 billion, as an example. A few years back, this was at \$300 million. Now, it is at \$2.85

A few years back, this was at \$300 million. Now, it is at \$2.85 billion, with a lot of flexibility added to it. We are saying these are dollars you can use to increase teacher quality. We relied on you to know if you need teacher quality increased in technology, where you see the reduction, that you might target those dollars for teacher in technology training.

So the flexibility added to the increased dollars in the teacher quality provides opportunities for the local people on the scene to make the kinds of decisions that they need in order to improve student achievement at that particular location.

So this represents for us an enhancement in teacher quality opportunities, not a reduction. We realize full well that the teacher quality is the highest leverage point in the student achievement. We just did not assume that we could, from Washington, identify the specific needs for every place in the Nation. That is why it is presented like that, Senator. It is not that we disagree at all that teacher quality is important.

Senator HARKIN. Well, it just seems to me that what you are saying is that the \$3.232 billion that we funded last year was just too much money.

Secretary PAIGE. No. That is absolutely not what I am saying.

Senator HARKIN. Well, if it is not, then you have \$3.07 billion this time. It had to be too much money.

## TITLE I TEACHER QUALITY FUNDING REQUIREMENT

Secretary PAIGE. We are looking at it not just as 2003. We look at it also including the money in from 2002, where the increase occurred, and so we are looking at that broader span. In addition to that, what is not included there is 5 percent of the Title I dollars that must be used for teachers. That is not included on that chart.

Senator HARKIN. 5 percent of the Title I money has to be used for teacher quality standards?

Mr. SKELLY. That is right. A minimum of 5 percent, and up to 10 percent, is for teacher quality programs under the No Child Left Behind Act.

Mr. HANSEN. It would be another \$50 million to \$100 million.

Mr. SKELLY. There is \$1 billion increase in the President's budget for Title I, so if you were to spend 5 to 10 percent of that, you would add another \$50 million to \$100 million for teacher quality to the budget.

Senator HARKIN. So what you are saying is that you have gotten a \$1 billion increase for Title I grants. Out of that increase in Title I, that billion dollars, 5 percent—

Mr. HANSEN. 5 to 10 percent.

Secretary PAIGE. A minimum of 5 percent.

Senator HARKIN. A minimum of 5 percent has to be used for the list of things we have right here.

Secretary PAIGE. Not necessarily the things that are on that list, but for teaching and teacher quality. There may be other needs that are not on that list, but for the broad category of teaching, these dollars must be used for that purpose. Senator HARKIN. Okay. Well, we will take a look at that. Five percent, and it is mandated that it has to be used for teacher quality. of these.

Mr. HANSEN. For general teacher quality—

Secretary PAIGE. That is right.

Mr. HANSEN [continuing]. For Title I teachers, right.

Senator HARKIN. All right. I will take a look at that. Okay. That may work. We will take a look at that.

Mr. SKELLY. The law also provides flexibility, as the Secretary was saying, to use some of the teacher quality money, the technology money, the Safe and Drug-Free Schools money, the innovative program grant money for Title I.

Senator HARKIN. 5 percent of \$1 billion is how much?

Mr. HANSEN. \$50 million.

Senator HARKIN. \$50 million. What they are telling me is that you have \$155 million cut here, even if you take the \$50—

Mr. HANSEN. It could be \$50 million to \$100 million, because it is capped at 10 percent. It is 5 to 10 percent, so it could be \$50 million to \$100 million.

Senator HARKIN. So it could be \$50 million to \$100 million.

Mr. HANSEN. Right.

Senator HARKIN. So we are still short, even if we used all of it, all 10 percent, we are still short for money.

Mr. HANSEN. You may want to consider the Loan Forgiveness Program as well to be added to the list, because that is for teacher enhancement.

Senator HARKIN. We are getting closer. We are narrowing the gap all the time here. Okay. Well, we may have to narrow it even further, but the problem is that with the budget we have a hard time closing that gap, because we are just taking it from other areas.

# LOAN FORGIVENESS FOR TEACHERS PROGRAM

I just have two other little areas that I wanted to go over with you on the loan forgiveness proposal. I congratulate you. I appreciate what you have done. I think this is a step forward in the right direction, I have said so publically, for math, science, and special ed teachers.

I guess what I would say is, as I look ahead, and we see all of the estimates for teacher shortages in the future, I am not certain that we are really stepping up to the plate here.

I am told, and, again, this is the data that we are given, if you have different statistics, please let me know, but we were told that we are going to need to fill 2.2 million teaching jobs over the next 10 years. More than 700,000 will be needed in rural and high poverty districts. Again, these are the ones that have difficulty attracting teachers in all subject areas, not just math, science, and special education.

In my State of Iowa, we face a real crisis. Forty percent of the current teaching force will be eligible to retire in the next 10 years. Forty percent. Seventeen percent, or one in six new teachers, will leave ranks after their first year of teaching.

We have a problem in nursing, also. The American Hospital Association says there is 126,000 registered nurse positions in the Nation right now. So what is happening, and I had met with some students at Iowa just last week, what is happening is that there are some young kids that might want to go into teaching, they come from middle class, maybe lower middle class backgrounds. You heard me talk about Rae in my opening statement, and she is working 40 hours a week, 40 hours, and taking 17 credits, getting the maximum Pell Grant, and she already has \$20,000 in loans just to go to school.

I can tell you, she is not living high on the hog. She is not driving a new car. She is not taking fancy vacations. She is simply paying her tuition, her room and board, and that type of thing, and working. Then they find out what a beginning teacher makes, and they say, "Well, gee, if I borrow this money, how can I go and be a teacher. I will do something else."

So we are finding that the pipeline is not being filled, because of the huge debt load that college students are facing when they get out. They want to go into something that pays a little bit more, business, or computers, or whatever, but not teaching, and not nursing. The same thing is happening right now with teachers we have out there. They get out, they have the debt, they go in, they teach for 1 year, and they are up against it, and they cannot make it, so they go off into the private sector. Well, that is what we are losing, and the private sector is after them.

They are teachers, they are smart. They probably know about computers, things like that, and I will tell you, they can get a lot more, even in Iowa, in jobs that are not teaching, and that is what is happening to them. So while I applaud you for your loan forgiveness for math, science, and special ed, I, quite frankly, Mr. Secretary, think that ought to cover all teachers.

## LOAN FORGIVENESS-NEEDED FOR ALL TEACHERS, NURSES

We ought to have a bold new program to provide for repaying debts, things like that, for all teachers. I would add nurses to that, too, because we are going to have this huge nursing shortage also in the country. Look at what they did for me when I got my GI bill. I got this money. I did not have to pay anything back. That was sort of like a Pell Grant, I guess, but I think we ought to realize that this is investment in our future.

Like I said, I like what you have done, but I just think it ought to be broader than just that. So I just ask for any comments, or observations, or suggestions, Mr. Secretary, just on that one item, on loan forgiveness.

Secretary PAIGE. Senator, the more I hear you express your interests and your concern about the teaching workforce and teachers, the more I find that we are in agreement with that. Our concerns are the same, and I share that interest completely.

The difference, I think, stems from the fact that my experience in leading one of the largest school districts in America right in an urban blight section leads me to believe that increased funding is necessary and part of the solution, but only part of the solution, and it blurs our vision to see the other problems. That is also backed up by the research. We find that part of our problem with the teacher shortage has to do with the systems that we use to bring people into the teaching workforce. Mrs. Johnson, at Harvard, did a study some years ago of the \$20,000 bonus that they had put on the table for people to come into teaching. They would get a \$20,000 bonus paid over 4 years. When she went back and examined it, she found out that the people who they had attracted into the teaching workforce did not come for the \$20,000, they came because they wanted to teach, and this system allowed them a shortcut through the bureaucracy that is required to get into the teaching workforce, to get into the classroom.

So I agree that we need to look for financial incentives, and I certainly agree that teachers must be paid more, but the system that we have the teachers in, has to also be improved, because good people will not work in bad circumstances. So we have to look a little broader than just the funding, so I think together that we could find ways to enhance this situation.

Senator HARKIN. Well, we are making those changes. With the bill, with the No Child Left Behind Act, we are making some of those changes. That is why I say, for the most part, I supported that bill. I am just concerned about the backing up. We will not get into that. But anyway, you said, and the administration said, we want a loan forgiveness program for math, science, and special ed. They did not say we are going to do this, but only after we change the system. They want to do it right now. So I say if that argument works for that group, it would work for all teachers, art teachers, and science teachers, and phys ed teachers, and others.

## SUPPLY AND DEMAND ASPECT OF LOAN FORGIVENESS

Secretary PAIGE. I find no way to argue with that, except to say that the logic that we used in order to include those three categories of teachers is that that is a supply-and-demand issue. We see right now that the supply of math teachers and special ed teachers are not in our favor.

In fact, in Houston, where I worked, right across the street from our school district headquarters was Compaq Computers, and not far away was Dell Computers, and not far away was Texas Instruments, and then there was the whole petroleum industry right there that took all of our math and science teachers. So there were just fewer of them than there were of physical education teachers and other teachers. One of the ways to support that is to look at a differential salary structure, based on supply and demand, which in a lot of our educational system we conduct ourselves as if that law has been repealed, as far as education is concerned.

Senator HARKIN. I am not certain I know of what you speak there. I do not know what you are talking about.

Secretary PAIGE. I mean these people who represent the shortages are paid the same as teachers who are teaching in fields where we have high surpluses. We would not do that in any other enterprise in civilized captivity.

Senator HARKIN. Well, I just think if you start down a system of differential pay depending upon the subject you teach, you are going to get wild swings. You are going to get a lot of people moving one way, and you are going to say, "Oh. Now we have to cut them, we are getting too many, and we do not have enough over here, in the arts and sciences, so we will increase it there, and then there will be there, and then, oh, we have too much there, then we have to move"—we will always be changing this thing.

Secretary PAIGE. That is exactly how the system works. I mean the same practices have made all of our major organizations in the United States, in the country, work; they all operate by that same system.

## DIFFERENTIATED TEACHER PAY, BASED ON PERFORMANCE

Senator HARKIN. But the private sector is different, I think, than the public sector and teaching. I think in teaching, what you have to do is provide the incentives for teachers on a broad basis to enter into education, to find those that are really good teachers, and to reward them, not just because they teach math or special ed, but how good they are as teachers.

Secretary PAIGE. I would agree with that completely. What I hear you saying is, that there should be differentiated pay for performance.

Senator HARKIN. Yes, but not just based on a subject.

Secretary PAIGE. Not based on supply and demand, but performance. We are in complete agreement about the performance. We are in complete agreement about that. I would just add supply and demand as well, and we could have some more discussion on it, but that is—

Senator HARKIN. That is why we should have, I think, loan forgiveness for teachers, period, not just for math, science, but for all of them.

Secretary PAIGE. That is a good argument.

## PELL GRANTS

Senator HARKIN. Okay. We are having a hard time getting in an argument here. I did want to just say that we are concerned about the Pell Grant situation, and the fact that we do not have any increases in your budget for Pell Grant increases. I think the advisory committee on student financial assistance last year called for increases in the Pell Grant program.

Now, again, Senator Murray said earlier, we did have a shortfall in Pell Grant. We had that in the past. We had that all the time. If you have high unemployment, if you have people being put out of work, you get more of a demand on the Pell Grants. We know that. Every time we have had that, the Congress comes in and makes up for the shortfall, and we will do that again, but this advisory committee called for an increase in the Pell Grant program to improve access to college education.

So, again, what is happening, it is kind of a vicious circle. Most States, because they have requirements for balanced budgets, that they have to constitutionally do that, because of the down turn of the economy, they are forcing cuts, and in almost every State I have looked at, what they have done is increase tuition at public colleges.

In my State, tuition will increase 19 percent, from the lowest revenue growth in 50 years. Well, we have a 20 percent decline in net farm income this year. That gives you some idea what we are facing in Iowa. So a 19 percent increase in tuition, and if the Pell Grants stay the same, we have a real problem there.

# PELL GRANT MAXIMUM AWARD

So I just think we need to increase the reward. We are at \$4,000 right now, and I think we need to increase it. I mean I just wonder what your views are on why we do not have something in the budget to increase the Pell Grant award.

Secretary PAIGE. Well, I guess the best response I could have, Senator, is that we are operating in an environment where there are a lot of priorities. We thought that if the \$4,000 target is reached, we would wish we could do more, but there are some other priorities that are calling us right now, and these have to be coupled with the environment, the economic environment that we are operating within.

So these are just priority decisions that we have made. I understand that we will have some more discussion with you. We respect your views on this, and wish to have your input, but we have submitted this as our best thinking.

Senator HARKIN. The problem is, obviously, Mr. Secretary, with the Pell Grants, a small increase is a big budget impact. So with the budget we have to work with, it is going to be pretty hard to make any significant increases in the Pell Grant, unless the administration would support that, then that helps a lot-Secretary PAIGE. Yes.

Senator HARKIN [continuing]. But without that, it is going to be very tough for us to make any significant increases in the Pell Grant.

## PELL GRANT PROGRAM INCREASES

Mr. HANSEN. Mr. Chairman, if I could-we do have a \$550 million increase in the Pell Grant program, and that does help us get to an all-time high in terms of number of students served in the program. So there are different ways you can look at the program. It is not just the maximum award. The total dollars in the program have gone up from about \$5 billion in 1996 to over about \$10.8 billion in our budgets just in the last 5 years. The number of recipients have gone up from 3.6 million to about 4.5 million, and the maximum award has gone up from \$2,400 up to \$4,000. So there has been some significant movement, and our budget does build upon this.

Our budget does allow for half-a-billion dollars of new money, which will compensate for the additional students that are going to now be coming into the program. I think as the Secretary indicated in his opening statement, our top three priorities in our budget are special education, Title I, and the Pell Grant program. Senator HARKIN. Well, I agree with you that you have to have

some money to allow for some new entrants, but it does not raise the \$4,000 cap. I understand that.

I think we are going to have to continue our dialog on that one, too, as we move ahead on this budget.

Secretary PAIGE. We look forward to that.

## CHAIRMAN'S CLOSING REMARKS-COMMITMENT TO EDUCATION

Senator HARKIN. Mr. Secretary, again, I want to thank you for being so forthright, and for your willingness to work with us on this. I know we have a tough budget situation, but, again, and I will let you have the last word, but I am just going to say that I know we have gotten new priorities, as I said, after September 11, but we just cannot let what happened on September 11, in our commitment as a Nation, to go after the terrorists, and to secure our Nation and our people, sort of paralyze us from doing the other things that are necessary to meet the needs of this country.

That is what this appropriations committee is about. We are going to try to do our best, and we will work with you as much as we can to try to do that.

# SECRETARY'S CLOSING REMARKS—BIPARTISANSHIP

Secretary PAIGE. Senator, I would just like to end by saying that since my short stay in Washington I have learned to have just enormous respect for the men and women who make these really difficult decisions. I have watched you, as you have argued the points that you feel are important, some of which we have different points of views, but I have always known the sincere effort that you have put forward in the House and the Senate, and I have always had great respect for that. So I would welcome the opportunity for us to continue to discuss some of these issues.

I think the greatest thing that has happened in this last year was the way the Congress came together behind the No Child Left Behind Act in such a powerful bipartisan way. The men and women who had strongly different points of view found ways to discuss these differences and reach agreements. So I would suggest that as a model, as we go forward with these kinds of discussions, and we appreciate the opportunity to be a participant.

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

Secretary PAIGE. Thank you.

# ADDITIONAL COMMITTEE QUESTIONS

Senator HARKIN. 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:]

## QUESTIONS SUBMITTED BY SENATOR TOM HARKIN

#### FEDERAL STUDENT AID PROGRAMS

Question. Mr. Secretary, the Administration is working around the clock to make sure that "no child is left behind." However, the budget proposed by the Administration for student aid programs does not seem committed to this goal. Your budget level funds almost all of the major student aid programs, including Federal Workstudy, the Perkins loan, the Supplemental Education Opportunity Grant and TRIO programs. In addition, the budget proposes maintaining the maximum Pell Grant award at only \$4,000. Our neediest students are the ones supported by these programs and the very students that will be left behind if a budget like the one proposed by the Administration passes. How can the Administration justify the level funding of these programs at a time when State budgets are squeezing out higher education and there is a rapidly growing population of needy students that want and should go to college?

Answer. Ensuring access to quality postsecondary education continues to be the major role as well as the Department's priority in higher education. I believe that our budget request for postsecondary education is consistent with this priority. The

President's fiscal year 2003 budget would expand new student financial aid to nearly \$55 billion, an increase of 5 percent over 2002. The number of student aid recipients would increase by 339,000 to 8.4 million.

## PELL GRANT PROGRAM

*Question.* In your strategic plan for education you make virtually no mention of the student aid programs, even in the section on postsecondary education. Yet, when President Bush ran for office, he made his support for Pell Grants a centerpiece of his higher education agenda. Is there a shift in the thinking about the Department's support for student aid? Are you looking at a new and different role in higher education?

Answer. The Pell Grant program is the foundation of the Federal student assistance effort and has been the most effective and well-targeted program in helping low- and middle-income students attend college. President Bush recognizes the importance of the Pell Grant program and has requested a substantial increase for Pell each year. Despite our war on terrorism and the additional funding needed to support our military and homeland security operations, the President has asked Congress for an increase of \$549 million, or 5.3 percent, over fiscal year 2002 for Pell Grants.

#### LEVERAGING EDUCATIONAL ASSISTANCE PARTNERSHIP PROGRAM

Question. Mr. Secretary, your budget eliminates the Leveraging Educational Assistance Partnership (LEAP) program. Since nearly all States are facing deficits, tuition rates are being forced up, and research by the Advisory Committee on Student Financial Assistance and others has documented the need for more State/Federal partnership program funding to close the growing college access gap between lowand high-income students, can you tell me why you think eliminating this program is a good idea?

Answer. The Leveraging Educational Assistance Partnership (LEAP) program was authorized in 1972 to encourage States to invest in need-based grant and workstudy assistance to postsecondary students; at that time, only 28 States had undergraduate need-based grant programs. Federal funds serve as an incentive to establish or expand need-based grant programs; States are required, at a minimum, to match LEAP grants dollar-for-dollar with State funds provided through direct State appropriations for this purpose.

All States now have need-based student grant programs, and State grant aid has increased by close to 150 percent in the last 10 years. Most States significantly exceed the dollar-for-dollar matching requirements. For example, in academic year 1999–2000, matching funds totaled roughly \$1 billion, \$950 million over the dollarfor-dollar match. This program has established the principle that State need-based grant aid is a necessary complement to Federal student aid in helping students pay for higher education, and we believe States will continue to honor this principle.

#### STUDENT LOAN ADMINISTRATION—SECTION 458 PROPOSED TRANSFER

Question. The President's 2003 budget request proposes the development of a new, discretionary Student Aid Administration (SAA) account that would consolidate all student aid management costs previously funded through the discretionary Program Administration and Federal Family Education Loans Program (FFELP) accounts and the mandatory Federal Direct Student Loan Programs (HEA Section 458) account. Secretary Paige, could you please explain why the President and the Department are seeking to move the mandatory funds obligated under Section 458 of the Higher Education Act of 1965, as amended, from a mandatory to discretionary account?

Answer. This Administration, and I personally, am dedicated to creating a culture of accountability in the Department, including a strong focus on performance measurement. The current student aid administration budget structure—split among multiple mandatory, discretionary, and subsidy accounts—hinders this increased accountability, which is also the foundation of the performance-based organization established to administer Federal student aid. Under a single discretionary account, student aid administrative activities will be subject to the same level of congressional scrutiny as other Department activities.

*Question.* What will be the hierarchy for disbursement of these funds under the new discretionary Student Aid Administration (SAA) account? What plans are in place to ensure that the funds are evenly and appropriately distributed under this new Student Aid Administration (SAA) account?

Answer. We are committed to effectively administering all the Federal student aid programs, including the direct and guaranteed loan programs. As is currently the case, specific decisions on the allocation of funds supporting student aid administration will be made by the Secretary and Deputy Secretary in consultation with the Assistant Secretary for Postsecondary Education, the Chief Operating Officer of the performance-based organization, and other Department senior staff.

*Question.* Budget documents have stated that the reason for this proposed change is that it would increase accountability for reducing costs. Please explain why it is easier to reform a program funded by annual appropriations as opposed to mandatory funding. Answer. The annual appropriations process, in which activities compete for re-

Answer. The annual appropriations process, in which activities compete for resources from a finite funding pool, imposes much-needed fiscal discipline and compels agencies to develop solid, well-documented justifications for their requests. To support its request, the Department is in the process of developing a true activitybased budget formulation process for the unified Student Aid Administration account. Such a process would allocate the Department's student aid management expenses by program and specific business process to more accurately determine the cost of individual activities or programs, budget administrative funds to each business process, set cost reduction targets, and easily compare actual performance to budget targets.

*Question.* Isn't it true that Congress established seven purposes in section 141 of the HEA for the creation of the Performance Based Organization (PBO)? How would this proposal better achieve all seven purposes?

Answer. By simplifying cost analysis and subjecting student aid administrative funding to the discipline and flexibility of the annual appropriations process, the proposal would primarily advance purposes (B), "to reduce the costs of administering these programs," and (C), "to increase the accountability of the officials responsible for administering the operational aspects of these programs." That said, the prudent and efficient allocation of administrative funds implicitly supports all the goals of the PBO and the Administration in general.

# STUDENT AID ADMINISTRATION FUNDS—CHANGING FROM MANDATORY TO ANNUAL DISCRETIONARY APPROPRIATIONS

Question. One of the purposes identified by the Congress for establishing the Performance Based Organization was to improve service to students and other participants in the student financial assistance programs authorized under title IV of the Higher Education Act. Given that administrative expenses for the PBO are closely associated with the number of loans issued in a given year—a level which could be difficult to predict—how will the proposal to make administrative expenses subject to annual appropriations better achieve that purpose behind the creation of the PBO? What would happen if funds appropriated fell short of the amount required to meet the operations of the PBO; how would services to students and other participants be affected?

Answer. Moving to annual discretionary appropriations will actually decrease the likelihood that funding will fall short of the level needed to support operations, since the funding level will be determined only a year in advance, rather than up to 5 years in advance as is currently the case. In addition, the fact that funding is mandatory does not safeguard it from reduction. As you know, mandatory funding currently supporting student aid administration has been repeatedly reduced through appropriations and reconciliation action over the years, and is capped at the 2001 level through 2003. That said, whether discretionary or mandatory, there is never a guarantee that administrative funding levels will be sufficient to cover operations costs. The Department is committed to effectively managing all of its programs; managers will make responsible choices in allocating available funds to minimize adverse impacts on students and other program participants.

adverse impacts on students and other program participants. *Question.* If the funding allocation for this new discretionary account failed to meet the President's budget request, which programs will suffer? Answer. As noted above, the Department is committed to effectively managing all

Answer. As noted above, the Department is committed to effectively managing all of its programs; managers will make responsible choices in allocating available funds to minimize adverse impacts on students and other program participants.

Question. Secretary Paige, I commend your focus on strengthening the management of the Department of Education and I appreciate your efforts to remove the student financial aid programs from the U.S. General Accounting Office (GAO) list of high risk programs. I understand that a Management Improvement Team you convened identified 661 recommendations associated with audits and reviews of financial, management and information system weaknesses. This Team has developed corrective action plans to address most of the recommendations. Did any of the action plans include a proposal to move Federal funding available for administrative expenses from the mandatory to the discretionary side of the budget?

Answer. Yes; action item number 37 in the Department's Blueprint for Management Excellence directly supported this proposal.

#### LOAN FORGIVENESS FOR CHILD CARE PROVIDERS

Question. If all eligible applicants received the full amount of forgiveness for which they are eligible, how much funding would have been required in fiscal year 2001? The average loan obligation forgiven is listed at \$13,333 for fiscal year 2001. If borrowers may have 20 percent forgiven in the first year of service—with a maximum of 100 percent for 5 years of service, how can the average loan obligation be \$13,333? How much will be required in fiscal year 2002 and fiscal year 2003?

Answer. The \$13,333 figure included in fiscal year 2003 and fiscal year 2003? Answer. The \$13,333 figure included in the Congressional Justification was based on preliminary data. Updated data indicate that fiscal year 2001 funding supported an average award of \$4,708 to 212 borrowers. Available funding in fiscal year 2001 was sufficient to support the full amount of forgiveness—that is, 100 percent of the outstanding loan balance—for all but 10 eligible applicants. The \$4,708 average loan obligation reflects 100 percent of the outstanding balance of the eligible applicants, 20 percent—or an average of \$942—of which was forgiven in fiscal year 2001. The remaining fiscal year 2001 funds have been set aside to support forgiveness costs for these borrowers over the next 4 years. The annual appropriation is obligated to for these borrowers over the next 4 years. The annual appropriation is obligated to assure that the full loan forgiveness amount will be available if borrowers complete the required 5 years of service; the guaranty of the full forgiveness provides the retention incentive the program is designed to provide.

*Question*. How has the Department promoted this demonstration program? Answer. The Department took a number of steps to increase awareness of the program, including publishing a notice in the Federal Register, posting information on Department websites, sending letters and accompanying fact sheets to five major national child care associations, and creating a special toll-free phone number for borrowers to call to obtain program information. These efforts resulted in over 3,000 phone calls for information and 642 applications for forgiveness.

Question. When will sufficient data be available to evaluate the effectiveness of this program?

Answer. By structuring the program to assure the availability of the full forgiveness amount, we will be able to track a cohort of borrowers across time to better study the effectiveness of loan forgiveness in encouraging individuals to remain in the child care field. Thus, the completion of the second year will provide data on what percentage of the initial recipients qualify for their second year of forgiveness, as well as a much better sense of both whether awareness of the program has grown.

## HIGHER EDUCATION—ASSESSING AND IMPROVING THE EFFECTIVENESS OF FEDERAL TRIO AND GEAR UP PROGRAMS

Question. The budget justification indicates that the Administration will assess the effectiveness of the TRIO programs and GEAR UP and develop strategies for fiscal year 2004 to improve the performance of both and direct resources to the most effective strategies. Please explain what specific actions the Administration will take to assess the effectiveness of TRIO programs and GEAR UP.

Answer. The Administration's performance assessment of the TRIO and GEAR UP programs is taking place on several different levels and will be an ongoing process. In the short-term, we are reviewing a wide-range of data that are currently available, particularly TRIO's Upward Bound and Student Support Services evaluations. We also are reviewing the performance reports that are submitted by grantees on an annual basis, and plan to modify those reports in ways that will provide more timely data related to project outcomes. As part of our long-term strategy, we have ongoing program evaluations that will provide a wealth of data on program impacts in the next couple of years, particularly for Talent Search and GEAR UP. Our goal is to create an environment of accountability where discussions about program performance are integrated with everyday programmatic decisions, and are informed by a combination of individual project reports and large-scale program assessments.

Question. What is the timetable for the assessment process'

Answer. As mentioned, we are currently reviewing findings from the Upward Bound and Student Support Services evaluations. We expect these reports to be released to the public this summer. Although the Congressional Justification anticipated a spring release of these reports, additional data analysis was necessary and the internal review process has lasted longer than expected. We also expect findings from the Upward Bound Math/Science evaluation to be available this summer. In 2003, we expect to release findings from the evaluations of the Talent Search and GEAR UP programs. In addition to each of these comprehensive evaluations, we are continually reviewing the effectiveness of individual projects and aggregating data from their annual performance reports.

#### STRATEGIES FOR IMPROVING PROGRAM EFFECTIVENESS

Question. What process or mechanism will be established for developing strategies for 2004 to improve the performance of both programs and direct resources to the most effective strategies?

Answer. Since last fall, the Administration has been engaged in discussions about effective strategies to improve the performance of TRIO and GEAR UP. These ongoing discussions generally fall into three areas: strategies that can be implemented immediately, strategies that require legislative or regulatory changes, and strategies that require additional funding. With regard to the first category, as noted in our recently released Annual Plan for 2002–2003, we are currently discussing changes to be implemented for this fall's competition in TRIO's Upward Bound program. Based on findings from the program's evaluation, we are looking at several different options that will allow us to improve program effectiveness by encouraging projects to target higher risk students and to provide additional work-study opportunities. Based on further discussions and new data that become available, the President's fiscal year 2004 budget and reauthorization proposals will encompass additional strategies that fall under the other two categories. For example, final decisions about funding for Upward Bound will not be made until we can assess the number and quality of applications that are received and the anticipated impact that each will have.

Question. Will these recommendations be part of the Administration's fiscal year 2004 budget proposal?

Answer. Yes, we anticipate that these recommendations will be included in the President's budget request.

#### ALLOCATION OF UNDISTRIBUTED FISCAL YEAR 2002 FUNDS

Question. How will the undistributed fiscal year 2002 funds be allocated? Answer. The funds listed as "undistributed" in the Congressional Justification will be used to provide additional work-study opportunities to an estimated 3,000 Upward Bound students.

Question. What specific options is the Department considering for allocating proposed fiscal year 2003 funding that is identified as undistributed in budget documents?

Answer. The Department is considering several options for these funds, including: providing additional work-study opportunities for Upward Bound students, sup-porting additional grant aid for Student Support Services students, targeting funds to improve program effectiveness in other ways, funding a larger number of new awards, and increasing awards for existing projects to serve more students.

#### DEMONSTRATION PROJECTS TO ENSURE QUALITY HIGHER EDUCATION FOR STUDENTS WITH DISABILITIES

Question. The Department is proposing to eliminate funding for the Demonstra-tion Projects to Ensure Quality Higher Education for Students with Disabilities pro-gram. The rationale for this proposed action is that new projects can compete for and receive funding under FIPSE and Special Education Research and Innovation. When the demonstration projects program did not exist in fiscal year 1998, only 4 grants that focused on higher education were awarded under the special education authority. In fiscal year 2002, almost 30 awards will be made under the demonstration projects program. What new funding is proposed in the fiscal year 2003 budget to support this level of commitment to quality higher education opportunities for students with disabilities?

Answer. The President's budget proposes an increase of \$7.9 million for FIPSE, including \$6.9 million to support all continuing projects from the Demonstration Projects to Ensure Quality Higher Education for Students with Disabilities program. In addition, we anticipate that a number of new and continuing projects will be funded under FIPSE's Comprehensive Program to serve disabled students. In fiscal year 2001, more than a dozen such projects were funded under FIPSE

Our budget also includes approximately \$10 million for new field initiated research addition and outreach projects under the Special Education—Re-search and Innovation program. As in the past, competitions for these awards will be open to projects proposing to address the postsecondary needs of students with disabilities. Currently funded projects include those that, for example, focus on pro-viding information to institutions of higher education on model practices for educating students with hearing impairments, and demonstrate a personal accommodation model to provide students with disabilities access to postsecondary education.

Applications will also be solicited for a competition for projects of national significance under the Special Education—Personnel Preparation program. Awards under this competition may also address postsecondary needs. For example, one currently funded project is providing a Web-based professional development course that prepares college staff to develop and implement summer college preparation programs for individuals with disabilities.

Other areas also provide support for postsecondary education. For example, under the Special Education—Technical Assistance and Dissemination program we currently support a national clearinghouse on postsecondary education, and the National Institute on Disability and Rehabilitation Research, funded under the Rehabilitation Services and Disability Research account, supports the National Center for the Study of Postsecondary Education, which, among other activities, provides technical assistance to institutions of higher education on serving students with disabilities.

## JAVITS FELLOWSHIP AND GAANN PROGRAMS

*Question.* Mr. Secretary, the Graduate Assistance in Areas of National Need (GAANN) and Jacob Javits programs attract exceptionally promising students into graduate study to pursue degrees in areas if national need-such as chemistry, information sciences, and engineering, as well as in the arts, humanities, and social sciences. The Administration proposes level funding these programs at a time when supporting advanced study in these areas is of great importance to the Nation. Since the stipend level paid to students increases each year, level funding essentially decreases the size and capacity of the program. The National Science Foundation (NSF) and the National Institutes of Health (NIH) have proposed increasing their graduate education budgets for fellowships and traineeships. Why have you not done the same, given the important niche these programs serve in the Federal Government's graduate education portfolio?

Answer. Due to the nature of award cycles, level funding in fiscal year 2003 will support an unusually large number of new fellows in both programs: an estimated 537 fellows in GAANN and 140 fellows in the Javits Fellowship program. These numbers are significantly higher than they have been the last couple of years.

#### CHILD CARE ACCESS MEANS PARENTS IN SCHOOL (CCAMPIS)

*Question.* Based on applications received in the latest award cycle, how much unmet need exists in terms of: amount of funds requested, child care capacity on or near campus and waiting lists for existing child care?

Answer. The Department is in the process of preparing the notice inviting applications for new CCAMPIS awards for fiscal year 2002. The closing date for receipt of applications for this competition is scheduled for June 2002.

With regard to the fiscal year 2001 competition, the Department received 232 applications and awarded grants to 222 out of 229 eligible applicants. Because the available funds exceeded the amount needed to cover continuations and make these new awards, the Department invited grantees from the fiscal year 1999 competition to increase their third year (2001) of CCAMPIS funding based on their 1999–2000 Federal Pell Grant disbursement figures. This invitation was also extended to fiscal year 2001 applicants because some applicants failed to request the maximum allowable. A good number of applicants responded favorably to this invitation by increasing their request for funding. Applicants requested approximately \$16.6 million and the Department awarded (up to the statutory limitation) approximately \$16.1 million in grant funding. The maximum grant awarded to an institution is limited to one percent of Pell Grant dollars at the institution.

Based on a review of about 50 applications, it appears that many of the applicants have waiting lists for child care. However, in some cases, schools may lack the physical space to accommodate significantly more children. Current law prohibits eligible institutions from using grant funds for construction, other than minor renovation and repairs to meet State or local health or safety requirements.

*Question.* What steps is the Department taking or planning to take to ensure that child care is not a barrier for students/families interested in pursuing postsecondary education?

Answer. The Department proposes to continue funding the CCAMPIS program in fiscal year 2003. The Department has requested \$15 million to cover the costs of continuing grants initiated in fiscal years 2001 and 2002.

Question. Last year the Department lapsed more than \$8 million in funds available for this program. What steps has the Department taken or planned to make sure these needed funds are fully utilized? Answer. The Department is undertaking a number of activities to heighten aware-

ness and increase utilization of the financial assistance available through the CCAMPIS program.

- In late February, Department staff presented at the National Coalition for Campus Children's Centers (NCCCC) conference in San Antonio, Texas. The conference, devoted to campus early childhood programs, gave Department staff an opportunity to share information and respond to questions from potential fu-
- an opportunity to share information and respond to questions from potential fu-ture applicants and current grantees on issues relating to the application proc-ess and available funding for the CCAMPIS program. The Department plans to conduct four Child Care pre-application technical as-sistance workshops across the country (St. Louis, MO; Miami, FL; Los Angeles, CA; and Washington, DC) to encourage potential applicants to apply and to as-sist them in submitting high quality applications. These workshops will also serve as a major outreach activity to increase the numbers of HBCUs, HSIs, and TCCUs that propose to provide quality and affordable child care services to their low-income students who are parents.
- the received and received and and and the services of the relative services to their low-income students who are parents. -The Department has posted information regarding the CCAMPIS program on its website at http://ed.gov/offices/OPE/HEP/campisp/. In addition, interested in-dividuals have access to information on CAMPUSCARE-L, an electronic discussion list devoted to topics related to the concerns of staff, faculty, and administrators in laboratory schools or children's centers on university or college cam-puses. The list is co-owned by the NCCCC and the ERIC Clearinghouse on Elementary and Early Childhood Education (ERIC/EECE).
- The Department is looking into the possibility of posting the closing date notice and additional CCAMPIS program-related information in the Chronicle of Higher Education.

#### TEACHER QUALITY ENHANCEMENT STATE GRANT PROGRAM

Question. The Administration has proposed overriding the authorizing statute for the Teacher Quality Enhancement Grant program. Under the State grants program, all but 26 States have received awards through fiscal year 2001 and budget docu-ments indicate that 23 new awards would be made in fiscal year 2002. What is the latest information about the number of new State awards made in fiscal year 2002? Answer. To date, no awards have been made in fiscal year 2002. The Department

plans to complete the competition for new State awards this summer. *Question*. Why can't awards be made to the remaining eligible States?

Answer. There is no reason that awards cannot be made to the remaining 26 eligible States. In fact, the Department's Budget Justifications assume that many of

ble States. In fact, the Department's Budget Justifications assume that many of these States will apply and be awarded grants in fiscal year 2002. In order to en-courage eligible States to apply, the Department intends to work closely with them, offering technical assistance and support in the application process. The Department is not planning to conduct another competition for new awards in 2003. The 31 States receiving their final year of continuation funding in 2001 and 2002 may not compete for new funding because the statute prohibits States from receiving more than one State grant. Once the Department has conducted the 2002 competition it is unlikely that there will be any remaining entities seeking funding. The Department believes that the program's 50 percent matching requirement may The Department believes that the program's 50 percent matching requirement may discourage some States from applying. Furthermore, as there have already been a number of competitions for this program, it is likely that those States most inter-ested in the program have already received a grant. The Department proposes that fiscal year 2003 funding for State grants be limited to the amount needed to cover continuation costs.

Question. How many of these unfunded States meet any of the priority criteria under section 205 (b)(2)(A)(i)–(iii)?

Answer. In theory, all of the unfunded States may meet these priority criteria. However, until specific grant applications have been received, it will not be possible to ascertain the precise number of the unfunded States that meet the priority criteria. Section 205 (b)(2)(A)(i)–(iii) of the HEA instructs that in awarding Teacher Quality Enhancement State Grants the Department give priority to applications that include reforms in three areas: reforms of certification requirements to ensure content knowledge, reforms designed to hold institutions of higher education accountable for the quality of teachers they prepare, and recruitment efforts aimed at reducing teacher shortages in high poverty urban and rural areas.

#### VOCATIONAL REHABILITATION INCENTIVE GRANTS

Question. The Administration has proposed creating a new program designed to provide financial incentives to State vocational rehabilitation (VR) agencies for helping individuals with disabilities obtain competitive jobs. Please describe how this proposed program would operate. What criteria would be utilized for determining which States receive awards, what factors would determine the size of the State awards and what guidelines would be provided to States on appropriate uses of these funds?

Answer. We are still in the process of developing the specific plans for the pro-posed Vocational Rehabilitation Incentive Grants program. However, I am happy to share with you how we envision this program operating. We plan to link the incen-tive grants to key measures under the current Evaluation Standards for the VR State Grants Program. We will initially focus on State vocational rehabilitation agencies that are the top performers under Performance Indicators 1.3 (percentage of individuals obtaining competitive employment) and 1.5 (VR consumers' earnings in comparison to the State's average wage). We also plan to include additional meas-ures on the number and percentage of Social Security beneficiaries under the Supplemental Security Income (SSI) and the Social Security Disability Insurance (SSDI) programs who are served by the State VR agency and the percentage of individuals who are SSI recipients or SSDI beneficiaries who obtain competitive employment. These measures are intended to reward States who make a significant effort to assist these individuals to obtain employment. Beneficiaries under these programs have significant disabilities and historically have been among the most challenging to serve. We are analyzing data on prior year performance to determine what the performance criterion should be in identifying top performers. Additionally, we are considering a future category of "most improved" (agencies who have shown the greatest improvement over two or more years) when we have sufficient experience with the Standards and Indicators to allow us to establish those criteria.

At this time, we cannot tell you what the actual size of the awards will be. The size of the award will depend on the results of our analysis of the performance data and the resultant pool of top performers. However, we anticipate that the size of the awards will be generally proportional to the size of the State VR agencies' grant allotment. At this point, we believe that the State VR agencies should have flexibility in spending award funds under the program as long as those expenditures are consistent with allowable costs under the VR State Grants Program.

#### VOCATIONAL REHABILITATION PERFORMANCE STANDARDS

Question. Under current law, doesn't the RSA require States that do not meet performance levels to develop program improvement plans that outline proposed efforts to achieve acceptable performance? What issues do States raise as barriers to

to achieve acceptable performance? What issues do States raise as barriers to achieving acceptable performance, and how would this new program support current RSA efforts to help States improve performance? Answer. Section 106 of the Rehabilitation Act requires State agencies that fail to meet the standards to develop a program improvement plan (PIP) outlining specific actions to be taken to improve program performance. We are currently in the proc-ess of publishing our first Evaluation Standards Performance Report. This report, ac well es other program performance information will be made available on the as well as other program performance information, will be made available on the Department's website. Subsequent to this report, we will be working with States who do not meet the Standards to develop PIPs. At that point, we will have better information about what barriers States are experiencing in their efforts to achieve acceptable performance.

The current Evaluation Standards and Performance Indicators are designed to ensure a minimal level of acceptable performance and raise the performance of low performing States. The incentive grants would award high performance. These grants would encourage State VR agencies at the top of the performance ladder to continue to improve or maintain high performance. In addition, we want to encourage States with satisfactory performance to strive for high performance.

#### RECREATIONAL PROGRAMS

Question. With a success/sustainability rate of nearly 75 percent, recreational programs have proven to be an effective approach to leveraging local funding to support the integration of individuals with disabilities into the community. What specific sources of funding are available to replace this modest Federal investment? Budget documents indicate that this program has limited national impact and that funding is more appropriately derived from States, local agencies and the private sector.

Why should the community integration needs of individuals with disabilities be left Answer. The major purpose of the Recreational Program is to provide seed money

for the establishment and operation of community-based recreational programs as well as to create opportunities for increased access to locally based recreational programs. RSA has found that after Federal funding ceases for recreational projects, the integration of individuals with disabilities into community-based recreational programs has continued with local public and private funding sources. In addition, the increased availability of existing accessible community-based recreational facili-ties demonstrates local support for the integration of individuals with disabilities into the community. While the Recreational Program is designed to promote incluinto the community, while the recreational Program is designed to promote inclu-sive recreational programs to integrate individuals with disabilities into community-based recreational programs, States have the responsibility to assist individuals with disabilities to achieve community integration by ensuring that public facilities such as parks and recreational programs are accessible. The Recreational Program has demonstrated the potential for supporting community integration through local and private funding sources and private funding sources.

and private funding sources. *Question.* Doesn't the Federal Government have a role in stimulating and leveraging local and private funding for programs that support the community inte-gration needs of individuals with disabilities? Answer. The Federal Government does play a large role in stimulating and leveraging State, local, and private funding for programs that support the commu-nity integration needs of individuals with disabilities. That role is clearly dem-Integration needs of individuals with disabilities. That fole is feeling definition on strated through many programs supported by the Rehabilitation Services Admin-istration (RSA). The largest program, the \$2.6 billion Vocational Rehabilitation State grants program, provides over 78 percent in Federal matching funds to assist States with their obligations in providing services for individuals with disabilities. In addition, the Centers for Independent Living program provides training in indi-vidual and systems advances that applications are grant of the services of vidual and systems advocacy that enables persons with disabilities to gain greater access to community resources.

#### PROJECTS WITH INDUSTRY

Question. The Administration has proposed eliminating direct Federal funding for Projects With Industry (PWI) projects and has requested legislative language to authorize States to use their Vocational Rehabilitation State Grants appropriation to cover continuation costs in fiscal year 2003. Does this mean that funding for some of the 75 PWI projects that just received funding in fiscal year 2002 could be eliminated next fiscal year?

Answer. Under the Administration's proposal, fiscal year 2002 would be the final year of direct Federal support for grants under the Projects With Industry (PWI) program. The purpose of the appropriation language proposed by the Administration is to assist the projects in their transition from Federal to State and local support. The language would provide State VR agencies with the authority and discretion to utilize their fiscal year 2003 funds to continue support for effective projects in their States. We expect that State VR agencies will continue to refer individuals to effective PWI programs for placement and other services. In the future, we anticipate that PWI projects, like other VR service providers, would be paid directly or by contract for their services by the State VR agency. The projects period for PWI projects receiving fiscal year 2002 funds is from October 1, 2002 to September 30, 2003. Thus, State VR agencies and PWI projects will have ample time to plan for the transition and ensure that any disruption in the delivery of services is minimized.

#### SUPPORTED EMPLOYMENT STATE GRANTS

Question. The Administration has proposed folding this program into the VR State Grant program, because it has achieved its statutory goal. The Supported Employment (SE) program does not require a State match, while the VR program does. According to the Fiscal Survey of the States, 2001, States are experiencing significant billion. Further, under this proposal, some States will actually receive less Federal support than they received last year. Given those realities, how will States continue to meet their commitment to serve those with the most severe disabilities with high quality supports and services?

Answer. We know that supported employment is often an effective strategy in as-sisting individuals with the most significant disabilities to obtain competitive employment in integrated settings. However, the Administration believes that a separate supplemental source of funding to encourage States to develop collaborative programs with appropriate public and private nonprofit organizations for the provision of supported employment (SE) services is no longer needed. The State Vocational Rehabilitation (VR) agencies recognize supported employment as an integral part of the VR State Grants program and a viable employment option for individuals with the most significant disabilities. The number of individuals receiving SE services has continued to increase even though the annual appropriation for the SE State Grants program has remained constant since 1996. State VR agencies continue to spend an increasing amount of VR State Grant funds (including State matching funds) to provide supported employment services for those individuals who require such services to participate in the integrated labor market. We believe that States will continue to meet their commitment to serve those with the most severe disabilities with high quality supports and services under our proposal.

#### Impact of proposal to merge supported employment program with vocational rehabilitation state grants

In considering this proposal, we examined the impact of merging the funds both in terms of the effect on required State matching funds and the total allocation of funds to States. Our 2000 and 2001 data indicate that for most States the financial impact will be minimal. Under the Rehabilitation Act, the Commissioner is required to reallot any available VR State Grant funds to States who request additional funds and can match those funds. Currently, about 80 percent of the 50 States, D.C., and Puerto Rico request additional funds in the reallotment process. In fiscal years 2000 and 2001, only a handful of States did not request additional funds and only 2 States were unable to meet their State match requirement and had to return part of their original allotment. Second, on average the relative increase in the total matching funds as a result of combining the VR and SE funds is minimal, about 1.5 percent. Third, fiscal year 2001 State expenditures for nearly one-third of the States exceeded the amount of funds they would be required to provide as match under the President's fiscal year 2003 budget request. Further, State VR agencies have been seeking increased appropriations for the VR State Grants program, which suggests that they will be able to match these funds. Given this information, it appears that the vast majority of States should not have a problem in providing sufficient funds to meet their State match requirement.

Because of the differences in the programs' funding formulas, we also examined the total amount of funds that States would receive under the proposed consolidation in the fiscal year 2003 President's request. Our analyses indicate that under the proposed consolidation, all States will receive an increase in Federal funds in fiscal year 2003 as compared to the total Federal funds they received under the VR and SE programs in fiscal year 2002. Consolidating the separate SE funding source into the larger VR State Grants

Consolidating the separate SE funding source into the larger VR State Grants program will send the message that supported employment is an accepted and valued outcome of the VR program. The consolidation would also streamline and eliminate burdensome and duplicative accounting and reporting requirements. Further, we intend to monitor State data to ensure that they do not reduce their efforts to provide supported employment services.

#### ASSISTIVE TECHNOLOGY PROGRAMS

Question. State Grant funding provided under title I of the Assistive Technology (AT) Act has been critical to building an infrastructure specifically designed to ensure that people with disabilities—regardless of age or disabling condition—have access to the technology devices and services they need to be independent and productive members of society. Without this national infrastructure, there will be unbridgeable gaps in access to AT devices and services throughout the country. Why does the Department's budget request propose eliminating Federal financial support for 23 States?

Answer. The Assistive Technology Act (AT Act) of 1998, which authorizes funding for the Assistive Technology (AT) State grants program, provides for a declining Federal share and limits funding for individual States to no more than 13 years. The Department's request would support the States that are authorized to receive funding in fiscal year 2003.

Question. Policy changes such as the Olmstead decision, Section 508 final guidelines, and the Telecommunications Act Sect. 255 were not anticipated when the sunset provisions related to Federal support of Tech Act Projects were originally conceived. Does the Department believe that State Tech Act projects have a role to play in building an infrastructure that ensures that people with disabilities can be independent and productive members of society? If so, how will their mission be achieved given that a recent National State Budget Officers Association survey revealed that almost all States are facing revenues that have fallen far below original estimates, resulting in net budget shortfalls estimated to be as high as almost \$40 billion?

Answer. The Department agrees that there have been significant changes since the passage of the Technology-Related Assistance for Individuals with Disabilities Act (Tech Act) in 1988. In addition to those mentioned in the above question, we note such developments as the passage of the Americans with Disabilities Act (ADA); the proliferation of electronic information technologies and their applications; changes in workforce practices, such as telecommuting; the emergence of new devices and new technological knowledge; alterations in the governing statutes, regulations, and policies of other Federal and State agencies; the characteristics and awareness of consumers; and the activities of the projects funded under the Tech Act and the AT Act, among other factors.

# Promoting access to and assessing current state-of-the-field assistive technology for individuals with diabilities

Promoting access to AT/IT is an important element of the President's New Freedom Initiative, and the Department is considering the best mechanisms to achieve this goal.

In order to reach an informed conclusion about the current state-of-the-field, NIDRR is undertaking several information-gathering efforts, based on our knowledge of the entire continuum of getting AT/accessible IT to consumers. Included are a needs study, with a population-based survey of individuals with disabilities concerning their uses, needs, and resources relative to AT/IT. A second area of inquiry is a survey of consumer organizations and public agencies at the State level—providers of assessments, prescriptions, training, and financing for AT. A third area will be an examination of those segments of the AT/IT continuum that could increase the flow of innovative and affordable technologies from the laboratory and the manufacturer into the consumer marketplace, and provide supports such as training, maintenance, replacement, and consumer safeguards.

#### AMERICAN PRINTING HOUSE FOR THE BLIND

*Question*. Last year, the Administration requested level funding for APHB, even though the Printing House asked for an increase justified by an expected increase in the number of students served. Budget documents indicate that the number of students served will increase this year by 1.2 percent. Once again, the Administration has requested level funding for APHB. How does the request provide sufficient funding to maintain operations, given the expected increase in the number of individuals served?

Answer. Funding for the Printing House has more than doubled in the past five years, going from \$6.68 million to \$14 million, an increase of 110 percent. At the same time, the number of students served through APH has increased by only 4.8 percent. The rate of increase also has slowed down, going from 2.8 percent in 1998 to .47 percent in 2000. In fiscal year 2001, the number of students served actually declined by 1.5 percent. The Department believes that its request of \$14 million for the American Printing House for the Blind (APH) for fiscal year 2003 provides more than sufficient funds to maintain operations at appropriate levels.

States are required to provide a free appropriate public education to all students with disabilities under the Individuals with Disabilities Education Act (IDEA), which includes the provision of all necessary educational materials. These programs have the primary responsibility for ensuring that all children with visual impairments receive a free appropriate public education, including all necessary specialized educational materials. Federal support for special education under the IDEA Grants to States, Preschool Grants, and Grants for Infants and Families programs has grown by over \$5.3 billion since 1996, or 178 percent. In addition, the fiscal year 2003 request would provide an additional \$1.02 billion for these programs. The funds provided under the appropriation for APH merely supplement the resources already available to the States to achieve this goal.

At the fiscal year 2003 request level, States will receive an additional \$186.72 per student with a visual impairment for specialized materials through APH based on its estimate of the number of students to be served in fiscal year 2003. APH funding for educational materials simply provides additional support to States to provide a free appropriate public education. We believe that additional funds are not necessary for educational materials and that the request provides sufficient funding to support a full spectrum of advisory services and research activities.

#### QUESTIONS SUBMITTED BY SENATOR ERNEST F. HOLLINGS

## BLUE RIBBON SCHOOLS

*Question.* Mr. Secretary, thank you for appearing before the Subcommittee today. I wanted to spend a few minutes discussing the future of the Blue Ribbon Schools program with you.

As you know, the Blue Ribbon process involves a school conducting a thorough self-examination, submitting an application to your department that outlines the leadership, professional development, curriculum, and student support services used by the school, and disclosing the implications of such policies on key academic indicators like student performance on norm-referenced assessments, student attendance rates and teacher attendance rates. On the basis of site visits and the quality of the application, your department bestows the Blue Ribbon designation on a select number of schools each year.

I am concerned by rumors that your department, Mr. Secretary, will eliminate the Blue Ribbon Schools program in favor of another awards program focused solely on student performance on standardized tests. While I believe that we should recognize schools that improve test scores, I feel that it is just as important that we recognize the practices and activities that lead to the improved test scores. That is exactly the information that we gain from the Blue Ribbon Schools.

A few years ago, I was shocked to learn that the Department kept these awardwinning Blue Ribbon applications that contain a great deal of information on successful research-based programs sitting in a filing cabinet, doing little more than gathering dust. In South Carolina, we have taken advantage of these Blue Ribbon best practices to generate measurable school reform and academic achievement. Hand Middle School in Columbia, SC used the same process and last year was designated the National Middle School of the Year by Time Magazine. In 1994–95, their test scores ranked at the 50th percentile among State schools. Within five years by using Blue Ribbon best practices, the school had progressed to the 90th percentile and had become one of the largest winners of State incentive funds given for measurable gains in achievement test scores. From 1995–99, every subpopulation's test scores increased with the highest gains in race, African-American, with an 85 percent gain. In the 1994–95 school year, Beaufort Elementary School was listed as one of South Carolina's 200 worst schools. Thanks to reforms modeled after the practices of Blue Ribbon Schools, Beaufort Elementary School turned itself around 180 degrees and won a Blue Ribbon designation of its own in 1999. Within a 5-year period in grades 2–5, standardized test scores increased by 15 Mean NCEs—from 40 to 56 NCE. I can think of no better example in South Carolina promoting school-wide reforms that left no child behind.

I strongly believe that room exists at the Department of Education to honor both schools that improve test scores and schools that undergo reforms that produce positive academic results. Mr. Secretary, what are your plans for the Blue Ribbon Schools program?

Answer.

## Focus on achievement for awards recognizing school performance

The Department is committed to recognizing schools that make significant progress in closing achievement gaps and in ensuring that all children learn to high standards. One main focus of our new program, which will build on the Blue Ribbon Schools tradition, will be recognizing schools with disproportionately high numbers of students from disadvantaged backgrounds that perform at the highest levels. We will, as before, recognize high performing private schools as well as public schools. And, we will recognize schools that implemented reforms that led to improvements in student achievement.

However, our focus is on achievement. Our commitment to leaving no child behind means that we must ensure that all students are learning, and we want our highest performing schools to be recognized. While we applaud schools that are working to reform their programs, we believe that national recognition should be reserved for those schools in which the reforms have led to actual improvement in student achievement. And, we want to know that the recognized schools are the schools in the community with the highest performance. It is difficult to explain why one school gets a Blue Ribbon award and yet, right down the road, another school with similar students can show much more in terms of student achievement but does not get the award. We want to ensure that the Blue Ribbon schools really are the highest performing schools—and, yes, test scores do give us objective data about that. I am pleased to announce that we will be simplifying the application process. Dur-

I am pleased to announce that we will be simplifying the application process. During our review of the program we discovered that many schools found applying for Blue Ribbon status to be burdensome. Some high performing schools did not apply for Blue Ribbon status because the application package required an inordinate amount of time—and the schools were too busy making certain their children were learning to take time to complete the application.

We will continue to make information on the recognized schools available so that others may learn from their accomplishments. In the past, the Department has supported workshops where Blue Ribbon Schools and aspiring schools could come together to discuss best practices, and we made the Blue Ribbon Schools applications available on our Department website. In the future, we will work with schools and teachers to improve our outreach efforts and make sure that they have timely and useful information about the program and about recognized schools.

# New "what works" clearinghouse

The Department also is planning to award a contract for a national clearinghouse that will provide information on programs and strategies that have been proven to be effective in improving education. The "What Works" Clearinghouse will allow educators to select programs and practices that have strong evidence of effectiveness based on solid, reliable, scientifically based research and evaluation.

#### QUESTIONS SUBMITTED BY SENATOR ARLEN SPECTER

### CAMPUS CRIME

Question. The United States Department of Education is charged with enforcing the Jeanne Clery Act, which requires institutions of higher education in the United States to disclose campus security information including crime statistics for the campus and surrounding area. The Department of Education may level civil penalties against institutions of higher education in amounts up to \$25,000 per violation or suspend them from participating in Federal student financial aid programs. The Clery's contend that guidance concerning reporting standards has often been hard to obtain, and when violations are alleged it is difficult to secure investigation and corrective action. To help remedy these problems, they have proposed that an office be established within the Department of Education that would be a central point of action.

It is my understanding that there is currently not a central office within the U.S. Department of Education responsible for enforcing the Jeanne Clery Act. Does the Department plan to establish a campus security policy compliance office to provide a central point for schools to obtain guidance and for enforcement actions to be handled?

Answer. We are committed to helping schools provide students with a safe environment in which to learn, and to keeping students, parents and employees well informed about campus security. The Department is working to ensure that families are made aware of safety concerns as well as preventive measures that colleges and universities are taking. The Department supports the Clery Act and is committed to ensuring that all postsecondary institutions are in full compliance.

The Department's Office of Postsecondary Education (OPE) and Federal Student Aid (FSA) office have responsibility for campus crime policy and compliance, respectively. Under this arrangement, OPE is responsible for policy governing the Clery Act, developing regulations and non-regulatory guidance and responding to policy questions from institutions and the public. FSA is responsible for ensuring institutional compliance, conducting on-site reviews and targeted reviews of campus crime statistics when complaints are received. FSA also provides information to institutions about their responsibilities under the Clery Act as part of on-going training and technical assistance activities. Substantial guidance and information on the Clery Act is provided in the Student Financial Aid Handbook; the Department has also established a website to provide guidance and information on Clery Act reporting requirements at: http://www.ed.gov/offices/OPE/PPI/security.html.

This year, the Department plans the following enhancements to its implementation of the Clery Act:

1. Issue a regulation codifying the recently added provisions related to the registration of sex offenders;

2. Produce a separate document for campus law enforcement to use in implementing the Clery Act requirements;

3. Establish a single point of contact for making complaints; and

4. Conduct a number of program reviews targeted at Clery Act implementation issues on the campuses of selected institutions.

Given these efforts, we do not believe that there is a need for a dedicated campus crime office.

# PENNSYLVANIA'S EDUCATION EMPOWERMENT ACT

Question. Under the Education Empowerment Act, the Pennsylvania Secretary of Education would use the Pennsylvania System of School Assessment to identify those districts with a history of low performance (scoring in the bottom-measured group of students statewide in math and reading for the previous two years). How do the accountability provisions in last year's ESEA reauthorization bill compare to those under Pennsylvania's Education Empowerment Act, under which 12 low-performing local educational agencies have been identified for technical assistance and corrective actions, and alternative governance structures have been established for the Philadelphia, Harrisburg, and Chester-Upland school districts?

Answer. Without knowing all the details of the Education Empowerment Act, it appears that the Pennsylvania accountability system includes some, but not all, of the provisions of the No Child Left Behind Act (NCLBA), which reauthorized the Elementary and Secondary Education Act. For example, Pennsylvania's use of school-level reading and math assessments to measure school district performance is consistent with the NCLBA, as is identifying districts for improvement following two years of poor performance. Strong accountability for school districts, with alternative governance arrangements for the worst performers, is another characteristic shared by the Pennsylvania system and the NCLBA.

However, it appears that Pennsylvania's system is focused on district-level accountability, rather than the school-level accountability that is at the heart of the NCLBA. Also, the NCLBA requires States to set annual measurable goals that will result in all students reaching proficiency in 12 years and to identify for improvement all districts and schools that are failing to meet those goals, not just the bottom performers.

Question. Is the Pennsylvania school district accountability program a model for the Nation as it begins to implement the new requirements under the ESEA Act?

Answer. Pennsylvania's system provides a good working model for the kind of strong accountability measures and corrective actions that we expect to see at the district level as a result of the NCLBA. However, it is not clear how this districtlevel approach plays out at the school level, which is the core of accountability under the new ESEA. Also, the new ESEA requires tough accountability for all districts and schools that fail to meet challenging State standards, not just the bottom performers that are the focus of Pennsylvania's system.

# PELL GRANT PROGRAM

Question. In fiscal year 2001 we appropriated \$8.8 billion to provide for a maximum Pell Grant of \$3,750. The appropriation was based on a 2.5 percent increase in the students applying for funds. However, because of the economic situation, there was a 7.7 percent increase in student participation which created a shortfall of \$860 million. In fiscal year 2002, we provided \$10.3 billion and a maximum grant of \$4,000, which created a shortfall of \$416 million. The total shortfall is \$1.276 billion. The fiscal year 2003 budget is an increase of \$549 million and a maximum grant of \$4,000.

Given the unexpected growth in the program over the past 2 years, do you expect that your estimates for fiscal year 2003 will create a further shortfall?

Answer. Under current estimates, which reflect recent applicant trends, our request for fiscal year 2003 will fully support the cost of a \$4,000 maximum award in the 2003–2004 academic year. This assumes that the \$1.3 billion shortfall will be funded through a supplemental appropriation in fiscal year 2002.

#### PELL GRANT SHORTFALLS SINCE ACADEMIC YEAR 1989–90

Question. Over the life of the Pell Grant program, how often have there been annual funding shortfalls? Please outline how each of these shortfalls has been addressed?

 —1989–90. The fiscal year 1990 appropriation designated \$131 million to support the prior year shortfall.
 —1990–91. This shortfall was addressed through a linear reduction imposed on

-1990-91. This shortfall was addressed through a linear reduction imposed on Pell Grant awards.

-1991-92, 1992-93. In fiscal year 1992, \$90 million was transferred to Pell Grants from the Educational Excellence account, and an additional \$40 million was appropriated to support Pell Grants as part of disaster relief funds associated with Hurricane Andrew. The 1993 appropriation designated \$240 million for use in the 1992-93award year. An fiscal year 1993 supplemental appropria-

tion included an additional \$341 million for 1992–93 Pell Grant costs. An additional \$30 million in funds appropriated for disaster relief related to Midwest flooding supported Pell Grant awards.

-1993-94. The 1994 appropriation designated \$250 million to support the prior year shortfall.

*Question.* Does your proposal to keep the maximum Pell Grant at \$4,000 for fiscal year 2003 mean that students served by the program will lose ground relative to the price of college?

Answer. Under our request for 2003, the average Pell Grant will have increased by 26 percent—from \$1,917 to \$2,410—from 1999–2000 to 2003–2004. This increase outstrips growth over the same period in cost of attendance at 2-year public (16 percent) and 4-year private (22 percent) institutions and is only slightly less than cost increases at 4-year public schools (29 percent).

#### INCARCERATED YOUTH OFFENDERS PROGRAM (PRISON POSTSECONDARY)

Question. Approximately two-thirds of Federal and State inmates released on parole are arrested within 3 years of leaving prison, and almost half are reincarcerated. The Department of Education found that participation in the State correctional programs lowered the likelihood of reincarceration by 29 percent. A Federal Bureau of Prison study showed a 33 percent drop in recidivism among Federal inmates who were enrolled in vocational education programs. Mr. Secretary, your budget eliminates the youth offender program. Given the evi-

Mr. Secretary, your budget eliminates the youth offender program. Given the evidence that programs like this reduce recidivism rates, why are you proposing to eliminate the program?

Answer. The Incarcerated Youth Offenders program provides grants to State correctional agencies to assist incarcerated youths, aged 25 or younger, in acquiring functional literacy and life and job skills. Formula grants go to States that choose to participate. The program includes spending caps of \$1,500 per student, per year, for instructional costs, and \$300 per student, per year, for related services, such as occupational assessment or post-release job placement assistance. The budget request is consistent with the Administration's effort to redirect re-

The budget request is consistent with the Administration's effort to redirect resources to high-priority areas and to eliminate small programs whose activities can be funded from other sources. The population served by this program can already receive support under Adult Education State Grants. That program provides up to 8.25 percent for education of prisoners and other institutionalized individuals. Funds can be used for basic education, special education programs, and English literacy programs. The appropriation for the Adult Education State Grants has increased in recent years and, as a result, more funding is available for the education of this population.

In addition, the Vocational Education State Grants program allows States to use up to 1 percent (an estimated \$11.5 million in fiscal year 2003) to serve individuals in State institutions such as State correctional institutions.

The Three State Recidivism Study, currently being conducted by the Correctional Education Association, focuses only on Maryland, Minnesota, and Ohio. The study is not designed to provide findings that can be generalized across States. Also, study data are limited with regard to length of participants' involvement in a corrections education program. In addition, the mean age of the participants in the study is about 31 years of age for the group that participated in correction programs and about 33 years of age for the group that did not participate, so data will not necessarily be valid for the population served by the Youth Offenders program, which serves students 25 years of age and younger.

#### PENNSYLVANIA'S CLASSROOM PLUS PROGRAM

Question. The Classroom Plus program provides a tutorial services program under which parents of certain pupils in grades 3-6 with low achievement test scores may apply for grants of up to \$500 to pay the cost of tutoring from State-approved providers. This program was started one year ago by Governor Ridge with funding from the State of \$23.6 million. How do the new Title I requirements for supplemental services compare to this program?

Answer. Classroom Plus appears to offer services very similar to those required under the new Title I supplemental services requirements. Both programs permit parents to select from a broad range of State-approved providers and both offer a similar level of financial support to pay for tutoring services. Under Title I, however, such services are part of the strong school-level accountability required by the No Child Left Behind Act (NCLBA). School districts must provide supplemental educational services to students attending schools that have failed to make adequate progress toward State standards for at least three years. All poor students attending such schools—not just low-achieving kids in grades 3–6—are eligible to receive services, although districts must give priority to low-achieving poor children if funding is insufficient to serve all eligible students.

*Question.* How might the State and Federal support for supplemental services be coordinated?

Answer. Pennsylvania clearly has a head start in developing an effective, statewide system of supplemental educational services that will meet the requirements of the new Title I law. In particular, it has already identified potential providers of such services—a key first step in making services widely available to parents and their children. While the State will need to adjust its eligibility criteria to comply with the NCLBA, it will now be able to use Federal education funds, including Title I funds, to expand the Classroom Plus program. The Department is currently preparing regulations and guidance on supplemental educational services, and will provide maximum flexibility within the law for adapting existing programs like Classroom Plus to meet the requirements of the new law.

# ADULT EDUCATION AND LITERACY

Question. Nationally, fewer than 10 percent of adults who could benefit from literacy programs are currently being served. The National Adult Literacy Survey found that over 40 million Americans age 16 and older have significant literacy needs, and that more than 20 percent of adults read at or below a fifth-grade level far below the level needed to earn a living wage. It also noted that 43 percent of people with the lowest literacy skills live in poverty, 17 percent receive food stamps, and 70 percent have no job or only a part-time job.

Mr. Secretary, your budget cuts the Even Start Family Literacy program and level funds the adult education State grant program. How will we make progress in this important area without additional investments?

Answer. The President's 2003 budget for education builds on major increases provided in recent years. For example, since fiscal year 2000, funding for Even Start has increased 67 percent, and Adult Education State Grants increased 28 percent. However, additional funding is clearly not the only answer to improvements in education, which is why the President's strategy is not only about investing in education but also about how to increase the return on that investment.

The 2003 request for Even Start would provide \$200 million, a decrease of \$50 million from 2002. The request is supported by the mixed evidence on Even Start's impact on literacy outcomes for children and adults. The two previous evaluations of the Even Start program focused on evaluating the components and outcomes of the Even Start model, which integrates early childhood education, adult education, and parenting education. On measures of literacy used in both of these evaluations, participating families consistently made gains each year. However, results from an experimental study during the first evaluation showed no difference in achievement between those who participated in Even Start and those who did not.

In terms of adult literacy, Even Start adults in the first Even Start evaluation achieved statistically significant gains on the Comprehensive Adult Student Assessment System (CASAS) and Test of Adult Basic Education reading and mathematics tests. However, in the experimental study, adults who received no assistance from Even Start achieved similar gains on the CASAS.

The President strongly supports efforts to ensure that all adults have the skills they need to be productive members of society. Toward that end, the Federal Government contributes about 25 percent of the total spent on adult education. The Department's Adult Education State Grants program supports State efforts to improve adult education, and the 1998 reauthorization put greater emphasis on accountability for results. States are just beginning to report data that can be used to consider the program's impact.

To provide additional information about how well the program is working, the Department is collecting and analyzing statistical data to understand better the scope and implications of literacy skills within the U.S. adult population, investing in research to better understand effective instructional strategies and interventions that benefit adult learners, and examining options to increase the impact of adult education programs on the national effort to improve adult education and English acquisition. Insights from these efforts will help inform the upcoming Adult Education reauthorization.

# QUESTIONS SUBMITTED BY SENATOR TED STEVENS

# PHYSICAL EDUCATION FOR PROGRESS

Question. Last week, Secretary Thompson testified before this Subcommittee and stated that 16 million Americans currently suffer from Type II diabetes—a preventable form of the disease. This type of diabetes is increasingly prevalent in children due to the lack of physical activity. Yesterday, it was reported that researchers found that one in four extremely obese children and one in five obese adolescents under the age of 18 have a condition known as impaired glucose tolerance—a precursor to type II diabetes. The good news is that changes in diet and increased exercise often can reverse impaired glucose tolerance, which, in turn, can prevent or delay the development of type II diabetes. In the U.S. today there are approximately 4.7 million children aged 6–17 who are overweight or obese. Since 1980, the prevalence of overweight children has nearly doubled and the prevalence of overweight adolescents has nearly tripled.

Given these statistics, Mr. Secretary, and the increased health risks of obesity, why did you zero out the \$50 million Physical Education for Progress program? Let me point out that this program helps to improve and expand physical education programs, including after-school programs for kindergarten through 12th grade.

Answer. I strongly share your views on the benefits to children of increased physical activity. I have a background in physical education, and I think physical education is important to children's well being. The President's 2003 budget request builds on the major increases provided in re-

The President's 2003 budget request builds on the major increases provided in recent years and gives States and school districts the resources they need to implement major changes called for in the No Child Left Behind Act. Our budget would maintain funding for large, flexible State grant programs, but would consolidate and eliminate many smaller and less flexible categorical programs, such as Physical Education, in order to reallocate scarce resources to other, higher-priority programs such as Title I, Reading First, and Special Education State Grants.

#### ALASKA NATIVE EDUCATION EQUITY PROGRAM

*Question.* Since 1998, we have slowly increased this program to give Alaska kids a little extra help. Given the fact that Alaska students' test scores are 40 percent lower than other students, why are you cutting this program by \$9.8 million?

lower than other students, why are you cutting this program by \$9.8 million? Answer. Coming up with a budget that would fit within our ceilings was difficult, and it required many tough choices. The 2003 budget shifts funding for small categorical programs, like the Alaska Native Education Equity program, in order to reallocate scarce resources to other, higher-priority programs. The request is consistent with the Administration's intent to reduce or eliminate small programs that have a narrow or limited effect, or that duplicate the efforts of other programs.

We are proposing significant increases for programs such as Title I Grants to Local Education Agencies and Reading First, in order to help many students achieve at higher academic levels, including many Alaska native students. The requested level of funds for the Alaska Native Equity program would be sufficient to cover the costs for all continuation grants.

# SUBCOMMITTEE RECESS

Senator HARKIN. Thank you all very much. The subcommittee will stand in recess to reconvene at 11 a.m., Thursday, March 21, in room SD-192. At that time we will hear testimony from the Honorable Ruth L. Kirschstein, Acting Director, National Institutes of Health.

[Whereupon, at 4 p.m., Thursday, March 14, the subcommittee was recessed, to reconvene at 11 a.m., Thursday, March 21.]

# DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2003

# THURSDAY, MARCH 21, 2002

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

The subcommittee met at 11:07 a.m., in room SD–192, Dirksen Senate Office Building, Hon. Tom Harkin (chairman) presiding. Present: Senators Harkin, Specter, and Cochran.

# DEPARTMENT OF HEALTH AND HUMAN SERVICES

# NATIONAL INSTITUTES OF HEALTH

STATEMENT OF RUTH L. KIRSCHSTEIN, M.D., ACTING DIRECTOR ACCOMPANIED BY:

ANDREW VON ESCHENBACH, M.D., DIRECTOR, NATIONAL CANCER INSTITUTE

CLAUDE LENFANT, M.D., DIRECTOR, NATIONAL HEART, LUNG, AND BLOOD INSTITUTE

LAWRENCE A. TABAK, Ph.D., DIRECTOR, NATIONAL INSTITUTE OF DENTAL AND CRANIOFACIAL RESEARCH

ALLEN M. SPIEGEL, M.D., DIRECTOR, NATIONAL INSTITUTE OF DI-ABETES AND DIGESTIVE AND KIDNEY DISEASES

AUDREY S. PENN, M.D., DIRECTOR, NATIONAL INSTITUTE OF NEU-ROLOGICAL DISORDERS AND STROKE

ANTHONY S. FAUCI, M.D., DIRECTOR, NATIONAL INSTITUTE OF AL-LERGY AND INFECTIOUS DISEASES

MARVIN CASSMAN, Ph.D., DIRECTOR, NATIONAL INSTITUTE OF GENERAL MEDICAL SCIENCES

DUANE ALEXANDER, M.D., DIRECTOR, NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT

PAUL A. SIEVING, M.D., Ph.D., NATIONAL EYE INSTITUTE

KENNETH OLDEN, Ph.D., DIRECTOR, NATIONAL INSTITUTE OF EN-VIRONMENTAL HEALTH SCIENCES

RICHARD J. HODES, M.D., DIRECTOR, NATIONAL INSTITUTE ON AGING

STEPHEN I. KATZ, M.D., Ph.D., DIRECTOR, NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

JAMES F. BATTEY, JR., M.D., Ph.D., DIRECTOR, NATIONAL INSTI-TUTE ON DEAFNESS AND OTHER COMMUNICATION DISORDERS RICHARD NAKAMURA, Ph.D., ACTING DIRECTOR, NATIONAL INSTI-

TUTE OF MENTAL HEALTH

GLEN R. HANSON, Ph.D., D.D.S., ACTING DIRECTOR, NATIONAL IN-STITUTE ON DRUG ABUSE

RAYNARD KINGTON, M.D., Ph.D., ACTING DIRECTOR, NATIONAL IN-STITUTE ON ALCOHOL ABUSE AND ALCOHOLISM

PATRICIA A. GRADY, Ph.D., DIRECTOR, NATIONAL INSTITUTE OF NURSING RESEARCH

DONNA DEAN, Ph.D., ACTING DIRECTOR, NATIONAL INSTITUTE OF BIOMEDICAL IMAGING AND BIOENGINEERING

FRANCIS S. COLLINS, M.D., Ph.D., DIRECTOR, NATIONAL HUMAN GENOME RESEARCH INSTITUTE

JUDITH L. VAITUKAITIS, M.D., DIRECTOR, NATIONAL CENTER FOR RESEARCH RESOURCES

STEPHEN E. STRAUS, M.D., NATIONAL CENTER FOR COMPLEMEN-TARY AND ALTERNATIVE MEDICINE

JOHN RUFFIN, Ph.D., NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES

GERALD T. KEUSCH, M.D., DIRECTOR, FOGARTY INTERNATIONAL CENTER

DONALD A.B. LINDBERG, M.D., DIRECTOR, NATIONAL LIBRARY OF MEDICINE

YVONNE T. MADDOX, Ph.D., ACTING DEPUTY DIRECTOR, OFFICE OF THE DIRECTOR

JACK WHITESCARVER, Ph.D., ACTING DIRECTOR, OFFICE OF AIDS RESEARCH

# SUSAN QUANTIUS, ASSOCIATE DIRECTOR FOR BUDGET

# CHARLES E. LEASURE, DEPUTY DIRECTOR FOR MANAGEMENT

# OPENING STATEMENT OF SENATOR TOM HARKIN

Senator HARKIN. This hearing of the Labor, Health and Human Resources, and Education Appropriations Subcommittee will now come to order.

I apologize to all of you for being a little late. I had a backup of different committee meetings this morning on the authorizing end of this appropriations committee, and I had to be there just for a few moments for that.

Ever since the early 1990's, some of us have had the goal of doubling the NIH budget. This year I am proud to say that that goal will be achieved, and I say publicly for the record it could not have happened without the strong support of my good partner, Senator Arlen Specter from Pennsylvania. During the time that he chaired this committee, we began that process, and now we are going to end it this year. I am very pleased that the President has included the necessary increase in his budget so that we can finish that goal of doubling the NIH budget in 5 years. It is, I think, a remarkable achievement.

I thank all of you for all of the support that you have given and for the information, the advice, and consultation necessary so that people would see the wisdom of doing this.

We are opening more doors all the time in basic research in every institute and every center at NIH. I am sure that every director here can tell of advances not only in basic research, but in the applications of that research to better treatments and better prevention, new blood tests that can detect ovarian cancer, the first vaccine against staph, new research on the importance of exercise in preventing type 2 diabetes. So, I look forward to the hearing to hear more about these advances over the rest of this morning. Funding is not the whole story, however. I believe we are going to have to address the issue of how much and to what extent those in the public policy area, those of us who are in the elected areas of Congress are going to interfere and try to set parameters on biomedical research.

As I said the other evening to a group assembled, to hear a lot of people talk out there, it is almost as if medical researchers somehow checked their morals and their ethics at the lab door. And I said, nothing could be further from the truth. It is those medical researchers in all the areas represented at this table today who spend their days, their months, their lives many times doing the research necessary to alleviate human suffering and disabilities and age-old illnesses that still plague mankind. So, to me there is really no higher calling than to do that. So, I can say without any hesitation that every biomedical researcher I have met in my life and I have met a lot of them—were individuals, men and women, of the highest moral and ethical standards who have only one goal in mind and that is to help people and to help people live better lives.

But I guess we are going to have to have that debate. It is unfortunate, but I guess we are going to have to.

On a more fortunate note, we are fortunate to have all of you here today, and we are fortunate to have Dr. Ruth Kirschstein, the Acting Director of NIH. Dr. Kirschstein, you and I have had a great relationship going back now, well, 18 years, now that I think about it. Well, that is how long I have been here.

Dr. Kirschstein has worked at NIH since 1956, and I guess that counts 46 years, and I trust that you will continue to bring honor, as you have in the past, on NIH for many more years to come. You have on more than one occasion stepped up to the plate to fill in and to lead the NIH. You have done a remarkable job of doing that, and you have my highest admiration and compliments for what you have done both in your own personal and your professional life in terms of your own discipline but also for what you have done to lead NIH. So, Dr. Kirschstein, thank you for that. We look forward to your remarks.

I will at this point leave the record open for any opening statement made by Senator Specter.

# SUMMMARY STATEMENT OF DR. RUTH L. KIRSCHSTEIN

I now would recognize Dr. Kirschstein who has been Acting Director of NIH since January of 2000. Your statement will be made a part of the record in its entirety, and if you would like to summarize, please proceed, as you so desire.

Dr. KIRSCHSTEIN. Mr. Chairman, Senator Harkin, thank you very much. It has been a great pleasure to interact with you over many of these years. I have enjoyed it. I have enjoyed everything I have done in this regard, and I appreciate all of the things you said.

I am appearing before this subcommittee today representing my colleagues who are basically at the table with me. They are the directors of the 27 institutes and centers and each of whom, in addition to me, has presented a written statement related to the President's budget proposal for the fiscal year 2003. I shall present the overview of the total administration budget for NIH. The Congress in general, this committee in particular, and especially, Senator Harkin, you and Senator Specter, as well as the American public, have been committed to doubling the funding of the NIH by the end of this fiscal year, 2003. Although scientific accomplishments often take years to produce new treatments or diagnostic tools, the confluence of the generous budget that you have provided to NIH and the extraordinary scientific opportunities have already begun to yield amazing results.

The current budget proposal, as you know, is \$27.3 billion, an increase of 15.7 percent over fiscal year 2002, and it does, as you said, complete the original commitment. It enables NIH to continue to take advantage of the broader and deeper opportunities now at hand to understand diseases and to improve health, and it opens the way for future progress in medical research.

Opportunities truly are at hand. Some are general. They benefit research in many areas, and others are specific dealing with particular diseases and disorders. Among the general opportunities, the complete draft of the DNA sequence of the human genome is the best known of the new tools, helping scientists in many disciplines to understand how the human body works and what causes disease.

But there are several other areas of investigation that are changing the way biomedical research is done. These include proteonomics, the computer-aided analysis of the patterns present in the large sets of proteins, which are the products of our genes, with the goal of understanding their function; combinatorial chemistry, a new way to generate new, large libraries of molecules that can be screened for the use as drugs; and new, advanced imaging techniques that enable scientists to see within the human body and within its cells as various functions are carried out. There are, as well, new and expanded opportunities in therapeutics and prevention that we will be undertaking.

These efforts, however, do not eclipse research into specific diseases and disorders, but rather enable us to acquire new knowledge to more fully understand and ultimately control or defeat cancer, Parkinson's disease, diabetes, Alzheimer's disease, asthma, heart disease, and many others, as well as to prepare for what we hope will not happen, incidents of bioterrorism. The President's budget for fiscal year 2003 provides the NIH and its institutes and centers with funding to deliver results on these promises.

Mr. Chairman, my written statement has a number of important examples of NIH accomplishments and there are many others that I could mention. However, in the interest of time, I would like to summarize some of the activities based on our proposal, and they are related to the very practical things that talk about the number of research grants that we will be funding and how we go about doing that.

We will fund the largest number of new and competing research grants that we have been ever able to fund and the largest total number as well. So, the research will progress. Areas will progress also in certain things we are studying, such as bioterrorism. We will use the contract mechanism. In addition, there will be expansion of the centers and some of our other activities.

# PREPARED STATEMENT

One important component that I think we should discuss is the fact that we have started the loan repayment program in fiscal year 2002, and we will double the number of contracts that we will provide to young physicians who want to do research and whose tuition, therefore, can be forgiven by these loan repayments. This, we think, is going to be a very, very important facet of what is going on.

So, Mr. Chairman, I will conclude by saying my colleagues are also available to answer any questions.

[The statements follow:]

## PREPARED STATEMENT OF DR. RUTH KIRSCHSTEIN

Mr. Chairman and Members of the Committee: I am Ruth Kirschstein, the Acting Director of the National Institutes of Health. I am honored to appear before the Subcommittee, representing my colleagues, the Directors of the 27 Institutes and Centers, each of whom has presented a written statement related to the President's budget proposal for fiscal year 2003. I shall present an overview of the total Administration budget for the NIH for fiscal year 2003.

The Congress, the Administration, and the American public have been committed to doubling the funding of the NIH by fiscal year 2003. Although scientific accomplishments often take years to produce new treatments or diagnostic tools, the confluence of generous Budgets and extraordinary scientific opportunity has already begun to yield amazing results. The current budget proposal of \$27.3 billion, an increase of 15.7 percent over fiscal year 2002, completes the original commitment, enables the NIH to continue to take advantage of the broader and deeper opportunities now at hand to understand diseases and improve health, and opens the way for future progress in medical research.

Opportunities truly are at hand. Some are general, benefitting research in many areas, and others are specific, dealing with particular diseases and disorders. Among the general opportunities, the complete draft of the DNA sequence of the human genome is the best known of the new tools, helping scientists in many disciplines to understand how the human body works and what causes disease. But there are several other areas of investigation that are changing the way biomedical research is done. These include proteomics—the computer-aided analysis of the patterns present in large sets of proteins (the products of our genes) with the goal of understanding their function; combinatorial chemistry—a new way to generate large libraries of molecules that can be screened for use as drugs; and new, advanced imaging techniques that enable scientists to see within the human body and within its cells as various functions are carried out. There are, as well, new and expanded opportunities in therapeutics and prevention that we will be undertaking. These efforts do not eclipse research into specific diseases and disorders, but enable us to acquire new knowledge to more fully understand—and ultimately to control or defeat—cancer, Parkinson's disease, diabetes, Alzheimer's disease, asthma, and many other diseases, and prepare for incidents of bioterrorism. The President's budget for fiscal year 2003 provides the NIH and its Institutes and Centers with funding to deliver results on these promises, some of which I will now describe.

### CANCER RESEARCH

The fiscal year 2003 budget request provides an estimated \$5.5 billion in cancerrelated research. By building upon past successes, we will accelerate the pace of cancer research and improve our ability to find better ways to help those whose lives are touched by cancer.

Last month, for example, scientists from the National Cancer Institute (NCI) and the

Food and Drug Administration (FDA) reported using proteins found in blood serum to detect cancer of the ovary, even at early stages. This new diagnostic method, built on the concept of proteomics, has great promise. Usually patients with ovarian cancer are diagnosed at a late stage and have only a 20 percent chance, or even less, of survival after five years. Preliminary studies of this new test are able to identify correctly, in a small number of patients, all of those with ovarian cancer who were at stage I of the disease. Not only is this test simple and accurate, requiring only a blood sample, but the approach has exciting potential for diagnosing many other cancers, as well as other diseases.

Last May, as discussed at last year's hearings, another new concept—the design of drugs based on understanding the molecular anatomy of tumor cells—produced Gleevec, which is taken as a pill to treat a chronic type of leukemia that usually strikes middle-aged or older people. While studies continue with Gleevec in patients with this type of leukemia, it is also being tested for those with other cancers, including those that attack the brain and nervous system, the soft-tissues such as muscle, and the gastrointestinal tract. An intensive effort is now underway to identify other cancer-causing proteins in other tumors so that drugs can be specifically designed to block their action.

With the increases requested for fiscal year 2003, the NIH will provide support to answer critical questions about controlling, preventing and screening for cancer. For example, the NIH will conduct the largest prevention study ever to determine if vitamin E and selenium can protect against prostate cancer. The study will include 32,400 men recruited through more than 400 sites in the United States, Puerto Rico, and Canada and is expected to take 12 years to complete. The NIH will also launch the first multicenter study to compare digital mammography to standard mammography for the detection of breast cancer. Digital mammographic technology provides images at higher resolution than standard mammography, and investigators want to determine if it can detect breast cancer more accurately.

These are just a few examples of compelling new avenues for cancer research. While increases for the National Cancer Institute constitute over 80 percent of the proposed increase for cancer research, many other NIH Institutes and Centers will also contribute to the emphasis placed on cancer. For example, the National Center for Complementary and Alternative Medicine will study the integration of complementary and alternative therapies into more conventional treatments for cancer, the National Institute of Neurological Disorders and Stroke will emphasize sophisticated ways to improve the treatment of brain tumors, and the National Institute on Deafness and Other Communication Disorders will continue its research on new therapies to treat patients with head and neck cancers, while preserving their ability to speak.

#### BIOTERRORISM RESEARCH

The threat of bioterrorism became a reality for the United States with the intentional delivery of anthrax spores through the mail, demonstrating our vulnerability and giving impetus to research to protect the public health. A number of government agencies have specific roles to play in protecting the public from bioterrorism; the role of the NIH is to conduct research to learn more about the viruses and bacteria that can be used in bioterrorism and about how the body responds to such assaults, and to develop counter-measures, such as diagnostic tests, vaccines, and treatments.

The fiscal year 2003 budget request for bioterrorism-related research is \$1.75 billion, an increase of \$1.47 billion over fiscal year 2002. Most of these funds will go to the National Institute of Allergy and Infectious Diseases (NIAID), which already has a remarkable track record for success in this area of science. For example, in November 2001, scientists funded by the NIAID reported a new understanding about the toxins released by the anthrax bacterium, providing leads for potential new therapies. The NIAID is now completing a study aimed at learning whether use of the current smallpox vaccine, if diluted to stretch the existing supply, could still convey protection; results are scheduled to be reported soon. Meanwhile, the NIAID continues to work on a new, safer smallpox vaccine as well as a new vaccine to protect against anthrax. In addition, members of the NIAID intramural research program have demonstrated the efficacy of an Ebola vaccine in a monkey model. This vaccine will soon enter early safety trials in humans. And as we all remember, Mr. Chairman, when HIV/AIDS was first recognized as an epidemic some 20 years ago, the NIAID took the lead at the NIH in swiftly mobilizing key stakeholders, planning research, providing resources, and translating basic findings into clinical practice. The NIAID has already convened a Blue Ribbon Panel of experts to review a stra-

The NIAID has already convened a Blue Ribbon Panel of experts to review a strategic plan prepared by NIAID to guide the effort against bioterrorism. Some elements of the plan include establishing Extramural Centers of Excellence for Bioterrorism and Emerging Infections around the country so that scientists can have the tools and the secure facilities they need to conduct their work; continuing the study of the genetics of microbes that might be used in bioterrorism; launching challenge grants to industry and academic centers to attract their long-term interest; and supporting clinical trials of next-generation vaccines and therapeutic agents. The Nation's research enterprise is alert to this urgent need and eager to expand its efforts.

## TRANSLATING RESEARCH INTO PRACTICE

Clinical research, or studies involving patients and healthy volunteers, is the crucial step for translating basic science into better health for everyone. Our new age of medical research—capitalizing on the Human Genome Project, the new field of proteomics, and advanced imaging technology—is providing unprecedented opportunities to design new ways to prevent, diagnose, and treat many diseases and conditions. But we will not realize the promise of new knowledge and new techniques without clinical research—and well-trained clinical researchers—to bring findings from the laboratory to the patient. Our clinical trials have become wider-ranging, more representative of the population, and larger and they must become even more so in the future. In fiscal year 2003, the NIH will place additional emphasis on clinical research.

For example, the National Institute on Aging (NIA) is accelerating research to slow the progress of Alzheimer's disease, to delay its onset, and to prevent the disease entirely. Already scientists have identified new targets to block directly the effects of the disease in the brain and are developing imaging and other tests to diagnose people in the early stages of the disease. Major prevention trials are under way using vitamin E and the drug Aricept, as well as folate, anti-inflammatory drugs, and estrogen. The NIA is also funding a five-year initiative to speed the development of immune-based approaches and other novel strategies for preventing Alzheimer's disease.

Another example: The National Institute of Neurological Disorders and Stroke (NINDS) will support a network of acute stroke centers across the United States, each capable of treating patients rapidly and serving as a clinical laboratory for scientific studies related to acute stroke, including tests of new drugs. The first effective treatment for acute ischemic stroke, the drug TPA, is only partly effective and cannot be used for all types of strokes. The NINDS has demonstrated the potential of others drugs for stroke in laboratory studies, and translating those findings into practical treatments would be enhanced by state-of-the-art centers for stroke.

practical treatments would be enhanced by state-of-the-art centers for stroke. The potential of such clinical studies to improve the Nation's health has made even more urgent our need to recruit and retain highly qualified health professionals as clinical investigators. The NIH plans to expand its current Extramural Loan Repayment Program for Clinical Researchers, which provides for repaying the educational loans of qualified health professionals who agree to conduct clinical research. The fiscal year 2003 President's budget request doubles this program by providing \$28 million over the fiscal year 2002 estimate.

#### RESEARCH ON DISEASE PREVENTION

Research to prevent disease has been a major aspect of the NIH's mission, and we plan to launch a number of prevention initiatives in fiscal year 2003, while continuing others started earlier. Although considered a traditional approach, vaccines are effective forms of prevention, and today's vaccine research takes advantage of the most up-to-date knowledge and technology. NIH scientists and NIH-supported scientists are producing and testing vaccines aimed at preventing otitis media (which causes ear infection and sometimes hearing loss in children), Ebola (an often fatal disease caused by a virus found in parts of Africa), dengue fever (a viral disease spread by mosquitoes), HIV/AIDS, Leishmania (a devastating disease spread by sandflies in the subtropics), and malaria. Just last month, scientists at the National Institute of Child Health and Human Development announced the development of the first vaccine against *Staphylococcus aureus* (often called "staph"), a major cause of infection and death in hospital patients. Also last month, scientists supported by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) reported the results of the Diabetes Pre-

Also last month, scientists supported by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) reported the results of the Diabetes Prevention Program. The research conveys a powerful message of hope to individuals at risk for type 2 diabetes, a life-threatening disease that has been increasing in this country parallel to the increase in obesity. The study showed that millions of overweight Americans at high risk for type 2 diabetes can delay and possibly prevent the disease with improved diet and moderate exercise. The same study found that the oral diabetes drug metformin also reduces the risk of type 2 diabetes, but not as effectively as lifestyle changes.

We know that lifestyle patterns contribute greatly to the risk of developing type 2 diabetes. Thus, the great challenge now is to identify those at risk for type 2 diabetes and encourage them to act on the findings of the study. We are prepared to do that since our legislative authority and the traditional mission at the NIH has always included both disseminating the results of research and communicating general health information directly to health care professionals, patients, and the public. In cooperation with the Centers for Disease Control and Prevention (CDC), the

NIH has already launched the National Diabetes Education Program to increase public awareness of diabetes, its risk factors, and strategies for preventing diabetes and its complications.

# OTHER FEATURES OF THE BUDGET REQUEST

Mr. Chairman, this is only a brief summary of our emphasis areas now and in fiscal year 2003. Our research portfolio is so broad, deep, and complex that, even in many more pages, I would still not be able to give a complete picture. Yet I am confident that the fiscal year 2003 budget request enables the NIH to sustain momentum of research already in progress, to open the way to new research opportunities in the coming fiscal year and in years to come, and to augment both our research infrastructure and our human capital. In fiscal year 2003 the President's budget request would fund a total of 9,854 new, competing research grants, or a total of 38,038 awards, the highest annual total ever. Intramural research increases by 15 percent over the fiscal year 2002 estimate, with most Institutes and Centers increasing by 9 percent, while the NIAID and the NCI increase by 52 percent and 11 percent respectively, as a result of the large increases in bioterrorism and cancer research. The Research Management and Support (RMS) funds are vital, if the NIH is to manage its programs and resources efficiently and effectively. The RMS funds are used by the NIH to sustain, guide, and monitor extramural and intramural research activities. This funding increases by 17 percent in total in fiscal year 2003. All Institutes and Centers except the NIAID and the NCI increase by 9 percent over the fiscal year 2002 estimate. The NCI and, in particular, the NIAID are requesting increased resources in RMS funding to effectively manage their large program increases.

Mr. Chairman, this concludes my opening statement. I would be glad to respond to any questions.

## PREPARED STATEMENT OF DR. ANDREW C. VON ESCHENBACH

Mr. Chairman and Members of the Subcommittee: I am Dr. Andrew von Eschenbach, the Director of the National Cancer Institute (NCI). I am pleased to appear before you to discuss some of the activities supported by the NCI and to present the President's budget proposal for fiscal year 2003. The significant budget increases over the past several years have allowed the NCI to continue on an aggressive path of discovery in cancer research. This path is aimed at the development of interventions that will continue to reduce the suffering and death caused by cancer.

Over the past 30 years, our nation has invested a great deal of its resources in cancer research. It is an investment that has enabled the NCI to conduct research and to support thousands of scientists throughout this country. It is an investment that has sustained promising research and more recently, data-sharing infrastructures and multidisciplinary collaborations. And it is an investment that is now paying significant scientific dividends. Where major breakthroughs were once measured in years or even decades, we are now moving forward at record pace. Every day, we uncover yet another footprint in the genetic and molecular process by which a cell becomes malignant, grows uncontrolled, invades, metastasizes, and ultimately kills.

While our knowledge of this complex process is still rudimentary, the path ahead is now clear and greater dividends are within reach. Even with our just emerging picture of cancer, we are exploiting this knowledge to devise better imaging and diagnostic tools and design new interventions to treat and prevent this devastating disease.

We stand on the threshold of a biomedical revolution, where multidisciplinary collaboration will translate the breakthroughs of basic research swiftly from the lab to the bedside. One recent example of success emerged in the fight against ovarian cancer, one of the deadliest cancers for women, in part due to lack of effective screening methods. A sophisticated computer-based screening tool has shown the ability to recognize protein profiles in the blood from women with diagnosed ovarian cancer and uses the information to detect new cancer cases in women at an early stage of disease. Current discovery of such molecular signatures of cancer may also make possible powerful, new tools for detecting cancer and its recurrence.

The elucidation of the biology of cancer is a scientific pursul. But the eradication of cancer is a human experience. The ultimate goal of the people of the National Cancer Institute is saving lives and improving the quality of life among cancer patients.

### CANCER TRENDS

Five years ago, NCI initiated an annual report to the Nation on the burden of cancer. This report is developed in collaboration with the American Cancer Society (ACS), the North American Association of Central Cancer Registries, the Centers for Disease Control and Prevention and its National Center for Health Statistics. Based on statistics from these sources, we are continuing to see encouraging overall trends, including continued decline in the rate of new cancer cases and cancer deaths.

Today, we can successfully treat or increase life expectancy for more than half of all cancer patients. We now have more options for prevention, including chemoprevention such as tamoxifen for breast cancer, and are developing more evidence-based interventions for cancer control. Adult smoking is down dramatically from the 1960s for men and the increase in smoking among women has finally reached a plateau. The latest statistics from the Report to the Nation that we will release this spring also show that while breast cancer incidence continues to rise (due to increase in early stage disease), overall breast cancer deaths continue to decline. And for the first time ever, we are seeing a small, but significant decline in breast cancer mortality among African-American women.

breast cancer mortality among African-American women. Yet even as these trends give rise to hope, they must also steel our resolve to use the fruits of discovery to the further benefit of patients. That's because we know that this year, based on ACS estimates, over 1.2 million Americans will be diagnosed with cancer this year, and about 550,000 Americans are expected to this disease, more than 1,500 people a day. The number of new cancer cases is still rising for some cancers such as esophageal, liver, melanoma, and non-Hodgkin's lymphoma. And there remains a disparate burden of cancer experienced by America's undeserved population. Another trend indicates that youth smoking continues to rise except in states with vigorous tobacco control programs. NIH estimated the overall costs for cancer to be \$156.7 billion in the year 2001.

Of course, behind these numbers lies the real and human face of cancer. It is the face of a child with retinoblastoma whose only hope is radical surgery that will leave him cured but permanently blind. It is the face of a young woman living with the fear that her breast cancer will recur. And it is the face of a grandfather whose lung cancer has shattered his dream of spending his golden years with his grand-children.

These faces demand urgency. It is an urgency that will be at the forefront of NCI's continued efforts to translate research quickly and safely to the cancer patient. I have highlighted several activities that illustrate NCI's accelerated approach to scientific discovery.

## HIGHLIGHTS IN CANCER RESEARCH

We understand that improved technology for early detection and diagnosis is critically needed for cancer to become a rare disease. For this reason, imaging research supported by NCI is advancing on several fronts. Now, with the recent reawakening of debate on mammography guidelines, it is more important than ever to redouble our efforts in this area. In addition to assuring women that the weight of the evidence still shows that mammography saves lives, NCI is accelerating research into better screening tools. Besides efforts to improve conventional and digital X-ray mammography, NCI supports research for several other technologies such as magnetic resonance imaging (MRI), ultrasonography, positron emission tomography (PET), and single photon emission computed tomography (SPECT). Already, with these technologies, scientists can "see" biological processes taking place in living tissues such as blood flow, oxygen consumption, and glucose metabolism.

A major research effort is also under way to create molecular imaging technologies that can noninvasively detect and display the actual molecular events taking place in the body. Imaging technology to detect cancer recurrence using flurodeoxyglucose (FDG) PET scans and dynamic MRI for functional therapy monitoring are among the sophisticated imaging techniques currently being investigated.

In addition, several PET studies are in progress for the evaluation, staging and monitoring of therapy using PET for woman with breast cancer. In a large clinical trial from the University of Pennsylvania, doctors are incorporating dedicated breast PET into the standard diagnostic regimen for women with breast cancer.

On the therapeutic front, researchers are making headway against certain forms of leukemia, where an abnormal protein complex called bcr-abl forms inside the cell and stimulates uncontrolled growth. A search for agents that would interfere with bcr-abl led to the identification of STI-571, later renamed imatinib mesylate (Gleevec®). In clinical trials with this drug, more than 50 percent of patients with myeloid blast crisis responded well as measured by a decrease in the abnormal leukemic blood cells. Gleevec® has moved swiftly from clinical trials to the cancer centers and is now available as treatment for patients with chronic myelogenous leukemia (CML). This drug is now being evaluated in the treatment of ovarian, certain types of brain cancer, as well as a very rare form of stomach cancer and prostate cancer.

In the area of prevention, research is pointing to certain agents that are capable to changing a person's risk for cancer. When basic research establishes a biological basis for an intervention, trials serve to test the hypothesis. For example, the Selenium and Vitamin E Cancer Prevention Trial (SELECT) will determine if seven or more years of daily supplements of selenium and/or vitamin E reduces the number of new prostate cancers diagnosed in healthy men. In addition, a Study of Tamoxifen and Raloxifene (STAR) will determine whether the osteoporosis drug raloxifene has equivalent breast cancer risk reduction benefits with reduced risk of side effects as compared to tamoxifen.

While the fast pace of discovery from these and other areas is welcome, the volume of data generated can often be overwelming to the research community. To address this, NCI supports a fully integrated cancer biology approach to discovery through a discipline called bioinformatics. NCI programs such as the Cancer Genome Anatomy Project (CGAP), the Proteomics Initiative, Mouse Models Program, the Drug Discovery Program produce information and enable the research community nationwide to access these Web-based data sets that serve as tools for collaboration and scholarly discovery. This ensures that the analyses and interpretation of data across disciplines proceed in parallel and synergistically so that discovery in one system informs research in the other.

one system informs research in the other. Bioinformatics enables researchers in CGAP to build, analyze, and interpret databases of genes expressed in cancer cells and of single nucleotide polymorphisms (SNPs), important markers for cancer risk-related genes. In proteomics, the ovarian detection tool that I mentioned earlier has demonstrated the power of bioinformatics to detect invisible patterns of disease. And in drug discovery, bioinformatics ensures that the most promising targets identified in the extramural research community can be exploited using the modern tools of cell-based drug analysis and gene-based high-throughput screening.

#### MAINTAINING MOMENTUM

Much of the research I've highlighted is being conceived and conducted by scientists in laboratories and clinics across the country and at NCI—building on the wellspring of scientific discovery. Our goal for fiscal year 2003 is to speed the rate of discovery and translation of those discoveries to cancer patients by expanding and facilitating researchers' access to resources and new technologies. To understand the basic processes of cancer and translate this research into clinical practice, we must link researchers with the resources and technologies they need while encouraging multi-disciplinary collaboration.

NCI will continue to create and sustain research infrastructures for collaboration, technology support and development, and access to resources that enable multiple scientific disciplines to address the complex questions before us. We will achieve this by expanding our nationwide infrastructure of cancer centers, centers of research excellence, networks, and consortia in ways that promote and facilitate complex scientific interactions and the sharing of information and resources.

Two important programs deserving of special mention are Rapid Access to Intervention Development (RAID) and Rapid Access to Preventive Intervention Development (RAPID). These programs expedite new agent development on the part of independent investigators in universities or biotechnology companies by making NCI's preclinical drug development resources and expertise available for moving novel molecules toward clinical trials.

Also key to our multidisciplinary approach are Specialized Programs of Research Excellence (SPOREs). Several major academic centers of excellence are now working on a wide range of scientific approaches to translational research—that is, focusing on the biology of cancer specifically as it may inform development of new treatments. NCI will expand the use of SPOREs in the coming year.

We will continue our efforts to ensure that the clinical trials program addresses the most important medical and scientific questions in cancer treatment and prevention quickly and effectively through state-of-the-art clinical trials that are broadly accessible to cancer patients, populations at risk for cancer, and the physicians who care for them. Despite major advances in our understanding of tumor biology and potential molecular targets for cancer prevention and treatment, our capacity to apply and test these findings in clinical settings has not kept pace. The NCI will invest more resources in developing and testing new therapies and increasing access to and participation in clinical trials. We will also expand surveillance data systems, methods, communications, and training to improve capacity for monitoring progress in cancer control and for exploring potential causes of cancer nationally and among diverse, underserved populations.

NCI is also launching research to improve the quality of cancer care by strengthening the information base for cancer care decision making. Researchers must better understand what constitutes quality cancer care, with an emphasis on the patient's perspective; identify geographic, racial/ethnic, and other disparities in who receives quality care; and strengthen the scientific basis for selecting appropriate interventions.

Finally, to sustain new ideas, we will continue to nurture and develop new scientists. To deliver new biology-based interventions, we must educate and train capable physicians. That's why NCI will continue to expand its efforts to design and implement opportunities for scientists at all career levels to meet the challenge of building a stable, diverse cadre of basic, clinical, behavioral, and population scientists trained to work together effectively and use the most advanced technologies.

#### CLOSING

NCI's mission is broad and our approach is necessarily ambitious, because, while our primary role and our expertise is research, our focus and sense of urgency is in serving the American people, the country's cancer patients and their families, friends and neighbors.

As director of NCI, a doctor, an investigator, and a cancer survivor, I share the urgency of America's cancer patients and I am confident that the efforts I've highlighted and many additional activities will bring us closer to the ending the death and suffering caused by this disease.

## BUDGET STATEMENT/GPRA

I am pleased to present the President's budget request for the National Cancer Institute for fiscal year 2003, a sum of \$4,724,505,000, which reflects an increase of \$514,784,000 over the comparable fiscal year 2002 appropriation.

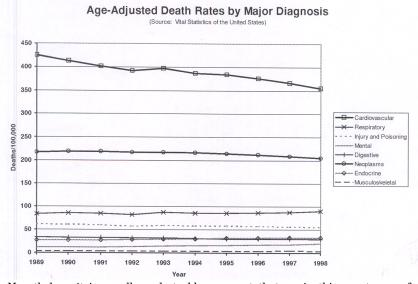
The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report which compares to our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

#### PREPARED STATEMENT OF DR. CLAUDE LENFANT

Mr. Chairman and Members of the Committee: I am pleased to address this Committee once again on behalf of the National Heart, Lung, and Blood Institute (NHLBI) and, in particular, to thank the Committee for its longstanding and generous support of the Institute's research programs. Let me begin by commenting on where we stand with regard to diseases of importance to the NHLBI, and then move on to describe several promising new research directions.

#### BURDEN OF DISEASE

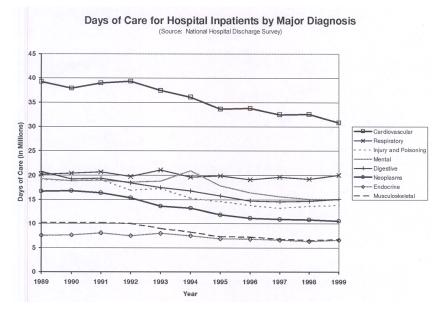
The first chart below, which summarizes mortality during the most recent 10 years for which data are available, provides welcome reassurance that the decline in the death rate for cardiovascular diseases is continuing the trend that began several decades ago. I believe it is fair to say that medical science has made more progress in this area than in any of the other major disease categories. This reflects the wisdom of our great investment in research, which has yielded unprecedented advances in treatment, both medical and surgical, and widespread attention by the public and the medical establishment to addressing risk factors such as hypertension and blood cholesterol.



Nonetheless, it is equally and starkly apparent that we in this country are far more likely to die of cardiovascular diseases than of any other cause.

Of equal or perhaps mor significance is the societal burden of living with disease. One measure of this burden is time spent in the hospital. As the chart on the next page indicates, cardiovascular disease patients spend more than 30 million days per year in acute-care hospitals, and respiratory ailments are the second most common reason for hospitalization. Beyond the pain and suffering, the cost associated with these hospitalizations demands our attention.

The enormous cost of treating diseases of concern to the NHLBI was also made apparent in a study published in the January 16, 2002, issue of the *Journal of the American Medical Association*. Reporting the results of a nationwide survey, the researchers identified medications that are most commonly taken. Fourteen of the top 21 prescription drugs address cardiovascular, lung, or blood problems. And, these data most assuredly understate the cost of treatment, given that many such drugs (e.g., beta blockers, statins) are underprescribed, and patients with limited financial resources are generally inclined to spend their money on medications that make them feel better (e.g., for menopausal symptoms, hay fever, arthritis pain, or depression) before they spend money on drugs to treat conditions such as hypertension and high cholesterol that, however threatening, produce no symptoms.



#### BASIC RESEARCH

As always, basic research is one cornerstone of our effort to alleviate the burden of disease. In this arena, we have been able to capitalize on our budget increases by putting into place a number of activities that would have been impossible under other circumstances. An example is our Programs in Genomic Applications, which seek to maximize the fruits of the new information about the human genome in order to identify the causes of disease, determine who is susceptible to it, and tailor treatments and, possibly, cures to the individual.

We are moving forward on other basic science fronts, based on recent scientific findings. For instance, we are stimulating research on cell-based therapy in the wake of astonishing discoveries that, contrary to everything we thought we knew before, cells of the heart and other organs are capable of regeneration. Examining hearts of people who had suffered fatal heart attacks, researchers found dividing cells in the area of the damaged heart muscle. Furthermore, doctors studying male patients who received heart transplants from female donors found evidence that male cells had somehow arisen and incorporated themselves into the donated heart tissue. If we could find a way to harness and direct the body's ability to regenerate cells, we would have an entirely new approach to therapy for diseases that are currently irreversible, such as heart failure.

Accumulating evidence suggests that inflammation—the body's normal, protective response to injury or infection—may be at the core of many chronic degenerative diseases. Its role in asthma has been well established, and reports that blood levels of a substance called C-reactive protein, a marker of inflammatory activity, are correlated with risk of heart attack and stroke suggest a role in atherosclerosis as well. Understanding the delicate balancing act of the immune system could pave the way for new preventive and therapeutic strategies. Related work from a number of laboratories has found that exposure to a variety of infectious agents, both viral and bacterial, is associated with development of vascular disease and of chronic obstructive pulmonary disease. We are vigorously pursuing basic research to elucidate the mechanisms underlying these phenomena in the expectation that it may ultimately lead to new approaches, perhaps even vaccines, to prevent disease.

The quest to develop gene therapies made a significant step forward this year. Researchers used—HIV the AIDS-causing virus that is notorious for its ability to find its way into the nuclei of cells—to deliver a therapeutic gene to the bone marrow of mice with sickle cell disease. A cure resulted. Before such a therapy can be attempted in human patients, more basic research is needed to establish its safety and develop a non-toxic way to rid the body of sickled cells—goals that we are supporting strongly.

### CLINICAL RESEARCH

As we pursue these and other basic research avenues, we are working to strengthen clinical research to ensure that findings from the laboratory have a swift and effective impact on patient care. Our research centers program is being reconfigured as Specialized Centers of Clinically Oriented Research (SCCORs) to sharpen its focus on the patient. We have made competitive funds available for investigators involved in SCCORs, clinical networks, and multicenter clinical trials to develop skills—development programs to enhance the training and career development of clinical investigators. We have made known to the community our strong interest in supporting Mentored Patient-Oriented Research Career Development Awards and Midcareer Investigator Awards in Patient-Oriented Research. And, we have worked with other NIH components to craft loan repayment programs that will encourage clinically trained individuals to funnel their talents into research.

# EDUCATION AND OUTREACH

To maximize the impact of research findings on the people whom we serve, the NHLBI is strongly committed to educating patients, health professionals, and the public about disease awareness, diagnosis, treatment, and prevention. The National Asthma Education and Prevention Program (NAEPP), for example, has developed and disseminated guidelines for asthma diagnosis and management; produced practical guides for patients, emergency department personnel, pharmacists, nurses, and schools; conducted media campaigns to promote asthma awareness among the general public and to encourage undiagnosed patients to seek care; and worked with communities to develop coalitions to address local asthma issues. The NAEPP serves as a focal point for coordination of all federal activities related to asthma, and has developed a plan to enhance collaboration among relevant agencies. And, finally, the impact of the NAEPP is being felt worldwide through the Global Initiative on Asthma, conducted in partnership with the World Health Organization.

#### AMOUNT OF PRESIDENT'S REQUEST

I am pleased to present the President's budget request for the NHLBI for fiscal year 2003, a sum of \$2,798,178,000, which reflects an increase of \$216,618,000 over the comparable fiscal year 2002 current estimate.

#### GOVERNMENT PERFORMANCE AND RESULTS ACT

The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's third annual performance report which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

I would be pleased to respond to any questions that the Committee may have.

# PREPARED STATEMENT OF DR. LAWRENCE A. TABAK

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Institute of Dental and Craniofacial Research (NIDCR) for fiscal year 2003, a sum of \$374,319,000, which reflects an increase of \$29,016,000 million over the comparable fiscal year 2002 appropriation. The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report, which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

#### IMPROVING THE NATION'S ORAL HEALTH

Over the past 50 years, our nation's investment in dental, oral, and craniofacial research has yielded tremendous advances in American public health. At this time when our nation is engaged in a war, it is interesting to reflect back to the World War II era when many patriotic, able-bodied young men were rejected from military service because they lacked the mandatory six opposing teeth to enlist in the military. In hopes of countering this public health problem, Congress established in 1948 the then National Institute of Dental Research to help eradicate dental decay and tooth loss in America. Today, NIDCR and its partners in public health reflect with pride upon the fact that few young men and women lose teeth. In addition, 70 percent of older Americans have not lost their teeth, compared to 54 percent just 20 years ago.

## COMMITMENT TO REDUCING HEALTH DISPARITIES

The NIDCR's mission to improve the nation's oral health remains far from finished, however. One reason is the sobering fact that many of the nation's oral health advances have yet to adequately benefit our underserved populations. Specifically, there is a clear and compelling need to push forward and reduce the higher incidence of oral cancer, gum disease, and tooth decay among the underprivileged in our society. The NIDCR remains firmly committed to forwarding this effort and pursuing it to its rightful conclusion. As a first step, NIDCR, in collaboration with the National Center for Minority Health and Health Disparities, has funded five Centers for Research to Reduce Oral Health Disparities in Boston, New York, San Francisco, Seattle, and Detroit. Another large study has been funded to examine the underlying causes of oral health disparities in rural West Virginia. This multi-year investigation will focus on the unusually high incidence of children born in this region with cleft lip and palate. The hope is that, with inexpensive dietary interventions during pregnancy, more mothers will give birth to babies free of this socially stigmatizing, expensive-to-treat problem.

# UNPRECEDENTED OPPORTUNITY FOR SCIENTIFIC DISCOVERY

The NIDCR leadership also recognizes that scientists today truly stand on the threshold of an unprecedented "Golden Age" in biology. The recent completion of the Human Genome Project, in tandem with the emergence of more powerful research technologies in the laboratory, are allowing scientists to catalogue with encyclopedic comprehensiveness the actual genes, proteins, and protein networks that power our cells. Such studies, an impossibility just a few years ago, have opened a valuable window into the genetic programs of some of the most complex developmental and disease processes involving oral and craniofacial tissues.

## TMJ DISORDERS: BUILDING THE SCIENTIFIC INFRASTRUCTURE

Given the tremendous opportunity that now exists for fundamental discovery in biomedicine, NIDCR has targeted as one of its high-priority research areas for fiscal year 2003 a group of conditions collectively known as temporomandibular joint (TMJ) disorders. These disorders affect the joint that connects the lower jaw (mandible) to the skull and the surrounding muscles that are used to chew and open the mouth. An estimated 5 to 12 percent of Americans report having pain associated with the temporomandibular joint. Studies suggest that TMJ disorders may be as much as two times more common in women than men.

By investing in this new initiative, the Institute plans to create the needed research infrastructure to allow multi-disciplinary teams of scientists to more rapidly and systematically tease out the molecular and physiological basis of these conditions. Only then can rational and targeted treatment approaches be devised to help control or alleviate the chronic pain and dysfunction that people with these conditions confront on a daily basis.

To begin building the needed research infrastructure, NIDCR plans to establish the first registry for people with TMJ disorders. The registry will help track the incidence and natural history of these conditions, a longstanding need in the field. The NIDCR also will make a concerted effort to identify biomarkers—genes, proteins, or even protein networks—that are adversely affected by TMJ disorders. Through this research, the Institute hopes to lay the intellectual foundation for the development of tests that generate meaningful, telltale diagnostic or prognostic information for doctors and patients. The Institute also will invest in the development of animal models that closely mimic TMJ conditions, providing an important scientific tool to test emerging hypotheses as the research progresses.

# RELIEVING ACUTE AND CHRONIC PAIN

One of the great challenges today in medicine is the management of pain. Yet, because most people experience pain differently, its study can be a lot like trying to analyze multiple moving targets at once. Among the variables involved in the pain process are: age, immune function, endocrine and neural activity, genetics, stress, psychological state, gender, and even cultural background.

Despite the inherent complexity of their work, NIDCR scientists and grantees continue to make progress in understanding the dynamics of pain and how to effectively control it in dental care and for pain sufferers in general. Recently, for example, NIDCR researchers used positron emission tomography (PET) to image the brain's chemical activity while human volunteers received a stimulus mimicking the chronic pain of temporomandibular joint disorders. This marked the first time ever that scientists had non-invasively analyzed sustained pain, while also (1) simulta-

neously monitoring brain scans of a key neurochemical system and (2) recording the self-reported pain ratings of human participants. The NIDCR scientists found that after experiencing pain in the jaw muscles for

20 minutes, the volunteers had a surge in the release of natural opioids, part of the brain's painkilling system, and a concomitant drop in pain and pain-related emo-tions. But, most significantly, the researchers discovered a major variation among volunteers in the baseline and pain-induced levels of naturally occurring opioids. In-

volunteers in the baseline and pain-induced levels of naturally occurring opioids. In-terestingly, when comparing placebo and pain-inducing conditions, the activation of the anti-pain response was dramatic in some volunteers, while in others it was much less pronounced. Those who had the greatest change tended to report the low-est experience of pain, both in its sensory and emotional aspects. This study provides new insights into the importance of the body's natural pain-killer system and the reasons why each of us experiences pain differently. The re-sults also show how brain chemistry regulates sensory and emotional experiences. The findings may help researchers better understand prolonged pain and find more effective ways to reliave it effective ways to relieve it.

# LEARNING TO REGENERATE ORAL AND CRANIOFACIAL TISSUES

The physical complexity of the human head and face has captured the imagination of artists since the beginning of time. However, this exquisite complexity sometimes can be problematic for clinicians who must treat injuries, diseases, and ge-netic defects of the craniofacial region. A noted example is the relatively rare genetic disorder, ectodermal dysplasia (ED). Children born with ED often have malformed and missing teeth, meaning they must cope with the rigors of wearing dentures for a lifetime. Yet, if scientists could learn to trick the body into regrowing a full set of healthy teeth, the quality of life for these children would be greatly enhanced.

The NIDCR leadership believes that the opportunity now exists to discover in a more rational, systematic manner how to effectively manipulate the body's developmental signals to regenerate oral and craniofacial tissues. To help forward this potentially high-yield research, the NIDCR plans to launch an initiative to develop biomimetic, tissue engineering, and stem cell approaches to restore craniofacial tissues. Specifically, the initiative will focus on learning how to repair and regenerate teeth, gums, and the bones that support these tissues; learning how to restore salivary gland function to help people with Sjögren's syndrome; and learning to develop diagnostic and treatment strategies for temporomandibular joint repair and restoration.

# REDUCING THE BURDEN OF ORAL CANCER

Most Americans have heard that early detection is often critical to beat cancer. Though this principle has been difficult to apply to some hard-to-access areas of the body, such as the pancreas and the ovaries, that is not the case for many oral can-cers. Precancerous oral lesions are often visible to the eye and readily accessible for

biopsy. Yet, according to American Cancer Society estimates, 7,400 Americans will die this year—in most cases needlessly—from oral and pharyngeal cancer. That totals an estimated 74,000 Americans who will succumb to oral cancer during the decade. Thousands more will undergo multiple surgeries to remove advanced tumors and reconstruct their faces and oral cavities.

What can be done to improve this needless public health problem? The NIDCR has invested in several approaches, starting with efforts to heighten public and pro-fessional awareness of oral cancers. NIDCR has funded an initiative to assess the rate of oral cancer in five states—New York, North Carolina, Florida, Michigan, and Illinois. At the same time, this initiative will assess public and professional knowledge of oral cancer risk factors, while also documenting and evaluating the practices used to diagnose oral cancers among various health professions. Included in this research is an assessment of the important public health question: How likely is it that an American will receive an annual oral cancer examination from a healthcare provider? The data generated from this research will allow individual states to tailor intervention strategies to their specific demographic and professional needs. Already, based on the results of an earlier pilot project, Maryland has developed a targeted training program for its health professionals on how to examine patients for oral cancer and identify early, developing lesions.

Second, NIDCR has invested in research to develop powerful new tests for the rapid diagnosis of oral cancer. The latter is an important point because, as with all cancer sites, abnormal lesions in the oral tissues can be difficult to characterize by simply staining and looking at them under a microscope. In fact, using current diag-nostic tests, it is impossible to know whether a suspicious oral lesion indeed will turn cancerous. Neither is it possible to determine whether a cancer will grow rapidly or slowly. Since current diagnostic tests cannot read the so-called "molecular signatures" of biopsied tissue—information that would greatly increase diagnostic specificity.

specificity. With the arrival of more powerful laboratory tools over the past decade, NIDCR scientists and grantees have helped to identify many molecular glitches that trigger oral cancer. In fact, the step-by-step progression model for oral cancer is among the most well developed in all of oncology. Given the tremendous potential for progress in the study of these deadly cancers, NIDCR has invested in powerful new molecular technologies that could yield improved diagnostic tests for oral cancers. Already, work is under way to develop a small computer chip—about the size of a quarter—that contains hundreds of genes associated with oral tumors and their metastasis. This chip, if validated, could offer a genetic sensor as an early warning system for a developing oral cancer.

Work also is under way to design a related diagnostic chip that doctors one day could use to detect, in a matter of minutes, the abnormal activity of the very proteins that trigger oral cancers. Such a level of molecular and diagnostic specificity has been a longstanding goal of science, and the great promise of molecular medicine is now closer at hand than ever.

With its longstanding commitment to scientific excellence, NIDCR will continue in coming years to support basic and clinical advances to improve the nation's oral health. This investment in the power of research represents not only hope for millions of Americans today, but improved health and quality of life for generations to come.

# PREPARED STATEMENT OF DR. ALLEN M. SPIEGEL

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) for fiscal year 2003, a sum of \$1,609,292,000, which reflects an increase of \$138,477,000 over the comparable fiscal year 2002 appropriation. The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report, which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan. I appreciate the opportunity to testify on behalf of the NIDDK, which supports research on a wide range of chronic, debilitating diseases. My testimony will highlight some examples of research progress, opportunities and plans.

#### DIABETES

In type 1 diabetes, immune system destruction of insulin-producing beta cells leads to lifelong dependence on insulin injections for survival. Last year, I told you that a team of researchers from Edmonton, Canada, had restored natural insulin production in a small number of patients by transplanting clusters of insulin-producing beta cells, called islets, taken from donor cadaver pancreases. This year, I am very pleased to report that scientists in a recently-established NIDDK intramural Transplantation and Autoimmunity Branch have achieved similar positive results in several patients. While we must closely monitor these patients to weigh the long-term effects of therapy, these early results are very encouraging. They provide an important "proof of principle" that islet transplantation can develop into a viable treatment for type 1 diabetes. The current shortage of cadaver pancreases, however, poses a beta-cell supply problem that must be solved if islet transplantation is to become a widely available treatment option. To address this problem, we have launched a multifaceted initiative to learn all we can about insulin-producing cells through a revolutionary "Comprehensive Beta Cell Project." This project will reveal the intricacies of beta cell biology, and define the patterns of gene expression at every stage of beta cell development within the pancreas. These studies will help researchers find ways to generate an unlimited supply of new beta cells for transplantation therapy in type 1 diabetes. Moreover, they should help clarify the basis for the failure of beta cells to secrete adequate amounts of insulin in type 2 diabetes. As we strive to develop a cure for type 1 diabetes, we are also working diligently to prevent new cases in those at risk. Building on expanded knowledge of the immune system, we have launched a nimble clinical TrialNet to ensure rapid pilot testing of innovative ways to prevent disease onset. In this way, the most promising approaches can be readily propeled into larger multi

In parallel with our beta cell efforts, we are pursuing stem cell biology—not only as a source of islets for cell-based therapy of type 1 diabetes, but also for its application to a host of other diseases, such as end stage liver disease, in which transplantation is curative, but inadequate organ supply limits the number of patients who can receive transplants. Our initiatives are consonant with extensive previous work on bone-marrow-derived and other adult stem cells, and with the President's decision to permit NIH funding of research using certain existing human embryonic stem-cell lines. With advice from an external strategic planning group, we have developed a linked series of initiatives and planned genomics projects to capitalize on the enormous promise that stem cells hold for restoring tissues and organs ravaged by disease. These initiatives will explore the versatility of progenitor stem cells to differentiate into virtually any specific cell type in the body.

by disease. These initiatives will explore the versatility of progenitor stem cells to differentiate into virtually any specific cell type in the body. In type 2 diabetes, we are tackling a public health problem of epidemic proportions, fueled by the rising tide of obesity in the United States. The prevalence of diabetes in adults is eight percent, equating to about 16 million people.<sup>1</sup> The number of Americans who have diabetes has increased 49 percent from 1990 to 2000 and is expected to burgeon further in the decade ahead.<sup>2</sup> Compounding today's grim statistics are particularly troublesome reports that both type 2 diabetes and obesity are on the rise in children and teens. This trend is especially strong among minority groups, such as Native Americans, Mexican Americans and African Americans, in whom adults are already disproportionately affected by both conditions. Thus, to-day's epidemic may well be the tip of an iceberg that will surface—with great menace for our health care system—as these newly affected youngsters grow into adult-hood.

Prevention is a critical means of halting the dual burden of diabetes and obesity. While treatments exist for those already affected, no strategy can be better than preventing, from the very outset, the interlinked health problems of type 2 diabetes and obesity. Impressive proof that prevention really works comes from our major clinical trial in type 2 diabetes, the Diabetes Prevention Program or DPP. Last year, I testified that we were nearing this trial's completion—hopeful of positive results. Today, I can report that the final results have far surpassed our hopes. So strikingly Today, I can report that the final results have far surpassed our nopes, so surrangly positive are the findings that we ended the trial one year ahead of schedule. The results were announced by Secretary Thompson at a press conference held at NIH on August 8, 2001, and reported in detail in The New England Journal of Medicine on February 7, 2002. With a lifestyle intervention consisting of only modest changes on February 7, 2002. With a lifestyle intervention consisting of only modest changes in diet and exercise, the development of type 2 diabetes was reduced by 58 percent in individuals at high risk for developing the disease. The beneficial effect of the lifestyle intervention applied across all racial, ethnic and age groups. Minority groups comprised 45 percent of the study population, and 20 percent were 60 years of age or older—thus demonstrating that this prevention strategy can be realisti-cally applied to the diverse U.S. population. In another arm of the study, the diabe-tes medication metformin was also effective, reducing the development of diabetes by 31 percent, but the drug was effective only in younger and heavier individuals. Now, armed with the impressive results of the DPP, we must translate these suc-cessful prevention approaches to the 20 million Americans with impaired glucose tolerance who are at high risk for the disease—with emphasis on the 10 million at tolerance who are at high risk for the disease-with emphasis on the 10 million at greatest risk. To this end, we are launching an initiative to develop cost-effective methods to identify those at high risk and to implement the lifestyle intervention on a wider scale. We are also supporting a network of centers to develop effective prevention strategies specifically targeting children at high risk for type 2 diabetes. At the same time, vigorous fundamental research provides a framework for combating obesity by providing insights into the processes regulating appetite and metabolism. Research on fat-cell hormones, such as the appetite-inhibiting hormone leptin, is proving that fat tissue is not a passive depot of energy, but an active participant in regulating metabolic processes. These findings may pave the way to the development of effective drugs to aid weight loss and prevent or reduce obesity. In addition, we will continue to support behavioral research and outcomes research with implications for public health policy-for example, the recent finding that breast feeding may help a mother prevent her child from becoming obese.

For diabetes patients, the major killer is heart disease. Our National Diabetes Education Program has therefore launched a new campaign urging Americans to know their "ABCs." The "A" stands for the hemoglobin "A" 1c test—an integrated measure of blood glucose levels. The "B" for blood pressure and the "C" for cholesterol levels emphasize important prevention strategies that are built on extensive

<sup>&</sup>lt;sup>1</sup>Harris MI: Diabetes in America: epidemiology and scope of the problem. Diabetes Care 1998;21 suppl 3: C11-C14.

<sup>&</sup>lt;sup>2</sup> Mokdad AH, Bowman BA, Ford ES, Vinicor F, Marks JS, Koplan JP. The continuing epidemics of obesity and diabetes in the United States. Journal of the American Medical Association 286:1195, 2001.

research by the National Heart, Lung and Blood Institute. This "ABCs" program is designed to help reduce mortality from heart disease and stroke in patients with diabetes

### DIGESTIVE DISEASES

In digestive diseases research. I am pleased to appounce the identification of the first gene that increases susceptibility to Crohn's disease, a debilitating form of inflammatory bowel disease or IBD. A new IBD Genetics Consortium will take full advantage of this discovery, and also speed the search for other culprit genes in this complex disease. Identification of novel susceptibility genes for Crohn's disease and ulcerative colitis should lead to improved diagnosis and treatments. We are convening a meeting on therapeutic endpoints for clinical trials in IBD to facilitate efficient testing of innovative therapies. We are also augmenting our clinical research efforts in liver disease with a planned consensus conference for hepatitis C treatment, a cohort study of adult-to-adult liver transplantation, and two clinical trial networks one for nonalcoholic steatohepatitis, a liver disease associated with insulin resistance and diabetes, and a second for biliary atresia, a serious pediatric disorder. We are developing plans for a hepatotoxicity network to apply advanced genomic methods to the serious problem of drug-induced liver injury.

# KIDNEY, UROLOGIC AND BLOOD DISEASES

The incidence of end stage renal disease (ESRD) is increasing at an alarming rate with 300,000 patients currently on chronic dialysis and projections of 600,000 patients on dialysis by 2010.<sup>3</sup> Only 31 percent of dialysis patients survive five years.<sup>4</sup> We are taking multiple steps to address this problem. In addition to emphasizing primary prevention and effective treatment of diabetes—the cause of ESRD in 45 percent of patients—we are establishing a new National Kidney Disease Education Program (NKDEP), which will initially target high risk groups. The NKDEP will promote early recognition of chronic kidney disease, and implementation of treat-ment measures proven to slow progression to ESRD. For example, our major clinical trial, the African American Study of Kidney Disease (AASK), showed conclusively that treatment with angiotensin converting enzyme (ACE) inhibitors is more effective than calcium channel blockers in preventing hypertensive kidney disease from progressing to ESRD in high- risk African Americans. We are also launching treatment trials for other important causes of ESRD such as polycystic kidney disease and focal segmental glomerulosclerosis. Mortality of patients with chronic renal insufficiency, primarily from heart disease, is extremely high. A new cohort study of patients with chronic renal insufficiency will help shed light on the causes of the cardiovascular mortality that affects these patients, and a trial that lowers homocysteine levels in the blood of kidney transplant patients will test whether this amino acid is responsible for increased heart disease in ESRD patients.

Our portfolio of urology research continues to flourish. This research is uncovering important knowledge about how bacteria attach to the bladder surface, and how we can use these insights to combat antibiotic resistance in the treatment of urinary tract infections. Major clinical initiatives in bladder disorders include clinical research networks to speed the testing of therapies for urinary incontinence and inter-stitial cystitis. Scientific recommendations of an expert panel, the Bladder Research Progress Review Group, will help guide our program development. Results of our major multi-center trial on Medical Therapy of Prostatic Symptoms (MTOPS) are to be announced later this year. We intend to bolster prostate research by making available biopsy tissue obtained in MTOPS for study by a network of investigators. We will also be launching a trial of saw palmetto and other phytotherapies widely used for symptoms of prostate enlargement.

In blood diseases, our strong portfolio in areas such as hematopoietic stem cell research and globin gene regulation is the basis for clinical advances. We are supporting studies on drugs to eliminate the toxic iron overload that is a byproduct of current treatment for Cooley's anemia. We are also supporting development of new non-invasive methods for accurate measurement of iron burdens in patients.

Mr. Chairman and Members of the Committee, these are just a few examples of our many research advances and initiatives. I would be pleased to answer any questions you may have.

<sup>&</sup>lt;sup>3</sup>U.S. Renal Data System. <sup>4</sup>U.S. Renal Data System.

Mr. Chairman and Members of the Committee: I am Audrey Penn, Acting Director of the National Institute of Neurological Disorders and Stroke. I am pleased to present the President's budget request for NINDS for fiscal year 2003, a sum of \$1,443,392,000, which reflects an increase of \$111,744,000 over the comparable fiscal year 2002 appropriation. The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

The mission of NINDS is to reduce the burden of neurological disease a burden borne by every age group, by every segment of society, by people all over the world. The Institute carries out this mission through research on the healthy and diseased brain, spinal cord, and nerves of the body, which together make up our nervous system. The intricacy of the brain is awesome, its workings are elusive, and an extraordinary variety of disorders affect the nervous system. Furthermore, the brain and spinal cord are difficult to access, sensitive to intervention, and reluctant to regenerate following damage. For these reasons, neurological disorders often defy the best efforts of medicine, even in the modern era. The last decade has brought the first treatments for acute stroke and spinal cord

The last decade has brought the first treatments for acute stroke and spinal cord injury, new immune therapies that slow the progression of multiple sclerosis, and increased drug and surgical options for treating Parkinson's disease, epilepsy, and chronic pain. Continuing advances in preventing stroke and birth defects, such as spina bifida, are also improving the public health. Still, treatments for most neurological disorders are far from adequate, often failing to stop or even slow the disease process. What is encouraging, however, is the variety of new treatment and prevention strategies under development: drugs that home in on the molecules that cause disease, stem cell therapies that replace lost nerve cells, neural prostheses that read control signals directly from the brain, vaccines that target neurodegeneration, implantable electronic stimulators that compensate for brain circuits unbalanced by disease, and behavioral interventions that encourage the brain's latent capacity to repair itself.

#### THE BURDEN OF NEUROLOGICAL DISORDERS

Our strategies are shaped not only by scientific insights but also by the sheer variety of neurological disorders. The causes of neurological disorders include trauma, infections, toxic exposure, developmental defects, degenerative diseases, tumors, gene mutations, systemic illness, vascular events, nutritional deficiencies, immune reactions, and adverse effects of essential treatments, such as cancer chemotherapy. Stroke, chronic pain conditions, dementia, and traumatic brain injury are among the leading causes of death and disability in the nation. Epilepsy, spinal cord injuries, multiple sclerosis, Parkinson's disease, the muscular dystrophies, autism, cerebral palsy, and peripheral nerve disorders, are common enough to be familiar to most Americans. But there are many other neurological disorders unfamiliar to most people until a family member is affected, and Congress has been active in bringing attention to less familiar diseases, including amyotrophic lateral sclerosis (Lou Gehrig's disease), Batten disease, the dystonias, facioscapulohumeral and congenital muscular dystrophies, Friedreich's ataxia, mitochondrial disorders, mucolipidosis type 4, neurofibromatosis, reflex sympathetic dystrophy, spinal muscular atrophy, spina bifida, and tuberous sclerosis. A complete list of neurological disorders would include hundreds more.

#### DIFFERENT DISEASES, COMMON THEMES

As scientists unravel the complex processes that underlie neurological disorders, ranging from acute stroke to the inexorable chronicity of Parkinson's disease, common themes are emerging, leading to the hope that similar therapeutic and preventive strategies will also apply. To put it another way, progress against a single disease is likely to have a bearing on many others. A few examples of cross-cutting research areas illustrate the broader trend. Scientists have implicated "free radicals" as culprits in brain damage from stroke

Scientists have implicated "free radicals" as culprits in brain damage from stroke and trauma, as well as neurodegenerative diseases like ALS, Parkinson's and Alzheimer's, and even infections that affect the brain. Free radicals are highly reactive chemicals that are normal byproducts of energy metabolism, but can damage cells if produced in excess or improperly controlled. This year scientists discovered that patients with a type of inherited ataxia, a movement disorder, had abnormal levels of a vitamin-like substance called coenzyme Q10, which helps protects cells from free radicals. When researchers provided coenzyme Q10 supplements, the patients responded with improved coordination, increased strength and less frequent seizures. Another research team demonstrated in a clinical trial that the drug allopurinol, chosen to help scavenge free radicals, helps protect the brains of high-risk infants undergoing heart surgery. Several other disease mechanisms repeatedly come into play in many disorders, including excitotoxicity from excessive release of normal brain signaling chemicals, abnormal calcium handling within cells, aggregation of proteins, and activation of "cell suicide" programs. Each of these provides targets for developing preventive and therapeutic strategies that may be widely applicable.

Just as common disease mechanisms help us confront the staggering variety of neurological disorders, there are therapeutic strategies that may apply to many diseases. Gene therapy is deceptively simple in concept, but difficult in practice. The complexities of working with nerve and muscle cells compound the problems. However, scientists have shown promising results in fixing or replacing defective genes in animal models of inherited disorders such as Duchenne muscular dystrophy, and research is demonstrating the potential of gene therapy even in non-inherited disorders, for example, by coaxing cells to make the nerve cell survival factor GDNF or the neurotransmitter dopamine in animals with Parkinson's-like disorders. Stem cells likewise present broad promise. For many years NINDS has supported pioneering research on animal and adult human stem cells, including therapeutic studies in animal models of stroke, spinal cord injury, Parkinson's disease, muscular dystrophy, and inherited metabolic disorders. In the past year, we have seen bloodderived cells convert into nerve-like cells, neural progenitor cells harvested from human brain tissue after death, and stem cells persuaded to become dopamine-secreting nerve cells needed in Parkinson's disease or insulin-secreting cells lacking in diabetes. We are intensifying research on all types of stem cells, as we initiate the study of human embryonic stem cells in accordance with the President's policy announced last August.

Stem cells and gene therapy may have captured the public's attention, but other therapeutic approaches are also promising. Deep brain stimulation (DBS) with implanted electrodes has helped some people with essential tremor and Parkinson's disease and may be more widely applicable to epilepsy, dystonia, pain, and depression. NINDS is building on the expertise of its neural prosthesis program, which helped develop the technology necessary for DBS over the last 30 years, to improve DBS. The Institute is also expanding its drug development efforts to capitalize on the growing understanding of disease at the molecular level. These efforts include high-throughput screening and testing of drugs approved by the FDA for other purposes.

The remarkable progress in understanding the fundamental biology of the brain, of course, is the foundation supporting studies of the common mechanisms of disease and the development of new preventive and therapeutic strategies. Genetics provides one unifying theme, often revealing the first clues to disease processes and yielding animal models for studying disease and testing treatments. The burgeoning research on brain plasticity how the brain adapts to experience and the environment may teach us how to encourage adaptive plasticity to foster recovery from stroke and trauma, and also how maladaptive plasticity contributes to chronic pain and dystonia.

# PLANNING AND ENABLING RESEARCH

Motivated by scientific opportunity, enabled by budget increases, and guided by strategic and disease specific planning efforts, NINDS is taking a more active role in directing research. The NINDS strategic planning process began in 1998 and drew upon the nations' leading scientists and physicians, the public and Institute staff. The effort coalesced around cross-cutting themes of neuroscience and resulted in the NINDS Strategic Plan: Neuroscience at the New Millenium which has provided a framework for the Institute's activities. These include intensified efforts, through workshops, grant and contract solicitations, and other means as appropriate, that target gene discovery, gene therapy, microarray technology, drug screening, stem cells, deep brain stimulation, pediatric neurology, and common mechanisms of disease, such as mitochondrial dysfunction and protein aggregation.

As NINDS testified last year, the strategic planning process also engendered an increased emphasis on clinical trials, prompted by the opportunities arising from neuroscience research and building on extensive NINDS experience in clinical trials for stroke and other diseases. Ongoing trials range from pilot studies to large phase III efforts, focus on prevention and on treatment, and test interventions that run the gamut, including drugs, surgery, gene therapy, deep brain stimulation, hormone

therapy, tissue transplantation, hypothermia, transcranial magnetic stimulation, radiosurgery, behavior modification, and diet, as well as rehabilitation methods. A partial list of disorders being addressed in trials includes: AIDS, ALS, brain tumors, cerebral palsy, attention deficit hyperactivity disorder, brain trauma, epilepsy, Turner syndrome, Parkinson's disease, Lyme disease, migraine, sleep disorders, dystonia,, hereditary ataxias, multiple sclerosis, pain, and stroke. Clinical trial results published during the past year report effective immunotherapy for the symptoms of stiff person syndrome-a rare movement disorder; successful field delivery of emergency care for seizures; clinical benefit of enzyme therapy for Fabry disease; improved management of chronic tension headache with added behavior modification; information regarding estrogen hormone- replacement therapy for women for secondary stroke prevention; and improvements in preventing stroke. To complement the clinical trials program, NINDS is developing a comprehensive program to expedite translational research. Translational research bridges from fundamental discoveries about the brain and disease, and rapidly accumulating results in animal models of diseases such as muscular dystrophy, ataxias, ALS, Alzheimer's, Parkinson's, Huntington's, and many others, to the identification of specific agents to be examined in clinical trials of safety and effectiveness.

NINDS health disparities and disease-specific planning efforts build on the foundation of the strategic planning process. The NINDS is implementing research priorities in stroke, neuroAIDS, epilepsy, pain, and cognitive and emotional health in minorities, and in infrastructure and partnership development in minority institutions. NIH has reported separately to Congress, as directed, about progress in implementing the *Parkinson's Disease Research Agenda* and the January 2002 Consortium meeting. The Agenda represents the most concerted attack NINDS has undertaken against any disease, from basic studies of brain mechanisms through large clinical trials, including efforts to refine existing therapies and to develop new strategies on the frontiers of medicine, such as stem cells, deep brain stimulation, and gene therapy. Among the many facets of this program, the Institute is embarking on a large clinical trial to test drugs that actually slow the course of the disease, rather than merely lessening symptoms.

Other disease-specific planning and implementation efforts are, or will soon be, underway. In March 2000, a landmark conference, "Curing Epilepsy: Focus on the Future," began a process through which epilepsy researchers, patient advocates, and NINDS staff formulated "benchmarks" for epilepsy research, and developed a process to engage the entire epilepsy research community in attaining those goals. NINDS has also reported separately to Congress on this effort, as requested. Major NINDS planning efforts in brain tumor and stroke are following the Progress Review Group (or PRG) model developed by the National Cancer Institute; the brain tumor effort in direct collaboration with NCI. In each PRG, more than 100 scientists and representatives of voluntary groups assess the current state of the science and identify future needs and opportunities. The Institute is also undertaking planning efforts in muscular dystrophy and tuberous sclerosis research in the coming year. NINDS is coordinating NIH efforts to implement the DHHS Bovine Spongiform Encephalopathy (BSE)/Transmissible Spongiform Encephalopathy (TSE) Action Plan. BSE, known ass "mad cow" disease, is one of the TSEs that pose a potential threat to the public health and economy, and the HHS plan includes surveillance, protection, research and oversight activities. It is important to emphasize that NINDS is also continuing to hold workshops focused on a wide range of specific disorders, such as dystonia, congenital muscular dystrophy, familial dysautonomia, pe-diatric neurotransmitter diseases, and Joubert syndrome. These meetings, and the ongoing informal interaction among NINDS professional staff, the research community, and disease advocates, catalyze research, while informing the Institute where specific solicitations or other actions may be warranted. Finally, unsolicited grants continue to be the backbone of NINDS research efforts. The collective wisdom of scientists and physicians throughout the nation is especially suited to confronting the broad spectrum of neurological disorders and the scope of science that is essential to progress.

In conclusion, it would be a disservice to patients and families to promise when cures will become available, because medical progress is notoriously difficult to predict. Yet researchers are cautiously optimistic that, by recognizing cross-cutting areas of scientific opportunity, while maintaining a continuing focus on the unique aspects of each disease, we are moving toward an era when curing or preventing neurological disorders will become commonplace. Thank you. 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 (fiscal year) 2003, a sum of \$3,999,379,000, which reflects an increase of \$1,456,933,000 over the comparable fiscal year 2002 appropriation. The NIAID budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIAID's second annual performance report, which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

# OVERVIEW OF NIAID

NIAID supports and conducts basic and applied research to better understand, treat and prevent infectious, immunologic, and allergic diseases. For more than fifty years, NIAID research has led to new therapies, vaccines, diagnostic tests, and other technologies that have improved the health of millions of people in the United States and around the world. The scope of the NIAID research portfolio has expanded considerably in recent years in response to new challenges such as bioterrorism; the emergence or re-emergence of diseases such as the acquired immuno-deficiency syndrome (AIDS), West Nile fever, dengue, malaria and tuberculosis; and the increase in asthma among children in this country. The growth of NIAID programs also has been driven by unprecedented scientific opportunities in the core NIAID scientific disciplines of microbiology, immunology, and infectious diseases. Advances in these key fields have led to a better understanding of the human immune system and the mechanisms of infectious and immune-mediated diseases.

#### RESPONDING TO THE THREAT OF BIOTERRORISM

The final four months of 2001 were among the most extraordinary—and tragic in American history. The September 11 attacks on the World Trade Center and Pentagon have transformed society in ways that we are only now beginning to discern. Superimposed on that tragedy were the first recorded cases of anthrax in the United States to result from an intentional human act. Of 18 confirmed anthrax cases associated with bioterrorism in the eastern United States in 2001, 11 individuals suffered the inhalational form of the disease; 5 of these people died.

Homeland defense is a multifaceted endeavor. Defense against and response to bioterrorism is a critical component of homeland defense, and our ability to detect and counter bioterrorism depends to a large degree on the state of biomedical science. As the lead agency at NIH for infectious diseases and immunology research, NIAID has developed a *Strategic Plan for Counter-Bioterrorism Research*, as well as a detailed *NIAID Counter-Bioterrorism Research Agenda*, with short, intermediate-, and long-term goals. The *Strategic Plan and Research Agenda* stress two overarching and complementary components: basic research into agents with bioterrorism potential and the specific and non-specific host defense mechanisms against those agents, and applied research with pre-determined milestones for the development of new or improved diagnostics, vaccine and therapies. We focus on research in six key areas:

*Microbial Biology.*—Research into the basic biology and disease-causing mechanisms of pathogens underpins all our efforts to develop interventions against agents of bioterrorism. NIAID supports research to better understand the factors that influence the virulence and invasiveness of a pathogen, as well as those that determine antibiotic resistance.

An important new tool in understanding all microbes is our ability to rapidly obtain microbial genome sequence information, including that of potential bioterror agents. Many such agents have already been sequenced; others, including different strains of Bacillus anthracis, the anthrax bacterium, are in the process of being sequenced. These efforts promise to facilitate the discovery of new medical interventions.

Host Response to Microbes.—In order to develop potent, safe, and effective vaccines, accurate diagnostics, and immunotherapeutics against microbes that may be used as bioterrorist agents, research has been accelerated to improve our understanding of the complex parameters of two components of the human immune system: innate and adaptive immunity.

Vaccines.—NIAID has bolstered research efforts on vaccines against many of the infectious agents considered to be bioterrorism threats, with an eye toward generating products that are safe and effective in civilian populations of varying ages and health status. For example, a three-tiered strategy for smallpox vaccine research has been developed. In the near-term, a clinical trial at several NIAID Vaccine and Treatment Evaluation Units suggests that it is possible to "stretch" the 15,400,000 available doses of licensed smallpox vaccine 5- or 10-fold by dilution. A concurrent initiative is the development of a new smallpox vaccine: a safe, sterile product grown in cell cultures using modern technology. This vaccine will be rapidly tested in human clinical trials; more than 200,000,000 doses will be produced and delivered to the Federal Government by the end of 2002. In the long-term, basic research promises to provide a third generation of smallpox vaccines that could be used in all segments of the population, including pregnant women and people with weakened immune system. Additional bioterrorism vaccines also are in development. For example, a new anthrax vaccine, based on a bioengineered component of the anthrax bacterium called recombinant protective antigen (rPA), will soon enter human trials. On the NIH campus, researchers at the NIAID Dale and Betty Bumpers Vaccine Research Center have developed a DNA vaccine that protected monkeys from infection with Ebola virus, and that will soon be tested in human volunteers. *Therapeutics.*—NIAID therapeutics research focuses on the development of new

Therapeutics.—NIAID therapeutics research focuses on the development of new antimicrobials and antitoxins, as well as the screening of existing antimicrobial agents to determine whether they have activity against organisms that might be employed by bioterrorists. For example, in collaboration with DOD and with support from CDC, NIAID has rigorously screened a large number of antiviral drugs against smallpox-related viruses. One of these agents is an antiviral drug called cidofovir, which is approved by the Food and Drug Administration (FDA) for treating certain AIDS-related viral infections. Cidofovir has shown potent activity against poxviruses related to smallpox in test tube studies and in animal models. NIAID has taken the lead in developing a protocol that would allow cidofovir to be used in emergency situations for the treatment of smallpox. Concurrently, other anti-smallpox agents are being investigated.

*Diagnostics.*—The overall goal of NIAID bioterrorism research on diagnostics is to establish methods for the rapid, sensitive, and specific identification of natural and bioengineered microbes as well as the determination of the microbe's sensitivity to drug therapy. These scientific advances will allow health care workers to diagnose and treat patients more accurately and quickly.

Research Resources.—Basic research and the development of new vaccines, therapeutics, and diagnostics depend on the availability of research resources, such as genomics/proteomics information, appropriate animal models, standardized reagents, and appropriate laboratory facilities. Among many initiatives, NIAID plans to accelerate training of investigators specializing in bioterror agents, establish the first four to seven of what will be ten regional Centers of Excellence for Bioterrorism and Emerging Diseases Research, develop a centralized research reagent repository, and expand the national bioterrorism research infrastructure. The latter will include the construction/renovation of BioSafety Level (BSL) 3–4 laboratories, necessary to work with the most dangerous pathogens.

# SPIN-OFFS OF BIOTERRORIM RESEARCH FOR OTHER DISEASES

We anticipate that the large investment in research on counter-bioterrorism will have many positive "spin-offs" for other diseases. The planned NIAID research on microbial biology and on the pathogenesis of organisms with bioterror potential will certainly lead to an enhanced understanding of other more common and naturally occurring infectious diseases that afflict people here and abroad. In particular, the advancement of knowledge should have enormous positive impact on our ability to diagnose, treat and prevent major killer-diseases such as malaria, tuberculosis, HIV/ AIDS, and a spectrum of emerging and re-emerging diseases such as West Nile fever, dengue, influenza, and multi-drug resistant microbes. Furthermore, and importantly, the NIAID research agenda on counter-bioterrorism will greatly enhance our understanding of the molecular and cellular mechanisms of the innate immune system and its relationship to the adaptive immune system. This clearly will help in the search for new ways to treat and prevent a variety of immune-mediated diseases such as systemic lupus erythematosus, rheumatoid arthritis and other autoimmune diseases. In addition, new insights into the mechanisms of regulation of the human immune system will have positive spinoffs for diseases such as cancer, immune-mediated neurological diseases, allergic and hypersensitivity diseases, as well as for the prevention of rejection transplanted organs.

### VACCINE DEVELOPMENT

Vaccine research, so important to our preparedness against future bioterrorism attacks, has long been a cornerstone of NIAID research. NIAID-supported research has led to the development of many new and improved vaccines that are now widely used; these vaccines have saved literally millions of lives and prevented untold illness and disability from infectious diseases. Success stories include the development of vaccines against Haemophilus influenzae type b, pertussis, chickenpox, pneumococcal disease, and hepatitis A and B. NIAID has three broad goals in vaccine research: identifying new vaccine candidates to prevent diseases for which no vaccines currently exist; improving the safety and efficacy of existing vaccines; and designing novel vaccine approaches, such as new vectors and adjuvants. To speed these efforts, NIAID has made a significant investment in the growing field microbial genomics, and has funded the genomic sequencing of more than 60 medically important microbes. Approximately 20 of these projects have been completed, including the bacteria that cause tuberculosis, gonorrhea, chlamydia, cholera, the parasite that causes malaria, as well as the mosquito that transmits malaria. The availability of the genomic sequences of these and other organisms will facilitate the identification of a wide array of new antigens for vaccine targets.

causes malaria, as well as the mosquito that transmiss mataria. The distinction of the genomic sequences of these and other organisms will facilitate the identification of a wide array of new antigens for vaccine targets. One of the important challenges for the 21st century is the development of safe and effective vaccines for the three greatest microbial killers worldwide: HIV/AIDS, malaria, and tuberculosis. These three diseases account for one-third to one-half of healthy years lost in less developed countries. NIAID has a robust portfolio of vaccine research and development for these and other diseases of global importance.

## ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)

Despite recent progress in treatment and prevention, human immune deficiency virus (HIV) disease and AIDS continue to exact an enormous toll throughout the world. An estimated 40,000,000 people are living with HIV/AIDS, and another 22,000,000 people with HIV/AIDS have died. More than 95 percent of these infections and deaths have occurred in developing countries, most of which are also burdened by other significant health challenges. In these nations, HIV/AIDS threatens not only human welfare, but social, political and economic stability as well. In the United States, approximately 850,000–950,000 people are living with HIV/AIDS; approximately 450,000 deaths among people with AIDS had been reported to the CDC as of the end of 2000. The rate of new HIV infections in this country has reached an unacceptable plateau of 40,000 per year, with minority communities disproportionately affected.

In the United States and other western countries, potent combinations of anti-HIV drugs (highly active antiretroviral therapy or "HAART") have dramatically reduced the numbers of new AIDS cases and AIDS deaths. Meanwhile, the toll of AIDS has accelerated elsewhere in the world, especially in poor countries where expensive HAART regimens are beyond the reach of all but a privileged few. Fortunately, this disparity in access to life-saving medications may be changing. Building on the research infrastructure NIAID has helped establish in Africa and elsewhere in the developing world, we are actively working with our international colleagues to link the provision of anti-HIV therapy to efforts in prevention research, with the goal of facilitating a comprehensive approach to the AIDS pandemic in poor countries. Concurrently, NIAID-supported investigators are testing a diverse range of HIV prevention and vaccine strategies. Prevention efforts in our country and abroad focus on several key areas, including behavioral modification, interventions to prevent mother-to infant transmission of HIV, and the development of topically applied microbicides that women could use to protect themselves against HIV and other sexually transmitted pathogens. Several vaccine candidates have recently shown remarkable promise in tests in non-human primates. The best candidates are rapidly being moved into human clinical trials at sites of NIAID's HIV Vaccine Trials Network in the United States and abroad, and at the NIAID Vaccine Research Center.

#### RESEARCH ON IMMUNE-MEDIATED DISEASES

NIAID-funded research in basic and clinical immunology has led to many promising approaches for treating individuals with immunologic conditions such as multiple sclerosis, type I diabetes and asthma. Researchers are developing novel ways of selectively blocking inappropriate or destructive immune responses, while leaving protective immune responses intact, an area of research known as tolerance induction. The NIAID-supported Immune Tolerance Network an international consortium of approximately 50 research groups, now has 16 clinical trials that are enrolling patients or will do so soon, in areas such as islet transplantation (for diabetics), kidney transplantation, autoimmune diseases, and asthma and allergic diseases.

For the past decade, NIAID also has focused on reducing the significant and growing burden of asthma among inner-city minority children. The current Inner-City Asthma Study has investigated novel interventions to improve the health of innercity children with asthma. One approach, called a physician feedback intervention, involves periodic reports to the child's doctor about the status of the child's asthma. These reports, generated from bi-monthly phone interviews with parents, recommend changes in the child's treatment regimen according to National Heart, Lung, and Blood Institute (NHLBI) guidelines, if warranted. Another method is an environmental intervention that involves identifying and removing asthma triggers such as cigarette smoke or cockroaches from the child's home. Both interventions are reducing health care utilization, and the children receiving the environmental intervention gained an additional three weeks of symptom-free days during the intervention year. We are working to make such interventions available nationwide.

#### CONCLUSION

With a strong research base, talented investigators in the United States and abroad, and the availability of powerful new research tools, we fully expect that our basic and applied research programs will provide the essential elements to enhance our defenses against those who would attempt to harm us with bioterrorism, to develop new tools in the fights against HIV/AIDS and other infectious diseases, and to improve therapies and management of immune-mediated diseases.

#### PREPARED STATEMENT OF DR. MARVIN CASSMAN

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Institute of General Medical Sciences (NIGMS) for fiscal year 2003, a sum of \$1,881,378,000, which reflects an increase of \$154,911,000 over the comparable fiscal year 2002 appropriation.

The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's third annual performance report, which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

year 2001 results to the goals in our fiscal year 2001 performance plan. Today, 40 years since NIGMS was established, we can look back and reflect on the many accomplishments of the Institute. NIGMS-funded research has played a major role in building a strong foundation for all of biomedicine, producing a steady stream of research advances in a spectrum of disciplines. These advances have emerged from fundamental research in very basic areas like genetics, chemistry, and cell biology; and from more applied areas of science such as the body's response to medicines and to injury caused by trauma or burns.

#### A GOOD MODEL

In our anniversary year, I think it is fitting to showcase some of the medical benefits that have grown out of NIGMS's strong investment in supporting basic research—especially that obtained from studies with non-mammalian model organisms. Years of basic research with model organisms continue to yield valuable information, including important medical insights. An explosion of new discoveries rooted in basic investigations of the biology of the common baker's yeast are paving the way for effective means to treat infections caused by microbial cousins of this common fungus, including the potentially dangerous yeast *C. albicans*. This species of yeast causes vaginal and gut infections and can cause life-threatening problems for people with weakened immune systems, such as AIDS patients or transplant recipients.

Other recent medical advances stemming from studies with yeast include several important research findings on biofilms, specialized "mats" of bacteria or fungi that tend to be particularly resistant to medical attack. Biofilms, which account for everything from dental plaque to unsightly toilet bowl stains, also thrive in the clogged airways of people with cystic fibrosis, where they create tremendous problems. NIGMS-funded research with baker's yeast has shown that these ordinary fungi can be made to form a biofilm structure, providing scientists with a robust, inexpensive, and safe system to study the properties of biofilms as well as test drugs to block the formation of biofilms.

There is no question that, for years to come, scientists will continue to relish the versatility and economy of baker's yeast, properties that make this model organism an extraordinarily resilient and productive research tool.

I would like to move on to an exciting story about a team of scientists who are getting some old drugs to try new tricks. Over time, the group's research findings on the chemical and physical properties of certain enzymes and other proteins involved in basic metabolism led to the idea that a certain class of chemicals may live a dual life. These so-called "bisphosphonates," the researchers discovered, are capable of blocking an enzyme critical to the livelihood of parasites, the organisms that cause malaria and other infectious scourges. But the same chemicals can also knock out a human enzyme whose activity breaks down bone during osteoporosis. This multifaceted group of researchers put their heads together and—blending chemistry, biology, and very fast computers—discovered that a key step in parasite metabolism could indeed be knocked out by the anti-osteoporosis medicines Fosamax®, Actonel®, and Aredia®. Their new research shows that fairly low concentrations of these FDA-approved drugs can do away with parasites while sparing human cells. The scientists are now testing the drugs in animal models of the diseases and so far have obtained cures—in mice—of certain types of leishmaniasis, another disease caused by parasites. If the medicines work well in animal models, testing the drugs in people could occur relatively quickly, since the medicines have already been approved for other uses, and therefore have already been tested for safety in people. Other fundamental lines of inquiry have led to unexpected practical benefits in

Other fundamental lines of inquiry have led to unexpected practical benefits in treating disease. Ten years of intense analysis of the properties and functions of a plant enzyme led to the discovery that the active ingredient in the weedkiller Roundup attacks this particular enzyme. The enzyme, the researchers learned years later, also happens to be present in parasites, fungi, and other microorganisms. From this discovery, the potential medicinal value of interfering with this enzyme came into clear view. Fundamental biophysical studies that show what this enzyme looks like up close have now handed scientists a blueprint for designing chemical compounds to disable the action of this critical molecule. This research will likely lead to potent new medicines to treat parasites, bacteria, and fungi that cause illness in people.

#### MEDICINES FROM LAND AND SEA

NIGMS's research investment in chemistry has yielded important medical treatments from the ocean, which can be illustrated by two examples. The first is a poison derived from the venom of a marine snail species called Conus. To marine predators, a small molecule produced by *Conus* snails is deadly and serves as a form of defense. But for people with certain forms of chronic pain, this molecule may be extremely helpful in numbing pain that is unresponsive to other methods of pain treatment. Nearly a decade of NIGMS research probing the properties and physiological effects of *Conus* poisons has matured into the discovery and production of the compound Ziconotide. This medicine has completed clinical testing and is awaiting FDA approval. If approved, Ziconotide will be the first marine organism-based pharmaceutical product. Due to the fact that so many Conus varieties exist in nature, and that each snail produces many different venoms, the pharmaceutical potential of this humble organism seems vast. Indeed, a number of other promising Conus-derived molecules are in the drug development pipeline for a range of clinical applications, including treatment for burn pain, eye pain, postoperative surgical pain, and certain nervous system disorders.

A second example of medicine from the sea is a chemical called "Et743," which was originally discovered in a Caribbean sea squirt called *Ecteinascidia turbinata*. Scientists have shown that Et743 is an extremely powerful killer of cancer cells, particularly soft-tissue sarcomas, and the drug is now in late-stage clinical testing. Despite the medical potential of Et743, a severe shortcoming early on was its very limited availability in nature. NIGMS-funded chemists made an important step in extending the utility of this chemical by figuring out how to make it easily in the lab. starting with simple materials.

ab, starting with simple materials. Getting back to land, I want to highlight some medical benefits offered through research with a terrestrial laboratory darling, the ordinary fruit fly. Fundamental research using these tiny red-eyed insects has shed light on many basic features of the development of all of the body parts of embryos, including the development of human embryos. NIGMS-supported scientists discovered a fruit fly gene whose protein product helps fly ovary cells move to where they need to go during the normal process of development of the ovaries. This fly gene is strikingly similar to a human gene that, when misspelled, is overproduced in human breast and ovarian cancers. The work not only adds to fundamental knowledge about how cells know where to go as they meld together into organs and tissues, but it also provides a useful tool for cancer researchers studying the causes and treatments for breast and ovarian cancer.

Recently, NIGMS-funded genetic research with fruit flies demonstrated that these insects may hold a key to curing a host of different human diseases. One study unearthed 548 fly genes that are so similar to genes involved in 714 different human genetic disorders that the likelihood of the similarity occurring by chance alone is 1 in 10 billion. What this means is that scientists can look for causes and treatments for blindness, cancer, Parkinson's disease, diabetes, and many other disorders using lab fruit flies that are inexpensive and can be bred very quickly. Ultimately, scientists predict that fly genes will play an important role in the study of at least 1,000 of the 5,000 known genetic diseases in people.

# RESEARCH TRAINING

NIGMS is proud once again to cite the Nobel Prize-winning work of two of its long-time grantees. Geneticist Dr. Leland Hartwell and chemist Dr. Barry Sharpless each received the Nobel Prize in 2001 for their work on the cell cycle and chemical tools called chiral catalysts, respectively. Such quality scientific research gets done by quality researchers, and a vital component of the NIGMS mission is training the next generation of scientists. NIGMS maintains its leading role at NIH in research training by supporting nearly 44 percent of the predoctoral trainees and roughly 29 percent of all trainees receiving training funds from NIH. In recognition of the interdisciplinary nature of biomedical research today, all of NIGMS's training programs place a strong emphasis on crossing disciplinary boundaries. Nearly half of the NIGMS-funded biotechnology predoctoral fellowship programs, for instance, are centered in engineering departments.

In keeping with its commitment to training a diverse research work force, NIGMS is vigilant to how institutions recruit and retain trainees who are members of underrepresented minority populations. To propel these efforts, NIGMS sponsored a successful workshop in May 2001 at which institutions shared best practices for minority recruitment and retention in their training programs. We are promoting continued sharing via a minority recruitment and retention strategies Web site.

Looking more globally at our minority programs, I want to bring to your attention a few very interesting and fruitful examples of outreach with Native American populations. Together with National Human Genome Research Institute staff, this past year NIGMS staff organized a visit to Diné College on the Navajo Reservation. Staff of the NIGMS Division of Minority Opportunities in Research continue to work tirelessly to motivate, guide, and assist minority institutions, faculty members, and other prospective grantees who are new to the NIH funding system. I would like to highlight one particularly innovative ongoing partnership with the Indian Health Service. Beginning in fiscal year 2001, NIGMS established a collaborative program designed to improve research and research training responsive to the needs of Native American communities. The Native American Research Centers for Health (NARCH) program supports partnerships between American Indian or Alaska Native tribes and research-intensive institutions.

#### SPECIAL INITIATIVES

Of course, a key component to providing top-notch training programs is to closely follow the directions in which science takes us, and NIGMS has listened carefully to what the scientific community has to say about what's needed to move science forward. To that end, I am happy to report that NIGMS-funded initiatives aiming to pull together science from different, complementary fields of study are moving ahead. Important progress is being made by researchers in the NIGMS-led NIH Pharmacogenetics Research Network, with four new research teams joining the existing effort in September 2001. Two new teams of scientists joined NIGMS's Protein Structure Initiative, and three multifaceted research groups were awarded large-scale "glue" grants to study how cells communicate via natural sugar molecules, how cells move around the body, and how the body responds to injury caused by trauma and burns.

#### CONCLUSION

NIGMS remains dedicated to developing and sustaining programs that ensure the advancement of the basic biomedical research that will fuel the discovery of tomorrow's medicines.

Thank you, Mr. Chairman. I would be pleased to answer any questions that you may have.

# PREPARED STATEMENT OF DR. DUANE ALEXANDER

Mr. Chairman and Members of the Committee: I am pleased to present the fiscal year 2003 President's budget request for the National Institute of Child Health and Human Development (NICHD) of \$1,218,112,000 which reflects an increase of \$100,870,000 over the comparable fiscal year 2002 appropriation.

The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the per-

formance data is NIH's second annual performance report which compares our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan. For almost 40 years the NICHD has conducted research that touches Americans

For almost 40 years the NICHD has conducted research that touches Americans throughout their lives. We seek to ensure that people are able to have the children they want at the time they want them; that women experience pregnancy without complications and suffer no adverse consequences from the reproductive process; that every child is born healthy and wanted; that all children experience healthy physical, cognitive, behavioral, and social development and reach adulthood free of disease and disability and able to fulfill their potential for a productive life; and that people of all ages who experience disability as a consequence of congenital defects, injury, or disease achieve maximum function through the best rehabilitation we can provide. We have a broad mission, and we have a dynamic program of research in all of these areas.

#### EARLY CHILDHOOD EDUCATION AND SCHOOL READINESS

Reading skills are essential to function in our society. Yet many children, particularly children born in poverty, never learn to read. This inability to read has profound and long term implications for the children in terms of their health, their participation in civic life, and their ability to function in an increasingly complex world. Our research has demonstrated that getting children ready to read before kindergarten is a critical step in actually learning to read. Children need to have a basic understanding that there is a connection between sounds, letters, words and print before and during kindergarten to learn to read by the first grade. Our research has also revealed that the vast majority of students who are poor readers in the first grade remain poor readers in the fourth grade and that almost all children who are good readers in the first grade remain good readers in the later grades. Early intervention is critical to developing good reading skills and the interventions should start before kindergarten. The NICHD, in cooperation with the NIMH and the Department of Education, is launching a new program to identify the most effective ways to help children develop their learning abilities. The program has a comprehensive focus that includes promoting cognitive, language and early reading and math abilities as well as self regulation skills, social competency, and emotional health. We strongly believe that every healthy child can and must learn to read.

#### ADVANCES IN MENTAL RETARDATION

Since the NICHD was established, we have made remarkable progress in identifying, treating, and preventing many of the causes of mental retardation. Today, parents do not have to fear phenylketonuria (PKU), congenital hypothyroidism, or Hemophilus influenzae type b meningitis because these major causes of mental retardation have been virtually eliminated. Moreover, other causes of mental retardation such as measles encephalitis, congenital rubella syndrome, and bilirubin encephalophy have nearly disappeared. And we are making progress in learning more about the most common inherited cause of mental retardation Fragile X syndrome.

NICHD has a long history of supporting research on Fragile X syndrome. In the early 1990s, our research led to the identification of the gene affected in Fragile X, FMR1. Last year, in a unique collaboration between the NICHD, the NIMH and the FRAXA Research Foundation, we funded researchers exploring the neurobiology and genetics of Fragile X syndrome. This year, we will establish three new Fragile X Research Centers to conduct research directly related to the causes, treatment and prevention of Fragile X syndrome.

We are also increasing our research in autism. Within the NIH, five Institutes are members of the NIH Autism Coordinating Committee (NICHD, NIMH, NINDS, NIDCD, and NIEHS). Since this Committee was established a few years ago, the NIH has substantially increased its support of autism research from \$22 million in 1997 to more than \$55 million in 2001. The Collaborative Programs of Excellence in Autism (CPEAs) are a major focus of our research in autism. The CPEAs, which we fund along with the NIDCD, link more than 2,500 families of people with autism to more than 75 researchers in 26 universities around the country. The CPEA Network in turn is linked to a six-nation European autism consortium. The Network serves as a resource for individuals with autism and their families. The CPEA Network is now studying the world's largest group of well-diagnosed people with autism whose genotype and phenotype are available. NICHD will also join other NIH Institutes in funding at least five new comprehensive Centers of Excellence in Autism Research as required by the Children's Health Act of 2000.

Our Institute is committed to understanding and eliminating the causes of mental retardation. We are equally committed to applying the results of our research to the

elimination of the barriers that people with mental retardation experience. The President's New Freedom Initiative calls for all Americans to be able to realize the dream of equal access to full participation in American society. For people with mental retardation, we came closer to realizing that dream in our collaboration with the Surgeon General on the Conference on Health Disparities and Mental Retardation. This unique conference was planned and carried out with the full participation of people with mental retardation. It resulted in a blueprint that we all can use to reduce these disparities.

# MOBILITY FOR ALL

Traumatic injury is the leading cause of death for children and adolescents in the United States. Major advances in medicine and emergency room services have helped children survive their injuries, but many survive with disabilities and long term effects on their quality of life. Their conditions are managed through a variety of rehabilitation interventions such as medications, physical therapy, and adaptive equipment or prostheses. However, we have little information on the effectiveness of many interventions for children. A wide range of developmental events distinguishes the rehabilitation of infants, children, and adolescents from that of adults. Therefore we are establishing a series of clinical trial planning grants in pediatric rehabilitation. Our goal is to assure that infants and children who experience traumatic injury are restored to their maximum function through the best rehabilitation we can provide.

Traumatic brain injury (TBI) is a leading cause of disability among adults. During the last two decades, our understanding of traumatic brain injury has increased dramatically. For instance, we now know that not all neurologic damage occurs at the moment of injury, but evolves over the ensuing minutes, hours and days. We are therefore establishing a multi-center network of clinical sites to evaluate the relationship between acute care practice and rehabilitation strategies and the long term well-being of TBI patients. Our goal is to identify which of the interventions are most likely to result in long term improvements.

# PREMATURE BIRTHS

Infants born prematurely have much greater risk of dying in infancy than do other infants. Premature birth puts infants at greater risk for life-threatening infections, for a serious lung condition known as respiratory distress syndrome, and for serious damage to the intestines. The earlier infants are born, the more problems they are likely to face. Some may develop lifelong disabilities, such as blindness, mental retardation, and cerebral palsy. The causes of premature birth remain a puzzle. Physicians have been largely powerless to prevent this serious, and often deadly, complication of pregnancy. Now, however, two groups of NICHD scientists have put many of the puzzle pieces in place and a clearer picture is taking shape. Recently, NICHD scientists and their colleagues discovered that a surge in a

Recently, NICHD scientists and their colleagues discovered that a surge in a stress hormone may signal the beginning of premature labor. They found that women who gave birth prematurely had higher levels of the stress hormone than did women who gave birth at full term. They also found that women who had a low level of education, received public assistance, or worked at jobs requiring them to stand or walk for more than six hours a day, also were more likely both to have high levels of the stress hormone and to give birth prematurely. These researchers are now looking for ways to reduce the levels of stress hormone during pregnancy to help prevent premature birth.

Our research is also changing the way we think about prematurity. Traditionally, researchers have believed that premature labor is an accident in which the uterus begins to contract before the unborn infant has reached full term. NICHD scientists have now uncovered evidence that in many cases, the fetus becomes seriously ill and chemically signals the beginning of labor in order to escape a hostile uterine environment. Instead of being an accident, the initiation of early labor may be a means that nature developed to spare mothers and babies from infection. We are now trying to find ways to identify women who have these infections and who may be at risk for premature labor and find successful ways to treat them. We are also exploring why African American women are more likely to give birth prematurely than are women in other ethnic groups. For example, we have discovered that some African American families are more likely to possess variations in the genes that signal rupture of the membranes, the prelude to labor. These variations may make it more likely that labor will begin prematurely.

#### DECLINE IN SIDS RATES

Since we began a public health campaign eight years ago urging parents and care-takers to place infants on their backs to sleep, we have witnessed a continuous and steady decline in the number of infants dying from Sudden Infant Death Syndrome or SIDS. Provisional data from the CDC show that the SIDS rate has declined by more than 50 percent since the campaign began. This remarkable achievement is a result of the thousands of individuals and the many organizations who have taken

part in this national public health education effort. Although the number of infants who die of SIDS has declined in all ethnic groups, twice as many African American infants die from SIDS as do white infants. To address and help eliminate this disparity, we are working with several national Afri-can American organizations including Alpha Kappa Alpha, 100 Black Women, and the Women of the NAACP who are meeting with parents and caretakers in schools, in churches, and in a variety of community settings on the ways to reduce the risks of SIDS. In the last 12 months more than 50 individual workshops have been conducted, and many more workshops are planned in the coming months in our effort to eliminate the disparity in the rate of SIDS.

#### DRUGS TO IMPROVE THE HEALTH OF CHILDREN AND PREGNANT WOMEN

Until fairly recently, over the counter and prescription drugs that were safe for adults were considered safe for children. However, in addition to being a smaller size, children's brains, bones, and metabolism are different from those of adults. Many of the drugs that have been shown to be safe and effective for adults have In any of a days share here been and in fact may behave very differently in children. In 1994 the NICHD established the Pediatric Pharmacology Research Unit (PPRU) network as a resource for testing the safety and effectiveness of drugs for infants, children and adolescents, and immediately began conducting research on drugs that have been inadequately studied. The network consists of a partnership among the NIH, the pharmaceutical industry, and university-based researchers. The PPRU network has grown considerably since the 1997 passage of the Food and Drug Administration Modernization Act. Thus far, the PPRU network has conducted more than 100 studies of drugs in children, including a new anti-diabetic drug. The work-ing group is also developing new and advanced techniques to monitor a child's blood sugar. The PPRU network demonstrates that studies of drugs can be ethically and efficiently conducted in children.

The study of drugs used during pregnancy is another area of significant concern. Surveys reveal that nearly two-thirds of all pregnant women take at least four or five drugs during their pregnancy. Most of these drugs have never received FDA approval for obstetric use. Funds in the fiscal year 2003 request will enable the NICHD to establish a network of Obstetric Pharmacology Research Units (OPRUs) to conduct studies of drugs during pregnancy to assess dose and safety issues in a way that will provide the necessary information for labeling for use in pregnancy.

#### WOMEN'S HEALTH RESEARCH

In another area of women's health, NICHD has established a Clinical Trials Network in Female Pelvic Floor Disorders and has funded eight sites in this network this year. Each site in the network supports a multidisciplinary team with the expertise, resources, and infrastructure needed to conduct the clinical studies in pelvic floor dysfunction, such as pelvic organ prolapse and incontinence. We are also col-laborating with the NIDDK in funding a Urinary Incontinence Treatment Network. Through this array of support of basic and clinical research we hope to discover better ways to prevent and treat pelvic floor disorders.

## ANTHRAX VACCINE

Scientists in NICHD's intramural laboratories, using funds provided in the DHHS Bioterrorism Initiative in the last three years, have developed a new approach to a vaccine against anthrax that they believe will require fewer injections, have fewer side effects, and induce better immunity. Funds in the fiscal year 2003 budget request will support clinical trials of this new vaccine. Mr. Chairman, I will be happy to provide answers to any questions you have.

#### PREPARED STATEMENT OF DR. PAUL A. SIEVING

Mr. Chairman and Members of the Committee: I am pleased to present the Presi-dent's budget request for the National Eye Institute (NEI) for fiscal year 2003, a

sum of \$631.8 million, which reflects an increase of \$49 million over the comparable fiscal year 2002 appropriation. It is my pleasure to testify today as the new Director of the NEI. I am grateful

It is my pleasure to testify today as the new Director of the NEI. I am grateful for the opportunity to assume this role during a time of unparalleled growth, progress, and opportunity in biomedical research. The National Eye Institute and the scientists it supports are committed to reducing the threats to our vision and to improving the visual health of our citizens. The research that they perform in this pursuit touches upon every area of scientific endeavor and every facet of the visual system. Vision scientists have advanced our knowledge of and improved treatment for a number of eye diseases during this past year, and they stand ready to seize the new opportunities and meet the challenges that await us in the field of vision research.

#### RETINAL DISEASE RESEARCH

The retina is the transparent, light-sensitive tissue that lines the back of the eye. Diseases and disorders of the retina and its blood vessels account for much of the blindness and visual disability in this country. In the United States, the most important of these include macular degeneration, diabetic retinopathy, retinitis pigmentosa and related disorders, retinal detachment, uveitis, and glaucoma.

NEI-supported scientists have made important progress in treating a form of childhood blindness. A genetic disorder called Leber's Congenital Amaurosis (LCA) causes blindness in children by mechanisms similar to those in retinitis pigmentosa. Scientists demonstrated successful gene transfer to restore vision in an animal model of this disease. Treatment was performed by introducing normal copies of the gene to replace the mutated gene. Exciting work lies ahead of us to determine whether this approach has potential as a sight-restoring therapy in humans. It is our best hope that this research will lead to a safe and effective means to restore vision or prevent vision loss in patients with LCA and provide a roadmap for the development of therapies for people with a variety of similar diseases. Researchers also released major findings related to the prevention of macular de-

development of therapies for people with a variety of similar diseases. Researchers also released major findings related to the prevention of macular degeneration. The Age-Related Eye Diseases Study, called AREDS, demonstrated that high levels of antioxidant nutrients and zinc reduced the risk of advanced age-related macular degeneration. Other NEI-sponsored scientists continue to conduct laboratory and clinical studies on the developmental, molecular and cellular biology, the molecular genetics, and metabolism of the photoreceptor cells that capture light; the initial neural processing of information that is transmitted to the visual centers of the brain; the pathogenesis of diabetic retinopathy; and a variety of other sightthreatening eye diseases and conditions. The ultimate goal of these studies is to develop effective therapeutic or preventive measures where none currently exist or to improve those treatments that are currently available.

#### CORNEAL DISEASE RESEARCH

The cornea is the transparent tissue at the front of the eye that plays an important role in refracting or bending light to focus visual images sharply on the retina. Because the cornea is the most exposed surface of the eye, it is especially vulnerable to damage from injury or infection. The leading causes of corneal blindness are herpes simplex virus (HSV) infection and other infections, corneal opacification or clouding, and inherited and degenerative diseases. Recent results from NEI-sponsored studies have provided important information about the spread of HSV and have suggested that rapid systemic treatment may be more effective than topical antivirals in treating acute, primary infections. Scientists have also learned more about the immune mechanisms involved in corneal transplant rejection and have suggested a means to increase transplant success.

The NEI supports a variety of other laboratory and clinical studies, including: the regulation of genes that express proteins unique to corneal tissue; investigation of the use of adult corneal stem cells to treat corneal damage due to disease or injury; the mechanisms that maintain corneal hydration and transparency; improvement in the diagnosis and treatment of dry eye; the physiologic basis for autoimmune disease involving the cornea; and corneal wound healing. These studies should ultimately improve our ability to limit or prevent damage to corneal clarity caused by injury, infection, or other disease processes.

# CATARACT RESEARCH

A cataract is an opacity of the eye's normally clear lens that interferes with vision. Cataract may develop at any time during life, although it is most often associated with advancing age. In addition to aging, cataract may be a consequence of diabetes and other metabolic disorders, trauma, exposure to ionizing radiation, or it may be inherited. Although cataract treatment in this country is one of the most successful of all surgical procedures, development of non-surgical approaches to preventing or treating cataracts remains a research priority.

NEI investigators have recently reported that women on estrogen replacement therapy are less likely to develop cataracts. Additionally, scientists have found that a subunit of a major protein component of the lens is highly effective in protecting cells from stress-induced cell death but may become overwhelmed, leading to cataract formation. These results suggest additional avenues of research that may lead to non-surgical therapies to prevent or delay cataract formation. NEI-sponsored research continues on the development and aging of the normal lens of the eye; the identification of the molecular and cellular components that maintain the transparency and proper shape of the lens; the control of lens cell division and differentiation; and the impact of continual oxidative insult on the lens.

#### GLAUCOMA RESEARCH

Glaucoma leads to blindness from damage to the optic nerve of the eye. Glaucoma is often, but not always, associated with increased pressure within the eye caused by inadequate drainage of aqueous humor, the fluid within the eye that nourishes the cornea and lens. Although glaucoma is primarily a chronic disease of aging, it may occur at any age. It can occur as a primary disorder or it can be secondary to other ocular or systemic conditions. Glaucoma is a major health problem and the number one cause of blindness in African-Americans. Glaucoma research is a primary focus for NEI's research on health disparities. More than two million Americans have definite glaucoma and it is estimated that another two million are unaware that they have the disease. Nearly 120,000 are blind from this disease.

In the past few weeks, NEI-funded investigators identified a new gene mutation on chromosome 10 that caused a form of adult-onset glaucoma. The gene codes for a protein that normally protects nerve cells from damage. Scientists have also recently identified a molecular marker of glaucoma in the trabecular meshwork, which forms the tissue that regulates the exit of aqueous humor from the eye. This same substance is the earliest marker for the buildup of fatty deposits in the linings of blood vessels damaged by high blood pressure. Other markers that are usually associated with oxidative stress and inflammatory reactions were also identified in cells from glaucoma patients. Such studies offer insights and hope for new and more effective therapeutic interventions.

#### STRABISMUS, AMBLYOPIA, AND VISUAL PROCESSING RESEARCH

Childhood vision loss most frequently results from strabismus, a misalignment of the eyes and the development of amblyopia, or lazy eye. Strabismus results in diseases in which visual processing is abnormal. Amblyopia can result from this misalignment or from unequal refraction between the eyes. Research on strabismus and amblyopia encompasses a broad range of clinical and laboratory studies on the structure and function of the neural pathways from the retina to the brain, the central processing of visual information, visual perception, the control of ocular muscles, and refractive errors.

cles, and refractive errors. Important new results from the Amblyopia Treatment Study are being released March 13. This study began recruiting patients in April 1999 to compare two different treatments for amblyopia eye patching or administration of a single eye drop of atropine per day. These exciting findings will change clinical practice in this country. NEI research support continues for a broad range of other preventative, therapeutic and laboratory studies that are concerned with the development and function of the neural pathways from the eye to the brain; wiring of the visual system of the brain during the young years of development; the central processing of visual information; visual perception; optic neuropathies; eye movement disorders; and the development of myopia.

#### HEALTHY PEOPLE 2010

Healthy People 2010 is a national initiative to prevent disease and promote health issues sponsored by the U.S. Department of Health and Human Services. Vision objectives, codified as *Healthy Vision 2010*, are highlighted in this initiative. The NEI coordinates the workgroup activities designed to accomplish these objectives. This vision focus area addresses visual impairment due to eye disease and refractive error; regular eye examinations for children and adults; vision screening for preschool children; and injury prevention. Initial activities include collecting baseline data on eye disease prevalence, so that progress can be monitored in treating the visual disabilities that lead to low vision and impair the productivity and quality of life of our citizens.

## HEALTH EDUCATION AND COMMUNICATION

The National Eye Health Education Program (NEHEP) was mandated by Congress and implemented by the NEI to increase awareness among health care professionals and the public of scientifically based health information that can be applied to preserving sight and preventing blindness. NEHEP works through its partnership of over 60 professional and voluntary organizations to implement three formal education programs covering glaucoma, diabetic retinopathy, and low vision. The newest of these programs is the Low Vision Education Program, designed to increase awareness of low vision and its impact on quality of life. As a part of this program the NEL launched a multi-year nationwide shonping center four of THE

The newest of these programs is the Low Vision Education Program, designed to increase awareness of low vision and its impact on quality of life. As a part of this program, the NEI launched a multi-year nationwide shopping center tour of THE EYE SITE—A Traveling Exhibit on Low Vision. The exhibit consists of five colorful kiosks and features an innovative interactive multimedia touchscreen program. The exhibit is targeted to all people over age 65, and Hispanics and African Americans of any age. These groups, their families, and friends are the primary audience for the exhibit.

Another NEHEP program theme highlights a new Medicare benefit for glaucoma detection, which became effective in January. The Medicare benefit includes coverage of a dilated eye examination with an intraocular pressure measurement for people at highest risk of developing the disease, including African Americans over age 50, people with diabetes and those with a family history of the disease. This new effort is being coordinated with other Federal agencies, including the Center for Medicare and Medicaid Services.

## GOVERNMENT PERFORMANCE AND RESULTS ACT

The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

Mr. Chairman that concludes my prepared statement. I would be pleased to respond to any questions you or other members of the committee may have.

## PREPARED STATEMENT OF DR. KENNETH OLDEN

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget for the National Institute of Environmental Health Sciences (NIEHS) for fiscal year 2003, a sum of \$619,769,000, which reflects an increase of \$48,290,000 over the comparable fiscal year 2002 appropriation. The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

## INTRODUCTION

Although most of the visible environmental problems of the 1950s and 1960s have been ameliorated, massive quantities of toxic agents are still polluting our environment. This includes chemicals that are known to be rodent and human carcinogens and neuro-, immuno-, or developmental-toxins. Whether current levels of exposure to these agents are contributing to the high or increasing incidence of cancer, Parkinson's and Alzheimer's Disease, asthma, autism, learning disabilities, diabetes, or other complex disorders is a matter of considerable concern. Finding answers to these questions has been a slow and difficult process. The traditional methodologies available to environmental health researchers have not been adequate to elucidate the intricate gene-environment interactions involved in the development of complex diseases.

Today, the environmental health sciences stand on the threshold of new and exciting opportunities. The knowledge and technologies spun by the Human Genome Project has unshackled this important discipline and created unprecedented technological opportunities to advance our understanding of environmentally-associated toxicities and diseases. By using a combination of new technologies (genomics, proteomics, and metabonomics), one can achieve an integrative view of gene-environment interaction at the level of the whole organism.

To exploit the disease prevention promise of these technologies, NIEHS has targeted three critical areas of research: (1) identification of the suite of gene-environment interactions involved in the development of the major diseases, (2) development of public health or medical prevention/intervention strategies, and (3) development of mechanisms to translate knowledge and technology into the practice of preventive and clinical medicine. By investing in these areas of research, NIEHS expects to be a major contributor to one of the most important functions of government—the protection of human health.

I will briefly describe three technologically-driven initiatives that represent major investments for the NIEHS, and have potential for preventing disease, making sound environmental health policy decisions, and reducing the time and costs associated with assessing the toxicity or carcinogenicity of chemical and physical agents in our environment.

#### SEARCH FOR ENVIRONMENTAL SUSCEPTIBILITY GENES

Throughout life, human and other organisms are subjected to environmental insults on a continual basis. As a result, sophisticated metabolic pathways have evolved to buffer against toxic injury. Collectively, these buffering pathways or mechanisms have been referred to as the "environmental response machinery." All human genes, including those that code protein components of the environmental response machinery, are subject to genetic variability that can result in outright failure or altered efficiency in a buffering or protective mechanism.

Although reference is made to the human genome, the concept of a single genome is misleading. Each individual's genetic makeup, with the exception of identical twins, is unique. While the genomes of individuals are 99.9 percent identical, the 0.1 percent variation leaves considerable room for individual differences among the approximately three billion nucleotide base pairs that make up the human genome. The variation in gene structure among individuals is known to play a significant role in disease development by increasing or decreasing sensitivity to environmental insults.

To date, very few environmental susceptibility genes have been identified, but with improvements in methods of gene discovery and genotyping, large-scale studies of the genetic basis for susceptibility to environmental exposures are now practical. Therefore, NIEHS initiated a search for such environmental susceptibility genes approximately three years ago with the announcement of the Environmental Genome Project (*Science* 278: 569–570; *Nature Genetics* 18: 91–93), by contracting with the genome sequencing laboratories developed by the Human Genome Project. The questions being addressed by the genome discovery project include: (1) Which of the genes coding for proteins involved in buffering against environmental insults vary structurally among individuals, (2) What is the relative distribution of the various forms of the genes in the U.S. population, and (3) What are the consequences of the genetic alterations with respect to toxic injury or susceptibility to environmental exposures? To date, we have completed the search for functional variations in 104 of the 544 genes initially targeted for analysis. This has been done in a sufficient population sample size so that we can be reasonably certain that variations discovered are representative of the U.S. population. However, I should stress that the 544 genes examined in this study do not represent all, or even most, of the environmental susceptibility genes in the human genome; most are yet to be discovered. In fact, NIEHS is collaborating with the National Human Genome Research Institute and other Institutes in the Single Nucleotide Polymorphism discovery and the Haplotype-Mapping projects to uncover other susceptibility genes. I should also emphasize that genes are not the only factors that contribute to dif-

I should also emphasize that genes are not the only factors that contribute to differences in susceptibility to environmental exposures; age or stage of development, behavior, and general health or nutritional status can have a spectacular influence. In the interest of time, these issues will not be addressed here, but they are among the top investment priorities of the NIEHS.

#### TOXICOGENOMICS

The vast majority of synthetic and natural chemicals in our daily environment have not been thoroughly screened for toxicity ("Toxic Chemicals," *Environmental Defense Fund*, 1993). Also, the demand for toxicity assessment has increased dramatically over the past decade because of the rapid evolution of drug discovery science and the build-up of chemical and physical pollutants in the environment resulting from activities of the increasing human population. Thus, more efficient and cost-effective toxicity screening methods must be developed. The conventional approaches of exposing laboratory animals to high doses of single chemicals are too slow, too expensive, use too many animals, and are not very informative with respect to mechanisms of toxicity.

<sup>\*</sup>Toxicogenomics is a new discipline, spun from the Human Genome Project, that merges toxicology with new technologies for analysis of genes (genomics), proteins (proteomics), and metabolites (metabonomics) derived from cells, tissue extracts or body fluids. This field of endeavor was formally inaugurated when NIEHS announced the development of the National Center for Toxicogenomics in November 2000 (*Science* 289: 536–537; Pollack, Andrew, *The New York Times*, 28 November 2000). The Center consists of an intramural laboratory and five university-based programs. Program coordination and database management are handled by the intramural component.

This approach to assessment of toxicity was made possible by development of the capacity to array thousands of DNA fragments, corresponding to specific genes, on matrices and hybridization with mRNA or cDNA. Using this approach to profile mRNA expression patterns, one can determine which genes are turned on or off by exposure to specific environmental agents. However, the mRNA product of a single gene can be sliced or processed to give rise to several proteins or peptides. Therefore, protein and metabolite analyses are necessary to understand the mechanisms and pathways involved in the development of disease or toxicity.

exposure to specific environmental agents. However, the mKNA product of a single gene can be sliced or processed to give rise to several proteins or peptides. Therefore, protein and metabolite analyses are necessary to understand the mechanisms and pathways involved in the development of disease or toxicity. Toxicogenomics is a promising technology, but one that will take a while to achieve the potential public health and economic benefits. Toxicologists must develop a knowledge base to discriminate between adaptive or pharmacological responses and toxicological effects, as virtually any change in the environment will influence the expression of many genes. Also, signature patterns must be correlated with conventional indices of toxicity. So, hundreds of chemicals and many experimental variables will need to be examined before we will know its full impact.

#### MOUSE GENOMICS CENTERS

Fortunately, almost every human gene appears to have a counterpart in the mouse, opening the possibility of constructing special mouse models containing the specific variations (polymorphisms) identified in the Environmental Genome Project. Such models are now being developed by use of gene "knock-out" and "knock-in" technology in several university-based Centers established for this purpose by NIEHS in 2001. These models will be made available to researchers upon request to investigate the relationship between particular genotypes and environmental exposures and diseases.

#### PUBLIC OUTREACH AND TRANSLATION OF RESEARCH

It is becoming increasingly important to get consumers more intimately involved and informed about science and its implications. To this end, NIEHS employs citizen-based priority setting through Town Meetings and Brainstorming Sessions held throughout the year in various regions of the U.S. These sessions involve the participation of the senior leadership of the NIEHS, elected officials, local industry, regional offices of other federal agencies, state and county health officials, university scientists, public interest groups, and lay citizens. On average, a Town Meeting attracts an attendance of 200 to 400 participants from the local community.

NIEHS also supports workshops and roundtables under the banner of the National Academy of Sciences to promote awareness and understanding of the new opportunities in environmental health and policy implications of the science. Furthermore, the 40 NIEHS-supported Centers are required to sponsor outreach activities in their local communities.

To ensure that progress is made in translating our science into the practice of medicine, NIEHS has developed several Centers programs that bring basic and clinical researchers (physician scientists) together in the same space. Examples of such programs include our existing Children's Environmental Health Research and Prevention Centers. This year we expect to develop similar centers on Parkinson's disease and breast cancer.

#### NATIONAL SECURITY

Over the past 35 years, the NIEHS has developed a cadre of first-rate researchers in the environmental health sciences. Five NIEHS-supported Centers in the New York area have more than 100 researchers with expertise in air pollution, asbestos toxicity, exposure assessment, children's health, and population-based epidemiology studies. Since September 11, they have initiated research activities in response to the attack on the World Trade Center with NIEHS support and coordination. Their efforts include exposure assessment, epidemiology, medical care and clinical evaluation, and community outreach and education. These activities are now being integrated into the government-wide effort coordinated by the Federal Emergency Management Agency.

The other area in which NIEHS has expertise and plans to contribute, is in the Nation's preparation to prevent toxicity and death from bioterrorism. Toxicogenomic technologies discussed earlier are capable of detecting, tracking, and containing chemical poisons or infectious microorganisms. Identification of susceptibility genes

and characterization of their function through toxicogenomics can provide importance clues for understanding, and ultimately preventing, the progression of diseases. The specific pattern of gene response can also provide clues about host defense mechanisms which can also be exploited for prevention. NIEHS plans to use the National Toxicology Program to conduct toxicological evaluations of defined mixtures of contaminants identified by environmental monitoring studies of ambient and indoor air and dust; and to evaluate the safety of therapeutic regimens and intervention measures likely to be employed in biological or chemical terrorism events. This technology is not limited to chemicals; it could also identify genes whose expressions are critical for a pathogen to overcome body or host defense mechanisms.

## SUMMARY

Investment in environmental health prevention research is the best hope of eliminating the epidemic of disease. Investment in such research will save lives, spare pain and suffering, and save money in the years ahead. The proposed and ongoing research will lead to more effective environmental surveillance systems with the capacity to rapidly analyze and assess the health risks of chemical and biological agents.

#### PREPARED STATEMENT OF DR. RICHARD J. HODES

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Institute on Aging (NIA) for fiscal year 2003, a sum of \$971,709,000, which reflects an increase of \$75,645,000 over the comparable fiscal year 2002 appropriation. The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report, which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

Americans over age 65 are more likely today than at any other time in history to be vigorous and productive. Life expectancy, disability rates, and health and wealth indicators have all shown significant improvement over the past decade. At the same time, healthy, comfortable older age continues to elude many Americans, particularly members of certain racial, ethnic, and socioeconomic groups. Diseases of aging, including Alzheimer's disease, cardiovascular disease, osteoporosis, cancer, diabetes, and arthritis, affect too many older men and women, seriously compromising the quality of their lives. And the challenges of dealing with a rapidly aging population will continue to grow: According to data from the U.S. Bureau of the Census, there are today approximately 35 million Americans age 65 and older. If current demographic trends hold, that number will double by the year 2030. NIA is committed to supporting high-quality research to address all aspects of aging, from conditions and diseases that primarily affect older people to physical, behavioral, and cellular characteristics of the aging process.

#### AMERICANS ARE LIVING LONGER AND HEALTHIER LIVES

Census data indicates that life expectancy in the United States is approximately 76 years, up from about 49 a century ago. This increase is largely due to improvements in health care, nutrition, and overall standard of living for most people. Longevity, particularly "super-longevity" (living 100 years or beyond), also has a significant genetic and molecular component. For example, several genetic polymorphisms are known to confer extreme longevity in animal models, and studies suggest that similar polymorphisms may operate in humans. Scientists have also found that a positive outlook in early life may be associated with greater longevity. More research is needed to understand the connection between early emotional state and length of life.

Not only are Americans living longer, but we're also remaining healthier into old age. The most recent National Long Term Care Survey (NLTCS), the latest of a series of surveys of the U.S. elderly population, continues to document a dramatic decline in the overall prevalence of physical disability among older Americans over the past two decades. While 26.2 percent of the elderly were assessed as disabled in 1982, this figure dropped to 19.7 percent in 1999. Of particular note is the sharp reduction in disability rates among African Americans during the 1990s, reversing trends from the 80s. Results from the NLTCS also show significant declines in severe cognitive impairment, with 900,000 fewer cases in 1999 than expected based on the 1982 rates a decline in prevalence from 5.2 to 2.7 percent. The finding that cognitive disability is declining is also supported by evidence from the Health and Retirement Study, which indicated that declines were especially large among those with less than a high school education and those ages 80 and older, groups in whom cognitive impairment is particularly prevalent.

#### CONQUERING ALZHEIMER'S DISEASE

Alzheimer's disease (AD), the most common cause of dementia among older persons, tragically affects as many as four million Americans, most of whom are 65 or older, according to the Alzheimer's Association. However, we have made progress in several important areas. For example:

We are identifying risk factors.—Identifying risk factors for AD will help us identify pathways affecting its development or progression and may lead to better predictors of the disease even before it is clinically apparent. Until last year, just four of the approximately 30,000 genes in the human genome were conclusively known to affect the development of AD pathology. Recent genetic studies suggest that as many as four additional and as yet unidentified genes may also be risk factors for late-onset AD. NIA-supported researchers are attempting to identify other risk factors through population studies.

We are improving our ability to diagnose AD early.—Scientists are developing and refining powerful imaging techniques that target anatomical, molecular, and functional processes in the brain. These new techniques hold promise of earlier and more accurate diagnosis of AD, as well as improved identification of people who are at risk of developing the disease. Recent studies suggest that positron emission tomography (PET) scanning of metabolic changes in the brain and magnetic resonance imaging (MRI) scanning of structural brain changes may be useful tools for predicting future decline associated with AD and other neurodegenerative diseases.

We are developing new, more effective treatments for AD.—One way to treat AD successfully may be to interfere with early pathological changes in the brain, including the development of AD's characteristic amyloid deposits and neurofibrillary tangles. A number of promising approaches, many of them targeted at the reduction of amyloid plaques, are being developed and tested in various model systems. In 2001, NIA funded research to find new ways to treat AD by targeting underlying disease processes and continuing development of a vaccine to prevent the disease. Recent studies have successfully used antibodies to clear amyloid plaques from the brains of mice that were genetically engineered to develop AD-like pathology. Other recent studies have shown that statins, the most commonly used cholesterol-low-ering drug, may be associated with a lower risk of AD, and that high blood levels of the amino acid homocysteine may increase risk. Increasing intake of folic acid and vitamins B6 and B12 can reduce blood levels of homocysteine, and NIA is planning a clinical trial of these substances to test whether supplementation can slow the rate of cognitive decline in people diagnosed with AD.

the rate of cognitive decline in people diagnosed with AD. NIA is currently supporting 18 AD clinical trials, seven of which are large-scale prevention trials. These trials are testing agents such as estrogen, anti-inflammatory drugs, and anti-oxidants for their effects on slowing progress of the disease, delaying AD's onset, or preventing the disease altogether. Other intervention trials are assessing the effects of various compounds on the behavioral symptoms (agitation, aggression, and sleep disorders) of people with AD. The NIA is also supporting studies that are testing interventions for improving AD patient care delivery and alleviating caregiver burden.

#### UNDERSTANDING THE BIOLOGY OF AGING

We are continuing to advance our understanding of the molecular and cellular changes that underlie aging processes. New technologies are providing answers to questions about how genes control cell and tissue function. Arrays of DNA corresponding to specific genes permit the comparison of expression of tens of thousands of genes at one time to determine which are turned on or off in a particular cell or condition. A collection of 15,000 mouse genes has been developed, including genes active in early development. To facilitate extensive use of this gene collection, NIA has made it available to research institutions worldwide. Verified sequences of each gene in the set are also available; by comparing the sequence information with genes that have already been well studied, scientists may be able to determine the function of these genes in mice. The Institute has also developed the NIA Microarray Facility, which provides investigators with low-cost access to microarrays developed from the set and will also provide for collecting and analyzing the gene expression findings of multiple investigators. Continued discovery of genetic pathways that influence longevity in a variety of experimental animal models may help in identifying both genes and molecular processes that affect health of aging humans.

## REDUCING DISEASE AND DISABILITY

In addition to AD, we have made a number of advances in other diseases and conditions. Our knowledge of the beneficial effects of exercise continues to increase; for example, last year researchers found that physical activity can stave off disability in older persons with osteoarthritis of the knee, a form of arthritis that is particularly common among people age 50 and over. NIA's highly successful campaign to encourage older people to exercise is working to translate research findings into action. Since the campaign was launched in 1998, NIA has distributed over 430,000 copies of its exercise guide and over 55,000 copies of its companion video to the public. In addition, a Spanish-language version of the guide was published in January 2002.

To address disability and disease in special populations, NIA implemented a major new study of health disparities among different racial, ethnic, and socioeconomic groups. The study, Healthy Aging in Nationally Diverse Longitudinal Samples (HANDLS), focuses primarily on cerebrovascular health, cardiovascular health, age-associated changes in cognition, and strength and physical functioning. Through this study, we hope to address hypotheses about aging and health disparities in minority and poor populations to understand the significance of environmental and genetic risk factors for disease. The pilot phase of HANDLS, in which investigators assessed the logistics and feasibility of this community-based study, was completed at the end of 2001, and the larger population-based phase of this study is scheduled to begin in late fall of 2002.

Other important research advances include:

Parkinson's Disease.—In an effort to develop a new model of Parkinson's disease, scientists exposed rats to rotenone, a common pesticide. Exposed rats showed pathological changes characteristic of Parkinson's disease, as well as motor behavior abnormalities, such as rigidity and decreased motor activity, that are frequently seen in Parkinson's disease patients. This new model of Parkinson's disease will be useful in designing and testing new therapeutic interventions, as well as further identifying environmental exposures that may be risk factors for developing the disease. Diabetes.—Diabetes is one of the major debilitating diseases that affect older peo-

Diabetes.—Diabetes is one of the major debilitating diseases that affect older people. Among the elderly, type 2 diabetes is the most common; it occurs when pancreatic beta cells produce insufficient insulin or when the body cannot use its insulin efficiently. NIA-supported researchers participated in the Diabetes Prevention Program, a major, multi-institutional study that was initiated by the National Institute on Diabetes and Digestive and Kidney Diseases and was designed to identify interventions that could prevent or delay the development of type 2 diabetes. The researchers found that people who are at high risk for diabetes can sharply reduce their risk by adopting a low-fat diet and moderate exercise regimen. This effect was most pronounced among study participants age 60 and over. Treatment with the drug metformin (Glucophage®) also reduced diabetes risk among study participants, but for unknown reasons was less effective among older participants. Nearly half of the study participants were members of racial and ethnic groups that suffer disproportionately from type 2 diabetes, including African Americans, Hispanic Americans, Asian Americans and Pacific Islanders, and American Indians.

*Cancer.*—Much remains unknown about cancer diagnosis, prevention, and treatment in older people. NIA supports a variety of cancer-related basic and clinical research projects, many of them in collaboration with the National Cancer Institute (NCI) and other NIH Institutes. For example, NIA has an initiative to expand knowledge on aging- and age-related aspects of prostate cancer in different populations. NIA and NCI have also created a partnership that has resulted in an aggressive research agenda within the NCI-designated cancer centers to reduce the burden of cancer for older persons.

Hip Fracture Recovery.—According to a recent study (Marcantonio et al., J Am Geriatr Soc 48: 618–624, 2000), 250,000 older Americans fracture a hip each year, and delirium, an acute confusional state, complicates recovery from hip fracture repair in at least one-third of these people. Besides being frightening to patients and their families, and difficult to manage in the hospital, delirium after hip fracture is also associated with poor recovery of function in both the short and long term. In a recent study aimed at reducing risk factors for delirium, geriatricians provided a variety of recommendations to the orthopedic physicians caring for the hip-fracture patients. This intervention led to a one-third reduction in the number of patients who developed delirium and a one-half reduction in the patients who developed severe delirium. Estrogen Replacement Therapy.—Each year, millions of American women turn to hormone replacement therapy (HRT) to relieve peri- and post-menopausal symptoms and for protection against age-related conditions such as heart disease and osteoporosis. However, HRT can have unwanted side effects. In a recent clinical trial, women over age 65 received one of three doses of estrogen. The highest dose was the amount most commonly prescribed today, and the lowest dose was onefourth of this amount. They found that the low dose markedly reduced bone breakdown, a reduction that was similar to that produced by the highest dose, and reduced the frequency of common side effects. In fact, low-dose therapy resulted in no more side effects than placebo. These findings suggest that a lower dose of estrogen may be just as effective as the regular dose, but have fewer side effects.

*Cardiovascular Disease.*—An exciting area of stem cell research lies in the ability of the body to use its own stem cells to repair damaged organs. In a recent study, mice with induced heart damage were injected with particular proteins called cytokines. Stimulated by the cytokines, the mice's own primitive bone marrow cells migrated to the heart, converted to several different types of cardiac cells, and contributed to repair of the damaged tissue, improving both heart function and survival of the treated mice. In a study of human heart transplant patients, scientists found that primitive cells from heart transplant recipients can migrate to and become a functioning part of the donated heart. These results are extremely preliminary, and further research is needed. However, the findings from these studies challenge the conventional wisdom that damaged heart tissue cannot be regenerated, and suggest that the body's own naturally-occurring stem cells may be able to repair tissue damage and fight disease.

#### CONCLUSION

It is becoming increasingly obvious that old age need not be associated with illness, frailty, or disability. In fact, we have made tremendous progress against all of the major diseases and conditions of aging. However, much work remains to be done. By continuing and intensifying research, NIA can move forward in meeting the promise of extended life by improving the health and well-being of older people in America.

# PREPARED STATEMENT OF DR. STEPHEN I. KATZ

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Institute of Arthritis and Musculoskeletal and Skin Diseases for fiscal year 2003, a sum of \$488,228,000, which reflects an increase of \$37,988,000 over the comparable fiscal year 2002 appropriation.

It is an honor for me to have this opportunity to share stories of research advances as well as highlights of the many opportunities we have in research on bones, muscles, joints, and skin. The mission areas of our Institute touch the daily life of millions of Americans, and we are committed to improving quality of life as well as longevity. Diseases within our mandate know no barriers in terms of age, gender, ethnicity, or socioeconomic status. In fact, many of the diseases in our mission areas disproportionately affect women and minority individuals, and we are committed to determining why this is the case.

## RESEARCH IN CHILDREN

While we typically associate chronic diseases with the elderly, the fact is that they can affect people of all ages, and can rob a child of the joys and activities of the young. The other reality is that children are not small adults—diseases affect them in different ways and treatments may have different effects in children than adults. In light of these and other realities, the NIAMS has undertaken a number of programs and activities focused on children to enhance our understanding of childhood diseases and to develop improved treatments for our younger generation. For example, it has been said that osteoporosis is actually a disease of childhood that is manifested in later years. We know how vitally important it is that children develop a strong skeleton in childhood so that they can withstand the age-related changes that occur in their bones later in life. Research supported by the NIAMS has resulted in the design of a 7-month, high intensity jumping regimen that will increase peak bone mass at two clinically critical sites, the hip and the spine. Investigators discovered that children who participated in the jumping program had a significantly greater change in bone mineral content in both the hip and spine compared with a control group, as well as showing positive differences in bone mineral density and bone area. This regimen, which can easily be incorporated into the regular elementary school curriculum, has potentially important public health implications with respect to optimizing peak bone mass attainment in young people. The NIAMS has also placed an enhanced emphasis on research on osteogenesis

The NIAMS has also placed an enhanced emphasis on research on osteogenesis imperfecta (OI), one of the most common genetic diseases of bone. OI is characterized by brittle bones that fracture easily, and is caused by mutations in the gene for a protein called type I collagen. NIAMS-supported researchers have recently reported very exciting progress in both the controlled introduction of genes into bone cells, as well as the ability to inactivate mutant genes that can cause disease. Further progress in OI research is expected as a result of several new grant awards from the NIAMS for projects ranging from cutting-edge gene and cell therapies to testing drug treatments in mouse models of the disease.

testing drug treatments in mouse models of the disease. In other research related to children, the NIAMS continues to lead the NIH's Pediatric Rheumatology Clinic. In addition to providing diagnosis, evaluation, and treatment of juvenile arthritis and other rheumatic diseases, the clinic facilitates the translation of research advances to improve patient care. A new study underway at the clinic is designed to determine the best medication combinations for treating children with juvenile rheumatoid arthritis. We recognize that we have much to learn about diseases in children and we are currently developing a new, broad initiative that will focus on multidisciplinary translational research projects in rheumatic and immuno-inflammatory skin and muscle diseases of children so that we can target those areas that present special challenges in children.

#### ARTHRITIS AND OTHER RHEUMATIC DISEASES

Research on osteoarthritis, a degenerative joint disease, took a big step forward with the launching of the new public-private partnership that teams several NIH entities, the FDA, and four pharmaceutical companies in the Osteoarthritis Initiative. Clinical research on osteoarthritis has been severely hampered by the lack of biological markers needed to assess the progression of this most common form of arthritis. The significant commitment required to undertake such a study has been beyond the scope of either government or industry alone, but is feasible and indeed underway through this new partnership. The NIAMS teamed with our colleagues in the National Institute on Aging in leading this effort to fund from four to six clinical research centers to establish and maintain a natural history database for osteoarthritis. The database will include clinical evaluation data and radiological images, as well as a biospecimen repository. All data and images collected will be available to qualified researchers worldwide to help hasten the pace of scientific studies and biomarkers for two chronic inflammatory diseases which affect many Americans, rheumatoid arthritis and lupus.

Lupus is a serious and potentially fatal autoimmune disease that occurs with greater frequency and intensity in African American women, and it affects many organ systems of the body. One of the challenging manifestations of lupus is the involvement of the nervous system, and researchers supported by the NIAMS have recently reported significant advances in our understanding of the molecular mechanisms involved in the changes that can occur in the brains of people with lupus. The identification of the particular antibodies involved not only helps us to understand the nervous system complications in lupus, but also provides some new therapeutic possibilities for this aspect of lupus that can be difficult and challenging for affected patients, their families, and their health care providers. To further enhance research in this area, the Institute has recently released a solicitation for applications on neuropsychiatric lupus, in an effort to stimulate additional study of the neurological and psychiatric syndromes associated with this chronic disease.

#### BONE BIOLOGY AND BONE DISEASES

Basic researchers have reported new insights into the complex effects of estrogen on bone. We know that the most common cause of bone loss is the decline in the female sex hormone, estrogen, in women after menopause. Estrogen also appears to be important in maintaining bone mass in men, although men have more of the male sex hormone androgen than estrogen. Recent research reports from work supported by the NIAMS have provided important clues to the complex relationship between estrogen and bone, and revealed as many research investigations do that we still have much to learn about the action of estrogen as well as the function of estrogen receptors. The most recent research reports indicate that either estrogen or androgen can act to increase bone formation and prevent net bone loss. In other research, scientists have shown that particular cells of the immune system called T cells can contribute to the bone loss that occurs when estrogen levels are low. These and other basic studies funded by the NIAMS are adding to the foundation of knowledge of normal function in bone biology and the changes that occur in bone diseases. Recent initiatives to stimulate further work in the bone sciences include the release of solicitations to encourage applications on new research strategies for the evaluation and assessment of bone quality, and one on basic and applied stem cell research for arthritis and musculoskeletal diseases.

# MUSCLE BIOLOGY AND MUSCLE DISEASES

This has been a very active year in the whole field of the muscular dystrophies as the NIAMS has joined our colleagues in the NINDS in targeting research in this area. Over the last two years, we have supported two successful scientific conferences, and issued research solicitations to the research community targeting those areas of particular opportunity that were identified by experts at the conferences. As a result of these activities, the NIAMS and NINDS recently awarded several new grants to support both basic and clinical research studies in facioscapulohumeral dystrophy (FSHD), the third most common genetic disease of skeletal muscle. We have also funded a number of projects in follow-up to a solicitation for proposals on therapeutic and pathogenic approaches for the muscular dystrophies. In addition, we continue to support a research registry in particular forms of muscular dystrophy that serves as an invaluable resource for scientists to collect and analyze new research data in their pursuit of better treatments for muscular dystrophies.

#### SKIN BIOLOGY AND SKIN DISEASES

Chronic wounds are a significant public health challenge, particularly in the elderly and people with diseases like diabetes that affect skin healing. A new living skin substitute showed a significant improvement in wound healing and a decrease in time to complete closure of the wound in people with diabetic foot ulcers. Newer technologies such as artificial skin equivalent systems can improve the rate of healing of existing wounds, as well as minimize or reduce the incidence of severe complications.

<sup>1</sup> Pseudoxanthoma Elasticum (PXE) is a systemic inherited disorder that affects the elastic tissue in the skin, eyes, and cardiovascular system, and it can result in severe and even fatal problems in affected individuals. The fascinating new dimension to our understanding of PXE is that, contrary to earlier beliefs, PXE is actually a metabolic disorder. The recognition that this is a metabolic disease offers new hope for the development of treatments based on metabolic modifications potentially including such approaches as diet manipulation or drug therapy. There is also the potential for PXE to be identified in affected people early so that treatment can be instituted before signs and symptoms of the disease actually occur. To boost research on PXE and other heritable disorders of connective tissue, such as Marfan syndrome and Ehlers-Danlos syndrome, the Institute recently released a solicitation, along with our colleagues at the National Heart, Lung, and Blood Institute, to encourage more basic and clinical studies of these disorders.

# HEALTH DISPARITIES

A number of diseases within the mission areas of the NIAMS affect women and members of minority groups disproportionately, including lupus, scleroderma, osteoarthritis, vitiligo, and keloids. In addition to the vigorous research portfolio that the NIAMS funds in these areas, I want to cite two programs that the Institute supports that address the critically important area of health disparities. We continue our active involvement in the Health Partnership Program, a model communitybased research program to study rheumatic diseases in the African American and Hispanic/Latino communities in the metropolitan, Washington, D.C., area. In addition, we enthusiastically support a newly initiated program that the NIAMS was active in creating—a new strategy for enhancing clinical research training in minorityserving institutions. The goal of this program is to produce well-trained clinical researchers who will go on to lead clinical research projects. Finally, in follow-up to a major scientific conference organized by the Institute, the NIAMS is developing a new initiative on health disparities in rheumatic and skin diseases.

## INTRAMURAL RESEARCH PROGRAM

The NIAMS Intramural Research Program (IRP) is a vital and growing program that has become a national and international resource, as well as a recognized site for scientific excellence on the NIH campus. A major new program that the IRP has undertaken is the initiation of a trans-NIH collaboration in musculoskeletal medicine. This effort will include the development of innovative fundamental science, clinical studies, and translational research. The collaboration is designed to build on strengths that are already present at the NIH, as well as foster the growth of new research and training programs in the critical and under-served area of musculoskeletal medicine.

#### CONCLUSION

Virtually every home in America is touched by diseases affecting bones, joints, muscles, and skin. We are committed to better understanding, diagnosis, treatment, and prevention of these diseases and disorders that are typically chronic, costly, common, and disabling. The vitality of our bones, joints, muscles, and skin is key to the length and quality of our lives. Medical research supported by the NIAMS has made significant strides in improving health and quality of life, and we are committed to pursuing promising research opportunities that will continue to improve the health of the American people.

The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is the NIH's second annual performance report which compared our I will be happy to answer any questions that you may have.

#### PREPARED STATEMENT OF DR. JAMES F. BATTEY, JR.

Mr. Chairman, and members of the Committee: I am pleased to present the President's budget request for the National Institute on Deafness and Other Communica-tion Disorders (NIDCD) for fiscal year 2003, a sum of \$371,951,000, which reflects an increase of \$28,880,000 over the comparable fiscal year 2002 appropriation. The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

Disorders of hearing, balance, smell, taste, voice, speech, and language exact a significant economic, social, and personal cost for many individuals. The NIDCD supports and conducts research and research training in the normal processes and the disorders of human communication that affect many millions of Americans. Human communication research now has more potential for productive exploration than at any time in history. With substantive investigations conducted over the past decades and the advent of exciting new research tools, the NIDCD is pursuing a more complete understanding of the scientific mechanisms underlying normal com-munication and the etiology of human communication disorders. Results of this research investment will foster the development of more precise diagnostic techniques, novel intervention and prevention strategies, and more effective treatment methods.

Excessive noise has long been recognized as an occupational hazard among adults, and hearing conservation programs have been implemented in the workplace. However, the resiliency of a child's auditory system following noise exposure needs fur-ther research. Chronic exposure to loud music, fireworks, lawn mowers or toys can accumulate over a lifetime to gradually produce irreversible damage to the sensory cells of the inner ear. The results of a recent survey conducted by the Centers for Disease Control and Prevention revealed that approximately 5.2 million American youths have some degree of hearing loss due to exposure to noise at hazardous levels.

Identification of Genes Causing Deafness.—Hearing loss occurs with a frequency of about 1 in 1,000 newborns and is also a prevalent, but not necessarily inevitable, feature of the aging process. Causes of hearing loss in children and the elderly include viral and bacterial infections, loud noise, head trauma, drugs or other chemi-cals that are toxic to the sensory cells of the inner ear, as well as mutations in genes critical for normal auditory function and development. NIDCD scientists are identifying the genes whose mutations result in hearing loss. Recently, NIDCD Intra-mural scientists identified a gene located on chromosome 10 that is involved in Usher syndrome type 1D (USH1D). Individuals that inherit two copies of this mulose their sight beginning in adolescence. The scientists discovered that USH1D gene are born profoundly deaf, have severe balance problems and gradually lose their sight beginning in adolescence. The scientists discovered that USH1D gene encodes a protein called cadherin-23. Knowledge of the function of cadherin-23 in the inner ear will provide new insight into cellular processes essential for normal auditory function, which may ultimately guide the development of improved diagnosis and treatment methods. NIDCD expects to support collaborations between its Intramural scientists and those of the National Eye Institute in these areas. NIDCD scientists also identified a gene (DFNB29) located on chromosome 21 whose mutation caused recessively inherited hearing loss. This gene encodes a protein, claudin-14, which is believed to help seal adjacent cells together in the inner ear thus preventing the leakage of endolymph fluid. The endolymph bathes the sound transduction cells and is essential for conversion of the mechanical energy of sound into an electrical signal that is sent to the brain. Studies are underway in a new mouse model to advance our understanding of the function of claudin-14.

Discovery of Novel Deafness Genes and Genetic Characterization of Hearing Impairment.—NIDCD has developed a substantial research portfolio to study existing mouse mutants as well as creating new mouse models to facilitate the discovery and analysis of genes whose mutation causes hereditary hearing impairment in humans. In a recent study utilizing the mouse mutant Waltzer, NIDCD Intramural scientists showed that mutations in the human cadherin gene family cause Usher Syndrome type 1D. This mouse model is a critical research tool for determining the identification of the mechanisms by which cadherin mutations cause this devastating deafness and blindness syndrome. In another NIDCD-supported study, a mouse nuclear gene has now been shown to interact with mutated genes in the mitochondria to significantly alter the severity of age-related hearing loss. This model system should provide important information regarding age-related hearing loss in humans, a relatively common and debilitating health problem within the aging U.S. population. These findings underscore the power of mouse genetics and the value of mouse models of deafness for the identification and detailed molecular characterization of human hearing impairment. Saintiets Identific Super Texts Parente Come Walter in the standard sta

Scientists Identify Sweet Taste Receptor Gene.—Understanding the molecular and cellular events that occur at the early stages of taste perception at the level of the taste receptor cell provides important insight into how we taste different sweet, bitter, salty and sour substances. A variety of distinct signaling pathways are activated by the basic taste qualities of salty, sour (acid taste), sweet, and bitter. Salty- and sour-tasting compounds activate ion channels that are located at taste receptor cells clustered within taste buds of the tongue and palate while bitter and sweet compounds bind to G protein-oupled receptors. Recently, four NIDCD-supported laboratories independently identified a gene, T1R3, at the mouse Sac locus that encodes a sweet taste receptor subunit. Differences in sweetener intake among inbred strains of mice are partially determined by variation in genes at the saccharin preference (Sac) locus. It was determined that the T1R3 receptor differs in amino acid sequence in "sweet preferring" versus "sweet indifferent" mouse strains. Both human and mouse T1R3 are G protein- coupled receptors, and are selectively expressed in subsets of taste receptor cells that are sensitive to sweet substances. *Abilities in Auditory Pitch Recognition are Largely Inherited.*—Auditory pitch rec-

Abilities in Auditory Pitch Recognition are Largely Inherited.—Auditory pitch recognition is a complex process that allows us to determine the pitch or tone of a sound. In this process, the ears receive the sound signal and the brain interprets this signal to produce the pitch we perceive. Individuals with problems in pitch recognition are sometimes referred to as "tone deaf." Severe deficits in pitch recognition may be associated with speech and language disorders. It was long known that tone deafness can run in families. However, it was not known whether this disorder was due to inherited genes or to a common environment shared by family members. To answer this question, NIDCD Intramural scientists performed a large study on twins. The results show that identical twins scored much more alike than fraternal twins on a Distorted Tunes Test. The data revealed that approximately 70–80 percent of an individual's score is due to their genes and 20–30 percent due to other factors. The discovery that individual differences in pitch recognition are mostly genetic opens up the possibility of using genetic methods and information from the Human Genome Project to find the genes essential for pitch recognition. Identifying such genes and how they function will provide new insight into how the brain processes sound.

How Basic Biology Translates into New Technology to Help the Hearing Impaired.—Over the past decade, NIDCD-supported scientists have been studying the amazing auditory capability of Ormia ochracea, a tiny parasitic fly with such acute directional hearing that it has inspired a new generation of hearing aids and nanoscale listening devices. Ormia can detect very small differences in sound-source position, a situation analogous to humans trying to detect who is speaking in a crowded room. This accomplishment is due to the unique anatomy of the eardrums of Ormia. The fly's eardrums are connected internally by a cuticle-based bridge that functions as a flexible lever. This unusual structure allows the membranes of the eardrum to vibrate in response to sound in two distinct ways, with different resonant frequencies. Trying to mimic the Ormia ear in silicon, engineering groups so far have developed prototype "microphone eardrums" that function "Ormia-like" as predicted but at ultrasonic frequencies. Additional research will be needed to generate prototypes that detect sound in the range of normal human hearing, that will be highly directional, fit inside the ear canal, and be affordable. Other applications of the *Ormia*-inspired silicon ear might include robotic listening devices. These latest findings have led to collaborations between neurobiologists and engineers to make a directional hearing aid that would be smaller, simpler and cost less than currently available devices.

Although hearing aid technology has advance rapidly over the last few decades, the various hearing aids available still do not function well in real world situations where sound from more than one source is present, and they are not particularly effective in restoring the listener's ability to cope with the problem of attending to a single speech source among competing speech sources. NIDCD-supported scientists are actively engaged in research to develop "intelligent" hearing aid systems that are capable of selectively locating and characterizing a sound in a crowd. *Functional Brain Imaging as a Tool to Understand Cochlear Implant Performance.*—The cochlear implant is the first clinically useful neural sensory prosthesis

Functional Brain Imaging as a Tool to Understand Cochlear Implant Performance.—The cochlear implant is the first clinically useful neural sensory prosthesis to replace a human sense. It converts sound into electrical impulses on an array of electrodes that is surgically inserted into the inner ear, bypassing the inner ear hair cells and stimulating the auditory nerve directly, restoring the perception of sound to persons who are totally, or almost totally, deaf. This device has allowed adults who lost their hearing to recover an ability to understand speech. Although speech perception performance of adults has steadily increased with new advances in cochlear implantation, wide performance variations exist among cochlear implant recipients. Differences in structural and functional abnormalities of the auditory system may play a role in this variability. However, little is known about the reorganization of the auditory system following deafness, or on the preservation or recovery of auditory function following cochlear implantation. NIDCD-supported scientists have completed preliminary studies examining functional brain imaging in individuals before and after cochlear implantation. The data suggest that preoperative to postoperative changes in the brain's responsiveness as measured by imaging are related to improvements in speech perception scores. Also, despite relatively similar hearing losses in each ear, significant differences in preoperative auditory cortex activation were observed between ears, which may help guide selection of the more appropriate ear for implantation.

Phase I Clinical Trial of an Otitis Media Vaccine Candidate.—Otitis media (OM) is the most common reason for a sick child to be evaluated by a physician, a public health burden estimated to cost approximately \$5 billion a year in the United States. In addition to the cost savings, prevention of OM is particularly important because repeated antibiotic treatment of OM often results in the appearance of drug-resistant strains of bacteria which can no longer be eradicated with first-line antibiotics. NIDCD Intramural scientists have developed candidate vaccines that would protect infants from OM caused by two major bacterial pathogens: nontypeable Haemophilus influenzae and Moraxella catarrhalis. These two pathogens account for two-thirds of OM cases in children, and there is no vaccine available for prevention of the disease. Pre-clinical testing with such vaccines from nontypeable H. influenzae demonstrated that the vaccines could generate specific immunity against the bacteria and reduce bacterial colonization in nose and throat, and reduce the incidence of OM in animal models. Additional clinical trial involving 40 normal human adult volunteers, one such vaccine directed against H. influenzae proved to be both safe and effective, eliciting a significant immune response against the bacteria. This candidate vaccine will soon be tested in a second trial for safety and effectiveness in children. For Moraxella catarrhalis, similar preclinical approaches were taken, resulting in several candidate vaccines. Pre-clinical testing in animal models with vaccines for Moraxella catarrhalis demonstrated that the vaccines were safe and effective, eliciting a significant immune response that inhibited bacterial growth.

Additional clinical trials are planned to test these candidate vaccines for safety and efficacy in humans.

Genetic Testing and the Clinical Management of Nonsyndromic Hereditary Hearing Impairment.—In the last decade, approximately 20 genes whose mutations result in nonsyndromic hearing impairment have been identified and isolated. Mutations in one of these genes, GJB2, accounts for about 25 percent of all autosomal recessive nonsyndromic hereditary hearing impairment in American children. With the identification of genes that contribute to hearing function, genetic testing becomes technically possible but not necessarily suitable for widespread clinical application at present. With the enactment of some type of legislation that requires universal hearing screening for newborns in 36 states, not only are infants with severe hearing impairment identified much earlier in life but infants with lesser degrees of hearing impairment are now also being identified. Many unresolved issues remain for clinicians as they characterize auditory performance in a newborn who fails hearing screening, design intervention strategies to optimize communicative success and ensure that a "medical home" exists for the infant with hearing impairment. The advances in the genetics of hereditary hearing impairment and in the early identification of hearing impairment have now converged. These advances have led some to suggest genetic testing/evaluation for all infants who are identified with a hearing loss at birth. In consideration of these developments, the NIDCD and the National Human Genome Research Institute are collaborating on an initiative to address the clinical relationship between genetic and audiologic/otologic information, as well as to address the clinical validity and utility of genetic testing in the diagnosis, treatment and management of nonsyndromic hereditary hearing impairment.

# PREPARED STATEMENT BY DR. RICHARD K. NAKAMURA

Mr. Chairman, and members of the Committee: I am pleased to present the President's budget request for the National Institute of Mental Health (NIMH) for fiscal year 2003, a sum of \$1,359,008,000, which reflects an increase of \$105,358,000 over the comparable fiscal year 2002 appropriation. In my statement I will highlight new NIMH initiatives that represent both what

In my statement I will highlight new NIMH initiatives that represent both what we are doing proactively to better meet the clinical treatment needs of people with severe mental disorders, and how we are responding to urgent national needs, including the psychological aftermath of the September 11 terrorist attacks. I also will describe selected findings that illustrate how NIMH is exploiting advances across a broad spectrum of neuroscience and behavioral science toward our goal of understanding the brain and, of understanding how, when its processes go awry, mental disorders can occur.

### MENTAL ILLNESS IS REAL AND CAN BE TREATED EFFECTIVELY

From our perspective at NIMH, one of the signal accomplishments of the past decade has been the continuing destigmatization of mental illness. Many parties, from patients and families, to grass roots organizations, to the media, to government have contributed to the task of public education. The landmark *Surgeon General's Report on Mental Health* struck a resounding chord with millions of Americans. Supported by a meticulous review of current scientific knowledge, it issued a straightforward message: Mental illnesses are real and are treatable, and recovery is possible. More than a scientific communication, this is a message of hope that has raised spirits across our Nation. As a marker of the success of NIMH in continuing to disseminate accurate education about mental disorders, I would note that our award-winning home page (www.nimh.nih.gov) now registers some 7 million hits each month.

## DEVELOPING NEW TREATMENTS FOR MENTAL ILLNESSES

Of course, our educational efforts must be backed up by productive science. We are confident our investments in basic science are on the right track. We also have launched an unprecedented series of clinical effectiveness trials characterized by large sample sizes and relatively few exclusion criteria; in order to further ensure the generalizability of findings, these trials occur not only in academic clinics but also in more "real world" settings including primary care settings. We are assessing outcome on the basis of symptom reduction and also use measures of functional rehabilitation. The approach also calls for aggressive dissemination of results.

babilitation. The approach also calls for aggressive dissemination of results. Now, in a major new enhancement of treatment improvement research, NIMH is launching a sweeping initiative designed to introduce fundamentally new approaches to the development of treatments for mental disorders. Somatic and psychological treatments available today are highly effective for many people with mental disorders. For significant numbers of persons, however, extant treatments are not effective. Too much time may be required for medications to exert therapeutic effect, thus rendering a treatment impractical in some instances; in other cases, certain individuals do not respond sufficiently to achieve full remission from an acute episode of illness or to avoid recurring episodes. With the advice of the Treatment Development Workgroup of the National Advisory Mental Health Council (NAMHC), we are exploring how federally funded research complements and can leverage work being conducted in the private sector. With respect to medications development, for example, we plan to step up our efforts to generate information needed by private sector entities whose business it is to develop and test promising new compounds. Additionally, a challenge of immediate importance for NIMH is to encourage the

field to move beyond thinking of new treatments only from the perspective of diagnostic entities such as schizophrenia or depression, and to focus down to the compo-nent symptoms that combine to form global diagnostic entities. Schizophrenia, for example, is characterized by dimensions such as disorganized thinking, misperception of reality, and cognitive impairment. The Food and Drug Administration (FDA) currently approves most drugs for psychiatric disorders only for diag-noses categorically defined in the Diagnostic and Statistical Manual (DSM) of Mental Disorders (4th Edition). Research that leads to an appreciation of psychiatric di-agnoses as "multi-dimensional" will position NIMH to partner with FDA and indus-try to achieve consensus on appropriate methods and clinical endpoints other than DSM diagnoses. If symptom complexes such as cognitive impairment in schizophrenia were to be recognized by the FDA as legitimate targets for new drug reg-istration, the pharmaceutical industry would be provided with powerful incentives to develop treatments targeting these specific disabilities and great benefits in health might accrue.

The Treatment Development Initiative will be an Institute-wide enterprise, with a key role to be assumed by the intramural Mood and Anxiety Disorders Program. a key role to be assumed by the intramural Mood and Anxiety Disorders Program. This newly established program has recruited senior investigators from academia and now stands at the leading edge of research aimed at understanding and meas-uring structural changes in the brain associated with depression, chronic stress, and post-traumatic stress disorder, and at developing brain-based biomarkers to be used in monitoring treatment progress and outcome. Other research objectives will en-compass studies of gene expression of proteins that may serve as potential targets for new drugs, development of more informative animal models, preclinical develop-ment of promising new compounds, and efforts to better dissect DSM syndromes into component dimensions that can be targeted for specific treatment. Meeting the urgent goal of expanding the array of interventions that will be effec-tive for more individuals with disorders is contingent on our long-term investments in diverse areas of research. I would like to highlight a few findings reported by NIMH-funded investigators over the past year indicating that we are, indeed, real-

NIMH-funded investigators over the past year indicating that we are, indeed, realizing dividends from our research conducted over the course of many years, for example, in refining brain imaging technologies and in exploiting cutting edge tools such as molecular genetics in the study of mental disorders

## VISUALIZING BRAIN CHANGES IN CHILDHOOD SCHIZOPHRENIA

Schizophrenia, the subject of the acclaimed new film, A Beautiful Mind, based on the book by Sylvia Nassar, is a cruel disease. According to the World Health Organization, schizophrenia affects approximately 1 percent of the population globally. The illness most often manifests in late adolescence or early adulthood. Psychotic symptoms, including hallucinations and delusions, can be severely and persistently disabling. Understanding brain changes that correlate with psychotic symptoms will give us insight into the origins of schizophrenia. In recent years, imaging studies have shown changes in the volume of various brain structures that correlate with nave snown changes in the volume of various brain structures that correlate with a diagnosis of schizophrenia. Last year, a team of NIMH investigators reported a study that used magnetic resonance imaging (MRI) to examine, over the course of 5 years, a group of teenagers with relatively rare early-onset schizophrenia, and to compare the brain scans of these young patients to those of a group of healthy con-trols. In the ill children, gray matter loss began in a small region of the parietal cortex, where gray matter is lost normally in adolescence. Over the course of the study, however, the images revealed a virtual wildfire of tissue loss spreading across the brains of these teens as schizophrenia progressed; the extent of these structural changes reflected the severity and time-course of symptoms. Identifying these changes and their causes will help researchers to understand the mechanisms of psychotic disorders and, in the long run, develop better treatments.

#### SEEKING CLUES TO GENETIC VULNERABILITY FOR AUTISM

Although no specific genes have been identified to date and no specific region of the genome has been linked unambiguously to autism, the presence of a strong ge-netic component is incontrovertible. The genetic, or heritable, component is thought to account for as much as 90 percent of the liability for autism. Evidence to date is most consistent with involvement of multiple genes, each having small effect, that together with nongenetic factors produce vulnerability. A number of Institutes are collaborating on studies of autism, and the pace of research is encouraging. Last year, an NIMH grantee reported a potential linkage to autism of variants of a gene called *wnt2*. The gene is expressed in the brain's thalamus, a region important for integrating information. The product of the *wnt2* gene appears to play a key role in brain development and behavior. The finding is intriguing in light of other studies demonstrating that mice that lack a signaling molecule called "Disheveled," which is in the same molecular pathway as *wnt2*, exhibit reductions in general social interactions, in huddling during sleep, and in other grooming behaviors—all behaviors that suggest symptoms of autism. The promise of genetics research is to shed light on the biology of the illness and, in turn, to lead to earlier diagnosis and improved treatments; ultimately, of course, we anticipate that genetics studies will lead to preventive interventions.

As this basic work proceeds, I wish to note that NIMH maintains a network of Research Units on Pediatric Psychopharmacology, or RUPPS, that includes five research groups dedicated to evaluating treatments for autism, examining, for example, dose ranges and regimens of medications and their effects on cognition, behavior, and development. Complementary studies of pediatric pharmacology are being supported by the National Institute of Child Health and Human Development (NICHD). I also am pleased to report that NIMH and NICHD soon will launch the first round of funding in the new STAART (Studies to Advance Autism Research and Treatment) Centers program called for in the Children's Health Act of 2000.

## 9/11: RESPONDING TO THE PSYCHOLOGICAL AFTERMATH

In opening, I mentioned that the Institute has been involved in our national response to the September attacks on our Nation. Even as we mourn the loss of the more than 3,300 persons who lost their lives that day in New York, Washington, and Pennsylvania, we must attend also to the cost of those tragic events to millions of Americans who have suffered and are living with horrific images and memories of 9/11. While communities are pressed to deal with immediate problems, it is important to learn what we can from these terrible events. NIMH is utilizing multiple research mechanisms, including Rapid Assessment Post Impact of Disaster (RAPID) grants and supplements to existing longitudinal and clinical studies. The RAPID program was established years ago to support research in the aftermath of an unforeseen event that necessarily requires expedited peer review and funding consideration. From a large number of inquires, we invited approximately 18 applications to undergo peer review. These propose to address topics including the epidemiology of exposure and reactions; the nature of settings in which victims/survivors present for care and what types of care are provided; the mental health impact of bioterrorism and on-going threats; the mechanisms by which trauma confers risk for adverse health outcomes; and use of various interventions to reduce the risk of disorder and disability. Several projects now are in review and plans are being made for funding.

In addition, we are enhancing ongoing epidemiological and clinical research studies by adding questions relevant to the impact of the attacks. For example, questions related to exposure to terrorist attack and the subsequent psychological distress were added to ongoing studies of adult and child mental health being conducted by investigators in New York. Research on the neurobiological mechanisms by which trauma increases the risk of mental disorder for children and adults also is being conducted in New York, and now will involve victims/survivors of the World Trade Center attacks. NIMH will also be looking to a number of national surveys of health and mental health to provide estimates of prevalence of mental disorders, functional impairments and disability, services needed and being used before and after the attacks.

In this context, we know that post-traumatic stress disorder, or PTSD, can be a chronic, debilitating disorder that develops in some but not all people exposed to severely threatening trauma. Insomnia and non-restorative sleep—and nightmares representing the trauma—are recognized symptoms of PTSD. Recent research indicates a relationship of dream characteristics and early adaptive vs maladaptive patterns of processing traumatic memory. These findings have immediate clinical utility in helping suggest persons to whom early treatments should be targeted.

#### JOHN EDWARD PORTER NEUROSCIENCE RESEARCH CENTER (NRC)

We are pleased that work is progressing on schedule in construction of the NRC. The foundation is being poured imminently, and six NIH institutes that have programs in neuroscience are slated to begin working in the facility in January 2004. Ultimately, the neuroscience programs of ten Institutes will be housed in the Center, greatly facilitating the exchange of information and its translations into clinical applications.

#### NIMH DIRECTORSHIP

Dr. Steven E. Hyman, NIMH Director from 1996 to December 2001, has returned to Harvard University as Provost. While we miss his energy and vision, we plan to

continue build on the progress of the past five years. A national search for a permanent director is underway.

nent director is underway. Mr. Chairman, the NIH budget request includes performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report, which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan. I will be pleased to respond to any questions.

## PREPARED STATEMENT OF DR. GLEN R. HANSON

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Institute on Drug Abuse for fiscal year 2003, a sum of \$967, 898,000 which reflects an increase of \$76, 960,000 over the comparable fiscal year 2002 appropriation.

# NIDA'S STRONG RESEARCH FOUNDATION

I feel very honored to be serving as the Acting Director of the National Institute on Drug Abuse (NIDA) at a time when new discoveries of significant promise are transforming our understanding of the brain and body and providing us with the knowledge we need to confront both the new and the old realities of the day.

Budget increases, visionary predecessors, and the unprecedented pace in neurobiology have allowed the National Institute on Drug Abuse to establish a strong research foundation from which to alleviate the complex public health problem of drug abuse and addiction. As the world's leading supporter of research on the health aspects of all drugs of abuse, including nicotine, NIDA addresses the most fundamental and essential questions about drug abuse and addiction, which range from understanding how drugs act on the brain; to identifying and minimizing the role that stress can play in drug use and relapse; to detecting and responding to emerging drug use trends such as "Ecstasy" and prescription drugs." This portfolio also continues to elucidate our understanding of drug abuse as a preventable behavior and drug addiction as a treatable disease.

Coupled with strong research is our ability to expand its dissemination to clinicians. Through coordinated dissemination and translational research efforts, NIDA ensures that even the most basic neurobiology discoveries systematically influence community prevention and treatment providers across the country so that our citizens can live healthier and more productive lives. For example, almost 1,000 people from both rural and urban communities are participating in treatment protocols where they are receiving science-based drug addiction treatment and medical care through their participation in NIDA's National Drug Abuse Treatment Clinical Trials Network (CTN). And even more citizens are stopping the initial use of drugs by participating in prevention programs that follow the science-based prevention principles identified and disseminated by NIDA. Much has been accomplished, but more remains to be done.

## DRUG ABUSE IS COSTLY AT MANY LEVELS

Directly or indirectly, every family and community is affected by drug abuse and addiction. We all have family members, friends, or acquaintances who abuse some substances. These drugs take a tremendous toll on our society; and they are costly at many levels. At the economic level, the cost of illegal drugs to our Nation was estimated by the White House Office of National Drug Control Strategy to be more than \$161 billion in 2000. When one adds the cost of the Nation's deadliest addiction—use of tobacco products—the cost soars to nearly \$300 billion each year.

Drug abuse is inextricably linked with the spread of infectious diseases such as HIV/AIDS, tuberculosis, and hepatitis C, and is also associated with domestic violence, child abuse, and other violent behavior. But because our research has shown that drug abuse is preventable and drug addiction is treatable, there is much reason for optimism.

#### BRINGING A MULTI-DISCIPLINARY APPROACH TO DRUG ABUSE REVENTION RESEARCH EFFORTS

Researchers have learned much about why people use drugs and have identified many of the risk and protective factors that can influence drug use. In the past year, research has also revealed new insight into how to tailor anti-drug messages to sensation- seeking adolescents to actually reduce marijuana use, and taught us not to group together high risk youth for prevention interventions. Despite our progress, research gaps remain. For example, researchers are trying to determine what influences adolescent decision-making, especially decisions about drugs. What thoughts and emotions are going on at the precise moment an adolescent makes the initial and subsequent decisions to try or not to try drugs? These are questions that can not be answered by prevention researchers alone. A transdisciplinary and multipronged research approach that integrates all areas of science—basic behavioral, cognitive, developmental, social, neurobiological, and clinical—to develop innovative directions in drug abuse prevention research, is the underlying premise for NIDA's new National Drug Abuse Prevention Research Initiative. Testing the effectiveness of new and existing science based prevention approaches through multi-site trials conducted at the local community level will also be important in this endeavor.

#### TREATING ADDICTION TO NICOTINE AND OTHER DRUGS OF ABUSE

Tobacco use remains one of the greatest risk factors for cancer. It is addiction to the drug, nicotine, that drives the continued use of tobacco in this country and abroad, despite the known negative consequences. Smoking cessation remains among the most successful and cost-effective approaches to reversing the tide of tobacco-related diseases, including cancer. New technologies and breakthroughs in neurobiology, such as the recent identification of the critical role that the gene tryptophan hydroxylase—an enzyme that produces the brain chemical messenger serotonin—plays in the initiation of smoking are providing new opportunities for NIDA and other NIH Institutes such as the National Cancer Institute to collaborate at the scientific and clinical levels. Developing novel and selective medications to better treat addiction to tobacco and other substances of abuse is of mutual interest to many in the private and public sectors. NIDA will continue to develop addiction treatments, especially treatments that are specifically tailored to adolescent populations, such as those being tested at our Teen Tobacco Treatment Research Center in NIDA's Intramural Research Program in Baltimore, MD.

lations, such as those being tested at our Teen Tobacco Treatment Research Center in NIDA's Intramural Research Program in Baltimore, MD. Developing new and effective ways to treat all addictions continues to be a high NIDA priority. Both behavioral therapies, such as cognitive behavioral therapies that have been shown successful in reducing cocaine use, and pharmacological approaches, will continue to be supported by NIDA. NIDA's Medications Development Program is about to bring two anti-cocaine medications to Phase III Clinical Trials this year. Not only are the medications Selegeline and Disulfiram showing success in cocaine-addicted populations, but they show promise as potential treatments for methamphetamine addiction as well.

#### EXPANDING NIDA'S CLINICAL TRIALS NETWORK

Recognizing that the path leading from new findings to changes in clinical practice can be lengthy, and that millions of people across the country are in need of quality drug abuse treatment, NIDA has established an infrastructure to more rapidly and systematically bring new treatments to those in need. When research-based treatments such as the behavioral therapy, motivation enhancement, and the pharmacological therapy, buprenorphine-assisted detoxification, are proven to work repeatedly in small controlled settings, they are developed into treatment protocols by researchers and practitioners and undergo rigorous multi-site trials to determine their effectiveness in community-based treatment settings. Currently, more than 15 treatment protocols are being tested or about to be tested in the established multisite trials across the country. In fiscal year 2003 NIDA plans to expand this infrastructure to ensure greater geographic distribution, and to reach underserved populations and regions underrepresented in the health care system, including individuals who have mental illnesses, those suffering from HIV/AIDS or other infectious diseases, adolescents who may be in need of drug treatment, and Hispanic and other minority populations.

#### AIDS AND OTHER MEDICAL CONSEQUENCES

Considerable scientific progress has been made in understanding, preventing, and treating HIV/AIDS and other infections among drug users. For example, NIDA-supported researchers have made tremendous progress in our battle against the Hepatitis C Virus (HCV). HCV infection is a major public health problem with 60 percent of all new cases of acute HCV infection attributed to syringe and needle sharing. One of the most critical problems in controlling HCV is the variability of the virus with more than 9 distinct types of virus known. NIDA researchers identified an antibody that can block HCV from binding to the CD81 receptor that is found in both liver and B cells. This may prove to be a useful therapeutic target. An antibody proven to block this receptor would have the potential of blocking HCV infection or modulating early infections in exposed persons by interfering with the Hep C viral life.

Given that the epidemiological patterns of drug abuse and risk behaviors are constantly changing and new infections of HIV and other blod-borne and sexually transmitted infections continue to emerge and spread, NIDA is encouraging re-searchers to apply new findings to develop new and improved approaches to prevent the acquisition and ongoing transmission of these infections, as well as strategies to improve access to diagnostic screening and care.

#### INTEGRATING TREATMENT INTO THE CRIMINAL JUSTICE SYSTEM

Drug abuse treatment has been shown to reduce drug use and its related criminal behavior. The majority of individuals in prisons have a drug problem that requires treatment. For these reasons many different approaches for bringing treatments into the criminal justice system have been tried, including treatment as an alter-native to prison, drug courts, drug abuse treatment in prison settings and treatment in computing actings of the real set. in community settings after release. Outcomes for each approach vary. NIDA is es-tablishing a research infrastructure to test models at multi-sites to establish a more integrated approach to the treatment of incarcerated individuals with drug abuse or addictive disorders. The National Criminal Justice Drug Abuse Treatment Research System will serve as the vehicle for blending public health and public safety approaches.

#### STRESS AND HOW IT INFLUENCES DRUG USE

Particularly relevant in light of the events of September 11 is the role stress plays in drug use and addiction. We are expanding our research to better understand the role that stress plays in initiation, escalation and relapse to drug use so we can de-velop more effective ways to manage and treat stress. While we know that people take drugs initially to experience their rewarding and pleasurable effects, we also know that they relapse to taking drugs even after long periods of abstinence, for entirely different reasons. Stress is identified by most patients as the predominant factor to relapse. People prone to relapse also identify the triggers of environmental cues associated with previous drug use, and the drugs themselves. We are just be-ginning to appreciate that each of these triggers may involve brain circuitry different from that involved in the initiation of use and each operates on its own pathway. For example, stress-induced relapse appears to involve the hypothalamo-pituitary-adrenal axis to release stress hormones such as CRF from the brain and cortisol (steroid) from the adrenal glands. In contrast, cue-induced relapse appears to involve portions of the amygdala; and drug-induced relapses involves the each trigger for relapse, such as the activation of CRF in the brain, NIDA will be able to more strategically identify and develop prevention strategies, as well as new targets for addiction medications.

#### GOVERNMENT PERFORMANCE AND RESULTS ACT (GPRA)

The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

#### THE FORMIDABLE FORCE OF SCIENCE

Continued progress can be expected in curtailing drug abuse and addiction if we continue to capitalize on the strong research foundation that NIDA has established. Research is critical to all of our Nation's endeavors and there is hope in knowing that new and growing public health needs such as Addiction, AIDS, Bioterrorism, and Cancer, and Diabetes, and others, are being tackled head on with the formidable force of science.

I would be pleased to respond to any questions. Thank you.

#### PREPARED STATEMENT OF DR. RAYNARD S. KINGTON

Mr. Chairman and members of the Committee: I am pleased to present the President's budget request for the National Institute on Alcohol Abuse and Alcoholism (NIAAA) for fiscal year 2003, a sum of \$418,487,000, which reflects an increase of \$32,541,000 over the comparable fiscal year 2002 appropriation. Alcohol-use disorders are among the most pervasive of the behaviorally mani-

fested diseases. One-quarter of our Nation's urban hospital beds are occupied by pa-

tients with behavioral or physical problems stemming from alcohol use.<sup>1</sup> More than 60 million American adults, adolescents, and children are alcoholic (physically dependent on alcohol) or abuse alcohol. Fourteen million of the adults among them are alcoholic.2

The consequences of alcohol misuse cost society \$185 billion every year, \$47 billion more than the annual cost of smoking.3 Alcohol misuse affects every age group, from fetuses exposed to alcohol in the womb to the elderly, and it affects these age groups differently. It cuts across genders and minority groups, which also respond to alcohol's toxic effects differentially. All of these consequences are preventable.

#### ADVANCES IN PREVENTION RESEARCH

About half of the risk of alcoholism is genetic, but environmental factors—peer pressure, culture, and community attitudes toward alcohol use, for example—can attenuate that risk. NIAAA conducts research on neuroscience and on environmental and behavioral strategies designed to prevent abusive drinking and its con-sequences. Investigators develop and test interventions at the individual, commu-nity, and policy levels, in specific populations, age groups, and settings.

In the past year alone, we have made significant advances in these areas. For example, a community-wide approach that focused on reducing the supply of alcohol available to youths achieved significant reductions in drinking by children and adolescents. Another program that took a comprehensive, community-wide approach to reducing drinking resulted in significantly fewer violent assaults and car crashes.

Preventing children and adolescents from drinking is a major focus of NIAAA's research, which reveals that people who start drinking early in life are more likely than others to become alcoholic. Behavioral scientists found that this increase in risk may be the result of a common pathology that underlies a number of behavioral disorders.

Epidemiologic data identify disease trends that require preventive interventions. NIAAA epidemiologists discovered a change in racial and ethnic trends in mortality rates of cirrhosis, the primary cause of which is alcohol misuse, by examining improved methods of reporting on death certificates. White Hispanic males now show a higher rate of deaths from cirrhosis than do Black non-Hispanic males, who were thought to have higher rates.

A collaborative epidemiology project by the NIAAA, the National Institute on Drug Abuse, and the National Institute of Mental Health is examining the burden of co-occurring alcohol, drug, and mental disorders and associated disabilities, world-wide. This NIH-funded World Health Organization project also is developing standardized methods of collecting, analyzing, and reporting resource utilization and costs of these diseases and disabilities in diverse cultural settings.

#### ADVANCES IN NEUROSCIENCE AND GENETICS RESEARCH

Intricate biological mechanisms are the intermediaries of alcohol's physical actions in the nervous system, which manifest themselves as behaviors toward alcohol. NIAAA's neuroscience and genetics research have generated significant findings in this area during the past year. For example, NIAAA-supported researchers established preliminary evidence that

increasing production of specific proteins in the brain through genetics techniques may some day have utility in reducing drinking. Investigators also strengthened the evidence that specific genes, on chromosomes 1 and 7, are involved in alcoholism.

Through a collaboration with the National Institute of Mental Health, our intramural researchers found that a genetic variation in the serotonin neurotransmitter system plays a role in the sensitivity of nerve cells to the toxic effects of alcohol. NIAAA's intramural researchers also found further evidence that some of the same mechanisms in the nervous system that regulate appetite for food may play a role in risk of alcoholism.

By understanding the interplay of biological and environmental factors that contribute to alcohol-use disorders, we are better positioned to identify markers for peo-

<sup>&</sup>lt;sup>1</sup>Moore, RD; Bone, LR; Geller, G; Mamon, JA; Stokes, EJ; Levine, DM Prevalence, detection, and treatment of alcoholism in hospitalized patients. "Journal of the American Medical Associa-tion" 261(3):403-407, 1989.

 <sup>&</sup>lt;sup>1</sup> (261(3):403-407, 1989.
 <sup>2</sup> Grant, BF et al. Prevalence of DSM-IV alcohol abuse and dependence: US, 1992. "Alcohol Health and Research World" 18(3):243-248,1994.
 <sup>3</sup> Updated estimate by the Lewin Group, October 1999, of Harwood, H., et al. "The Economic Costs of Alcohol and Drug Abuse in the US," 1992. National Institute on Drug Abuse, 1998.
 U.S. Dept. of the Treasury. "The Economic Costs of Smoking in the US and the Benefits of Comprehensive Tobacco Legislation," Washington, DC, 1998.

ple and populations at risk, and points for pharmaceutical and behavioral interventions.

#### ADVANCES IN RESEARCH RELATED TO THE TOXICITY OF ALCOHOL

The tissue-damaging effects of alcohol are not limited to the nervous system. Alcohol is a toxin, and it can injure any tissue in the body, with significant medical sequelae; for example, liver disease, some kinds of cancer, and brain damage.

Among the tissues most vulnerable to alcohol's toxicity are those of unborn fetuses, whose nervous systems are particularly susceptible to alcohol's effects. The most severe outcome is fetal alcohol syndrome (FAS), which results in a lifetime of neurobehavioral deficits and disabilities. For the first time, using living mammalian models, investigators have found that administering two different, naturally-occurring substances, choline and nerve-growth factors, can prevent alcohol-induced brain damage to the developing fetus. This is a significant finding, since no treatment for FAS exists, currently.

Intramural investigators discovered a potential explanation as to why chronic, heavy drinkers are completely unresponsive to treatment for hepatitis C virus infection. Hepatitis C infection is a prevalent disease, particularly among alcoholics, and the current treatment of choice is expensive. Investigators found that a protein produced in response to inflammation suppresses the biochemical pathway of the drug used for treatment and boosts activity of the genes whose protein products block the effects of the treatment drug.

#### RECENT INITIATIVES

During the five-year doubling of the NIH budget, NIAAA has established major new initiatives designed to advance research in each of the areas essential to its mission.

The Integrative Neuroscience Initiative on Alcoholism (INIA) is advancing our understanding of alcohol's actions in the nervous system. INIA integrates findings from multiple disciplines, from the genetic to the molecular and behavioral levels. Our intramural program also established an integrative neuroscience research program that combines cellular and molecular biology studies, considered the most powerful approach to the neural basis of alcohol abuse and alcoholism.

We have established several initiatives that are enabling us to capture the potential of new genetics technologies. On the molecular level, an initiative that focuses on the use of advanced instrumentation soon will enable our scientists to examine directly alcohol's interactions with the brain's neurotransmitter systems. In doing so, scientists can couple molecular events with behavioral events, in real time. This technology will provide essential information for our neuroscience research.

The initiatives described above are moving us closer to identifying optimal targets for therapeutic interventions. We have launched a major effort to develop medications that are more widely effective in treating alcohol abuse and alcoholism. Studies include tests designed to determine what types of patients respond favorably to currently available medications, and whether combining medications with specific behavioral therapies improves success rates.

behavioral therapies improves success rates. The increases in the NIAAA budget also have enabled our intramural researchers to establish a liver biology program. Investigators in this program already have produced an important breakthrough; they have found that a specific protein of the immune system protects liver cells from the toxic effects of alcohol. NIAAA recently established two new initiatives on alcohol-related liver disease.

Because some minority groups and women appear to suffer disproportionately from alcohol-induced organ damage, such as liver disease, we have established an initiative to study disparities in alcohol toxicity. A recently established collaborative initiative focuses on FAS prevention. Prominent in these investigations are studies of specific minority groups, such as Native Americans and African Americans, who are disproportionately affected by FAS.

We also are stimulating research to develop biomarkers that detect early, alcoholinduced toxic changes in cells. Another initiative is to develop a biosensor that monitors alcohol levels continuously, to elucidate how drinking behaviors lead to organ damage.

Our prevention program is conducting studies to assess whether interventions that have proven to be successful in majority populations also are effective for specific minority groups. The program also encourages research that examines whether high-alcohol-content, low-cost beverages, such as malt liquor, disproportionately affect minorities.

Youth is a special focus of our prevention research, and the initiatives we have established over the past five years include a major effort to prevent alcohol problems among college students and another to prevent alcohol use among young adolescents. College drinking is more destructive than previously recognized, and the NIAAA Council's Task Force on College Drinking has brought together the college and research communities in an unprecedented national dialogue.

# OUTREACH

Ultimately, NIAAA's research is intended to benefit the public's health. We attempt to achieve that goal in a number of ways. For example, our Research to Practice Initiative is a collaboration between NIAAA and the Substance Abuse and Mental Health Services Administration's Center for Substance Abuse Treatment. Representatives from these two agencies meet with treatment providers and administrators to exchange information about current research findings and obstacles to providing treatment that practitioners encounter. The agencies then arrange for experts to serve temporary residencies in treatment programs, to ensure success.

perts to serve temporary residencies in treatment programs, to ensure success. Women of child-bearing age are the focus of the D.C. Initiative, a major effort to prevent FAS in the District of Columbia, which has one of the Nation's highest FAS rates. The project is designed to prevent drinking among African-American women who are pregnant or can become pregnant.

On April 9, after three years of investigations, the NIAAA Council's Task Force on College Drinking will release a report that includes recommendations for colleges, researchers, and communities. NIAAA will hold regional workshops that will involve 3,200 colleges, and will provide brochures for parents, college administrators, high-school guidance counselors, and community leaders. Papers and panel reports that served as the basis for the Task Force's report will be published in scientific journals; for example, a supplement to the April 2002 issue of the *Journal* of *Studies on Alcohol*, on college drinking, will include 18 review articles adapted from papers commissioned by the Task Force. An interactive NIAAA website serves as a resource for college personnel, researchers, and the public.

Alcohol Screening Day, a nationwide event sponsored by the NIAAA, enables people to receive free screening for alcohol problems and, if needed, referrals. This year's Screening Day will take place on April 11. We anticipate more than 2,000 participating sites, more than half of which will be college campuses.

We are reaching children and adolescents through our *Leadership to Keep Children Alcohol-Free*. Thirty-three State governors' spouses have joined this project to reduce drinking by young people; a crucial effort, given our research findings that early initiation of drinking portends higher risk of alcoholism later in life. We also are preparing public service announcements on underage drinking.

## GOVERNMENT PERFORMANCE AND RESULTS ACT

The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's third annual performance report, which compares our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan. As performance trends on research outcomes emerge, the GPRA data will help NIH to identify strategies and objectives to continuously improve its programs.

#### PREPARED STATEMENT OF DR. PATRICIA A. GRADY

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Institute of Nursing Research for fiscal year 2003, a sum of \$130,809,000, which reflects an increase of \$10,058,000 over the comparable fiscal year 2002 appropriation.

For over a century, the nurse's role in care of the sick has been well known, especially in times of war or disasters. What is also important in this new century is the role of nurse as scientist—bringing to the scientific process an additional perspective critical to health, examples of which will be highlighted today. Our science is young, yet it is already making innovative changes to practice. These contributions were evident as NINR celebrated its 15th anniversary at the National Institutes of Health with a scientific symposium that featured nursing research programs of excellence.

The nursing shortage, however, which is capturing national attention, is emerging just when challenges to the healthcare system are increasing. Therefore, it is critical that nursing research produce results that improve health and quality of life for the American people. Innovative strategies to address these challenges must be identified, and they must be scientifically tested.

#### RESEARCH TO HELP CAREGIVERS

Major challenges for healthcare are the increase in age of our population, the increase in chronic illness, and the earlier discharge of patients from hospitals, which, taken together, have created a greater need for informal caregivers. These caregivers are generally family members, friends, or neighbors. According to the 1997 National Caregiver Survey by the AARP, more than 22 million adults are informal caregivers, published in 1999 in *Health Affairs*, indicates that most caregivers are middle-aged, married women, almost half of whom have young children. They provide most of the long-term care in our country, yet the economic value of their services, estimated at \$196 billion in 1997, is not included in cost of illness figures. The healthcare system, in effect, depends on their collective assistance. Research to address caregiver issues is critical at this important juncture.

In addressing these issues, nursing research has focused on helping caregivers avoid or reduce their burdens, including stress, especially related to chronic illnesses, such as dementia, emphysema, and congestive heart failure. Caregivers must manage disruptive behaviors, including wandering, aggression, and sleep-wake disturbances, and they may be required to administer medication and use unfamiliar equipment, such as suctioning devices and ventilators. NINR-supported research also identifies caregiver techniques to improve their own health and quality of life.

Although subgroups of caregivers characterize their situation as a positive experience, there is also a high incidence of stress among caregivers that can lead to depression, physical illness, and increased mortality. A recently published study of a community-based 14-hour training program for caregivers, held during a two-week period, found that three months after the training, 25 percent of participants reported lower levels of depression, 28 percent reported improvement in behavioral problems of their care recipients, and 9 percent indicated that they felt less burdened. This brief intervention provided caregivers with information and practical skills for dealing with dementia, and ways to improve confidence, coping skills, and communication. The results are illustrative of the possibilities of using coaching and teaching to reduce the negative effects of caregiving. Further research is needed to identify techniques that work best—for example, those that can be generalized and those that may only apply to specific situations.

# RISKS OF UTERINE RUPTURE IN FUTURE PREGNANCIES FOLLOWING INITIAL CESAREAN BIRTH

A recent study published in *The New England Journal of Medicine* has captured the public's attention. This study demonstrated that cesarean delivery can increase the risk of uterine rupture during labor in a subsequent pregnancy. Researchers analyzed records of over 20,000 women who gave birth to a second child after an earlier cesarean delivery. The risk of uterine rupture when having a second cesarean delivery with no labor is 1.6 per 1,000 births. The risk of rupture during spontaneous labor for this population is over three times as great, and if prostaglandins are used to induce labor, the risk increases 15 fold. Since 60 percent of women with prior cesarean deliveries attempt labor with the next pregnancy, this is important information for use in patient education. Mothers-to-be also need to know that initial cesarean delivery will affect future births.

# LEARNING DEFICITS IN CHILDREN TREATED FOR ACUTE LYMPHOBLASTIC LEUKEMIA

For children with Acute Lymphoblastic Leukemia, who now have considerably improved long-term, disease-free survival rates, there are also long-term consequences, including academic difficulties caused by aggressive, life-saving treatments. These treatments involve the central nervous system and include whole brain radiation and high dose chemotherapy. Nursing research has shown that these children have declines in arithmetic, verbal fluency and visual and motor-related skills, which affect their success in school. Young survivors showed these deficits for up to four years after their treatment regimens ended. A pilot study testing a remedial math intervention to minimize this type of deficit has shown early positive results. A larger study to test this intervention is now in progress.

## REDUCING RISKS OF A SECOND CARDIAC ARREST

In addition to finding ways to reduce or eliminate treatment side effects, nursing research also examines how to lower risks accompanying disease. Preliminary results of a biobehavioral intervention on patients who had cardiac arrest showed that there was an 86 percent reduction of mortality from cardiovascular disease in these

patients for up to two years. The intervention consisted of training in physiological relaxation using biofeedback; coping skills for depression, anxiety, and anger; and health education about cardiovascular risks. Although the underlying reasons for these positive results are not fully understood, it is hypothesized that decreases in psychological distress improve cardiovascular prognosis. This study underscores the importance of biobehavioral approaches for survivors of cardiac arrest.

#### NEW AND EXPANDED INITIATIVES

In fiscal year 2003, NINR plans to expand activities that address the health disparities prevalent in our society by incorporating such factors as ethnicity, culture, gender, socioeconomic status, and geography. This area has always been an important tenet of nursing science and is one of its special strengths. Since ethnic minority groups have a number of health problems associated with higher morbidity and mortality rates than do majority groups, NINR will continue to focus on these issues. A major new emphasis will be on community research partnerships in which community members help to identify and address key health concerns. A workshop to delineate possible research areas and strategies was held earlier this year to begin this activity.

As the Committee is aware, NINR is advancing research on end-of-life and palliative care, and is the lead coordinator of NIH research in this area. In addition to investigating new models for palliative care, next year we plan to focus on pediatric and genetic end-of-life issues, with continued efforts to include minorities in our research programs. Next year NINR will expand the research agenda to address care issues for resi-

Next year NINR will expand the research agenda to address care issues for residents in long-term facilities, such as nursing homes and assisted living. The number of assisted living residents is projected to increase from approximately 1 million in 1998 to more than 1.7 million in 2025, according to the National Center for Assisted Living. NINR plans to solicit studies that deal with issues such as residents' functional mobility, transitional problems in adjusting to their loss of independent living, and prevention of falls and depression,

Another emphasis is health promotion for adolescents to reduce their high-risk behaviors that will affect their health later in life. We will encourage studies that test health promotion interventions to decrease smoking, substance abuse, and risky sexual behavior, and improve nutritional status in school, at work, and in communitybased settings. Research to test culturally and linguistically appropriate interventions involving ethnic minorities will provide valuable answers to address these problems.

Since nursing research is important to improve better health, it is imperative that NINR work at building future capacity. The nursing shortage will impact nursing research by reducing the number of investigators available to conduct studies that add to the scientific base for practice. To ensure a stable research workforce for the future, NINR plans to use several new approaches, including earlier entry to research careers. Research career development of minority nurses will be emphasized to enhance research on health disparities. One innovative strategy is being carried out in collaboration with the new National Center on Minority Health and Health Disparities. Together we developed pilot research partnerships between established research intensive institutions and minority-serving institutions. The goal was to increase diversity in the nurse researcher pool and to increase research to reduce health disparities. The second phase of this activity is currently under way and shows much promise.

The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

In closing, we are in a high pressure period of increasing demands for empirically based nursing care, while facing a possible diminution of both nurses and nurse researchers. Research provides career challenges for nurses that will stimulate their intelligence, their empathy, and their energy. Nursing research offers the opportunity to enhance the health for all of our Nation's people.

Thank you, Mr. Chairman. I will be pleased to answer questions the Committee may have.

# PREPARED STATEMENT OF DR. FRANCIS S. COLLINS

Mr. Chairman and Members of the Committee: During fiscal year 2003, the field of genetics will observe a major anniversary, and the National Human Genome Research Institute will reach an unprecedented accomplishment. Fifty years ago, in the spring of 1953, Drs. James D. Watson and Francis Crick reported the discovery of the double helix structure of DNA, a landmark achievement in the annals of scientific research. In 2003 the Human Genome Project expects to complete the final DNA sequence of the human genome. NHGRI and their partners in the International Human Genome Sequencing Consortium announced the working draft of the human genome sequence in June 2000, published the initial analysis in February 2001, and since then have been working to correct all the remaining spelling errors and fill in all the gaps. The Human Genome Project is on target to meet that deadline and expects to finish the analysis in time for the 50th anniversary of the Watson-Crick paper.

The availability of the genome sequence of humankind could be said to mark the starting point of the genome era in biology and medicine. There is now much important work to do to deliver on the promise that these advances in genomics offer for human health. While sequencing the human genome has been NHGRI's most visible goal, the Institute has also been conducting important genetic and genomic research in a variety of areas, including working to understand the way individuals differ from each other at the genetic level and the impact these variations may have on health. In addition, the Institute leads in the development of new technologies, such as DNA chips and tools for proteomics, and has been creating novel research strategies to study the function of genes and genomes.

#### A NEW RESEARCH PLAN FOR NHGRI

The Human Genome Project has, since its inception, been guided by a series of overlapping 5-year plans. These plans have laid out ambitious goals to advance our understanding of the human genome and the associated ethical, legal and social implications. The plans have been instrumental to the success of the Project by clearly enumerating our program objectives to the scientific community and the public, and by providing measurable objectives to guide our work and gauge our progress and success.

In December 2001, the NHGRI convened about 200 experts, including scientists, researchers in the ethical, legal, and social implications (ELSI) of the Human Genome Project, consumers, and policy experts to think very broadly and creatively about the future of genomics. Over the course of the following months, we will host several workshops to explore specific topics in detail and enumerate specific goals appropriate for NHGRI. We will take stock of where we are and where we have come from, critically evaluating the challenges and opportunities that lie before us and creating a bold new vision for the future of genomics.

#### EARLY AND STUNNING RESULTS FROM THE HUMAN GENOME SEQUENCE

Obtaining an accurate reference version of the human sequence has always been the most compelling goal of the Human Genome Project. Between March 1999 and June 2000, the production of human genome sequence data in Institute-supported laboratories skyrocketed. During this time, scientists sequenced 1,000 DNA letters a second—24 hours a day, 7 days a week. The resulting working draft sequence covered over 94 percent of the human genome, with 33 percent in highly accurate finished form by February 2001. By January 2002 the amount in highly accurate finished sequence had risen to 65 percent. The final sequence will be completed in 2003, two years ahead of the original ambitious schedule.

The draft sequence of the human genome is already having a major impact on biomedical research. In the 12 months following the February 2001 publication in Nature of the publicly funded draft sequence, the paper has been cited in over 700 scientific reports, making it one of the most cited papers in all of science for the past year. These citations clearly demonstrate the widespread utility of the publicly available genome sequence and its enormous early impact to advance biomedical research in a wide array of areas.

The rationale for the Human Genome Project, and the strong and sustained Congressional support for it, has been the promise of improving human health. We are already beginning to see the fruits of that investment. Some of the citations of the Nature publication represent research that could not have been accomplished in nearly the same way or would not have been as profound were it not for the draft sequence of the human genome. More than 50 genes involved in human disease have been discovered, based on access to the public human genome sequence data. The examples cited below show the direct connection the genome sequence is having on improving human health.

#### Prostate Cancer

Using the draft sequence of the human genome, scientists at Johns Hopkins University and the NHGRI have found the first gene associated with an inherited form of prostate cancer. In a study of 91 high-risk prostate cancer families the researchers mapped the first hereditary susceptibility to prostate cancer to a region of chromosome 1 that they called the Hereditary Prostate Cancer 1 Region, or HPC1. They have now identified a specific gene—called RNASEL—in the HPC1 region that contains DNA misspellings associated with prostate cancer. Misspellings in this one gene do not explain all forms of inherited prostate cancer, but the discovery of this gene is an exciting step towards understanding the causes of this common and devastating form of cancer. Ultimately, this discovery should bring us closer to being able to prevent the disease as well as better diagnostics and treatments.

## Kidney Disease Gene

The recent identification of the gene for autosomal recessive polycystic kidney disease (ARPKD) by a team at the Mayo Clinic again shows the great power of the draft human sequence. The publicly available sequence of the human genome played an important role in the discovery of this disease-causing gene. With the identification of the responsible gene and the characterization of a rat model of the disease, rapid progress in understanding ARPKD can now be anticipated.

#### THE FUTURE OF GENOMICS

The Human Genome Project and the NHGRI have always aimed to develop new information, tools and technologies that would enable scientists to gain a deeper understanding of the genetic contributions to disease, and to use this knowledge to improve human health. The imminent completion of the project's initial goals presents a compelling opportunity to focus aggressively on translating the spectacular research advances into medical advances. With the completion of the Human Genome Project soon at hand, much additional basic research, guided by a genomic approach, remains to be done to shed light on the many mysteries of life. At the same time, genome research offers a myriad of other opportunities for connecting detailed knowledge of the human genetic instruction book with important problems in clinical research. These basic and applied paths are not mutually exclusive, and finding the right balance between them, although challenging, will be the most effective approach in the end.

#### Comparative Genomics

To understand the function of the human genome sequence, scientists would like to compare it to the genome sequences of many other organisms. This approach relies on the fact that functionally important regions of DNA are conserved over long periods of evolutionary time. By comparing the human genome sequence with those of the rat, mouse, and other organisms, similar regions are readily apparent, indicating that something biologically interesting such as the existence of a gene or important regulatory element must be present at that location of the genome.

# Simplifying the Study of Complex Genetic Diseases: The Haplotype Map of the Human Genome

Prior to the completion of the draft sequence of the human genome, most studies of diseases using genetics focused on single gene disorders such as cystic fibrosis and Huntington's disease. With the tools of the Human Genome Project, finding the genes for diseases caused by alterations in single genes has become relatively straightforward. Many common diseases, however, such as diabetes, cancer, heart disease, psychiatric disorders, and asthma are influenced by complex interactions between multiple genes as well as by non-genetic factors such as diet, exercise, smoking, and exposure to toxins.

A key next step of the Human Genome Project will be the generation of a "haplotype map" of the human genome. This comprehensive resource for human biomedical research will capture the complete catalogue of the common genome ancestral segments—"haplotype blocks"—observed in the major human populations. This map will provide a new tool for scientists to scan the entire genome and identify more rapidly and effectively those genetic variations associated with disease risk and drug response in the human population. That, in turn, will help researchers develop an understanding of the complex biological processes that give rise to the disease and assist scientists in discovering treatments or cures for these illnesses. This new and exciting project is expected to be a public-private partnership and the data will be immediately and freely accessible.

# Health Disparities Strategic Plan

From its inception NHGRI has been concerned about including individuals from various groups in its activities. As the Institute has grown in size and complexity the need for this has become even more imperative and a variety of initiatives have been started and continue to evolve to address this need. The NHGRI staff recognizes the inherent value of increasing diversity among the research workforce as well as engaging and empowering people from minority communities through joint research projects, information sharing, dialogue and the development of partnerships. In order to achieve these goals, NHGRI has developed a plan that lays out a multifaceted approach to address issues of health disparities. The plan encompasses research, training, and education/outreach activities.

#### ETHICAL, LEGAL AND SOCIAL IMPLICATIONS

From its inception, NHGRI has taken on the responsibility to address the broader ethical implications of rapid advances in genetic information and technology. Since 1991, it has committed 5 percent of its budget to studying the ethical, legal, and social implications (ELSI) of genome research.

The ELSI Research Program has continued to support significant and innovative research on the ethical, legal, and social implications of human genome research. Research projects supported in fiscal year 2001 included projects in the areas of the privacy and fairness in the use and interpretation of genetic information; clinical integration of new genetic technologies; issues surrounding genetics research; and public and professional education.

As the Institute develops its new research plan, the ELSI issues will be carefully integrated. It will be extremely important to consider these issues as new fields of genomic discovery appear. It will also be essential for ELSI funded research to inform policy development in the area of genetics.

#### EDUCATION AND OUTREACH

# National Coalition for Health Professional Education in Genetics

In 1996, along with the American Medical Association and the American Nurses Association, the NHGRI founded the National Coalition for Health Professional Education in Genetics as a national effort to promote health professional education and access to information about advances in human genetics.

## NHGRI/ORD Genetic and Rare Diseases Information Center

There are more than 6,000 genetic and rare diseases afflicting more than 25 million Americans, but many of these illnesses affect relatively few individuals. As a result, information about these rare disorders may be limited or difficult to find. In order to respond to this need, the NHGRI and the Office of Rare Diseases (ORD) have established the NHGRI/ORD Genetic and Rare Diseases Information Center to provide information on genetic and rare disorders to the public. The Information Center will meet the ever- increasing information needs of the general public, including patients and their families, health care professionals, and biomedical researchers by: 1) serving as a central, national repository of information materials and resources on genetic and rare diseases, 2) collecting and disseminating information on the diagnosis, treatment, and prevention of genetic and rare disorders, and 3) coordinating with organizations and associations interested in genetic and rare disorders.

## CONCLUSION

The investment in the Human Genome Project is already paying off in terms of advances in biomedical science that promise unprecedented advances in human health. We are moving into a new phase of genomics which will give us a deeper understanding of the genetic contributions to disease. Our vision is that by focusing on the applications of genetics to human health we will make great strides towards treating and curing many complex diseases. The NIH budget request includes the performance information required by the

The NIH budget request includes the performance information required by the Government Performance and Results Act of 1993. Prominent in the performance data is NIH's second annual performance report which compares our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

Mr. Chairman, I am pleased to present the President's budget request for the National Human Genome Research Institute for fiscal year 2003, a sum of \$466,695,000, which reflects an increase of \$35,977,000 over the comparable fiscal year 2002 appropriation.

# PREPARED STATEMENT OF DR. DONNA J. DEAN

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Institute of Biomedical Imaging and Bioengineering (NIBIB) for fiscal year 2003, a sum of \$121,378,000, which reflects an increase of \$9,356,000 over the comparable fiscal year 2002 appropriation.

Increase of \$9,305,000 over the comparable itscal year 2002 appropriation. Over the past year, it has been my privilege to preside over the formation and early development of the NIBIB, striving to provide a new and enriched focus at the National Institutes of Health (NIH) for bioengineering and imaging sciences. I can report to you today that, with help and support from the trans-NIH community, the NIBIB has taken significant steps in creating a research program in biomedical imaging and bioengineering that Congress envisioned when passing the NIBIB Establishment Act in December 2000.

#### MILESTONES TO SUCCESS

Guided by legislative language, and with input from the biomedical imaging and bioengineering communities, a mission statement was developed in March 2001, to articulate the NIBIB overall vision, goals and objectives. Upon my appointment as Acting Director in April, I was able to focus immediately on NIBIB's future as defined by the mission—"to improve health by promoting fundamental discoveries, design and development, and translation and assessment of technological capabilities in biomedical imaging and bioengineering, enabled by relevant areas of physics, chemistry, mathematics, materials science, information science, and computer sciences." Our Institute will foster and support an integrated and coordinated program of research and research training that can be applied to a broad spectrum of biological processes, disorders and diseases and across organ systems. The foundation upon which the NIBIB will build its success comes from the appli-

The foundation upon which the NIBIB will build its success comes from the applications submitted by investigator-initiated research. NIBIB staff worked with the NIH Center for Scientific Review to implement referral guidelines and procedures so that applications relevant to the NIBIB mission would be appropriately directed to the Institute. In addition, Institute staff monitored the ongoing peer review process for grant applications already in the pipeline that would be eligible for NIBIB funding.

In accordance with the NIBIB mission to foster trans-NIH collaboration, the administration of the NIH Bioengineering Consortium (BECON) was transferred to the NIBIB. The BECON has been in existence since 1997 and has served as the focus of bioengineering extramural research at the NIH. The Consortium consists of senior-level representatives from most of the NIH Institutes and Centers (ICs) as well as representatives of other Federal agencies concerned with biomedical research and development. NIBIB joins the BECON as an additional institute representative and, in its administrative role, is committed to maintaining the successful coordination of trans-NIH bioengineering research, training, and communication programs.

programs. The NIBIB is committed to supporting collaborations with other Federal agencies, and outside organizations, as indicated in our mission, to promote translation of cross-cutting technologies in bioengineering and imaging into biomedical applications. For example, the NIBIB and the Department of Energy (DOE) partnered to sponsor a workshop on "Applications of Thermography in Medical Diagnosis and Therapy", which served to identify clinical applications of the technology and to facilitate research partnerships between the DOE national laboratories and NIH investigators. In addition, with support from the NIBIB and the Institute of Electrical and Electronics Engineers (IEEE), the "International Symposium on Biomedical Imaging: Macro to Nano" will take place this July. These activities provide a forum to showcase current technology and applications, identify future biomedical needs and the emerging technologies, and assist in the process of planning the future research agenda.

On October 1, 2001, the NIBIB announced its establishment to the public through the launch of the official Institute website (http://www.nibib.nih.gov). The site serves as a conduit of information for those with an interest in the Institute and the fields of biomedical imaging and bioengineering. Comprehensive information about the history, mission, legislative activities, budget, staff, vacancy announcements, research and training opportunities and the administration of the Institute is available on the website. To date the website has received almost 700,000 hits from over 22,000 individuals and groups. Feedback indicates that the website is reaching a wide audience and providing useful information. In addition, significant efforts are being made to communicate directly with the

In addition, significant efforts are being made to communicate directly with the groups that look to the NIBIB for research support. We have targeted outreach activities specifically for engineering, physical and quantitative science communities, many of whom may be new to NIH programs and procedures. As Acting Director, I have made presentations across the nation to organizations that represent biomedical imaging and bioengineering communities. In addition, our staff have attended numerous meetings to inform the scientific communities about the NIBIB mission and current and planned research opportunities. For example, in recent months, we have met with academic, industrial, and government representatives in the states of Connecticut, Hawaii, Kentucky, New York, Pennsylvania, North Carolina, Indiana, California, and Virginia to discuss the development of consortia that support regional economies and multi-disciplinary biomedical research programs.

#### BUILDING A RESEARCH PORTFOLIO

The overarching goals of the NIBIB research program are to develop fundamental new knowledge, foster potent new technologies, facilitate cross-cutting capabilities and nurture a new generation of researchers. To that end, several scientific areas have been identified for targeted research that is uniquely suited to the NIBIB mission. Among these are microtechnology and nanotechnology, diagnostic imaging, molecular-and cellular-level imaging, biosensors, biophotonics, materials, computational biology and computer technology. In addition, the training portion of the NIBIB mission will involve facilitating training programs for scientists with backgrounds that combine the biological and medical sciences with the allied engineering and physical science disciplines to develop the expertise they will need to carry out biomedical imaging and bioengineering research in the years to come. The next phase of building the NIBIB research and research training portfolio involves developing initiatives that will stimulate activities in these areas.

As one of the first steps in building the NIBIB research portfolio, scientific staff worked to identify ongoing research programs within the other NIH Institutes and Centers (ICs) involving areas of biomedical imaging and bioengineering that would be appropriate for NIBIB participation. For example, the "Bioengineering Research Partnerships" Program Announcement (PA) solicits applications from researchers seeking to establish multi-disciplinary research teams to address a significant area of bioengineering research within the mission of NIH. Another PA, "Technology Development for Biomedical Applications," invites applicants who are developing novel instruments, devices, methodologies and software for use in biomedical research. In order to form partnerships with other ICs as articulated in our mission, the NIBIB has joined a variety of other initiatives across NIH.

To further enhance our research portfolio, the NIBIB is proud to announce our first two scientific initiatives in the areas of biomedical sensors and molecular-level imaging. Biomedical sensors can be defined broadly as devices that detect specific molecules or biological processes and convert this information into a signal. Biology and medicine have gained enormous insight into the life process by discovery, development and application of sensors. To advance this technology, the NIBIB recently issued a Request for Applications (RFA) entitled "Sensor Development and Validation." The purpose of the RFA is to support basic and applied research targeted at sensor development. In addition, the NIBIB will be the lead sponsor of an international assessment of the status of biosensor technology along with several other Federal agencies.

Federal agencies. Discoveries in molecular and cellular biology present extraordinary opportunities for biomedical imaging to play an important role in the early detection, diagnosis and treatment of disease. The support of fundamental discovery and technical development of imaging technologies, before specific disease- or organ-oriented applications are determined, is critical, and is highlighted in the NIBIB mission. Another RFA recently issued by NIBIB, entitled "Research and Development of Systems and Methods for Molecular Imaging," addresses this important scientific need, and will support novel investigations for development of molecular imaging and spectroscopy that can be applied to multiple biological or disease processes. The NIBIB's current portfolio supports a broad range of cross-cutting biomedical

The NIBIB's current portfolio supports a broad range of cross-cutting biomedical research and enabling technology development in areas such as biomaterials that encourage neural regeneration, microneedles for painless drug delivery, high-resolution imaging of soft tissue, and sensor microarrays for instantaneous chemical identification.

## FUTURE STRATEGIES

In the upcoming year, the NIBIB will begin to focus its research agenda and develop programs in such areas as nanotechnology and reparative medicine. Many scientists believe that nanotechnology is a new field of research that will enable the development of a new generation of scientific and technological approaches, as well as tools and devices used in research and clinical settings. One area where nanotechnology could be applied to medical therapy is the development of nanoparticle materials for drug discovery, production, and delivery. Nanoparticle materials offer significant improvements in bioavailability and efficiency through oral and injectable pathways. Since cellular- and molecular-level interactions occur on the nanometer scale, such technologies have the potential to offer significant improvements over current treatment options. The NIBIB plans to stimulate research in this area, based on recommendations from the 2000 BECON symposium entitled, "Nanoscience and Nanotechnology: Shaping Biomedical Research". Reparative medicine represents a critical and highly visible frontier in biomedical and editional means the fold in tigener partice and plane

Reparative medicine represents a critical and highly visible frontier in biomedical and clinical research. A key component of the field is tissue engineering, the goal of which is to repair or replace tissues and organs by delivering DNA, proteins, protein fragments, implanted cells or scaffolds to areas where they are needed. The NIBIB has a role in this endeavor to explore the following areas: self-monitoring materials for cell-, drug-, or gene-based therapies; predictive, low-cost *in vivo* and *in vitro* models; accelerated testing and failure analysis; and approaches to understanding the biology-biomaterial interface. In accord with recommendations from the 2001 BECON symposium entitled, "Reparative Medicine: Growing Tissues and Organs", we are developing initiatives to address these needs.

Other areas presenting rich opportunities for NIBIB research are included in our plans for future programs. In imaging device development, we plan to support research and development of generic biomedical imaging technologies before specific applications are demonstrated. In implant science, critical needs are development of tools for assessing loads and stresses in an operating environment, rapid simulation and prototyping methods and life-time predictive methods for design and analysis at the time of implant design, and during dysfunction and failure. Imaging processing and analysis offer challenges in the development, design, and implementation of image acquisition and information analysis algorithms, image-guided procedures and techniques for deriving physiology and function from multidimensional images.

Planning for a research training program is a high priority for the NIBIB, considering the recent Department of Labor report which indicated that biomedical engineering jobs would increase by more than 31 percent by the end of the decade. To determine needs in trans-disciplinary training, the NIBIB participated in a joint NIH-National Science Foundation (NSF) workshop on training and education in the fields of bioengineering and bioinformatics that brought together researchers and educators from across the nation. Preliminary plans include funding for multiple components at all career levels, including experiences at the pre-doctoral and postdoctoral levels, a summer training experience for quantitative science students, and institutional grants through the NIH National Research Service Awards (NRSA) program. Our goal is to facilitate the trans-disciplinary training and education necessary to assure the availability of future generations of highly-trained professionals to meet the anticipated national demands.

As a dynamic and synergistic Institute, the NIBIB is pleased to be a part of the Federal science and technology research enterprise in the 21st century high-tech information age. We look forward to establishing our role in this important endeavor. Mr. Chairman, I would be pleased to answer any questions you or the Committee

may have.

#### PREPARED STATEMENT OF DR. JUDITH L. VAITUKAITIS

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Center for Research Resources (NCRR) for fiscal year 2003, a sum of \$1,091,374,000, which reflects an increase of \$78,836,000 over the comparable fiscal year 2002 appropriation.

We cannot do today's science with yesterday's tools. As director of the National Center for Research Resources, I hear regularly from the scientific community that to do quality work, scientists must have access to state-of-the-art research tools and technologies. NCRR provides the biomedical research community with the research tools, specially designed research facilities, biologic models of human disease and other resources necessary for studies that define the causes of human disease. I am pleased to have this opportunity to share with you recent research contributions made possible by NCRR-funded programs, and to outline our future plans for facilitating biomedical discovery through development of novel technologies and strategic provision of research resources.

<sup>1</sup> NCRR's crosscutting research resources transcend the entire spectrum of scientific inquiry funded by the institutes and centers within the National Institutes of Health (NIH). Each year more than 28,000 investigators, supported by more than \$4 billion in competitive grants from other NIH components, as well as from other Federal agencies and the private sector, use NCRR-supported research resources to conduct their studies. To get the most out of dollars committed to research resources, NCRR encourages investigators and institutions to share scarce or expensive research resources. In addition, NCRR supports research resource facilities for both basic and clinical research that are shared institutionally, regionally or nationally. Those include networks for General Clinical Research Centers (GCRCs), Regional Primate Research Centers, Biomedical Technology Resource Centers, Research Centers in Minority Institutions, and many other resources, including biorepositories—all essential to NIH-supported research. The clinical research settings of the GCRCs allow countless investigations of human diseases, both rare and common. The biologic models validated and supported by NCRR have exposed many of the basic mechanisms that underlie human disorders. NCRR-funded technology resources have broad-ranging applications, ranging from molecular structures to views of the brain affected by degenerative processes, including Alzheimer's and Parkinson's diseases. Other resources include those for generating vectors for human gene transfer, and centers for isolation of human pancreatic islet cells for transplantation into patients with Type 1 diabetes mellitus. Resource sharing is a cost effective approach to funding biomedical research.

The challenge for NCRR is to keep pace with the biomedical community's chang-ing needs for research tools and to ensure that tomorrow's research queries have tomorrow's critical instrumentation and technologies in hand. The research re-sources and tools needed for scientific investigations change dramatically over time as more complex research queries are posed and require new technologies and bio-materials with greater sensitivities and much higher through-puts. Many research tools now considered critical to understanding the cause of disease and protecting the health of Americans were unheard of just a few years ago. For instance, the Magnetic Resonance Imagers, or MRIs, now found in hospitals and medical centers across the country were rare and experimental less than 20 years ago. Today MRI is an essential clinical tool, saving countless invasive surgical procedures each year. NCRR supported the development of MRI from its earliest iterations-as an obscure technology used only in chemistry labs—to the clinical tool that physicians have come to depend on. NCRR continues to support the evolution of MRI and other technologies, including mass spectrometry and synchrotron beam lines for crystallographic studies of macromolecules encoded by the tens of thousands of genes within the human and other genomes. These advanced technologies evolved from the basic research efforts of physicists and engineers who needed these sophisticated instruments for studies of particle physics. The NIH biomedical research community, frequently in collaboration with investigators from other federal agencies, adapted the physicists' tools to study the molecular causes of disease and to develop specific therapies to prevent, cure or ameliorate the disease.

# ADVANCED TECHNOLOGIES

The shared resources supported by NCRR provide a fertile environment to stimulate collaborations among investigators. Interdisciplinary research teams are indispensable as scientists begin to address more complex research problems. One example is the exploration of the human genome and the macromolecules encoded by the more than 30,000 genes identified to date within the human genome. Working at the scale of the proteome (proteins expressed by the genome), investigators may need to characterize thousands of proteins to address fundamental questions that cannot be answered by examining just one protein at a time. To assist examination of such complex problems, NCRR will initiate a program to support a system or an integrative approach for biomedical research resource centers equipped thematically with the most advanced technologies, including structural and protein purification techniques, mass spectrometry, and DNA microarrays to address the biocomplexity of research. Research teams at these centers will include investigators with wideranging but complementary expertise, including physicists, physical chemists, engineers, bioinformaticists, computer programmers, and both physicians and basic scientists trained in sophisticated biomedical research.

In order to respond rapidly to scientists' changing needs, NCRR works in trusted partnership with the biomedical research community and with other NIH institutes and centers. An overwhelming number of scientists we hear from have identified an urgent need for bioinformatics tools to collect, manage, analyze, and share the enormous data sets that arise from genomics, proteomics, and imaging efforts. Last year, NCRR launched an ambitious pilot project known as the Biomedical Informatics Research Network (BIRN). BIRN is a collaborative effort with the San Diego Supercomputer Center, the National Science Foundation, and several universities. An essential feature of the BIRN testbed is the creation of infrastructure that can be deployed rapidly to other research sites throughout the country, and promises to have applications beyond neuroimaging, the project's initial focus. Another successful pilot venture is the Internet-based network, CFnet, which

Another successful pilot venture is the Internet-based network, CFnet, which NCRR established a few years ago in partnership with the Cystic Fibrosis Foundation. The initial goal of CFnet was to determine if phase 1 and 2 clinical trials could be facilitated across several GCRC sites with web-based data management. The effort proved so successful that we anticipate extending CFnet to an additional 12 GCRC sites and will include phase 3 clinical trials. NCRR, in collaboration with Internet 2, plans to establish a comparable network at the eight minority-serving medical schools to facilitate their participation in clinical trials and in studies designed to examine the factors contributing to health disparities and ways to eliminate them. This network will be extended to the entire cohort of institutions currently supported through NCRR's Research Centers in Minority Institutions program. NCRR also plans to initiate networking with a subset of academic institutions within the Institutional Development Award (IDeA) program.

#### GENOMICS AND GENETIC MEDICINE

NCRR supports national repositories for biologic models, which play an indispensable role in uncovering the basis of human health and disease. The genomes of animal species are remarkably similar to ours; consequently, animal models offer a wealth of information about human gene function. NCRR plans to support national resources to systematically validate, classify and characterize genetically altered animal models. National genotyping laboratories will be established to serve both the clinical research and animal model communities.

Research with embryonic stem cells may hold the key to treatment of disorders for which no effective therapies exist. These cells have the potential to develop into any type of cell in the body. To explore the full potential of these cells, NCRR will fund studies of several animal models, including nonhuman primates and rodents, to identify the factors within their microenvironments that induce embryonic stem cells to transform into insulin-producing islet cells, blood-forming cells, dopamineproducing neurons, and more—ultimately for therapeutic purposes.

Despite the fact that half of all NIH-funded research grant applications include animal-based research, relatively few veterinarians are research trained, and veterinary schools have too few faculty who can serve as mentors or role models for students. To address this need, NCRR proposes to establish academic Centers of Veterinary Research Excellence (COVRE) in colleges of veterinary medicine. The goal of COVRE is to develop a pool of research-trained veterinarians who will fill a rapidly growing need in biomedical science. COVRE will provide competitive support to further develop the research infrastructure—the research facilities, instrumentation and investigator development—of Veterinary Schools of Medicine.

# RESEARCH TRAINING AND CAREER DEVELOPMENT

To address the need for research trained physicians and dentists in patient-oriented research, NCRR will expand its support for several NIH-wide career development programs. The NCRR proposes to enhance support for the Mentored Patient Oriented Research Career Development Awards (K23), and Mid-Career Investigator Awards (K24). NCRR will continue to be a major supporter of the institutional Clinical Research Curriculum Awards (K30). In fiscal year 2001, NCRR demonstrated its commitment to the development of a cadre of clinical researchers by supporting more K23 awards than any other NIH component except one. NCRR will expand support of the loan repayment program for NCRR-supported junior investigators (dentists and physicians) who are pursuing patient-oriented clinical research career development.

NCRR proposes to expand support for clinical research pilot studies in GCRCs so that promising junior investigators and established investigators with novel ideas may collect important preliminary data to support the feasibility of research questions proposed in their research grant applications. NCRR also intends to begin funding of a new institution-based career development program for physicians and dentists. The Mentored Clinical Research Scholar Program was created as an institutional patient-oriented career development program. The program flexibly integrates educational instruction through seminars, workshops and formal courses that may lead to advanced degrees and the acquisition of biomedical research expertise in a mentored setting. Candidates must participate for a minimum of two years but not longer than five years and may be eligible for the loan repayment program. Candidates may earn an M.S., M.P.H., or Ph.D. degree in areas relevant to clinical research. The goal is to prepare physicians and dentists for independent careers in patient-oriented research. Another NCRR effort is to enhance medical students' interest in clinical research careers through support for the Mentored Medical Student Clinical Research Program. This program provides medical and dental students with support for one year of didactic clinical investigation and mentored research at institutions with a GCRC or an RCMI Clinical Research Center. The goal is to provide support for up to 5 students per GCRC site per year. A similar program for veterinary students will be expanded.

#### RESEARCH CAPACITY BUILDING

NIH proposes to continue support for construction or renovation of extramural research facilities through the Research Facilities Improvement Program in fiscal year 2003. The research community has expressed a need for Biosafety Level (BSL) 2/ 3/4 facilities for handling dangerous bacteria, viruses, and other agents; good manufacturing procedures (GMP) facilities for manipulation of cell therapies and production of vectors for human gene transfer. Applications from smaller institutions will be given special consideration for funding. Separately, at least \$5 million of funds appropriated for construction for fiscal year 2003 will be required to finish building a chimpanzee sanctuary system.

a chimpanzee sanctuary system. The NIH Institutional Development Award (IDeA) Program provides support to enhance the biomedical research capacities of institutions in states that have not fully participated in NIH research funding in the past. To develop and enhance their research infrastructure, NIH launched two program initiatives, the Centers of Biomedical Research Excellence (COBRE) and Biomedical Research Infrastructure Networks (BRIN). In response to recommendations of institutional officials and investigators in the IDeA states and Puerto Rico, NCRR proposes to create an Internetbased network with distributed databases, using Internet 2 to link the BRINs and COBREs, to foster collaborations among the participating institutions. IDeAnet will provide access to bioinformatics tools for data analysis and visualization as well as access to scalable computing up to the teraflop level.

#### HEALTH DISPARITIES

Finally, in order to address health disparities, NCRR proposes to establish Comprehensive Centers for Health Disparities Research. These Centers will develop the capacity of RCMI medical schools to conduct basic and clinical research in type 2 diabetes and cardiovascular disease, both of which disproportionately affect minority populations. The Centers will provide support to further develop the requisite research infrastructure, recruit magnet clinical investigators, recruit and develop promising junior faculty, and facilitate substantial collaboration between the RCMI grantee institutions and more research-intensive universities. Partnerships between investigators at GCRC sites will be developed.

Mr. Chairman, the NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

I will be happy to respond to any questions you may have. Thank you.

# PREPARED STATEMENT OF DR. STEPHEN E. STRAUS

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the National Center for Complementary and Alternative Medicine for fiscal year 2003, a sum of \$113,823,000, which reflects an increase of \$8,843,000 over the comparable fiscal year 2002 appropriation.

The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report that compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan. Fiscal year 2001—NCCAM's third year—was one of exciting growth and produc-

Fiscal year 2001—NCČAM's third year—was one of exciting growth and productivity. Substantive progress was made towards advancing each of the four primary goals articulated in NCCAM's five-year strategic plan: stimulating and supporting research, research training, outreach, and facilitating integration.

#### BUILDING FOR SUCCESS

NCCAM's evolving success has depended on our firm adherence to a series of guiding principles. First, we solicit the best research ideas from a wide base of our stakeholders, investigators, and practitioners from the many mainstream and complementary and alternative medicine (CAM) disciplines and fields; we incorporate

similarly wide perspectives into peer-review; and we invest in only the most competitive, exacting, and important work. Second, our portfolio emphasizes clinical research because CAM practices are already widely used, and the American people need information that is based on scientific evidence so that they can make informed health care choices. Third, the range of clinical conditions addressed by CAM and the cost of clinical studies, especially large trials, dictates that we leverage our intellectual and capital resources through collaboration with sister Institutes, Centers, and agencies. Fourth, CAM products and practices, in spite of their wide use, are often of variable quality. Thus, we must ensure the highest standards of safety and reproducibility of our studies. The progress made in each of these areas has been facilitated by our creation of

The progress made in each of these areas has been facilitated by our creation of programs in international health research, special populations research, and clinical and regulatory affairs (PCRA), as well as the establishment of an Intramural Research Program (IRP), including the appointment of the first NCCAM Director for Clinical Research. The PCRA coordinates and monitors NCCAM-funded multi-center trials, including related Institutional Review Board (IRB) and data and safety monitoring activities. Further efforts to enhance research quality include NCCAM-funded preparation of high-priority clinical research-grade botanical products such as cranberry, Echinacea, saw palmetto, and milk thistle, for which existing supplies sold to consumers are too variable in product content and quality. The IRP creates on the NIH campus an environment for collaborative research, training, and clinical care with CAM modalities.

Evidence of our success over the past three years includes a nearly 25-fold increase in grant applications to NCCAM and a commensurate increase in the quality of our awards. Our research portfolio has begun to demonstrate the breadth and complexity typical of work supported by the more established Institutes. We have expanded our support for investigator-initiated studies on the basic mechanisms of action and clinical applications for diverse, widely used CAM therapies. NCCAM manages a substantive Centers program to investigate a range of botanical products, cancer therapies, cardiovascular disease treatments, and women's health approaches, among others, while thousands of research subjects have been enrolled into the most rigorous Phase III studies of CAM treatments ever conducted (Table). We have steadily increased the number of research training awards for pre- and postdoctoral fellows, physicians, nurses, and CAM practitioners. Our outreach efforts have benefitted from an award-winning web site and an Information Clearinghouse enriched with new fact sheets, reports, and publications for the public and the research and health care communities.

Phase III clinical trials	Status	Cosponsoring NIH Insti- tutes/Centers	Target enroll- ment
Shark cartilage as adjunctive therapy for lung cancer Ginkgo biloba to prevent dementia Acupuncture for osteoarthritis pain Glucosamine/chondroitin to treat osteoarthritis Vitamin E/selenium to treat prostate cancer Hypericum perforatum to treat minor depression EDTA chelation therapy to treat coronary artery disease Saw palmetto/P. africanum to prevent progression of benign prostatic hypertrophy.	Enrolling subjects Enrolling subjects Enrolling subjects Enrolling subjects Enrolling subjects Awarded Announced	NCI	756 3,000–3,500 570 1,588 32,400 300 (min.) 1,600 (est.) 3,000 (est.)

SELECTED RANDOMIZED, CONTROLLED PHASE III CLINICAL TRIALS SUPPORTED BY NCCAM

Allow me to highlight our approaches to and plans for some of the most complex and important facets of human health—cancer, neurosciences, and HIV/AIDS—and international health as illustrative of our overall strategy.

## CANCER

Surveys show that many cancer patients, hoping to improve their prognosis or to reduce the side effects of conventional treatments, use CAM modalities; others choose a CAM therapy as an alternative, especially for those cancers that are not responsive to conventional therapies. This widespread use has made studies of CAM approaches to cancer a high priority for NCCAM, as evidenced by a notable increase in investment in this area. NCCAM is collaborating with the National Cancer Institute and leading cancer specialists to examine diverse complementary and alternative therapies for cancer and its complications, as palliative care treatment, and as options for care at the end of life. We jointly support CAM programs at specialized cancer centers; we co-fund the largest ever studies of the dietary supplements selenium and vitamin E for prevention of prostate cancer and shark cartilage as adjunctive therapy for lung cancer (Table). Our portfolio of recently funded studies ranges from basic molecular and pharmacological studies of herbal products used by cancer patients, to assessments of massage, spiritual approaches, and complex nutritional regimens. We hope to support additional rigorous Phase I and II studies of a variety of popular alternative treatments for which the scientific literature provides limited or no evidence to confirm their safety or effectiveness: high-dose antioxidants (e.g., vitamin C or Coenzyme Q10), herbal mixtures (e.g., Flor-Essence, Essiac, PC-SPES, or traditional Chinese medicines), single whole plant extracts (e.g., mistletoe, oleander, or green tea), biopharmacologics (e.g., MTH-68, or 714-X), or complex regimens (e.g., Revici or Gerson therapies).

#### THE NEUROSCIENCES

Another large component of the NCCAM research portfolio focuses on important public health needs and opportunities in the neurosciences, including studies on pain, mental health, stroke, addiction, and neurodegenerative disorders, as well as the neurobiological effects of placebos and diverse CAM therapies. Together, these studies promise to determine the range of neurological conditions for which CAM therapies may be beneficial and to further elucidate the intricate processes of the human nervous system.

Even though acupuncture has enjoyed millennia of empiric development and widespread use in Asia, it has been poorly explicated or accepted by the standards of contemporary biomedicine. Currently, NCCAM investigators are learning more about acupuncture's mechanisms of action and its value for pain relief. Several different basic science studies are applying powerful new brain imaging techniques (such as functional magnetic resonance imaging and positron emission tomography) to identify physiological linkages between needle insertion sites, ancient acupuncture meridians, and critical brain neurotransmitter and endogenous opioid pathways Many of NCCAM's studies are dedicated to investigating how effective acupuncture is at managing pain relative to other contemporary approaches. For example, in collaboration with the National Institute of Arthritis and Musculoskeletal and Skin Diseases, NCCAM will complete the largest and most rigorous trial to date of the safety and efficacy of acupuncture for the pain of osteoarthritis of the knee (Table). NCCAM supports smaller studies for other conditions including: carpal tunnel syndrome; temporomandibular disorder and postoperative dental pain; and back pain. Collectively, this is the largest ever compendium of formal acupuncture studies.

Collectively, this is the largest ever compendium of formal acupuncture studies. The dominant theme of research in NCCAM's IRP focuses on the body's cardinal communications network that links the mind/brain and body: neural, endocrine, and immune systems and their responses to significant age-related life stressors, such as depression, chronic pain, cognitive decline, and sleep disorders, all of which are prime targets of CAM approaches. One of the first intramural studies will examine the use of acupuncture to control nausea associated with aggressive cancer therapy.

The placebo effect also hinges on the powerful dialogue between mind and body, representing a change in a patient's condition that occurs in response to administration of otherwise inert substances or participation in a psychophysiological activity in a healing context. Research has shown that placebos affect treatment outcome. In November 2000, NCCAM, the National Institute of Diabetes and Digestive and Kidney Diseases, and 15 other Institutes, offices and health agencies cosponsored a major international conference to examine social, psychological, and neurobiological contributions to the placebo effect, and the ethical use and evaluation of placebo actions in clinical trials. In response to recommendations from the conference, NCCAM has planned and will fund, in collaboration with nine other NIH Institutes and Centers, new research initiatives aimed at elucidating the neurobiological mechanisms that mediate placebo effects, and supporting studies of social and behavioral factors that facilitate placebo responses in clinical practice settings.

#### HIV/AIDS

People with HIV/AIDS often incorporate CAM modalities into their treatment strategies. Consequently, NCCAM is building an innovative and broad-based research portfolio to determine the safety and efficacy of CAM modalities used by these individuals. NCCAM plans to solicit studies that build on ongoing in vitro, animal, and early phase clinical studies that address: the potential antiretroviral action of a number of CAM therapies either alone (e.g., dehydroepiandrosterone [DHEA]) or in concert with approved anti-HIV drugs (e.g., licorice [*Glycyrrhiza glabra*] and St. John's wort [*Hypericum perforatum*]); the amelioration of undesirable side effects of conventional treatments (including garlic to prevent the unusual

deposition of fatty tissues under the skin, known as lipodystrophy); or the restoration of the immune system by dietary supplements (e.g., alpha lipoic acid or creatine). Because palliation is one of the purported benefits of many CAM therapies, NCCAM also supports several research projects on improving the quality of life for people with advanced AIDS (parallel studies are being conducted with people who have advanced cancer), including massage therapy to treat depression and improve the quality of life, cognitive behavioral coping and Tai Chi to reduce stress, and the role spirituality plays in sustaining one's will to live.

### INTERNATIONAL HEALTH RESEARCH

Recognizing that a global CAM research network would also enhance CAM research activities in the United States by affording investigators access to unique bioresources and traditional therapies, NCCAM established a research program on international health in fiscal year 2001. The goal is to promote the validation of indigenous CAM practices by encouraging their rigorous assessment in their native context in a culturally sensitive manner. Collaborations with the Fogarty International Center, the World Health Organization, and other agencies are facilitating these endeavors. In accord with the strategic plan for this effort, NCCAM has begun by convening international workshops and plans to solicit applications to develop an international site of CAM research excellence.

#### CONCLUSION

While many CAM remedies have been employed for centuries, we still have much to learn about them. By continuing our studies on their underlying mechanisms and clinical effects, we will discern which approaches are safe and effective, and therefore suitable for incorporation into medical practice, while well-informed consumers will reject those that are not.

I am now happy to take your questions about NCCAM's activities and plans.

### PREPARED STATEMENT OF DR. JOHN RUFFIN

Mr. Chairman and Members of the Committee: I am honored to appear before you as the Director of the National Center on Minority Health and Health Disparities (NCMHD) to present the President's budget request for fiscal year 2003, a sum of \$187.159 million, which reflects an increase of \$29.294 million over the comparable fiscal year 2002 appropriation. The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report which compares our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan. As performance trends on research outcomes emerge, the GPRA data will help NIH to identify strategies and objectives to continuously improve its programs.

Thanks to the support of the Congress, the National Center on Minority Health and Health Disparities was created in January 2001, as mandated by Public Law 106–525. NCMHD's mission is to lead, coordinate, support, and assess the NIH effort to reduce and ultimately eliminate health disparities. The Center will achieve its mission by conducting and supporting basic, clinical, social, and behavioral research, promoting research infrastructure and training, fostering emerging programs, disseminating information, and reaching out to minority and other health disparity communities. NCMHD envisions an America in which all populations will have an equal opportunity to live long, healthy and productive lives. Over the past year, NCMHD has worked diligently with its partners, the other Institutes and Contors (ICA) and Office at NIH to implement its atoutony require

Over the past year, NCMHD has worked diligently with its partners, the other Institutes and Centers (ICs) and Offices at NIH, to implement its statutory requirements. I am grateful for the extensive support and cooperation that the Center has received from Dr. Ruth Kirschstein, Acting Director of NIH, and all of the other IC Directors. The help of the other ICs is demonstrated in the Center's achievements that I will discuss today. Last year, I informed you of what we were planning to attain. Now, one year later, I am proud to share with you highlights of what we have accomplished. The Center has successfully developed its organizational structure and continues to hire new staff to carry out its programs and initiatives.

#### NIH COMPREHENSIVE STRATEGIC PLAN AND BUDGET

For the first time in the history of the National Institutes of Health, it will have a comprehensive Strategic Plan and Budget that will be a guiding mechanism for the conduct and support of all NIH minority health disparities research and other health disparities research activities. NCMHD was honored to be charged with the development of this plan in collaboration with the Director of NIH and the Directors of the other NIH ICs. The Center has submitted the Strategic Plan and Budget to the Office of the Director, NIH, for review.

The Plan was developed with substantial input from various stakeholders including the public, academia and health professionals representing those who disproportionately experience disparities in health. It describes current activities and future plans of the NIH to address the health disparities crisis, to build a culturally competent cadre of biomedical and behavioral investigators and to increase the number of minority clinical and basic medical scientists who are essential to the success of our efforts. There are three main goals of the plan research, research infrastructure and community outreach which encompasses information dissemination and public health education. Within each goal there are areas of emphasis and objectives to accomplish the priorities identified or mandated. Each objective outlines an action plan, time-line, performance measures to monitor and report progress and outcome measures to demonstrate accomplishment and ultimate impact. The Plan will continue to be an evolving document over the next five years. Once finalized, it will be posted on the NCMHD website at www.ncmhd.nih.gov on a continuing basis, and comments from the public will be welcomed at any time. We will update and revise the Strategic Plan and Budget annually with the continued collaborative input of the other NIH ICs, and we will provide annual reports on our progress.

#### NCMHD CONGRESSIONALLY MANDATED PROGRAMS

NCMHD also has made rapid progress in implementing its three major congressionally mandated programs—the Loan Repayment Program, the Endowment Program for Section 736 (PHS Act) institutions, and the Centers of Excellence Program. Currently, we are in the preliminary phase of implementing the Centers of Excellence Program, which we have named Project EXPORT, "Centers of Excellence in Partnerships for Community Outreach, Research on Health Disparities, and Training." We are grateful to the NIH ICs for providing us with the necessary mechanisms and support which made it possible for the NCMHD to launch in fiscal year 2001 our two new loan repayment programs and the Endowment Program for Section 736 institutions.

### THE LOAN REPAYMENT PROGRAMS

In fiscal year 2001, the Center established the Loan Repayment Program for Health Disparities Research, mandated in law, and the Extramural Clinical Research Loan Repayment Program for individuals from disadvantaged backgrounds, the authority for which was delegated to the Center by the Acting Director of NIH. The Loan Repayment Program for Health Disparities Research is aimed at increasing the number of highly qualified health professionals in health disparity research careers, and focuses on basic, clinical, and behavioral research with priority given to biomedical research. The Extramural Clinical Research Program seeks to increase the number of highly qualified health professionals from disadvantaged backgrounds who pursue clinical research careers. Applicants to the loan repayment programs, must have a health professions degree, such as a M.D., Ph.D., D.O., D.D.S., or equivalent doctorate degree. Individuals completing their residencies, post-doctoral training, and internships may also apply.

We are pleased to report that the first round of loan repayment awards were made to 45 health professionals in fiscal year 2001, eight months after the Center's creation. Twenty eight awards went to the Health Disparities Research Loan Repayment Program, and seventeen awards to the Extramural Clinical Research Loan Repayment Program. A total of 125 applications were received. Based on the tremendous interest in the program, during the current fiscal year we anticipate receiving about 350 applications. We plan to announce the fiscal year 2002 awards in September.

### THE ENDOWMENT PROGRAM

The Center is fortunate to have had similar success in implementing the Endowment Program for Section 736 Institutions, as required by Public Law 106–525. These institutions are Centers of Excellence already established by the Health Resources and Services Administration (HRSA) under Section 736 of the Public Health Service Act. The purpose of this program is to facilitate capacity building for minority health disparities research and other health disparities research at institutions that have a demonstrated commitment to educating and training researchers from minority and health disparity populations. In fiscal year 2001, the NCMHD made the first round of endowment awards to five institutions. The Center will continue its commitment to the Endowment Program this year. The preliminary phase of the application process will begin with the release of the next RFA in April to culminate with the issuing of fiscal year 2002 awards in September.

# CENTERS OF EXCELLENCE PROGRAM

Our efforts to implement our Project EXPORT Centers of Excellence Program are well underway. The purpose of the Project EXPORT program is to develop and implement a network of centers of excellence at academic institutions with a significant number of students from racial and ethnic minority and other health disparity populations. This program aims to promote the conduct of minority health and/or health disparity research aimed at reducing disparities in health status; promote the participation of members of health disparity groups in biomedical and behavioral research, prevention and intervention activities through education and training; and build research capacity in minority serving institutions. The RFAs for the program have been released, and the Center is currently accepting applications through May 24. We have just successfully completed a series of four technical assistance workshops across the country, which provided the community with guidance on all aspects of completing and submitting applications for the program. The attendance and level of participation at the workshops was outstanding, and we look forward to receiving a number of highly competitive applications. We expect to announce the fiscal year 2002 awards in September.

### NEW INITIATIVES

NCMHD is excited about the opportunity to undertake new approaches to the health disparities crisis. The Center is presently exploring the development of the following additional programs for fiscal year 2003:

(1) The Virtual University Program: to improve training outcomes for students from minority and other health disparity groups, improve the transition from undergraduate to graduate programs and to independent investigators, and serve as a resource for continuing education and/or retooling for faculty at minority serving institutions.

(2) The Rural Poor and other Health Disparity Groups: NCMHD will collaborate with the National Institute on Dental and Craniofacial Research (NIDCR) to support 1) planning grants for research to prevent or reduce oral health disparities, 2) pilot grants for research to prevent or reduce oral health disparities, and 3) research infrastructure and capacity building for minority institutions to reduce oral health disparities.

(3) Community Outreach: the NCMHD is committed to creating communication channels that lend themselves to the bi-directional, interactive nature of effective outreach. Accordingly, the NCMHD will divide its outreach efforts into three major objectives: (1) Outreach to Communities and their Community Based Organizations; (2) Outreach to Health and Social Service Professionals; and (3) Outreach to Health, Research and Social Service Institutions, Professional Organizations, and the Business Sector.

(4) Mississippi Delta Project: with a medical research agenda for the Mississippi Delta Region, the NCMHD will concentrate on (1) solidifying the organizational and technological network within the community to conduct research on health disparities; (2) increasing the level of involvement of community residents in the health research; (3) facilitating the availability of culturally-appropriate health education material; and (4) establishing a base for involvement of small businesses with these entities.

### CONCLUSION

The NCMHD is grateful to the Congress, the Administration and the NIH Institutes and Centers for the overwhelming support that each has provided the Center in transitioning from the Office of Research on Minority Health, to the National Center on Minority Health and Health Disparities. I am proud of the progress that the Center has made over the past year in establishing its organizational structure and programs. The American people can now learn about the Center's activities and programs by accessing our new website at www.ncmhd.nih.gov which is now averaging about 50,000 hits a month. Through continued and increasing collaborative ventures, NCMHD will work diligently to define the health disparity issue for every American, and garner their support to someday ensure an America in which all populations will have an equal opportunity to live long, healthy and productive lives.

## PREPARED STATEMENT OF DR. GERALD T. KEUSCH

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the Fogarty International Center for fiscal year 2003, a sum of \$63,833,000 which reflects an increase of \$6,480,000 over the comparable fiscal year 2002 appropriation.

## SCIENCE FOR GLOBAL HEALTH

For 34 years now, the Fogarty International Center (FIC) has built alliances for global health to advance medical research for the, benefit of all. We live in an interconnected, international community and because science is an inherently international endeavor, FIC initiatives reach across borders and contribute knowledge to enhance health here at home while narrowing the gap in health status between rich and poor countries.

We face many global health challenges and threats. The World Health Organization (WHO) estimates that 1,200 people die each hour from an infectious disease. AIDS has killed more than 22 million people, leaving in its wake households without bread-winners, orphaned children, and unspeakable human suffering. In the United States, 45,000 people become infected each year. As we battle AIDS, TB, malaria and other infectious diseases on the rise around the globe, we confront new microbial threats and drug-resistant strains of common foes. At the same time, we know that chronic diseases will become more important causes of the global burden of disease in the coming decades (WHO/World Bank Report, 1996). With aging of populations and changing demographics, due to new economic growth, heart disease, stroke, diabetes, mental illness and other chronic diseases, will all add to the increasing health burden on the global community. As we combat today's diseases challenges, we must prepare for those on the horizon. Sound science is at the foundation of our approach to addressing these global health threats. As a nation, our interest in global health stems not only from our humanitarian concerns as we work to alleviate human suffering, but also from an enlightened self-

As a nation, our interest in global health stems not only from our humanitarian concerns as we work to alleviate human suffering, but also from an enlightened self-interest. Traditionally, such interests focus on protecting our nation from imported diseases. Now we recognize the political and economic benefits as well: healthy, stable countries make strong allies and trading partners. Yet, our self-interest goes beyond these issues. Through partnerships with scientists from around the world, including those in developing countries, we are able to identify new strategies and new understandings of disease processes, including for AIDS, TB, and chronic diseases such as heart disease, that affect us all. In light of the tragic events of September 11, these partnerships take on new meaning. As President Bush noted to the U.N. General Assembly soon after the tragedy, "My country is pledged to investing in education and combating AIDS and other infectious diseases around the world. Following September 11, these pledges are even more important. In our struggle against . . . poverty and despair, we must offer an alternative of opportunity and hope." The programs of the FIC provide both scientific opportunity and hope for generations of scientific leaders, especially those in the poorest, most marginalized parts of the world.

#### NARROWING THE KNOWLEDGE GAP

FIC currently addresses global health challenges through twenty research and research capacity building programs as well as through its leadership of global scientific alliances. Working in over 100 countries and through more than 120 U.S. universities, medical schools and schools of public health, FIC-supported scientists are in the vanguard in advancing research and in training the next generation of scientists. The pairing of research with research training is the cornerstone of FIC's approach toward building capacity in the developing world, and it has produced over time spectacular and enduring results. A complete description of the FIC Strategic Plan is available on the Web at http://www.nih.gov/fic/about/Slan.html.

Film is available on the web at http://www.nin.gov/nc/about/Sian.html. FIC's AIDS International Training and Research Program, now in its 14th year, has provided Ph.D.-level, Master's-level and advanced short course training to thousands of scientists in the developing world. Research successes supported through that program include identification of effective strategies to reduce HIV transmission from mother to child, insights into risk behavior that leads to HIV infection and related intervention strategies, and development of technologies to ensure the safety of the blood supply. Importantly, scientists who received training through the AIDS program are competitive for other NIH funds, as well as funds from other science agencies, and become the leaders in science in their home countries as new studies and clinical interventions are developed and tested. Among the outstanding leaders associated with FIC's research capacity building programs is Dr. Nelson Sewankambo, a long-standing FIC affiliate of our AIDS program, now Dean of the School of Medicine in Kampala, Uganda. Dr. Crispus Kiyonga, Minister of Health of Uganda, has received advanced training in AIDS research methodologies with FIC support to Johns Hopkins University. Both individuals had a major impact on the formulation and implementation of AIDS policies that have contributed to the decline in overall HIV infections in Uganda. Today, Dr. Kiyonga leads the United Nations Global Fund for AIDS, TB and Malaria, a newly-established fund to address the burden of those diseases in the developing world. In addition, Dr. Phillippa Musoke, once a trainee in the AIDS program, later competed successfully for NIH funds and went on to make one of the seminal discoveries in Uganda on the use of anti-retroviral drugs to block mother to child transmission of AIDS. Looking more broadly at the impact of the AIDS program on individual career development and scientific productivity, a review of the presentations at the most recent AIDS International Conference held in Durban, South Africa, in June 2000 shows that fully 25 percent of all research papers were authored or co-authored by FIC-supported scientists from developing countries. Ultimately it is people who drive progress.

Using the same capacity building paradigm as with AIDS, FIC supports research and research training in other critical areas of global health concern, including in the fields of maternal and child health, environmental and occupational health, and tobacco and health, while building essential capacity in ethics and information technology. While training the next generation of researchers, key advances in critical areas have emerged: a U.S.-Peru team developed a low-cost diagnostic test for multi-drug resistant TB that is fast, cost-effective and can be used in resource-poor settings; a U.S.-Brazil team tracked the spread of penicillin resistance in populations; a U.S.-China team elucidated the risks associated with unsafe blood products and the spread of HIV; and a U.S.-Russia team defined intravenous drug use and sexual practices related to the burgeoning AIDS epidemic in Russia to identify effective interventions. As a companion to these research capacity building programs for developing country scientists, FIC supports a career development program for junior U.S. scientists to allow them opportunities to conduct research on global health issues in developing country institutions.

FIC's support for research also includes work that spans diverse disciplines to generate new knowledge. For example, the International Cooperative Biodiversity Groups program, launched in 1993, fosters drug development from diverse plants and microorganisms. At the same time, working through community groups and local governments, it works to conserve biodiversity and promote economic development where these source organisms are located. A number of novel lead compounds to combat a range of diseases, including AIDS, TB, malaria, leischmaniasis, bacterial infections, and cancer, are now in animal testing programs in collaboration with pharmaceutical partners. Additionally, FIC is working to strengthen the knowledge base of the linkage between health status and economic development through joint awards to economists and health scientists. Launched with other NIH partners and the World Bank, this new FIC program supports studies to promote collaborative decision making among Ministries of Development, Finance and Health in the developing world, for example studies that document the link between the nutritional status of children and adult economic productivity, providing the evidence base for appropriate interventions.

### GLOBAL LEADERSHIP

As a leader in the global health arena, FIC initiates partnerships and implements research and training with other NIH components on issues of common interest as well as with other U.S. agencies, science funding agencies abroad, international organizations, foundations and other non-governmental groups. FIC is the Secretariat for the Multilateral Initiative on Malaria (MIM), a global alliance of organizations and institutions committed to advancing malaria research and building research capacity in the developing world. FIC works closely with the National Institute of Allergy and Infectious Diseases, the National Library of Medicine, the WHO and science funding agencies in France, the United Kingdom, and other countries to advance the goals of the MIM. In addition to its support for collaborative research projects and training in malaria, the Secretariat will hold the third Pan-African and International Malaria Conference in Arusha, Tanzania in November 2002. Other examples of FIC's leadership in key global health areas include a major project to develop a new assessment of "Disease Control Priorities in Developing Countries," in partnership with the World Bank, WHO, and the Bill and Melinda Gates Foundation. This new initiative will develop data on disease burden and health care infra-

structures in the developing world as a means to inform policy makers. FIC has been selected by the partners as the Secretariat for the Project. In another area, FIC is playing a leading role in advising on the development of the Global Alliance for Improving Nutrition, a public-private sector partnership to enhance global health through food fortification and other nutritional interventions.

### MEETING UNMET GLOBAL HEALTH NEEDS: FISCAL YEAR 2003 INITIATIVES

Translating AIDS and TB advances from bench to bedside in the developing world.—As the global community continues to work to address the paired pandemics of AIDS and TB, donations of anti-AIDS drugs, increased funding from foundations and other circumstances make it possible to consider more aggressive care for those already infected while working to prevent new infections. As countries in the developing world gear up to test new treatment protocols, the need for enhanced clinical research skills and support becomes more and more important. Building on the foundation that FIC and its partners have established over many years, FIC has spearheaded the development of a new program to expand training in AIDS and TB to include clinical, operational and health services research. This program, developed closely with NIH partners as well as with other U.S. agencies and non-governmental groups, will build the capacity in poor countries so that research advances made at the bench may be rapidly translated into the delivery of health care for those who are in greatest need.

Combating Brain Drain from Developing Countries.—As we work to address global health challenges, ensuring that scientists from the developing world who train in the U.S. have opportunities to conduct research on their return home is increasingly critical. To foster their productive "re-entry," FIC and partners at NIH will expand the pilot effort to provide competitive awards to junior scientists from the developing world who have "graduated" from FIC training programs in U.S. universities or who have received training in the NIH intramural laboratories in Bethesda. This program encourages continuity of the scientist-to-scientist: collaboration, builds capacity in global health areas in the developing world, and encourages junior scientists from the developing world to return home because they can establish independent research careers, and builds relationships between our nations.

Addressing the Growing Burden of Brain Disorders.—Mental illness and brain disorders will contribute increasingly to the global burden of disease in the coming decades (Institute of Medicine Report on Neurological, Psychiatric and Developmental Disorders, 2001). In addition to the human suffering associated with these conditions, they contribute to significant losses in economic productivity. FIC will work with partners across NIH to address the challenges of neurological, psychiatric, and developmental disorders in the developing world. In fiscal year 2003, FIC will launch a program to build research capacity in the field of brain disorders while supporting operational research to identify and implement interventions that are relevant, feasible and affordable in low-resource settings. It is expected that the benefits of this program will be realized not only in the developing world but also in the United States, for populations that share genetic and cultural similarities with those in resource-poor settings abroad. The Linkages between Health, Environment, and Economic Development.—Under-

The Linkages between Health, Environment, and Economic Development.—Understanding the linkages between sustainable development, environmental change and health is a great challenge to those who set national health policy, especially in resource-limited nations. Building on current FIC research programs that address the impact of improving health on economic productivity on the one hand, and research to understand the impact of environmental degradation on the other, FIC will launch a new program to more fully understand the relationships between health, environment, and economic development. This research program will focus on the effects of urbanization in low-resource countries, the health effects and consequences of agricultural practices, waterborne diseases, nutrition and food safety, and the economic, social and health costs and benefits of globalization.

Stigma and Global Health.—One of the pervasive problems affecting health globally is the stigma attached to certain diseases and its powerful impact on individuals, families and communities. Stigma inhibits individuals from obtaining diagnostic services or care, and from participating in research studies designed to find solutions to their condition, and results in ostracism, physical harm or even death. As the prevalence of stigmatizing conditions, including AIDS, mental illness, drug use and others, increases in the coming decades, the impact of stigma will also increase. Building on the out-comes of the FIC-led "International Conference on Stigma: Setting a Research Agenda" held in September 2001, FIC and partners across NIH will launch a new research and training program to enhance our understanding of the social and cultural determinants of stigma, both in the United States and in the developing world, and the behavioral responses resulting from stigmatization in different cultural settings. This understanding is fundamental to the identification and testing of effective behavioral interventions.

Trauma and Injury—New Challenges.—Every day the global toll from trauma and injury from all causes is almost 16,000 deaths, and far greater numbers incur permanent disability (WHO Report; 1999). In the coming decades, road traffic accidents, injuries and trauma will contribute increasingly to the global burden of disease. FIC and NIH partners are working to address this challenge through the development of a multidisciplinary program to link basic research on trauma, burns, wound-healing, post-traumatic stress disorders and other conditions with training for scientists from the developing world. One objective is to develop low-cost effective interventions that would be applicable in the developing world as well as within the developed world.

#### CONCLUSION

As we enter the 21st century, the health challenges facing the United States and the global community will continue to converge. With strong scientific partnerships across national borders, we are positioned to tackle shared health problems and to develop shared solutions. The programs of the FIC are critical to building these partnerships and to advancing medical research for the benefit of all the world's people.

The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report, which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

## PREPARED STATEMENT OF DR. 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 2003, a sum of \$315,163,000, which reflects an increase of \$33,411,000 over the comparable fiscal year 2002 appropriation.

It is a phenomenon that has challenged the NLM and changed the way we operate: the ability to freely and instantaneously provide access via the Internet to the information we have accumulated for decades. MEDLINE, our database of more than 11 million references and abstracts to medical journal articles is now being searched 400 million times a year. MEDLINEplus, our extensive information resource for the general public, is viewed 100 million times a year. This activity dwarfs previous usage of the NLM's bibliographic services, whether electronic or print. It has changed fundamentally how the Library operates: how and what it collects, how it preserves information, and how it disseminates biomedical knowledge.

print. It has changed fundamentally how the Library operates: how and what it collects, how it preserves information, and how it disseminates biomedical knowledge. The consequence of this communications revolution is most easily seen in the greatly expanded user community we serve. This community includes not only traditional audiences—health professionals, scientists, educators, students, and librarians—but now, also, for the first time, the general public. Surveys of Internet usage show that health information is one of the most cited reasons for searching the Internet, and we estimate that fully one-third of MEDLINE searching (and almost all of MEDLINEplus usage) is by the public. We believe that the trend toward virtual ubiquity in electronic information access will accelerate and that the NLM must be able to move quickly to ensure that those who need reliable health information have access to it. The effort to double the NIH budget, which is fulfilled in the fiscal year 2002 President's Budget request, makes this a realistic goal for the Library.

An example of NLM's ability to respond rapidly to changing circumstances was its action in putting up on its Web site information about bioterrorism and biowarfare, including extensive information about anthrax and smallpox. NLM information specialists, both medical librarians and specialists in toxicology information, reviewed existing resources and quickly made reliable data available to all. In fact, in the weeks following September 11, more people looked at anthrax information on MEDLINEplus than looked at cancer information.

Despite the NLM's extensive involvement with computer and communications technology, the staff is ever mindful of its responsibility to maintain the integrity of the world's largest collection of medical books and journals. Increasingly, this information is in digital form, and the NLM, as a national library responsible for preserving the scholarly record of biomedicine, is working with the Library of Congress and others to develop a strategy for selecting, organizing, and ensuring permanent access to digital information. Regardless of the format in which the materials are received, ensuring their availability for future generations remains the Library's highest priority.

#### SERVING SCIENTISTS AND THE HEALTH PROFESSIONS

From the fledgling database first mounted in 1971, usable only by trained librarians, MEDLINE has grown into the world's largest bibliographic database of biomedical literature. Anyone with access to the World Wide Web can easily search it. Some 4,600 journals published around the world are currently indexed for MEDLINE. The Library is also converting information from the 1950s into MEDLINE form, so that valuable research information on smallpox and tuberculosis, to take just two pertinent examples, will be available to today's scientists and health professionals.

The sophisticated yet easy-to-use access system for searching MEDLINE on the Web is called PubMed. Since its introduction in 1997, continual improvements have been made, and today PubMed offers a high degree of flexibility to users. For example, it now has links to half of the journals in MEDLINE, permitting access to the full text of articles referenced in the database. Where such links are not available, users may avail themselves of the PubMed feature known as "Loansome Doc" to order an article directly from a library in the National Network of Libraries of Medicine.

A new service to the scientific community is PubMedCentral. This Web-based digital archive of life sciences journal literature was created by NLM's National Center for Biotechnology Information. Publishers electronically send peer-reviewed articles be included in PubMedCentral. A journal may deposit material as soon as it is published, or it may delay release for a specified period of time. NLM guarantees free access to the material; copyright remains with the publisher or the author. There are at present a dozen journals in PubMedCentral, with more soon to come online.

The National Center for Biotechnology Information (NCBI) designs and develops databases to store genomic sequence information and creates automated systems for managing and analyzing knowledge about molecular biology and genetics. With the release of the "working draft" of the human genome in 2001, the global research focus is turning from analysis of specific genes or gene regions to whole genomes, which refers to all of the genes found in cells and tissues. To accommodate this shift in research focus, NCBI has developed a suite of resources to support the comprehensive analysis of the human genome and is thus a key component of the NIH Human Genome Project. NCBI is responsible for all phases of the NIH GenBank database, a collection of all known DNA sequences. GenBank is growing rapidly with contributions received from scientists around the world and now contains more than 13 million sequences and is accessed by 50,000 researchers each day.

Scientists use not only the sequence data stored in GenBank, but avail themselves of the sophisticated computational tools developed by NCBI investigators, such as the BLAST suite of programs for conducting comparative sequence analysis. Entrez is NCBI's integrated database search and retrieval system. It allows users to search enormous amounts of sequence and literature information with techniques that are fast and easy to use. Using this system, one can access NCBI's nucleotide, protein, mapping, taxonomy, genome, structure, and population studies databases, as well as PubMed, the retrieval system for biomedical literature. NCBI's Map Viewer provides graphical displays of features on NCBI's assembly of human genomic sequence data as well as cytogenetic, genetic, physical, and radiation hybrid maps. The public "Human Gene Map" is another example of an important analysis tool developed by NCBI researchers. GeneMap represents an outline of the draft human genome and contains the location of more than 35,000—about half—of all human genes.

#### SERVING THE PUBLIC

There was an unexpected consequence of making MEDLINE freely available on the Web in 1997: what had been a scientific information resource used almost exclusively by medical librarians, scientists, and health professionals was discovered by consumers. NLM estimates that 30 percent of all MEDLINE searching is being done by the public. In an effort to arm the public with more useful information, the NLM, in 1998, introduced MEDLINEplus, a source of authoritative, full-text health information from the NIH institutes and a variety of non-Federal sources.

MEDLINEplus has grown tremendously in its coverage of health and its usage by the public. There were one million unique users in January 2002. The original two dozen "health topics," containing detailed consumer information on various diseases and health conditions, have been increased to more than 550. Other information available through MEDLINEplus includes medical dictionaries, an extensive medical encyclopedia written in lay language with thousands of illustrations, detailed information about more than 9,000 brand name and generic prescription and over-the-counter drugs, information in Spanish, directories of health professionals and hospitals, and links to organizations and libraries that provide health information for the public. The most recent additions to MEDLINEplus are illustrated interactive patient tutorials and a daily news feed from the public media on health-related topics. To be added soon is an information resource called NIHSeniorHealth, which the NLM is preparing in collaboration with the National Institute on Aging.

active patient tutorials and a daily news feed from the public media on health-related topics. To be added soon is an information resource called NIHSeniorHealth, which the NLM is preparing in collaboration with the National Institute on Aging. The 550 MEDLINEplus health topics have links to a database of ongoing and planned scientific studies—ClinicalTrials.gov. This database is a registry of some 5,700 trials for both federally and privately funded trials of experimental treatments for serious or life-threatening diseases. Most of the studies are in the United States and Canada, but about 70 countries are represented in all. ClinicalTrials.gov includes a statement of purpose for each study, together with the recruiting status, the criteria for patient participation in the trial, the location of the trial, and specific contact information.

There are several new NLM databases of interest to the public. One is "CAM on PubMed." This allows users to limit a MEDLINE search to articles about complementary and alternative medicine (CAM). The CAM on PubMed subset currently contains a quarter million references to journal articles related to CAM research. Another new online service is a Web site aimed at the special needs of the inhabitants of the far north. "ArcticHealth," as it is called, provides access to evaluated health information from hundreds of local, state, national, and international agencies, as well as from professional societies and universities. The new site has sections devoted to chronic diseases, behavioral issues, traditional medicine, environment/pollution, and environmental justice.

#### OUTREACH

The National Network of Libraries of Medicine (NN/LM) continues to be the NLM's primary collaborator in outreach to the biomedical community and to the public. The NN/LM consists of 8 Regional Medical Libraries, 150 resource libraries (at medical schools and other major institutions), and 4,400 libraries at hospitals, clinics, and local health institutions. In 2001 the NLM competitively awarded new 5-year contracts to eight institutions to serve as Regional Medical Libraries. The goal of the Network is to provide access to accurate and up-to-date health information for health professionals, patients, families, and the general public, irrespective of their geographic location. The NN/LM places a special emphasis on outreach to underserved populations in an effort to reduce health disparities. For example, there are programs to assist in remedying the disparity in health opportunities experienced by such segments of the American populations.

One highly successful NLM outreach program has been strengthening Historically Black Colleges and Universities so that they can train people to use information resources in dealing with environmental and chemical hazards. Under this program, more than 80 minority institutions have received such training, and it was recently expanded to include a Hispanic serving college and a tribal college. NLM is using these schools as conduits to work with underserved communities in promoting highquality Internet connectivity and the use of technology for research and education. The same NLM division that operates these programs also makes local awards to promote better information access for patients, families, and caretakers dealing with HIV/AIDS. In all these programs dealing with minority populations, NLM seeks to involve a wide variety of grass-roots organizations, from local health departments to churches, schools, and public libraries.

#### RESEARCH AND DEVELOPMENT

The Library remains at the cutting edge of research and development in medical informatics—the intersection of computer technology and the health sciences. It does this both through a program of grants and contracts to university-based researchers and through R & D conducted by the NLM's own scientists. The Library was a leader in the High Performance Computing and Communications initiative of the nine-ties and is presently working to ensure that the health sciences are prepared to take full advantage of the Next Generation Internet. NLM's Lister Hill National Center for Biomedical Communications conducts a wide range of research to improve biomedical communication and also oversees a broad-gauge telemedicine program and the Visible Human Project.

The Library has funded a variety of innovative telemedicine projects that demonstrate the application and use of the capabilities of the Next Generation Internet. "A Clinic in Every Home" is an especially promising telemedicine project with the Iowa Department of Public Health and the University of Iowa. Building on work successfully done under an existing contract with NLM, this project is providing a test-bed for medically underserved rural Iowa residents to provide them with access to high quality health care. The expectation is that using such a system will both raise the quality of health care and lower health care costs.

Applications involving the Visible Humans will also use the expanded capabilities of the Next Generation Internet. The Visible Human male and female data sets, consisting of MRI, CT, and photographic cryosection images, are huge, totaling some 50 gigabytes. The datasets are licensed to scientists at more than 1,400 institutions around the world. Projects range from teaching anatomy to practicing endoscopic procedures to rehearsing surgery. One new aspect of the Visible Human evolution is the project to develop an extremely detailed atlas of the head and neck in collaboration with four NIH Institutes and the National Science Foundation. The application of cutting edge technologies in this project will allow interactive dissection of anatomic structure and "fly-through" anatomic relationships, for example, traveling down the optic nerve and viewing the ophthalmic artery and its tributaries.

NLM Extramural Programs have an important role in supporting R&D in biocommunications. One timely example is the early warning public health surveillance system developed at the University of Pittsburgh and recently demonstrated to the President. NLM's grant program also is a key supporter of NIH's "Biomedical Information Science and Technology Initiative." The Library is funding 12 training programs at universities across the nation for the express purpose of training experts to carry out research in general informatics and in the genome-related specialty of bioinformatics. The NLM has recently augmented each of the training programs with a "BISTI supplement" and has also funded two planning grants that will eventually lead to the development of what are called National Programs of Excellence in Biomedical Computing.

tually lead to the development of an acceleration of the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's third annual performance report which compared our fiscal year 2001 results to the goals of our fiscal year 2001 performance plan.

### PREPARED STATEMENT OF DR. YVONNE T. MADDOX

Mr. Chairmen, Members of the Committee: I am pleased to present the President's budget request for the Office of the Director (OD) for fiscal year 2003, a sum of \$258,544,000 which reflects an increase of \$19,720,000 over the comparable fiscal year 2002 appropriation. The OD provides leadership, coordination, and guidance in the formulation of policy and procedures related to biomedical research and research training programs. The OD also is responsible for a number of special programs and for management of centralized support services to the operations of the entire NIH.

The OD guides and supports research by setting priorities; allocating funding among these priorities; developing policies based on scientific opportunities and ethical and legal considerations; maintaining peer review processes; providing oversight of grant and contract award functions and of intramural research; communicating health information to the public; facilitating the transfer of technology to the private sector; and providing fundamental management and administrative services such as budget and 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), and the Offices of: Science Policy; Communications and Public Liaison; Legislative Policy and Analysis; Equal Opportunity; Budget; and Management. This request contains funds to support the functions of these offices.

In addition, the OD also maintains several trans-NIH offices and programs to foster and encourage research on specific, important health needs; I will now discuss the budget request for each of these trans-NIH offices in greater detail.

### THE OFFICE OF AIDS RESEARCH

In response to the AIDS pandemic, NIH has developed a comprehensive biomedical and behavioral research program to better understand the basic biology of HIV, develop effective therapies to treat it, and design interventions to prevent new infections from occurring. The role of the Office of AIDS Research (OAR) is to plan and coordinate this research program that is sponsored by 25 NIH Institutes and Centers (IC's); to serve as a focal point for AIDS policy and budget development; and to monitor and foster plans for NIH involvement in international AIDS research activities.

The OAR develops an annual comprehensive AIDS research plan and budget, based on the most compelling scientific priorities that will lead to better therapies and prevention for HIV infection and AIDS. Those priorities are determined through a unique and collaborative process involving the NIH institutes and non-government experts from academia and industry, with the full participation of AIDS community representatives. The plan is divided into five Scientific Areas of Emphasis and four Areas of Special Interest. The plan serves as a framework for developing the NIH AIDS budget, for determining the use of NIH AIDS-designated dollars, and for tracking and monitoring those expenditures. The fiscal year 2003 budget request for OAR is \$58.3 million.

### THE OFFICE OF RESEARCH ON WOMEN'S HEALTH

The Office of Research on Women's Health (ORWH) is the focal point for women's health research at NIH and strives to ensure that research supported by NIH addresses the health concerns of women, that women are appropriately included as subjects in clinical research, and that women are encouraged to pursue and succeed in careers in biomedical research.

Subjects in biomedical research. The priorities for research and the science-based initiatives of ORWH are based on the recommendations in the report of the Task Force on the NIH Women's Health Research Agenda for the 21st Century, "An Agenda for Research on Women's Health for the 21st Century" with consideration of new advances in science and continuing gaps in knowledge. ORWH will strive to address these scientific initiatives about women's health and sex and gender factors in disease. In fiscal year 2003, the OD budget request of \$40.7 million includes an increase of \$3.3 million over the fiscal year 2002 enacted budget of \$37.3 million for ORWH to implement recommendations within this agenda, including the prevention and detection of ovarian and cervical cancer, new and emerging issues surrounding the inclusion of women in clinical studies, successful aging and health-related quality of life issues, sex and gender differences in health and disease, developing an initiative with OAR to address priorities for prevention, care, treatment, and support for girls and women with HIV/AIDS, research regarding women and eye disease, and reproductive health including the full range of gynecologic and obstetrical conditions, fibroids, and the menopausal transition.

ORWH will support centers for research and career development including a cadre of interdisciplinary researchers doing women's health research. ORWH, NIH IC's, and the Agency for Healthcare Research and Quality will support career development programs that promote the pursuit of interdisciplinary research careers relevant to women's health and encourage basic and clinical research careers. ORWH will also encourage networks of interdisciplinary researchers by providing opportunities for them to meet yearly and exchange ideas and experiences at NIH. In addition, ORWH and the NIH IC'S will support Specialized Centers of Research on Sex and Gender Factors Affecting Women's Health to study and advance interdisciplinary research to better understand the basic molecular, cellular, and physiologic mechanisms underlying the response of both women and men to therapeutic interventions and hormonal factors. Finally, ORWH will continue to work with OER and OIR to monitor compliance with and facilitate analysis by gender of the policies for the inclusion of women and minorities in clinical research.

### THE OFFICE OF BEHAVIORAL AND SOCIAL SCIENCES RESEARCH

NIH has become increasingly aware of the importance of the contributions from behavioral and social sciences research to improving the health of the population. The Office of Behavioral and Social Sciences Research (OBSSR) provides leadership within the NIH community in identifying and implementing research programs in behavioral and social sciences that are likely to improve our understanding of the processes underlying health and disease and provide directions for intervention. OBSSR works to integrate a behavioral and social science approach across the programs of the NIH. The fiscal year 2003 OD budget includes \$25.8 million for OBSSR, an increase of over \$2 million or 9 percent above the fiscal year 2002 appropriation.

In its efforts to increase support for behavioral and social sciences research, OBSSR frequently identifies important topics that have relevance across many NIH IC's. One such initiative that OBSSR is developing is in the area of environmental influences on gene expression. The dramatic advances in genetic research in the recent past have only served to underscore that health outcomes are a result of interplay between genetic make-up and environmental influences. While the human genome has been characterized, the environment is less well understood. OBSSR, in collaboration with several Institutes, is undertaking an initiative to improve the understanding of the key environmental factors that affect gene expression and health.

While the results of many behavioral and social science studies hold great promise for improving health, the incorporation of those results into health care is often slow or nonexistent. OBSSR is joining with several NIH Institutes to explore opportunities to work with the Centers for Disease Control and Prevention and the Agency for Healthcare Research and Quality to improve the translation of evidence-based behavioral and social interventions into health care.

Many of the most exciting scientific developments are occurring at the intersection of behavioral and social science research and biomedical research. OBSSR and several IC's are in the process of developing new approaches to training individuals to be prepared to undertake a program of research that extends well beyond traditional disciplinary boundaries.

### THE OFFICE OF DISEASE PREVENTION

The Office of Disease Prevention (ODP) has several specific programs/offices that strive to place new emphasis on the prevention and treatment of disease. In fiscal year 2003, the Office of Dietary Supplements (ODS) within ODP will con-

In fiscal year 2003, the Office of Dietary Supplements (ODS) within ODP will continue to promote the scientific study of the use of dietary supplements. The Office will continue to support investigator-initiated research through the Research Enhancement Awards Program (REAP) and through program announcements with other IC's at NIH. The Office will also stimulate research through conduct of conferences, workshops, and presentations at national and international meetings. In continuing efforts to inform the public about the benefits and risks of dietary supplements, the ODS expanded the International Bibliographic Information on Dietary Supplements database to include a consumer-oriented search strategy. ODS is nearing completion of public-oriented information pages (Fact Sheets) about specific vitamin and mineral dietary supplements for wide dissemination in print and on the Internet. These are to be followed by a series of Fact Sheets for botanical and herbal supplements, which are being developed in conjunction with the National Center for Complementary and Alternative Medicine. The fiscal year 2003 budget request for ODS is \$18.5 million.

In fiscal year 2002, ODS will commission an evidence-based review on the relationship between omega-3 fatty acids and coronary heart disease. A report of the review, done in collaboration with the National Institute of Heart Lung and Blood Institute and other NIH IC's, will be available in fiscal year 2003. The results of the report will serve as the basis for planning an NIH research agenda on omega-3 fatty acids. To determine the efficacy and safety of dietary supplements containing ephedra, ODS with other Federal partners, commissioned an evidence-based review of ephedra efficacy and safety. This report is currently being drafted and will be available late summer, 2002. ODS has also nominated ephedra for study by the National Toxicology Program of the National Institute of Environmental Health Sciences.

Congressional language in the fiscal year 2002 appropriation report has directed ODS to enhance an ongoing collaboration for the development, validation, and dissemination of analytical methods and reference materials for botanical dietary supplements. ODS will work with other Federal partners, non-governmental organizations, industry, and academia to meet this objective. In February 2002, ODS held a public stakeholder's meeting to receive comment on the development and validation of analytical methods and reference materials for dietary supplement products.

Another component of ODP, the Office of Rare Diseases (ORD), develops and disseminates information to patients and their families, health care providers, patient support groups, and others and forges links among investigators with ongoing research activities in this area. The ORD continues to support workshops and symposia to stimulate research and to identify research opportunities related to rare diseases. To provide better and faster information, ORD, together with the National Human Genome Research Institute (NHGRI), established the Genetic and Rare Diseases Information Center to respond to requests for information about genetic and rare disorders. The fiscal year 2003 budget request for ORD is \$11.3 million.

The ORD is also planning to respond to the critical needs of patients with rare, life threatening diseases by establishing regional and intramural centers of excellence. These centers will support rare diseases research and diagnostic research that will eventually benefit many of those patients whose diagnoses have been elusive despite extensive prior efforts to determine the exact nature of their illnesses.

### THE OFFICE OF SCIENCE EDUCATION

The Office of Science Education (OSE) plans, develops, and coordinates a comprehensive science education program to strengthen and enhance efforts of the NIH to attract young people to biomedical and behavioral science careers and to improve science literacy in both adults and children. The Office develops, supports, and directs new program initiatives at all levels with special emphasis on targeting students in grades kindergarten to 12, their educators and parents, and the general public. It maintains a website as a central source of information about NIH science education resources, establishes national model programs in public science education, such as the NIH Mini-Med School, and promotes science education reform as outlined in the National Science Education Standards and related guidelines. OSE works closely with the NIH extramural, intramural, women's health, laboratory animal research, and minority program offices on science education special issues and programs to ensure coordination of NIH efforts.

Begun in fiscal year 1997 as a major new initiative in collaboration with the NIH institutes and centers, the Office of Science Education (OSE) develops and distributes standards-based curriculum supplements for use in K-12 classrooms. These supplements are distributed free-of-charge to science teachers and school administrators throughout the United States, and are designed to complement existing life science curricula that are used at the state and local levels. The NIH Curriculum Supplements align with the National Science Education Standards; incorporate inquiry-based learning activities; promote peer collaboration, problem solving, and critical thinking skills; and include cutting-edge science and up-to-date medical research findings that are translated into real-world scenarios.

As of summer 2001, over 40,000 copies of the first three titles in the series (*Cell Biology and Cancer, Emerging and Reemerging Infectious Diseases, and Human Genetic Variation*) have been distributed to teachers across the nation. This represents a potential audience of more than 1.5 million high school students. Preliminary evaluation research of the effectiveness of the curriculum supplements conducted in New York City has yielded promising results. Students' ratings of how well the material covered was connected to their lives were 96 percent higher in classrooms using the NIH Curriculum Supplements. Students using the NIH Curriculum Supplements also out-performed their peers on a standardized test of science achievement.

## LOAN REPAYMENT AND SCHOLARSHIP PROGRAM

The NIH, through the OIR maintains the Loan Repayment and Scholarship Program (LRSP). The LRSP supports the following programs: the Clinical Research Loan Repayment Program for the repayment of the educational debt of awardees if they agree to conduct clinical research as NIH employees; the Undergraduate Scholarship Program in which scholars agree to serve as NIH employees after graduation, one year for each year of scholarship support received; and the General Research Loan Repayment Program which provides support for physicians and scientists engaged in both basic and clinical research activities at the NIH. Technical and logistical support is also provided for two extramural loan repayment programs funded with the IC's.

Thank you for giving me the opportunity to present this statement; I will be pleased to answer questions.

### PREPARED STATEMENT OF DR. 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 NIH for fiscal year 2003, a sum of \$2,769,997,000 an increase of \$255,043,000 above the comparable fiscal year 2002 appropriation. The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second performance report which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan.

The NIH represents the largest and most significant public investment in AIDS research in the world. It supports a comprehensive program of basic, clinical, and behavioral research on HIV infection and its associated opportunistic infections and malignancies that will lead to a better understanding of the basic biology of HIV, the development of effective therapies to treat it, and the design of better interventions to prevent new infections. Perhaps no other disease so thoroughly transcends every area of clinical medicine and scientific investigation, crossing the boundaries

of the NIH institutes. The Office of AIDS Research (OAR) plays a unique role at the NIH. The OAR, fulfilling its Congressional mandate, coordinates the scientific, budgetary, and policy elements of the NIH AIDS program, supported by nearly every Institute and Center; prepares an annual comprehensive trans-NIH plan and budget for all NIH-sponsored AIDS research; facilitates NIH involvement in international AIDS research activities; and identifies and facilitates scientific programs for multi-institute participation in priority areas of research.

### THE EXPLODING PANDEMIC

The December 2001 AIDS Epidemic Update of the Joint United Nations Programme on HIV/AIDS (UNAIDS) states, "AIDS has become the most devastating disease humankind has ever faced." Since the epidemic began, nearly 60 million people worldwide have been infected with HIV. UNAIDS reported that AIDS has killed more than 22 million people, surpassing tuberculosis and malaria as the leading infectious cause of death worldwide. The impact of AIDS on developing nations and many countries of the former Soviet Union is profound, with even greater potential disaster still to come. The UNAIDS report states, "the epidemic is driving a ruthless cycle of impoverishment." AIDS is reversing decades of progress from important public health efforts, lowering life expectancy, and significantly affecting education, agricultural output, and commerce of all kinds. Lost productivity and profitability, the cost of sickness and death benefits, and the decline in a skilled workforce in the developing world will have economic effects worldwide. AIDS is affecting the military capabilities of some countries as well as the international peacekeeping forces. In Africa, the epicenter of the pandemic, AIDS is sabotaging economic development, leading to massive social breakdown, and creating a generation of orphans. If the global spread of HIV/AIDS continues unchecked, South and Southeast Asia, and perhaps China will follow the disastrous course of sub-Saharan Africa. AIDS remains a serious threat in Latin America and the Caribbean. UNAIDS also reports that HIV incidence now is rising faster in Eastern Europe and Central Asia than anywhere in the world, with a 15-fold increase in reported new infections in the Russian Federation in just the past three years.

### THE AIDS EPIDEMIC IN THE UNITED STATES

In the United States, the HIV/AIDS epidemic continues to expand and evolve, presenting new and complex scientific challenges. The Centers for Disease Control and Prevention (CDC) reported last month that the total number of individuals living with HIV in the United States is increasing as the use of antiretroviral therapies has prolonged the lives of HIV-infected individuals. At the same time, the rate of new HIV infections has not declined in over a decade, remaining at approximately 40,000 new cases each year. This means that the overall epidemic is continuing to expand. HIV infection rates are continuing to climb among women, racial and ethnic minorities, young homosexual men, individuals with addictive disorders, and people over 50 years of age.

An additional concern is that although antiretroviral regimens have extended the length and quality of life for many HIV-infected individuals in the United States and Western Europe, unfortunately a growing proportion of patients receiving these therapies are now experiencing treatment failure. Some patients find it difficult or impossible to comply with arduous treatment regimens, develop toxicities and sideeffects, or fail to obtain a satisfactory reduction in viral load even while adhering to treatment regimens. In addition, serious complications, including heart, liver, and kidney problems, insulin resistance, and body composition changes such as deforming fat deposits, have emerged in individuals who have been on long-term antiretroviral regimens. An increasing number of treatment failures are linked to the increasing emergence of drug-resistant HIV, presenting another serious public health concern.

## COMPREHENSIVE AIDS RESEARCH PLAN AND BUDGET

To address the compelling scientific questions that this worldwide epidemic presents, the OAR develops an annual comprehensive trans-NIH AIDS research plan and budget, based on the most compelling scientific priorities and opportunities that will lead to better therapies and prevention strategies for HIV infection and AIDS. The planning process is inclusive and collaborative, involving the NIH institutes as well as eminent non-government experts from academia, foundations, and industry, with the full participation of AIDS community representatives. The Plan is also unique, as it serves as the framework for developing the annual AIDS research budget for each Institute and Center, for determining the use of AIDS-designated dollars, and for tracking and monitoring those expenditures. The Plan establishes the NIH AIDS scientific agenda for the Scientific Areas of Emphasis of AIDS research: Natural History and Epidemiology; Etiology and Pathogenesis; Therapeutics; Vaccines; and Behavioral and Social Science. As the epidemic expanded, we recognized that we also needed to take a planning approach that cross-cut these scientific areas. Thus, the Plan also addresses the critical cross-cutting areas of Racial and Ethnic Minorities; Women and Girls; Microbicides; Prevention; International Research; Training, Infrastructure, and Capacity Building; and Information Dissemination.

The Plan initiates the budget development process. Based on the objectives and priorities established in the Plan, the Institutes and Centers submit their AIDS research budget requests to OAR, focusing on new or expanded program initiatives for each scientific area. The OAR reviews the IC initiatives in relation to the Plan, to OAR priorities, and to other IC submissions to eliminate redundancy and/or to assure cross-institute collaboration. The law requires that the NIH Director and the OAR Director shall together determine the total amount allocated for AIDS research. Within that total, the OAR allocates the AIDS research budget levels to each IC based on the scientific priority of the proposed initiatives at each step of the budget development process up to the time of the Conference Committee. This involves consulting regularly with the IC Directors. This process allows the OAR to ensure that NIH AIDS research funds will be provided to the most compelling scientific opportunities, rather than distribution based solely on a formula. The overarching themes that continue to frame the NIH AIDS research agenda are: prevention research, including development of vaccines, microbicides, and beparities interventions, critically needed to reduce HIV transmission; therapeutics

The overarching themes that continue to frame the NIH AIDS research agenda are: prevention research, including development of vaccines, microbicides, and behavioral interventions, critically needed to reduce HIV transmission; therapeutics research to develop simpler, less toxic, and cheaper drugs and drug regimens to treat HIV infection and its associated illnesses, malignancies, and other complications; international research, particularly to address the critical needs in developing countries; and research targeting the disproportionate impact of AIDS on minority populations in the United States. All of these efforts require a strong foundation of basic science, the bedrock of our research endeavor.

### TRANS-NIH COORDINATION

OAR plays a crucial role in identifying scientific areas that require focused attention and facilitating multi-institute activities addressing those needs. This is a twoway process. In some cases these issues are raised within OAR and shared with the Institutes; in other cases, an one or more Institutes may ask the OAR to bring other Institutes together to address an area of research or a specific grant or project. OAR can foster this research through a number of mechanisms, such as establishing working groups or committees; sponsoring workshops or conferences to highlight a particular research topic; sponsoring reviews or evaluations of research program areas to identify gaps or needs; and designating funds and supplements to jumpstart or pilot program areas.

For example, a number of years ago OAR identified microbicides research as an area needing additional attention on the part of a number of Institutes. Microbicides research has proved particularly challenging, as there is no definitive clinical evidence as yet establishing that a product applied topically in humans can prevent HIV infection. Microbicides research requires a complex multidisciplinary and multisectoral approach by teams of scientists with a broad array of expertise, with in creased pharmaceutical company involvement. To address this important need, OAR established a Trans-NIH Microbicides Working Group, comprised of program staff of relevant institutes and offices, which worked together to help plan the first international conference on microbicides. There are many more examples where OAR has played a key role in coordinating institute participation in a specific research project, such as the NIAID-sponsored multi-institute HIV Prevention Trials Network, and the Adolescent Trials Network, sponsored by NICHD and co-supported by a number of other institutes. OAR coordinated the efforts of NIDDK and other institutes in supporting a highly meritorious and innovative research project to comprehensively study the serious metabolic side-effects and complications of antiretroviral therapy. Insight gained from this multi-site collaborative study will have direct impact on the development of better tretment regimens for HIV-infected individuals.

### INTERNATIONAL RESEARCH

To address the increasing urgency of the AIDS pandemic, the OAR has established a new initiative and strategic plan for global research on HIV/AIDS aimed at slowing the disaster and reversing its destruction of communities, economies, and nations worldwide. The Global AIDS Research Initiative and Strategic Plan reaffirms NIH's long-standing commitment to international AIDS research and will significantly increase research efforts in the coming year to benefit resource- and infrastructure-poor nations. NIH supports a growing portfolio of research conducted in collaboration with investigators in developing countries. Results of this research benefit the people in the country where the research is conducted as well as people affected by HIV/AIDS worldwide. Critical to the success of these international studies are foreign scientists who are full and equal partners in the design and conduct of collaborative studies. To that end, NIH also supports international training programs and initiatives that help build infrastructure and laboratory capacity in developing countries where the research is conducted.

#### RACIAL AND ETHNIC MINORITIES

OAR has placed high priority on research to address the disproportionate impact of the HIV/AIDS epidemic on racial and ethnic minority communities in the United States. OAR is directing increased resources toward new interventions that will have the greatest impact on these groups and making significant investments to improve research infrastructure and training opportunities for minorities. OAR has provided additional funds to projects aimed at: increasing the number of minority investigators conducting behavioral and clinical research; targeting the links between substance abuse, sexual behaviors and HIV infection; increasing outreach education programs targeting minority physicians and at-risk populations; and expanding our portfolio of population-based research. OAR also has initiated a series of Training and Career Development Workshops specifically designed for racial and ethnic minority investigators.

#### SUMMARY

The worldwide human and economic toll of this insidious disease is profound. Our response requires a unique and complex multi-institute, multi-disciplinary, global research program. This diverse research portfolio demands an unprecedented level of scientific coordination and management of research funds to enhance collaboration, minimize duplication, and ensure that precious research dollars are invested in the highest priority areas of scientific opportunity. The nation's investment in AIDS research is reaping even greater dividends, as AIDS research is unraveling the mysteries surrounding many other infectious, malignant, neurologic, auto-immune, and metabolic diseases.

The authorities of the Office of AIDS Research allow NIH to pursue a united research front against the global AIDS epidemic. We are deeply grateful for the continued support this Committee has provided to our efforts.

## PREPARED STATEMENT OF STEPHEN A. FICCA

Mr. Chairman and Members of the Committee: I am pleased to present the President's budget request for the Buildings and Facilities (B&F) Program for fiscal year 2003, a sum of \$632,800,000, which reflects an increase of \$306,700,000 over the comparable fiscal year 2002 appropriation.

#### ROLE IN THE RESEARCH MISSION

The fiscal year 2003 Budget establishes a new HHS Facilities Construction and Management fund that will finance all construction projects for NIH and CDC within the Office of the Secretary. The fund will allow HHS to prioritize and manage construction projects effectively.

The Buildings and Facilities (B&F) program supports the physical infrastructure required to carry out the in-house component of the biomedical research mission of the National Institutes of Health (NIH). In turn, the fiscal year 2003 Buildings and Facilities budget request supports long-standing commitments to create, expand, and sustain a robust, modern, safe and secure physical infrastructure for the conduct of basic and clinical research across the spectrum of biologic systems and diseases. It also provides new, specialized containment facilities in which the United States will conduct research on a variety of biologic materials that present a health threat as emerging infections and/or bioterrorism agents.

The NIH B&F plan is the product of a deliberate strategic planning and priority setting process. This process is overseen by the NIH Facilities Planning Advisory Committee (FPAC) and captured in the NIH Strategic Facilities Plan. The FPAC, comprised of Institute Directors and other senior IC scientific and management staff, advises the NIH Leadership and Director on the long-range capital facilities investments that are needed to sustain NIH research programs and priorities. The FPAC is also instrumental in adjusting priorities as necessary to deal with unanticipated public health challenges and changes in national priorities. The goal of the planning process is to optimally meet the changing facility needs of the NIH research programs in the Washington, D.C., region and across the NIH field stations with a mix of owned and leased facilities.

with a mix of owned and leased facilities. The NIH Strategic Facilities Plan is structured as a logical sequence of programs and projects orchestrated to enable the NIH to build facilities critical to new and expanding research initiatives and programs and to concurrently manage and maintain existing NIH real estate assets.

The construction program supported by the proposed fiscal year 2003 budget request strikes a balance among three critical facility priorities: the creation of new facilities for new and expanding scientific opportunities, as well as for research on biologic materials that present a health threat as emerging infections and/or bioterrorism agents; the upgrading of existing facilities to keep pace with the changing requirements of ongoing NIH programs, and the responsible stewardship of the entire NIH real estate portfolio. The fiscal year 2003 B&F proposal is organized into six broad Program Activities: New Construction; Essential Safety and Regulatory Compliance; Physical Security Improvements; Repairs and Improvements; Renovations; and Equipment and Systems. The fiscal year 2003 request provides funds for specific projects in each of the program areas. The projects and programs enumerated are the end result of the aforementioned NIH Strategic Facilities Planning process and are the NIH's capital facility priorities for fiscal year 2003. The fiscal year 2003 B&F budget request of \$632,800,000 is an increase of \$306,700,000 from the comparable fiscal year 2002 level. As a result of this increase, the NIH will be able to fulfill its commitment to integrating neuroscience research in the John Edward Porter Neuroscience Research Center; maintain responsible funding support for the ongoing essential safety, renovation, repair and related

The fiscal year 2003 B&F budget request of \$632,800,000 is an increase of \$306,700,000 from the comparable fiscal year 2002 level. As a result of this increase, the NIH will be able to fulfill its commitment to integrating neuroscience research in the John Edward Porter Neuroscience Research Center; maintain responsible funding support for the ongoing essential safety, renovation, repair and related projects that are vital to proper stewardship of the entire portfolio of real property assets; continue with the integration of the new Mark O. Hatfield Clinical Research Center (CRC) into old Building 10; increase the physical security of NIH facilities; and at Ft. Detrick.

The John Edward Porter Neuroscience Research Center will enable the integration of the neuroscience research community at the NIH. The Center is conceived as a place where the best and brightest scientists from many disciplines will collaborate in state-of-the-art laboratories to develop and evaluate therapies for some of the most complex problems in biomedical research. The Center will house researchers from nine Institutes and multiple disciplines under one roof. It will be designed to support high-priority research initiatives using innovative strategies in cell biology, neuroimaging and bio-informatics to better describe the link between biochemistry and behavior, to elucidate the nerve cell degenerative processes, and to explore other lines of inquiry that are emerging from the genetic mapping of the brain. New facilities are needed to support this vision because nearly all of the space that houses NIH neuroscience research is substandard. Current facilities for cellular and molecular neuroscience on campus are inadequate to meet the challenges of highquality, high-risk research projects. The fiscal year 2003 request would support the construction of the second phase of this facilities project; Congress appropriated funds for the first phase in fiscal year 2001 and 2002. The fiscal year 2003 Building and Facilities budget request also contains major facility investments that are a response to the United States' heightened attention

The fiscal year 2003 Building and Facilities budget request also contains major facility investments that are a response to the United States' heightened attention to Homeland Security. These include construction of a set of high-containment facilities at the Bethesda, Maryland, campus and at Ft. Detrick, Maryland, as well as a series of projects that will substantially increase the physical security of NIH facilities.

While NIH continues to take advantage of unique research opportunities for new treatments and cures, the recent tragic events have revealed the need for an expanded program of medical research on all aspects of bioterrorism. The capability to detect and counter terrorism depends to a substantial degree on the relevant medical science and basic research. There is an increased need for basic research to accelerate knowledge of the physiology and genetics of potential bioterrorism agents, immune system function, and response to each agent, and the pathogenesis of each disease, and for tests to rapidly diagnose, vaccines and immunotherapies to prevent, and drugs and biologics to treat diseases caused by agents of bioterrorism. The massive research agenda required to protect the American population against present and future attacks by these agents must include construction of facilities in which such agents may be safely studied. Facilities and procedures for the handling of these lethal agents with no threat to laboratory and clinical personnel or

to adjacent communities comprise an integral element of the research program. These proposals for new construction, renovations and improvements are key elements to responding to the new research agenda while ensuring the continued vitality of the NIH biomedical research enterprise.

### FISCAL YEAR 2003 BUDGET SUMMARY

The fiscal year 2003 budget request for Buildings and Facilities is \$632.8 million. The B&F request totals \$464.1 million for new construction composed of \$4 million for the information technology infrastructure to complete the first phase of construction of the John E. Porter Neuroscience Research Center; \$168 million to fund the construction of the second phase of the Center; \$186.1 million to construct the Center for Bioterrorism and Emerging Infections—new laboratory space on the NIH Be-thesda campus for rapid response programs dealing with select infectious agents that may be used as weapons of bioterrorism and other emerging infections; \$105 million to construct a Biosafety Level 4 (BSL-4) Lab/Clinic at Ft. Detrick, Maryland, that will provide the specialized, highcontainment lab facilities needed to conduct biomedical research on the most dangerous and highly infectious diseases that could become or have been bioterrorism weapons; and \$1 million to continue the Concept Development Studies program. There is a total of \$6 million for essential safety and regulatory compliance programs composed of a combined sum of \$0.5 million for the phased removal of asbestos from NIH buildings; \$2 million for the continuing up-grade of fire and life safety deficiencies of NIH buildings; \$1 million to systematically remove existing barriers to persons with disabilities from the interior of NIH buildings; \$0.5 million to address indoor air quality concerns and requirements at NIH facilities; and \$2 million for the continued support of the rehabilitation of animal research facilities. For physical security improvements, the request includes \$80 million to bolster NIH's ability to provide a safe and secure environment for the con-duct of the NIH mission on its sites. In addition, the fiscal year 2003 request includes \$56.5 million for the continuing program of repairs, improvements, and maintenance that is the core of the B&F program; \$24.2 million for the Building 10 transition program; and \$2 million to upgrade mechanical systems at NIEHS.

### GOVERNMENT PERFORMANCE AND RESULTS ACT (GPRA)

The NIH budget request includes the performance information required by the Government Performance and Results Act (GPRA) of 1993. Prominent in the performance data is NIH's second annual performance report which compared our fiscal year 2001 results to the goals in our fiscal year 2001 performance plan. My colleagues and I will be happy to respond to any questions you may have.

Senator HARKIN. Thank you very much, Dr. Kirschstein. I just want to get in a little bit on that loan repayment. I am not certain I understand it all, but before I do that, I would like to yield to Senator Cochran for any opening statement.

# OPENING STATEMENT OF SENATOR THAD COCHRAN

# Senator COCHRAN. Mr. Chairman, thank you very much.

Dr. Kirschstein, I want to congratulate you on the outstanding job you have done as interim director. I think it has been clear, from my point of view, that you have not just been an interim director, you have actually moved NIH forward in some very innovative and impressive ways, and I congratulate you for that and say that we look forward to continuing to work with you in the future.

# PREPARED STATEMENT

I have some additional comments for the record, Mr. Chairman, which I would like to put in the record.

[The statement follows:]

### STATEMENT OF SENATOR THAD COCHRAN

Dr. Kirschstein, thank you for joining us today to discuss the National Institutes of Health budget. We have focused much effort on increasing this budget over the past several years and appreciate the opportunity to hear how these increases are leading to better medicine.

I want you to know we continue to support increases in NIH funding. We have had great success in increasing NIH Appropriations. However, as we continue to move forward we must strive to improve the quality of the research. And, we must strive to focus this research on the most pressing health issues. Our goal should be to make sure this research benefits all Americans.

One example of such research is the Jackson Heart Study. This study is a collaborative effort of the University of Mississippi Medical Center, Jackson State University and Tougaloo College, and it is one of the major, groundbreaking studies in the area of cardiovascular disease in African-Americans. Another example I am familiar with is the new National Institute of Biomedical

Another example I am familiar with is the new National Institute of Biomedical Imaging and Bioengineering. I believe imaging and related technologies fill an important gap in both diagnosis and treatment of disease. Such technologies expand the ability to practice innovative medicine in every rural and underserved area of our country.

One of the ways we move this technology to underserved areas is through the coordination of activities and technologies of the NIH and other federal agencies. For example, at the Medical Center at the University of Mississippi we have the ability to utilize NASA satellite imaging technology to perform surgery in Japan or even perform emergency surgery aboard the space shuttle while it is in orbit.

Now, if we can use this technology to reach these far away places, we can surely find ways to use the technology at the University of Mississippi, or University of Iowa Medical Center, to reach rural, underserved areas of the country. This is just one example of how we should insist on developing new technologies through integrated partnerships and make sure we translate these technologies into practical strategies that reach patients. I support your efforts in this area and look forward to the future.

Research directed toward underserved areas must increase. And I believe it is essential for some of this research to be conducted in the areas of the country where the most urgent health needs exist. Research and the reason for the research must intersect. Researchers in these underserved areas know far better the challenges facing their patients.

While we will always insist on the most scientifically sound research, we must find ways to build the research infrastructure. The NIH should take an active role in making sure research reaches the underserved areas of our country. I look forward to hearing how we can continue to address this issue. I'm interested in helping NIH succeed in this effort.

Finally, Dr. Kirschstein, I want to thank you for your leadership on both the budget and your leadership of the NIH. You have gone beyond serving in an interim capacity. You have not only guided the NIH through a time of transition, you have moved it forward. The next director must now be prepared to continue that forward, innovative movement. The health of Americans depends on it. Thank you.

Dr. KIRSCHSTEIN. May I just say thank you, Mr. Cochran.

Senator HARKIN. Thank you, Senator Cochran.

We are now joined by our ranking member and, as I said earlier, one of the driving forces behind the doubling of NIH which we are accomplishing this year. I said it before, but I will say it again. It could not have happened without the leadership of Senator Specter.

## OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. Well, thank you very much, Mr. Chairman. I consider it a partnership. I liked it a little better when I was the chairman.

But I like it with your being the chairman.

We have shown on this committee and Senator Cochran who is soon to be ranking and soon to be chairman of the full Appropriations Committee. We function in a nonpartisan way, and I learned a long time ago, if you want to get something done in Washington, you have to cross party lines. And this subcommittee is exhibit A on doing that. To paraphrase John Kennedy, the brain power assembled in this room today exceeds that when Jefferson died alone.

This is the Federal Government's premier group in my opinion. I get into trouble with everybody else in the Federal Government, but I think that the NIH is the crown jewel of the Federal Government and sometimes I say perhaps the only jewel.

This subcommittee, as you know, has taken the lead on the funding. A few years ago, it was \$11 billion, and now it is \$23 billion. And now it is very fashionable. And the President's budget adds \$3.7 billion.

When we first started to add the first billion dollars to NIH, we asked the Budget Committee for it, got turned down, and went to the floor and lost 63 to 37. But this subcommittee got out a sharp pencil and found a billion from priorities.

So, having lost on our effort to get an extra billion, the next year we asked for \$2 billion. That is the way you do business in Washington. We got turned down again. But we found the money on priorities and the last vote that we had was 96 to 4, and the 4 dissenters agreed that NIH was important but thought that we should be giving others some extra funding.

But we have taken very special care of your institutes because of the great progress you have made, and you have a very heavy burden to produce. You have got to produce. And it is not possible for us to have the kind of congressional oversight to get into your business, and you do not really want us there, but you are great professionals.

We have had the stem cell battle, and you know all about that. Now we have got the therapeutic cloning battle. The next time you give a label to something, please do not call nuclear transplants cloning. We face a real tough battle, and there has to be a mobilization nationally.

Bettilou Taylor has drafted a letter which we have sent to every newspaper in the country to try to mobilize a vote which we are going to have in the Senate on legislation which would ban socalled therapeutic cloning. We will have a great export of brains if that happens. It will tie your hands and tie the hands of scientists. So, we have our work cut out.

I am delighted to be here and look forward to the testimony. Thank you, Mr. Chairman.

Senator HARKIN. Thank you, Senator Specter.

Senator SPECTER. If I might just add, we have on the floor today a battle on Federal nominations for the judiciary. We had a big battle last week, as you know, about Judge Pickering, and Senator Lott has filed a motion to give hearings to all the judges who were nominated last May 9 at least by this May 9. So, I am going to have to excuse myself at a point earlier than I would like to, but I will follow the testimony very closely.

No. I will ask a question. Dr. Kirschstein, again I congratulate you on the work that you have done, taking over really as the director, a very, very difficult job.

# EFFECTIVENESS OF BUDGET INCREASES

Is the National Institute in the position to document for the doubters about the effectiveness of the tremendous increases which have been voted for you?

Dr. KIRSCHSTEIN. Yes, sir, we are. Much of that is in the opening statements of each of the institute directors. They also have collections of information about that, and we collected and have things done centrally.

In addition, because of the Government Performance Review Act, we have been engaged for the last 2<sup>1</sup>/<sub>2</sub> or 3 years in evaluating the research that we have done. We bring in—and we did twice in a row, annually—advisors from outside universities, medical schools, et cetera, and people from the lay interested public through our Council of Public Representatives and our Advisory Committee to the Director to review the accomplishments that each of the institutes has prepared as having taken place over the previous year. That is a requirement of the GPRA act.

Senator SPECTER. Dr. Kirschstein, as you know, for my questions in the past, I have asked what you accomplished with the increase you got last year, what you will accomplish if we are able to get you \$3.7 billion more this year.

Dr. KIRSCHSTEIN. Yes.

Senator SPECTER. Are answers available to those two questions in writing?

Dr. KIRSCHSTEIN. Yes, they are.

Senator SPECTER. Okay. Well, I will take a look at them. Thank you very much.

Thank you, Mr. Chairman.

Senator HARKIN. Thank you, Senator Specter.

# LOAN REPAYMENT PROGRAM

Dr. Kirschstein, I just wanted to pick up on the one thing you said about the loan repayment program. The President's budget takes it from \$28 million to \$56 million. Is that about right? It will take it from \$28 million to \$56 million? I think that is right. I would ask maybe the budget people on that.

Dr. KIRSCHSTEIN. Yes.

Senator HARKIN. Now, can you help me a little bit with that? This is a program that I think is invaluable because what it does is it says to people who have gone through medical school, as I understand it—correct me if I am wrong. Obviously, they have got a lot of debts. I do not know what the average is, but I think it is about \$100,000.

Dr. KIRSCHSTEIN. \$100,000.

Senator HARKIN. \$100,000 right now. So, obviously, if you are going to go into research that is not paying all that much, it is hard to pay back those loans. So, this is a way of enticing or getting young people who want to do research to be able to afford to do so.

How is that operated? I do not know the nuts and bolts of it, and I do not mean to get all into it. But take an average student with \$100,000 and they have come out of medical school. What could this do for that student?

Dr. KIRSCHSTEIN. It will forgive per year \$35,000 of the loan plus the interest and also the taxes involved. The loan repayments are done as a contract between NIH, the particular institute involved, and the individual young physician who knows that he will get, based on a submission of data on his loans and on a summary of what he plans to do, where he or she plans to work, in what field, at what organization either in further training in a career or in a very early stage of getting individual research grants with a career, how he will go about it. It will repay up to \$35,000 per year for 2 to 3 years, and it gets paid in a lump sum.

So, the \$20 plus million that we will expend in 2002 will pay off totally the debt of about 250 young people. We are going to double it in fiscal year 2003, and it will be another 500 people doubling the number.

Senator HARKIN. In their contract, do they have to agree to at least stay in research for a certain amount of time?

Dr. KIRSCHSTEIN. They have to agree to start their careers in research, and we want them to start for a certain amount of time. I am not sure there is a specific time indicated.

Senator HARKIN. I just did not know. Find out for me.

Dr. KIRSCHSTEIN. We will.

It is a wonderful program. We have been doing it for a number of years in a very small way within our intramural program. We have been anxious to do it for the physicians who are in research throughout the country who want to go into research for a very long time and finally got the authorization to do so.

Senator HARKIN. One of the reasons I am happy that the President put this in and we are going to be very supportive of this is that with the doubling of the NIH funds over 5 years, I think it sends strong signals to a lot of young people to enter research, that they can get the research grants funded at a better rate than what we have ever done before. But if they cannot afford to get into research because they are married, they have families, and they are at the age where they are probably starting families, they just cannot afford to do it. So, we have got to open that door. That is why I am delighted that we have got the funds in there.

I assume those monies will be used. In other words, with the doubling of that money, you could use that money for getting researchers in.

Dr. KIRSCHSTEIN. The first awards will be made at the end of fiscal year 2002, and we will report back to you at the hearing next year. We will be following these people to see what is going on. This is a program that is near and dear to the heart of every one of the institute directors, who would be pleased to expand on these statements that I have made.

The applications have been received. There are a large number of them coming. We anticipate that it is possible over the years that we may get 5,000 applications a year.

Senator HARKIN. That is what our committee needs to know. What does it look like out there in terms of how many people are applying for it and see what we need to do for next year.

Dr. KIRSCHSTEIN. We will keep you apprised.

Senator HARKIN. I appreciate that.

# BUDGET LEVELING

Dr. Kirschstein, I said earlier I am a little concerned about what is going to happen after this year. This year, as you know, the President has requested a \$3.7 billion increase that will complete the commitment over that 5 years, and that will bring us up to \$27.3 billion. However, in the budget for next year, after that, according to the budget, at least the projected budget for fiscal year 2004, we are looking at a 2.1 percent increase, 2.2 percent, 2.3 percent, 2.3 percent.

And I am concerned what is going to happen in those out-years, what NIH is doing to prepare for that. What is going to be the impact on NIH after next year when we only get a 2.1 percent increase? I do not know what inflation is. It may be an inflation increase. So, it really is a flat line.

Could you talk about what might be a more appropriate increase? I am just concerned that everything is just flat-lined at that point. I do not think that was ever our objective in doing this.

What started this, I remember, years ago was one of your predecessors saying to me and to others that because we had gone so many years without really adequate increases in NIH funding, that the number of peer-reviewed grants that were being funded was getting less and less and less. Whereas, it used to be maybe one out of three or one out of two in some cases, now it is one out of five, one out of six. And I said at the time—this is several years ago—well, what do we need? Well, if you look at it, to get back where we were back in—I do not know—back in the 1960's or 1970's, we really needed to get up on a plateau. You needed to double it to get back up there. So, I think that was really a lot behind what we did.

But the goal was never just to double it and then just flat-line it after that. It was to get it up and then keep the increases going so that you could keep that rate of approval of peer-reviewed grants going at a good rate rather than falling right back into the same old trap we did in the past. So, if you could speak to that, I would certainly appreciate that. What does it look like out there if we only have 2.1 percent and 2.2 percent increases?

Dr. KIRSCHSTEIN. Mr. Chairman, we have been concerned about this too, and we have been looking at what we can do, if as the administration's position is, that the increase will be 2.1 percent, to sort of smooth what might happen in at least the first of the future years.

First of all, the President's budget projects a 2.1 percent increase, and we understand that.

Second, as a result, we have thought about many of the things that we should be doing during fiscal year 2002, as well as what we will do in 2003. We will make every attempt to provide the kinds of things that researchers need to be able to do their work effectively which, in the past years that you have been describing, they were not able to obtain, such as large pieces of equipment, such as the construction of laboratory buildings, that you have been interested in, such as the data banks and the tissue and cell banks and information technology, which we can provide money for in 1 year and then those things with maintenance costs will be able to be continued for several years to come.

Nevertheless, we are as cognizant as anyone else that science is not going to stop evolving and expanding because the doubling has ended. The scientific opportunities, if anything, are going to be greater because we have opened the doors. You started off your statement by saying that. So, we have also looked at what other things can be possible.

Now, if we know that we are going to have a 2.1 percent budget, we will try to plan how to make some of the activities that we are engaged in, that have come from initiatives that are developed as a result of some of this, constrained for a little bit as we concern ourselves with the level of numbers of research grants and this one in two or one in three that you have been talking about.

We are actually going to have a 1-day retreat of all the institute directors. We decided that this morning. We had planned it for a particular day. We have to change it because of certain circumstances. We are going to try to collectively work out the best ways to go about this.

But I want to make it clear that we all feel that science does not stop because the doubling effort has stopped, and we would like to say that the opportunities probably lend themselves to talking about not a doubling, not 15 percent, but somewhere between an 8 and 10 percent increase.

Senator HARKIN. Thank you very much, Dr. Kirschstein. My time is up.

Senator Specter.

## RESEARCH APPLICATIONS

Senator SPECTER. When we make an evaluation of the NIH budget, we hear about the increasing number of applications. What percentage of applications for grants are now being awarded?

Dr. KIRSCHSTEIN. About 30 percent in fiscal year 2002 and we anticipate the same percentage in 2003.

Senator SPECTER. To what extent are the applications increasing?

Dr. KIRSCHSTEIN. There has been a large influx of increasing applications.

Senator SPECTER. How many in the last 3 years, if you have those figures?

Dr. KIRSCHSTEIN. I do not know that we have the total number of applications, but we can extrapolate from the number of new and competing that were awarded. It is about 38,000 because we are funding 9,000, and we are funding about a third.

Senator SPECTER. Well, if you are still at 30 percent and you have significant increases in—

Dr. KIRSCHSTEIN. We received a total of 30,000 applications in 2002, and we are expecting 33,000 in 2003. That's estimated.

Senator Specter. How many in 2001?

Dr. KIRSCHSTEIN. I do not have it, but it is probably somewhat less than what was in 2002.

Senator SPECTER. Could you provide for us the number of applications in the last 5 years and the number granted?

Dr. KIRSCHSTEIN. Yes, sir.

Senator SPECTER. Could you use more money?

Dr. KIRSCHSTEIN. Mr. Specter, the Congress and the administration have been enormously generous. In discussions that we have had, because not only have we gotten more applications, but we believe—and there is reason to believe—that the progress that we have made is due to the fact that more of the applications that we are receiving are of high quality. Whereas, we have in the past said that we were pleased to have about one in three applications funded—and we still are. Believe me, we still are—we have probably, in many cases, applications of a quality that we would be pleased to be able to provide funds for about 40 percent and in some cases 45 percent of the number of applications we receive.

Senator SPECTER. Well, it is obviously difficult to increase the level of funding \$3.7 billion. No doubt about that. But we have often wondered about how many doors remain closed when 70 percent of the applications are turned down. It raises a question as to how many worthwhile applications are being rejected. I come back to the proposition that we are a very wealthy country. We have a Federal budget of \$2,100,000,000,000, and to have \$23 billion or \$26.4 billion is not an excessive contribution for medical research.

# PARKINSON'S DISEASE

It is not possible, in the course of a very brief hearing, to go into any great detail, but Dr. Penn, how are we doing on Parkinson's? In the past we have had some estimates we might be within 5 years of curing Parkinson's. Is that now down to 4 or perhaps 3?

Dr. PENN. I would like to say so, sir, but I cannot say today that it will be 3 years. I think we have made remarkable progress, and we certainly have a control mechanism that we are working on, really very forcefully, and this is deep brain stimulation, which I believe you have heard about before.

A cure is going to require a great deal more research and a great deal of work to get the proper molecules into the brain, and we have to be very careful with the brain. So, for me to say "cure," I would like to, and I did before, but I think I will not say 4 years. I will leave it open.

Senator SPECTER. But you did before.

Dr. PENN. I know, sir.

Senator SPECTER. Were you under oath then, Dr. Penn?

Dr. PENN. Probably.

Senator SPECTER. Are the stem cells very helpful on the cure of Parkinson's?

Dr. PENN. In the models of Parkinson's—and we have excellent models—the embryonic stem cells, both in the mouse model and in the non-human primate model, are able to do real repair. Now, remember, this is not truly Parkinson's disease, as all of the patients know it, because what we have done is poison those cells. So, the stem cells can replace.

However, in Parkinson's itself, there is a great deal of interest, a great deal of planning, and the question is, which cells to use? If we could possibly turn on the cells that are already in the brain, that we know now are there thanks to our investigators, this would be wonderful. Senator SPECTER. Do you need the nuclear transplant to be sure that a patient who has Parkinson's will not reject the stem cells?

Dr. PENN. Well, as you know, sir, we are not advocating nuclear transfer. And I am really not sure this process would be necessary. I think we have enough information that we can develop dopaminergic cells, the transmitter cells, and we can use those. We have to do a lot more than that, though, because we have to get the cells in the right place. We have to make them grow. We have to hope that they—

Senator SPECTER. Pardon me for interrupting you, but my time is about up and I want to ask another question of another doctor. Dr. PENN. Yes, sir.

## THERAPEUTIC CLONING

Senator SPECTER. Would you favor legislation which would prohibit so-called therapeutic cloning?

Dr. PENN. I think that legislation that would prohibit—I would prefer to say—I mean, if it is absolutely necessary—and some think it is—

Senator SPECTER. And some think it is not. What do you think? Dr. PENN. I think that we do not know if we need it for this purpose.

Senator SPECTER. Do you think we need it for other purposes?

Dr. PENN. Some do. I cannot really come down on that because I really think there is a great deal to know about stem cells. We are in the middle of finding it out, and we are going to test all these things in our model systems first. I sure hope it is not necessary.

Senator SPECTER. Senator Harkin and I were conferring about your answer, Dr. Penn. We have had very considerable testimony on the subject, and it has been to the effect that when you have someone with Parkinson's, as an example, and you take a cell and remove the DNA from the egg and put the cell of Parkinson's victim, that you then find that you do not have the stem cells rejected. Is that incorrect?

Dr. PENN. That is correct, sir. But we are not necessarily at the point where we would automatically get rejection of cells developed in other ways.

Senator SPECTER. But would you like to have the freedom to be able to undertake the process I just described?

Dr. PENN. I believe that, as you know, the National Academy of Sciences has come down on this side. They definitely think that this is worth doing, and as I said, I need evidence on both sides, and I need evidence from the models that all of our investigators are working on. We happen to be really close to getting things done there.

Senator SPECTER. I am sorry. I did not understand that last part.

Dr. PENN. We are very close to, as I said, almost curing this disease in the models, but I cannot today say that nuclear transfer for Parkinson's is what I would advocate at this time. I need more information.

Senator HARKIN. Our time is up. I have to move on to Senator Cochran.

But I just have to say, Dr. Penn, that that is contrary to every scientific input that has come into the committee.

Dr. PENN. Yes, sir.

# LPA RESEARCH

Senator SPECTER. May I ask Dr. Lenfant just a question or two? How are you doing on your research on LPA?

Dr. LENFANT. Quite well, Senator. As you know, our limitation today is more on how to treat it than to doing the research itself. We have at the present time one medication which is available which is called niacin which has lots of side effects, and for that reason, compliance or even taking the medication, if you want to take it, makes it very difficult.

The good news is I understand that within 6 months, perhaps 1 year or 18 months, a new medication will become available, and the preliminary data, which I am aware of, seem to indicate that there will be no side effects.

Senator SPECTER. Thank you very much. Thank you, Mr. Chairman.

Senator HARKIN. Thank you, Senator Specter.

I am sorry. Senator Cochran.

Senator COCHRAN. Mr. Chairman, thank you.

# MINORITY HEALTH

In my State of Mississippi, there is a study underway, partially funded by the Centers for Disease Control and supported actively in a collaborative role by the University of Mississippi Medical Center, looking at why the African American community is disproportionately affected by certain illnesses and diseases, particularly hypertension, heart disease, related troubles of that kind. We welcomed this and we encouraged this activity in our State because we think it will serve a very important public health need.

To what extent is NIH involved in providing the research underpinning or assistance in helping find the answers to those questions?

# JACKSON HEART STUDY

Dr. KIRSCHSTEIN. To a very large extent, Senator Cochran. As you know, we have a study that is supported by the National Center for Minority Health and Health Disparities, as well as the National Heart, Lung and Blood Institute, called the Jackson Heart Study, and I might ask the directors of those two institutes to make comments about that. Dr. Ruffin?

Senator COCHRAN. Thank you.

Dr. RUFFIN. Thank you. Mr. Cochran, I will let Dr. Lenfant address the scientific issues that are going on there, but what I would like to say is that you have three of your universities in the State of Mississippi that are actually involved in the Jackson Heart Study: Tougaloo College, Jackson State University, and then, of course, the University of Mississippi Medical Center.

There is much that is being done over at Tougaloo College as it develops a strong epidemiological training initiative, and also at Jackson State to recruit African Americans participants into the study.

I think the study really got going when all three of those institutions became involved in that particular partnership, and that program is working very, very well in the State of Mississippi.

I will let Dr. Lenfant address some of the scientific issues of the study.

Senator COCHRAN. Thank you very much.

# NEW RECRUITMENT APPROACH

Dr. LENFANT. Senator, I would like to echo what Dr. Ruffin said about the study in Jackson and how well it is doing. We had difficulties at the beginning of the study, because the recruitment of subjects was difficult. But actually just last week I met with Dr. Connolly and Dr. Jones, the leaders from the medical school there, and we have worked out a new approach to our recruitment. And I do know that in just 1 week we have seen a step-up in the recruitment, which leads me to be quite optimistic about the future of the study.

I should say also that we are entirely committed to it. In fact, you may have heard that we call it the Framingham of the South. You surely have heard about Framingham in Massachusetts. And we are establishing this community down there which I think is going to be quite successful.

# DISPARITIES AND ETHNIC DIFFERENCES

Now, to address the issue of the research, throughout the country, there are many institutions, including the University of Mississippi where we have there a very large program on the study of high blood pressure, the causes, the manifestations, and the treatment, but throughout the country there are many, many studies which are focusing on the disease itself, stroke, high blood pressure, heart disease, but also on the reasons for the disparities and ethnic differences.

We are making progress. I have to say it is difficult for a variety of reasons that I could submit to the record, if you want, but I think we are making progress. And in fact, we are beginning to see a reduction in the difference in mortality rates between the various ethnic groups.

Dr. KIRSCHSTEIN. Senator Cochran, I would like to expand a little bit. When I was answering Senator Harkin's question about what we think are the opportunities and what we would like to do in further years, among the things is work with States like Mississippi even more than we have up to now to assure that biomedical research has a more stable base there than there has been in the past. As you know, I and many of my colleagues have been down there on several occasions, and we are making plans. We started the BRIN program. We would like to expand that. So, one of the things that would please me inordinately is if we could continue to have some expansion, we could continue to work with States like Mississippi.

Senator COCHRAN. That is very good news, and I appreciate very much the explanation and the response to my inquiry on this subject. I have been very much encouraged that we are being asked to build on the legacy really of Dr. Arthur Guyton who was a pioneer, and many of you know him personally. I guess his physiology textbook is still maybe the textbook in medical schools around the country. We are very proud of that reputation that he really built for us. But seeing it now expanded to include related activities and research programs and this program in particular is very heartening to me.

I am delighted with the opportunities that we may have to do other things too. I know the National Institute of Biomedical Imaging and Bioengineering is looking at the possibility of some research efforts in the State, and we encourage the pursuit of that idea too and want you to know that we want you to tell us ways that we can be helpful here on the subcommittee and in funding. If we can break down some barriers or provide additional assistance to help make these dreams come true, I want to be actively involved in doing that.

I see my time is up. I want to compliment too the NIH researchers who developed the basis for new techniques in screening and discovering impairments that cause children to be unable to read at early ages. And we are now seeing NIH's work in that research area translated into teaching techniques, screening, diagnostic activity which are making it possible for children to learn to read who would not otherwise be able to and have full and normal lives because of the work at NIH. I think these are examples—and I know there are many others. Juvenile diabetes. I want to ask about that, and Parkinson's and many other areas where NIH has really caused a huge difference in the lives of Americans. And I want to congratulate you all for continuing that kind of work, the excellence in research that you have become famous for.

# READING RESEARCH

Dr. KIRSCHSTEIN. Thank you, Senator Cochran. If the committee will permit us, I am sure Dr. Alexander would be delighted to expand on the activities related to learning to read.

Senator COCHRAN. Thank you.

Dr. ALEXANDER. Senator Čochran, we particularly appreciate the support that you have given to this research program for Mississippi. This reading research is a program conducted over the last 15 to 20 years. It has been experimentally based and translated into the classroom and really formed the foundation for the President's legislation, No Child Left Behind, the education legislation that the Congress passed with overwhelming support earlier this year.

We are very happy that the contributions of the NICHD research enabled this to happen. We are continuing that research effort. We are working with the Department of Education, with the National Science Foundation, and others to continue and expand that research, as well as to translate it into the classroom setting as States work to implement the requirements that instruction be research-based and evidence-based. So, we are very happy we have been able to succeed in this way.

Senator COCHRAN. Thank you very much.

Thank you, Mr. Chairman, for your indulgence.

Senator HARKIN. Thank you. I am sorry I had to just duck out there for a minute.

We have got to set up a time and we have to set up some points where we can bring each of the institute directors down where we can have some more time to interact with each of the institute directors. We are just rushed this year right now. We have done that in the past, and I intend to reinstitute that sometime in the near future.

We have got all the institute directors here, and just for my own knowledge and for the knowledge of others who are here and for our staffs, I would just like to go around and make sure that I introduce everyone. Perhaps just stand when I call your name. I just want to make sure that our staffs know exactly who everyone is here. We have got some new people. We have got some long-time people, but we have got some new people too. So, I am going to take a little bit of time to do this. You have taken the time to come all the way down here and I just at least want to recognize each of the individual directors.

I guess I am going to start on this side with Dr. Andrew von Eschenbach, the Director of the National Cancer Institute. Thank you, Doctor.

The next is Dr. James Battey, Director of the National Institute on Deafness and Other Communication Disorders. Thank you very much, Dr. Battey.

Next is Dr. Audrey S. Penn, Acting Director of the National Institute of Neurological Disorders and Stroke. Dr. Penn.

Next would be Dr. Steven Straus, Director of the National Center for Complementary and Alternative Medicine. Dr. Straus.

Next would be Dr. Lawrence Tabak, Director of the National Institute of Dental and Craniofacial Research. Did I pronounce that right?

Dr. TABAK. Tabak.

Senator HARKIN. Thank you, Dr. Tabak.

Next would be Dr. Steven Katz, Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases. Dr. Katz.

Next is Dr. Richard Hodes, Director of the National Institute on Aging. Thank you, Dr. Hodes.

Next is Dr. Marvin Cassman, Director of the National Institute of General Medical Sciences. Thank you, Dr. Cassman.

Next is Dr. Duane Alexander, Director of the National Institute of Child Health and Human Development. Thank you, Dr. Alexander.

Next is Dr. Paul Sieving, Director of the National Eye Institute. Dr. Sieving.

Going around the table, Dr. Jack Whitescarver, Acting Director of the Office of AIDS Research.

Next is Dr. Kenneth Olden, Director of the National Institute of Environmental Health Sciences. Dr. Olden.

Next would be Dr. Gerald Keusch, Director, Fogarty International Center. Did I pronounce that right, Dr. Keusch?

Dr. KEUSCH. I probably mispronounce it as Keusch.

Senator HARKIN. All right, I got that now.

Next would be Dr. Glen Hanson, Acting Director of the National Institute on Drug Abuse. Dr. Hanson. Next would be Dr. Patricia Grady, Director of the National Institute of Nursing Research. Dr. Grady.

Coming around the table, Dr. Raynard Kington, Acting Director, National Institute on Alcohol Abuse and Alcoholism. Dr. Kington.

Next would be Dr. Donald Lindberg, Director of the National Library of Medicine. Dr. Lindberg.

Next would be Dr. Donna Dean, Acting Director, National Institute of Biomedical Imaging and Bioengineering. Dr. Dean.

Next would be Dr. John Ruffin, Director of the National Center on Minority Health and Health Disparities. Dr. Ruffin.

Next would be Dr. Richard Nakamura, Acting Director of the National Institute of Mental Health. Dr. Nakamura.

Next would be Dr. Judith Vaitukaitis.

Dr. VAITUKAITIS. It sounds like a disease. Vaitukaitis.

Senator HARKIN. Dr. Vaitukaitis, Director of the National Center for Research Resources. Dr. Vaitukaitis.

Next would be Dr. Francis Collins, Director of the Human Genome Research Institute. Dr. Collins.

Next would be Dr. Allen Spiegel, National Institute of Diabetes and Digestive and Kidney Diseases. Dr. Spiegel.

Next would be Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases. Dr. Fauci.

And next, Dr. Claude Lenfant, Director of the National Heart, Lung, and Blood Institute.

Dr. KIRSCHSTEIN. And, Mr. Chairman, if I might add, I will introduce the people at the front table.

Senator HARKIN. Would you please? Yes.

Dr. KIRSCHSTEIN. Dr. Yvonne Maddox is the Acting Deputy Director of NIH. And to her immediate right is Mr. Charles Leasure, who is the Deputy Director for Management, and to my left is Sue Quantius, who is the Director of the Office of Budget.

Senator HARKIN. Well, thank you very much, Dr. Kirschstein. Again, I thank you all for being here. As I said, we had a process some time ago that I am going to get back to where we are going to have—we will not do it in one day, but what we will do is we will have groups of maybe four or five institute directors come down. We will set aside a couple of hours to go over their areas so that I can become more knowledgeable in the different areas that are there and so my staff can also. I will work with you to try to set that up and to arrange that at some time in the near future.

Dr. KIRSCHSTEIN. Senator Harkin, we would be pleased to do so. Many of us remember doing that in the past with you and it was a very successful endeavor.

Senator HARKIN. We are going to return to that. I just was unable to do that this spring. I may not wait until next year.

Dr. KIRSCHSTEIN. Fine.

Senator HARKIN. I may just do it sometime coming up this summer. I will be glad to work with you and the other institute directors to set up those points in time when we can do that.

Dr. KIRSCHSTEIN. Fine, sir. We look forward to it.

Senator HARKIN. I do too. I always found those in the past to be the most enlightening times of my service here.

There are a couple of things that I wanted to go over. Dr. von Eschenbach, this has to do with pancreatic cancer. 99 percent of people who get pancreatic cancer die. It is the highest death rate of all cancers.

Now, before you came to NCI in last year's appropriations report, we requested that NCI develop a professional judgment budget for research on pancreatic cancer for the next 5 years. The goal was to ascertain how much we are actually spending on pancreatic cancer compared to the current funding level to see what was needed to make some inroads in this awful disease.

As I said, this happened before your watch. I would just ask that at some point would you please advise us here as to where you are on that budget for pancreatic research and how many pancreatic researchers we have. I have heard there is a severe shortage. I do not know. Just focus on that a little bit.

# PANCREATIC CANCER

Dr. VON ESCHENBACH. Thank you, Senator. I can give you an interim update, and I would be happy to provide you with a more detailed analysis.

There have been a number of initiatives that have been launched in response to the directive. They include both epidemiologic studies to look at the distribution and causation with regard to pancreatic cancer. There is also a very important group of studies going on to look at environmental linkages, including diet and exposure to things such as tobacco, to begin to understand the causation of pancreatic cancer.

There is a 10-point research program that has been instituted to begin to define basic laboratory investigations with regard to the mechanisms by which pancreatic cancers occur and then progress.

And in addition to that, very importantly specialized programs of research excellence have been funded that focus on the problem of pancreatic cancer, and the particular importance of these SPORE initiatives is the fact that they bring together both basic scientists, as well as clinical scientists, so that we create a translation of the information that occurs in the laboratory to actual development of interventions in the clinic that can treat and perhaps even prevent pancreatic cancer. One of those happens to be at Johns Hopkins where about 50 percent of their gastrointestinal SPORE is devoted to pancreatic cancer, and then at the University of Nebraska there is one of those programs that is totally directed to pancreatic cancer.

So, we are beginning to emphasize the approach to this cancer on understanding its nature, understanding how to detect and define it, and then, most importantly, how to treat it.

# EARLY DETECTION

Senator HARKIN. I understand the problem is in detection. You just do not know you have it until it has become quite invasive.

Dr. VON ESCHENBACH. That is unfortunately correct, sir, and a very important challenge.

Senator HARKIN. I assume there is some research going on on early detection methodologies perhaps?

Dr. VON ESCHENBACH. One of the important areas I think that might also impact upon that is the larger agenda that is occurring with regard to molecular or functional imaging technologies where we will be able to detect cancers at earlier stages and then, as you alluded to in your opening remarks, some of the interesting work that is being done in being able to detect cancers by virtue of protein profiles in the blood stream. That has been demonstrated as proof of principle in ovarian, and hopefully we will now apply it to a series of other cancers including, hopefully, pancreatic.

Senator HARKIN. Interesting. I never thought about that. That is interesting. So, you can take what you have done on ovarian cancer and maybe apply that to some other cancers then. Dr. VON ESCHENBACH. Yes, sir, exactly.

Senator HARKIN. Fascinating. Well, thank you very much. Just keep me advised on that then when you get the full report done on what you think we need for that next 5 years.

Dr. VON ESCHENBACH. Thank you, sir.

Senator HARKIN. Dr. Kirschstein-I see my time is up. Senator Cochran, do you have some more questions?

Senator COCHRAN. No, Mr. Chairman, I have no other questions. Thank you.

Senator HARKIN. Thank you, Senator. I just had a couple that I wanted to follow up on.

# STEM CELLS

I do want to return to the issue that Senator Specter raised and that is stem cells. When President Bush announced last year that Federal funding could be used for research on human embryonic stem cells, I was disappointed that he limited it only to those cell lines that were in existence on August 9 at 9 p.m. I asked, could we have not made it 10 p.m. or midnight?

The reason I say that is because, obviously, that is a very arbitrary cutoff date and time.

But until we get the rule changed, I strongly urge NIH to fund as many grants as possible under those guidelines. I understand there were only nine grant applications to the NIH for studying human embryonic stem cells by the first deadline of November 27 last year, 2001. Dr. Kirschstein, can you tell us now or could you tell the committee at some point soon when will NIH decide how many of those applications will be funded?

Dr. KIRSCHSTEIN. Those applications are in review at the present time, sir, in the primary review. They will be going to the advisory councils in the May/June period, and the meritorious ones will be funded prior to the end of this fiscal year.

Some of us were more surprised than others as to the number. But it was a short period of time, no matter which way you think about it, from August 9th to the end of November. And furthermore, the lines which had to be listed on the registry were from disparate sources and the sources need to have sustenance to make sure that they can produce and people need to be trained on how to use them.

So, right from the beginning, we announced that we would provide, first of all, administrative supplements to anybody who had research that was related and that could go ahead with reasonably sized budgets of \$50,000 approximately to do the work, but second, to provide the ability for scientists to go the various places where the stem cells are being produced, the ones that are on the registry, and learn how to particularly work with those lines. Every cell culture of stem cells may be different and, indeed, we have known from years from the days that early cell cultures started that the cells have a great deal of individuality and you have to learn how to manipulate them and how to work well with them.

In addition, we have been providing for training and for the ability to build up the supply.

Senator HARKIN. Dr. Kirschstein, do you know how many embryonic stem cell applications you have received since November 27? Dr. KIRSCHSTEIN. It has been more but not a large number. And

Dr. KIRSCHSTEIN. It has been more but not a large number. And we are not surprised. Scientists want to present their best scientific effort, and once they realized they could use the lines, they have been garnering probably preliminary data, putting applications together carefully, and we expect the number to grow.

# INTELLECTUAL PROPERTY RIGHTS

Senator HARKIN. I have heard different opinions about whether scientists' access to these stem cell lines will be limited because of intellectual property issues involving patents both here and overseas. Dr. Spiegel, your institute will likely be a key player on stem cell research because of the potential for curing diabetes. At least, that is what I am told anyway. I just wondered if you have any thoughts on this problem of intellectual property issues.

Dr. SPIEGEL. Let me just say that I will defer to the legal experts. Dr. Kirschstein may want to designate someone specifically for that purpose.

The Office of Extramural Research and the Office of Technology Transfer have gone to great lengths to try to surmount these issues. There have been individual negotiations with the people at Wisconsin, and with the University of California, San Francisco. Every effort has been made to surmount these issues. I will defer to others who have the specific legal expertise.

The only other comment I would make is that you are exactly right. In terms of type 1 diabetes, we at NIDDK are mounting every effort not only in terms of islets relevant to type 1 diabetes but also in terms of research on adult hematopoietic stem cells to differentiate into liver cells. With the mechanisms you heard about—support for infrastructure and training mechanisms so people can learn how to culture these cells, and a variety of other mechanisms, such as grant supplements—we expect to be vigorously supporting this area.

Senator HARKIN. Thank you, Dr. Spiegel.

## ANTHRAX VACCINE

Dr. Kirschstein, the NIH budget that we have before us from the White House includes \$250 million for procurement of a next generation anthrax vaccine. Now, while I obviously think this is a worthy investment, given the problems surrounding the current vaccine, my question is, why is NIH funding the procurement of this vaccine? It is my understanding that CDC has responsibility for the stockpile. They purchased the smallpox vaccine. Should CDC not be funding this rather than NIH? I just ask that question. I am just wondering why this is in the NIH budget and not under CDC. Do you have any observations on that at all? Dr. KIRSCHSTEIN. Dr. Fauci is the expert on that.

Senator HARKIN. Dr. Fauci.

Dr. FAUCI. Yes. I am an expert in telling you that I cannot explain it.

That is the short answer. I could give you a longer answer.

The responsibility for the development of the next generation anthrax vaccine, which is a recombinant protective antigen, is a project that antedated the submission of the President's budget and now is incorporated into it and will continue over the next, I would project, Mr. Chairman,  $1\frac{1}{2}$  to 2 years for the development of that next generation vaccine. So, that is really the product and the candidate that we are referring to, the recombinant protective antigen.

The wording that is in the language for the budget uses the word "procuring." I would imagine that that is going to be a combination of the development of and then ultimate procurement of the vaccine, because it is a process that is going to be seamless. As we are developing it, we are going to have to be collaborating with industrial partners for the actual production of and then ultimate procurement of the vaccine. But the precise reason for that language in there I cannot explain.

Senator HARKIN. Well, my concerns are there are a couple, three items that are in the NIH budget which my staff has picked out which really legitimately look like they should be funded from other sources. There is one DOD. There is this one that I just talked about at CDC. And I will look to see whether or not this is procurement or development. I am not certain I know myself.

Dr. FAUCI. Yes, but I think what we are referring to is probably going to be a combination of both. Even though it specifically says procurement, we cannot engage in "procurement" yet because we have not developed it yet.

Senator HARKIN. Well, then maybe the whole \$250 million is for development?

Dr. FAUCI. That is not what the language says, so I think that really needs to be clarified.

Senator HARKIN. I think, staff, we have got to go back to OMB and ask them what they mean by that.

I also wanted to look for—well, it is not your problem. There is some DOD money also in there that I am concerned about also.

## EYE DISEASES IN THE AGING POPULATION

Dr. Sieving, an NEI study released yesterday shows that my State of Iowa has the second highest rate of vision impairment and blindness of all the States in the country. So, obviously, that was brought to my attention right away. 3.7 percent of Iowans have vision impairment compared to the national average of 2.85 percent. I do not know how the study was designed, but I assume a part of it is because we have the highest proportion of elderly over age 85 of any State in the Nation. Maybe that is the reason. I do not know. Like I say, I have not looked at it.

But it led me to try to focus on this question about any new research to prevent and treat vision impairment. Again, I do not know whether this is just because of certain people that get into my office or get to me or I see in Iowa, but I am hearing more and more about macular degeneration now than I have ever heard. So, is there something happening out there or what? Has the incidence of macular degeneration perceptibly increased in the last few years?

Dr. SIEVING. That is an interesting question, Senator. I think the answer to that is very simple. We are all getting older. We have a birthday every year, and with aging, some of the aging diseases become more prevalent. The aging diseases that affect the visual system include macular degeneration, diabetes, diabetic retinopathy, cataract, and glaucoma. Consequently in the U.S. population, the prevalence of those conditions appears to be increasing, or is increasing because the population is aging.

As one thinks to the future of the intersection of better health care, longer survival, and an aging population pool that will be increasing, the prevalence and the need to do something about these diseases will also be increasing in the years ahead.

These, in general, are complex diseases. Cataract fortunately can be ameliorated with appropriate surgery with a good success rate, but macular degeneration and glaucoma are neurodegenerative diseases that affect the neurons in the retina at the back of the eye. As we all know, I think neural and neurologic diseases are difficult to treat at the moment. So, we have ahead of us the task of understanding the etiology of these neurodegenerative processes and ultimately devising appropriate strategies to intervene.

The Eye Institute is busy with that task. We have a very vital extramural pool of scientists who are working on aspects of transplantation of neural tissue. We have work going on in neuroprotection. But I think the most fundamental work we have going on is to understand the basic biological mechanisms that are responsible ultimately for the genesis of these conditions, so that we can appropriately target the real biological root causes.

We did have one success story this last year, one I am saying because some of these success stories are a long time in coming. This was the Age-Related Eye Disease Study, or AREDS, an epidemiologic intervention study, that had its genesis about 10 years ago. For the past 7 years, a large population approaching a number somewhat less than 5,000 subjects with macular degeneration were treated with antioxidant nutrients, vitamins C, E, and beta carotene, and the addition of the essential mineral zinc. It was found that with high-dose supplementation, the population at risk for macular degeneration was—the incidence of additional vision loss was slowed by a little bit less than 30 percent. On a population basis, that has a very significant impact on the social morbidity and the economic morbidity that macular degeneration causes in our elderly population. So, we are pleased with that and we look forward to understanding the biological causes of it to see if we can build on that success.

Senator HARKIN. What were the vitamins? What was it beta carotene? I am sorry.

Dr. SIEVING. I am pleased that you are interested.

It is antioxidant vitamins C,  $\tilde{E}$ , and beta carotene, which is a form of vitamin A, and the addition of zinc which is essential in some of the metabolic pathways of the cells in the outer part of the neural retina.

## VISION IMPAIRMENTS/NUTRITION

Senator HARKIN. Dr. Straus, is your center doing anything on this along with them?

Dr. STRAUS. Mr. Chairman, that study was well underway before the creation of the Center for Complementary and Alternative Medicine. But Dr. Sieving and I have met on a number of occasions and discussed opportunities to work together in following up the very agenda he discussed. We are funding some other nutritional studies at Johns Hopkins today looking at lutein, the red pigment from red vegetables and fruits, for other retinal disorders.

Senator HARKIN. Well, I am delighted to know that you are working together on this. That is very interesting, some of the stuff you just said, Dr. Sieving.

## HEALTH INFORMATION TO PUBLIC

I just have one more thing that I want to bring up. A part of NIH's statutory mission is to disseminate good, accurate information about health to the public as quickly as it becomes available. I am concerned about the Department's plan to add another layer of bureaucracy to this process. As I understand it, right now the people at NIH, who have the job of translating research into useful information for the public, work directly with the scientists, and together they decide what kind of educational materials to distribute. But under the Secretary's plan, those decisions would not necessarily be made by scientists, they would be made downtown at the Department headquarters.

Dr. Lenfant, I guess maybe it would be your institute that has put together some excellent education campaigns. I am cognizant of those. I have seen them over the past. They are designed to prevent heart disease, for example, save lives when heart attacks occur. How would your process for developing these campaigns be affected? How would it be different in the future under this new plan?

Dr. LENFANT. Well, Senator, at this time, we have received little information as to how that would work. But one thing I can say on the positive side is that if the people who do communication education are far away from where the information originates, that is, the science itself, I think this gap will have the tendency to widen and much will be lost in the end that is in the educational process. I have to say if that is what is going to happen, I would be very concerned. But, of course, I do not know how that would work actually.

Dr. KIRSCHSTEIN. Senator, we have been having discussions with the Department and we have made it clear that we believe that the people who transmit the information to the public must be kept closely allied to the science and the science leaders who are represented at this table in regard to how and what information gets translated to the public. We believe that they will allow that closeness to continue. That issue has not been totally decided yet, but you have a proposal in the budget for what is to be done.

Dr. LENFANT. If I may add, Mr. Chairman, I think that for education to work, you have to have a dynamic process that goes back and forth between where the knowledge is developed and what it is that you are communicating. And it is not static; it has to move back and forth. I think it is critical that we recognize these two functions: knowledge acquisition and the dissemination of that knowledge.

Senator HARKIN. Well, I have asked the Secretary and I am going to ask the Secretary, for whom I have the highest regard and respect, Secretary Thompson. But what was broken here? If there was something wrong, what is trying to be fixed? And I am trying to get that information. I have not gotten it yet, but I am going to continue to ask that. What is it about the way that it was done in the past that this change in operation of having it clear down at the Department is meant to address? I have not gotten a satisfactory answer to that yet, but I will continue to ask the question.

I have very deep concerns about adding that other layer to it, both in terms of slowing down the access to information and dissemination but also in terms of perhaps coloring it one way or the other. I do not think it should be. I think I would rather leave that in the hands of the scientists and not people who may have perhaps other agendas to follow.

Well, with that, I want to thank you all very much for being here. Thank you, Dr. Kirschstein. I thank all of the institute directors who are here for taking your valuable time to be here today.

I look forward to having a more in-depth dialogue with you as the year goes ahead. As I said, I would have done it this spring, but I have another hat to wear and I have got to get a farm bill through and it has taken a lot of my time. But that only happens once every 5 or 6 years, so hopefully as this year goes along, we will be able to have a more in-depth dialogue with each of the institute directors.

But to each of you, you have my highest compliments, my highest respect and admiration, and I hope what is plainly obvious, my support. Thank you very much.

Dr. KIRSCHSTEIN. Thank you, Senator Harkin. We have appreciated it.

Senator HARKIN. Thank you.

## PREPARED STATEMENT

We have received the prepared statement of Senator Larry Craig which will be placed in the record.

[The statement follows:]

#### PREPARED STATEMENT OF SENATOR LARRY CRAIG

Good morning. Thank you for attending today's hearing of the Labor, Health and Human Services, Education Subcommittee. I would like to thank the witnesses for agreeing to testify before this committee on the fiscal year 2003 Budget for the National Institutes of Health.

Recently Congress passed the Labor, Health, Human Services, Education fiscal year 2002 appropriations bill which increased funding for the NIH by \$2.7 billion. I think that you will agree with me that this money is a step in the right direction toward solving the numerous diseases that affect millions of Americans and that this Congress is committed to health research and education.

Funding for biomedical research, of all diseases, is a high priority because medical research is a key to eradicating disease and improving the quality of life. The benefits from medical research are far-reaching. New discoveries return value to patients and their families, they translate into better diagnosis, better treatment, and better prevention of disease, as well as in discovering new methods of treating the afflicted.

I believe that the NIH should be given adequate funding to support fiscal year 2003 research programs that move us toward cutting-edge treatments and preven-tion efforts, while helping to reduce overall health care costs. However, as we all know there are harsh budget realities that we must work within. We must find a way to provide the appropriate level of funding for health programs while being fis-cally responsible. We can make significant strides in the field of medical research while still working toward a balanced budget. I'd like to thank each of the witnesses for being here today and for sharing their insights into this complex problem. I look forward to hearing your testimony.

## ADDITIONAL COMMITTEE QUESTIONS

Senator. HARKIN. 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:]

## QUESTIONS SUBMITTED BY SENATOR HARRY REID

#### INTERSTITIAL CYSTITIS

Question. Despite progress in interstitial cystitis (IC) research, we still do not know the etiology or understand the pathogenesis of this disease. How are you going to ensure that progress continues specifically in IC research?

Answer. We believe progress will be achieved through the NIDDK's continuing support of a multi-faceted approach to interstitial cystitis (IC) research. The question of immediate management of the complex array of symptoms suffered by patients with IC is being tackled by the NIDDK's Interstitial Cystitis Clinical Trials Group, which is currently running two clinical trials with different approaches to IC treatment. One trial is comparing combinations of oral medications for the most effective relief of symptoms, while the other is testing the efficacy of a therapeutic bladder wash to relieve pelvic pain and frequent urination.

To facilitate the identification and treatment of all individuals with IC, and to gain knowledge of the full range of risk factors and clinical symptoms, awards have been made to research the epidemiology of IC, specifically broadening the surveyed population. The recently funded "Urologic Diseases in America," a retrospective will also assist researchers in identifying individuals with IC and in learning more about the burdens of this disease.

Research on management of the debilitating pain suffered by patients with IC will also be supported through collaborative efforts with other disease experts well-versed in pain management-such as those familiar with irritable bowel syndromeas was recommended at the recent meeting entitled "Blader and Interstitial Cys-titis: Progress and Future Directions." This meeting was co-sponsored by the NIDDK and the Interstitial Cystitis Association.

A critical element in our progress to combat IC is research to understand its un-derlying causes. Thus, basic research remains at the top of the list of NIDDK's re-search priorities in IC. At the moment, the most promising research avenues for IC lie in a better understanding of normal bladder physiology and of the pain pathways that are affected in IC. The recent identification of an anti-proliferative factor produced by the bladder and found only in the urine of IC patients has already provided clues into both the pathogenesis of the disease and to normal bladder function. The discovery has also generated many new research questions for pursuit. New findings about the pain pathways in the bladder have sparked intense investigation. Researchers are eager to investigate how the perturbation of these pathways releases chemicals which may, in turn, cause the altered bladder function observed in IC.

To ensure that progress in IC and other bladder disease research continues, the NIDDK recently established the Bladder Research Progress Review Group (PRG). This group of external scientific experts met last summer in order to draw up a map for future research directions in bladder disease, including IC. The PRG made sci-entific recommendations on high-priority research areas for IC such as etiology and pathogenesis. These recommendations will be invaluable in aiding the NIDDK and its National Advisory Council to determine the best means possible to support this research.

I would also add that, because the etiology and pathogenesis of interstitial cystitis are still unknown, the NIDDK's continued support of basic research on the structure and functioning of the bladder provides a crucial framework for accumulating a knowledge base from which IC-specific research will surely benefit.

Question. The trend in funding specific research on IC has significantly decreased in 2000 and 2001. And of the \$88 million in new research grants that the NIDDK is expected to fund in fiscal year 2003, only \$5 million would go to urology and nothing to IC. Although I realize ongoing research is being funded, I am very concerned about this downward trend and deeply disturbed that no new monies are being directed at IC—particularly toward basic science.

Answer. The President's Budget Request for NIDDK for fiscal year 2003 includes an overall increase for noncompeting and competing research project grants of approximately \$86 million, which we intend to use to benefit all of our research programs. In recent years, we have increased both urology research, as a broad field of research, and interstitial cystitis and basic bladder research studies, as a specific area within the larger field of urology. We estimate that we spent approximately \$76.5 million on urology research in fiscal year 2001, and intend to spend approximately \$88.2 million in fiscal year 2002 and \$95.5 million in fiscal year 2003, based upon the current budget request. Within these overall totals, we spent \$12.3 million on interstitial cystitis and basic bladder research in fiscal year 2001, and intend to spend approximately \$14.3 million in fiscal year 2002, and \$15.5 million in fiscal year 2003, based upon the current budget request. Studies supported with these funds include clinical trials of IC therapies and research exploring the basic mechanisms of bladder disease, including bladder dysfunction, and possible underlying causes of IC. For both urology research in general and IC-related research specifically, the number and quality of research applications received by the Institute may affect the funding total, but we are engaged in active efforts to identify and pursue research opportunities. For example, our establishment of the Bladder Research Progress Review Group (PRG) is culminating in a set of recommendations for future research directions, and we will stimulate research applications from the investigative community in the areas of opportunity identified by the PRG.

## JUVENILE DIABETES

*Question.* Juvenile diabetes has a devastating impact on every organ in the body and often leads to serious, life-threatening complications. Therefore, virtually every NIH Institute has a role to play in juvenile diabetes research. How do you ensure that all relevant NIH Institutes collaborate to advance research to treat the devastating complications of this disease and ultimately find a cure?

Answer. One important route for facilitating collaboration is the Diabetes Mellitus Interagency Coordinating Committee (DMICC), which the NIDDK chairs. This committee has representatives from the Centers for Disease Control and Prevention, the Food and Drug Administration, Agency for Healthcare Research Quality, and other Health and Human Services agencies. It coordinates research on all aspects of diabetes, including type 1, or juvenile, diabetes and its complications. The DMICC has been a focal point for catalyzing NIH-wide research on key issues relevant to juvenile diabetes, including the eye, kidney, and heart complications, and the disturbing increase in type 2 diabetes in children.

Another avenue of collaboration is the trans-HHS Planning and Evaluation Strategy Group that guides the use of special funds for type 1 diabetes research, which were provided by the Balanced Budget Act of 1997 and the 2001 Consolidated Appropriations Act. The NIDDK chairs this Planning and Evaluation Strategy Group, which includes representatives from multiple NIH institutes and centers, the CDC, the FDA, AHRQ, the Juvenile Diabetes Research Foundation, and the American Diabetes Association. The Planning Group has met several times to identify areas of scientific importance for type 1 diabetes research initiatives. In February 2001, the Group met to consider the most recent proposals for the special type 1 diabetes research funds, which were submitted by the participating NIH institutes and centers, and the other HHS agencies.

To leverage support for type 1 diabetes research, high priority has been given throughout the resource allocation process to proposals to which HHS components would commit regularly appropriated funds, proposals that cross institute or agency boundaries, and proposals that could attract new scientific talent who have relevant experience to diabetes research.

Members of the Planning Group have also suggested leading scientists to serve on external advisory panels on the use of the special type 1 diabetes funds. One such panel met in April 2000 and another advisory meeting is planned for May 2002. A significant number of Planning Group representatives attended the initial meeting in 2000 and are expected to also participate in the upcoming session. The success of this ongoing planning process is demonstrated by the scope of the special type 1 diabetes funding program. Each of nine NIH institutes and centers and the CDC have lead responsibility for at least one type 1 diabetes research initiative that has been supported by the special funds through fiscal year 2002; further, the majority of these initiatives represent collaborative efforts between multiple NIH components. The NIDDK is presently leading the development of a mandated report to the Congress on the use of the special funds for type 1 diabetes research. This report is expected to be transmitted to the Congress in January 2003.

#### QUESTIONS SUBMITTED BY SENATOR HERB KOHL

#### EPILEPSY

Question. As you know, over 2.5 million Americans have epilepsy, including at least 750,000 with intractable epilepsy. The annual direct and indirect costs of epilepsy are estimated to exceed \$12.5 billion. But while NIH funding has increased by nearly 15 percent each year, Epilepsy funding has increased by only 8 or 9 percent each year. Given the huge impact of epilepsy, it seems that epilepsy research lags far behind what is needed—despite the encouragement of Congress over the past few years to intensify efforts to find a cure. What do we need to do to ensure that more resources are devoted to curing epilepsy.? Answer. We are working with scientists and the epilepsy community in a con-

Answer. We are working with scientists and the epilepsy community in a concerted effort to accelerate research on epilepsy. As you note, intractable epilepsy, which is especially a problem in children, must be a high priority. The scientific community is motivated by the burden of epilepsy on society and energized by the new opportunities arising from progress in neuroscience research. In March 2000, the National Institute of Neurological Disorders and Stroke (NINDS), together with several patient advocacy groups sponsored a White House-initiated conference, "Curing Epilepsy: Focus on the Future." A major outcome of the Cure Conference was the creation of an epilepsy planning group including researchers, clinicians, representatives of the advocacy community, and NINDS professional staff. This group developed seventeen specific research "benchmarks" for the epilepsy research community to use to measure their progress towards finding a cure for epilepsy. The benchmarks were published on the NINDS website in January 2001. Central to the concept of the Benchmarks is the belief that they are milestones

Central to the concept of the Benchmarks is the belief that they are milestones for the entire epilepsy community. In order to emphasize this collaborative relationship, the Epilepsy Benchmarks planning group has developed the concept of "stewardship" under which senior well-established individuals in the epilepsy community will accept primary responsibility to be a steward for a given benchmark, working in conjunction with the NINDS to ensure that the scientific community is fully engaged and appropriate resources are allocated to achieve the benchmarks. We are all committed to working together toward developing ways to prevent and cure epilepsy.

*Question.* We are anxiously awaiting your Epilepsy Research Agenda requested by April 1 of this year, along with projected funding requirements for implementing the plan. What are the first steps required to carry it out? Can you ensure that the NINDS research will continue to search for cures for epilepsy, rather than simply treatments for symptoms? Do you see any specific research areas which might offer potential breakthroughs?

Answer. NINDS, working together with the epilepsy community, has already made significant progress on the Benchmarks implementation plan, including confirming the initial list of Benchmarks stewards and working with several advocacy groups to produce a lay summary of the Benchmarks. We have held a number of workshops focused on specific topics arising from the Benchmarks, such as animal models for epilepsy research, anti-epileptic drug monotherapy, and epilepsy genetics, with meetings soon to be held on subjects such as brain imaging and epilepsy. We have also solicited applications to promote cross-disciplinary collaborative projects among junior investigators in the fields of patient-oriented research, developmental neurobiology, genetics, advanced technology, imaging, pharmacotherapeutics, or other research areas that would be likely to lead to a cure for epilepsy. In addition to efforts focused exclusively on epilepsy, NINDS is enhancing efforts in several cross-cutting areas of research that are likely to have a bearing on epilepsy, including gene discovery, gene therapy, pediatric neurological diseases, pediatric brain imaging, and translational research. NINDS is committed to building on its ongoing significant efforts in epilepsy and, through the concept of stewardship, to working closely with the research and advocacy communities to achieve the Epilepsy Benchmarks and move the field toward the ultimate goal of curing epilepsy.

While progress has been made, the treatments we now have for epilepsy are far from perfect. This is especially so for the many people whose epilepsy is "intractable." Even for those people whose seizures can be controlled, the side-effects of treatment are often a significant problem, with special concerns for children and women. Perhaps the biggest reason our sights have changed from symptomatic treatment to a cure is that the science has advanced to the point that we can begin to see avenues toward finding a cure. So, we should not underestimate the difficulties, but I assure you we are committed to the goal, defined by the landmark meeting "Curing Epilepsy: Focus on the Future" as "preventing epilepsy in those at risk and no seizures, no side effects in those who develop the disorder."

There are many areas of science that offer potential for breakthroughs. We must attend to all because medical advances are so difficult to predict and because epilepsy arises from several different causes, so no single approach is likely to be best for every person who has epilepsy. Understanding how genes contribute to epilepsy, whether directly or as a determinant of susceptibility is obviously important to pursue. Likewise as gene therapy develops, some forms of epilepsy may be candidates for that approach. The burgeoning understanding of brain plasticity—that is, how the brain changes in response to its environment and experience-has many ramifications, both as a potential contributor to the development of epilepsy and as a strategy for overcoming seizures or the problems that arise from treatments. The enormous advances in understanding the molecules that control electrical activity in brain cells provides many new targets for developing drugs that act more specifically to control seizures without side effects. Better understanding of how the brain develops is leading to insights about the development of epilepsy for many children. Technologies such as deep brain stimulation, triggered by intelligent sensors that detect the signs of oncoming seizures, is yet another possibility. There are certainly others I could mention, but perhaps what is most encouraging is the extent to which advances in so many areas of neuroscience may come to bear on epilepsy research in the foreseeable future.

*Question.* The Congressional Report Language this year-encourages the establishment of an Interagency Coordinating Council to coordinate research efforts in epilepsy between the NINDS, the National Institute on Aging, the National Human Genome Research Institute, the National Institute for Child Health and Human Development, and the National Institute of Mental Health. How do you envision taking a leadership role in coordinating the efforts of these various Institutes? How do you envision these cross-agency efforts furthering the search for a cure?

Answer. The National Institute of Neurological Disorders and Stroke (NINDS) is the lead NIH Institute for epilepsy research, but several other NIH Institutes also fund epilepsy related projects, including the National Institute of Mental Health (NIMH), the National Institute on Aging (NIA), the National Institute for Child Health and Human Development (NICHD), and the National Human Genome Research Institute (NHGRI). NINDS is working with these Institutes to coordinate epilepsy research efforts, including their involvement, as appropriate, in the implementation of the research benchmarks. This includes joint sponsorship of workshops and conferences, joint funding of initiatives, and periodic meetings to identify and discuss areas of common interest and opportunities for collaboration. NINDS has already initiated such efforts. For example, NHGRI is participating in a recent workshop on molecular analysis of complex genetic epilepsies; NIA and NIMH are cooperating with NINDS in a Request for Applications entitled "Gene Discovery for Neurological and Neurobehavioral Disorders" which was directly relevant to the Epilepsy Benchmarks for discovery of genes that predispose individuals to epilepsy; and similar cross-NIH efforts are underway on topics such as gene therapy.

NINDS also recognizes the importance of working with patient advocacy groups. The March 2000 conference on curing epilepsy represented a cooperative effort by NIH, working together with the Epilepsy Foundation, the American Epilepsy Society, Citizens United for Research in Epilepsy (CURE), and the National Association of Epilepsy Centers. The efforts to develop the Benchmarks were also a cooperative effort and we are continuing along those lines as we implement the benchmarks.

Central to the concept of the Benchmarks is the belief that they are milestones for the entire epilepsy community. Thus, NINDS plans to coordinate with other NIH Institutes and Centers efforts to implement the Benchmarks. Additionally, we plan to include the epilepsy professional organizations, and the epilepsy patient community in research activities. All of these entities must work collaboratively if the goals are to be reached.

#### VASCULAR DISEASE

Question. There seems to be evidence that vascular diseases—including stroke, high blood pressure, and diabetes—are associated with an increased risk of Alzheimer's disease. Some promising initial studies suggest that cholesterol-lowering drugs and changes in diet could reduce that risk. Is the Institute investing in this area of research and are you collaborating with the Heart, Lung, and Blood Institute?

Answer. There is intriguing evidence from both NIA-funded basic science studies in animals and human clinical studies that vascular disease itself, as well as vascular risk factors, may be involved in the development of Alzheimer's disease. For example, an NIA study suggests that high blood pressure in midlife is a risk factor for developing AD. Researchers are currently investigating the effect of raising blood pressure on behavior and development of brain pathology in young and middle-aged animals.

There is also evidence that both cholesterol-lowering drugs and dietary changes may reduce risk of AD. For example, mice that carry a gene for early-onset AD and are fed a high-cholesterol diet show an increase in the formation of brain plaques that are pathologically similar to the plaques seen in human AD patients, and a clinical study indicated that increasing total cholesterol was associated with AD risk in humans. In addition, recent results from a number of epidemiological studies indicate that people who had taken statins, the most common type of cholesterol-lowering drugs, were at reduced risk of developing AD. In addition to cholesterol, high blood levels of the amino acid homocysteine are

In addition to cholesterol, high blood levels of the amino acid homocysteine are associated with an increased risk of heart disease and stroke, and in a recently published report from the Framingham Heart Study (a National Heart, Lung and Blood Institute study, in which NIA funds one component), it was reported that high homocysteine is also a risk factor for the development of dementia and AD. The relationship between AD and homocysteine is of particular interest because blood levels of homocysteine can be reduced, for example, by increasing intake of folic acid (or folate) and vitamins B6 and B12.

There are a number of ongoing and planned clinical trials to investigate the effects of lowering cholesterol with statins and lowering homocysteine with vitamins (B6/B12/folate) on AD. The NIA funds an add-on study to the NHLBI-supported Women's Antioxidant Cardiovascular Study to assess the effect of B6/B12/folate on the development of cognitive decline and dementia. Through the Alzheimer's Disease Cooperative Study clinical trials consortium, NIA is planning clinical trials of the cholesterol-lowering drug simvastatin and vitamins B6/B12/folate to delay progression of AD among people who have the disease.

#### MINORITY AGING/ALZHEIMERS

Question. By 2030, minorities will represent 25 percent of the elderly, compared with 16 percent today. Some studies are now showing a higher prevalence of Alzheimer's disease in certain minority groups. New evidence suggests that two diseases that are especially common in minority populations—namely diabetes and hypertension—are associated with an increased risk of Alzheimer's disease. Does NIA have any plans to pursue research in this area in fiscal year 2003?

Answer. NIH recognizes the high prevalence of Alzheimer's disease (AD) in racial and ethnic minorities and plans to continue research in this area. One important and expanding research focus is on the possible interactions among other health conditions, particularly cardiovascular disease and diabetes, and the risk of developing AD. Both high blood pressure and diabetes are prevalent in some minority populations; and the NIA is funding a number of epidemiological and basic science studies to identify such risk factors, and their interplay with genetic risk factors, on the likelihood of developing AD. Many NIA-supported epidemiology studies are specifically designed to include minorities, with some emphasizing possible interactions between other organ systems and the brain. For example, in an NIA-funded study published last year, researchers at Columbia University showed a modest association between diabetes and the risk of AD in a group of patients that were 45 percent Hispanic and 32 percent African-American. Studies on possible mechanisms linking diabetes and cognitive decline and AD are underway.

Increased systolic blood pressure (the "top number" in a blood pressure reading, measuring the pressure on the blood vessel walls as the heart beats) has also been associated with increased risk for AD in several epidemiology studies. The mechanisms by which high blood pressure may contribute to AD brain pathology is being studied in animals and humans. In one study, researchers are comparing patients with vascular dementia (cognitive dysfunction caused by damage to the blood vessels in the brain) and patients with AD. By following these patients using positron emission tomography (PET scans) to study the brain's metabolism, as well as other tests, researchers hope to better understand the mechanisms leading to both conditions, and possible interactions between them. The Institute also recently funded a number of research projects to investigate the relationships among hypertension, aging, cognition and brain pathology The 29 NIA-supported Alzheimer's Disease Centers are conducting research on

The 29 NIA-supported Alzheimer's Disease Centers are conducting research on etiology, pathogenesis, treatment and the effects of the disease on the daily life of patients with AD and their families. Many Centers have set up Satellite clinics in minority neighborhoods to enhance the recruitment of minority subjects into research programs. In recent years, minority subjects represented approximately 16 per cent of the patients enrolled in the Alzheimer's Centers. Research is being carried out to determine differences in the age of onset among different patient groups, the differential influence of risk factors that affect development of disease in various racial and ethnic populations, responses to experimental drug treatment, and coping and support strategies used by minority families and communities to deal with the stresses of caring for patients with AD. The Aging (NIA) and the National Center on Minority Health and Health Dispari-

The Aging (NIA) and the National Center on Minority Health and Health Disparities (NCMHD) have worked collaboratively on supporting research efforts on Alzheimer's disease and other aging related conditions affecting minority populations. The NIA and NCMHD are collaborating in two broad program areas, the Nathan Shock Centers of Excellence in Basic Biology of Aging and the Resource Centers for Minority Aging Research (RCMAR).

The Nathan Shock Centers of Excellence in Basic Biology of Aging are designed to stimulate and enhance research into the basic biological processes of aging. Ultimately, research at the Centers is expected to yield breakthroughs in understanding the course of normal aging and the diseases and conditions that affect older people, such as Alzheimer's disease, frailty, and cancer. This program has placed significant emphasis on increasing the expertise of minority investigators and minority-serving institutions in biology of aging research. The RCMAR program represents one of NIH's most focused efforts to build the national research infrastructure for minority aging research. The six RCMAR Centers are actively involved in establishing a research mentoring mechanism in minority health, enhancing professional diversity in minority health research, developing measurement tools tailored to minority populations, and developing strategies for recruiting and retaining minority research participants. RCMAR efforts include research on AD.

## INFORMATION DISSEMINATION

Question. Over the past few years, we have seen remarkable strides in understanding Alzheimer's disease. The question is how quickly can some of that new information be put into the hands of physicians and hospitals? Along the same lines, do you feel that there are sufficient clinical researchers trained to translate all of this new knowledge into treatments and better patient care?

do you feel that there are sufficient clinical researchers trained to translate all of this new knowledge into treatments and better patient care? Answer. The National Institute on Aging (NIA) places a high value on sharing our improved understanding of Alzheimer's disease with both the public and medical communities, especially physicians and other health care providers. To accomplish this mission, the NIA has developed a number of programs and products to ensure the transmission of accurate and up-to-date information about Alzheimer's disease. In 1990, the Congress directed the establishment of the Alzheimer's Disease Education and Referral (ADEAR) Center at NIA. Since that time, the ADEAR Center has delivered the latest information about Alzheimer's disease, news releases, exhibits at professional meetings, and liaison with other NIA programs such as the Alzheimer's Disease Centers (ADCs) program and the Alzheimer's Disease Cooperative Study (ADCS). More recently, NIA has established a web site to provide information 24 hours a day, and worked with the Food and Drug Administration (FDA) and the National Library of Medicine (NLM) to provide up-to-date information about clinical trials being conducted in the field of Alzheimer's disease and other dementias.

Two publications are specifically aimed at the medical community-the annual *Progress Report on Alzheimer's Disease and the quarterly newsletter Connections.* The *Progress Report* details the advances being made in Alzheimer's disease research at NIA and the other NIH Institutes. This report is distributed widely to medical professionals, hospitals, researchers, and interested members of the general public. Through notices in their newsletters and other publications, we are able to help medical professionals keep up-to-date on AD research developments. Copies of the Progress Report are provided to the Alzheimer's Disease Centers, who distribute them at local conferences and meetings. Thus, we are able to use one centrally developed publication to share information through many channels. In the past 10

years, the size of the report has more than doubled. The current and past editions of the report are available at the ADEAR web site, and can be downloaded from a pdf file.

In addition to these resources, we provide health professionals, hospitals, Alzheimer's Association chapters, community and voluntary groups, and our grantees with publications to help them educate the public about Alzheimer's disease. To increase the reach of our efforts we have tried to capitalize on the new technologies available to communicate our messages about Alzheimer's disease research. For example, the AD clinical trials database provides the latest information about clinical trials that are being conducted. At the ADEAR web site, physicians and others can locate detailed information about current trials as well as the clinical trial sites located nearest to them. In many cases, direct linkage is provided to the study through an email hot link. In addition, members of the medical community can sign up for automatic email notification when new trials are posted. Last year more than 600,000 individual visits were made to the ADEAR web site.

The NIA has a history of training physician scientists by using several grant mechanisms—Alzheimer's Disease Centers, Program Project research grants, Leadership and Excellence in Alzheimer's Disease (LEAD) grants, the Alzheimer's dis-ease Cooperative Study and career development awards (K series)—all of which have provided multi-disciplinary training and mentorship to young physicians. To further augment research training for new investigators, the NIA is providing funds for young physician scientists under the Alzheimer's Disease Clinical Research and Training Awards program, (Public Law 106-505, the Public Health Improvement Act) passed during the 106th Congress. Six awards are being made in fiscal year 2002 under this new program and we are in the process of soliciting new applications for fiscal year 2003. The next generation of clinical researchers will be better prepared to translate research advances into clinical practice because of better training in the basic mechanisms underlying the disease process. One example is in the area of molecular neuropathology and brain imaging where it is imperative to advance our diagnostic capabilities to measure changes in the brain that reflect the early development of Alzheimer's disease and related dementias. Understanding the basic mechanisms will permit a new generation of physician scientists to develop diagnostic markers that identify persons who are at risk or are in the early stages of the disease so that therapeutic intervention can be implemented early enough to prevent or slow the development of the disease. Better diagnosis may be achieved either by visualizing brain pathology directly using advanced imaging techniques or by measuring changes in blood levels of molecules produced in the brain that reflect the presence of the disease. As new knowledge accumulates, physicians and scientists will meet periodically to decide which of the new findings best reflect the presence or severity of disease and, by consensus, decide how the findings can be translated into clinical practice to help in the diagnosis and management of the disease. Once consensus is reached, new practice guidelines will be distributed to the wider medical community

*Question.* Last fall the NEI released the results of the Age-Related Macular Degeneration study revealing that people at high risk of developing advanced stages of Age-Related Macular Degeneration lowered their risk of advanced development of this disease by taking a combination of vitamins and zinc. What has been done to translate the research results into treatments for people at risk of developing AMD?

Answer. In an effort to rapidly disseminate and translate into medical practice the results of the Age-Related Eye Diseases Study (AREDS), the National Eye Institute (NEI) coordinated both a national and locally-based campaign to inform the public of the results through print, radio, television, and internet coverage. An estimated 174 million people had the opportunity to hear or read about the AREDS results that were released at a national press conference conducted concurrently with the publication of the results in the journal Archives of Ophthalmology. The results were also released through a VISION Public Information Network for Eye Institutes and Departments of Ophthalmology and Schools and Colleges of Optometry to ensure the public and health professionals are aware of the findings.

#### GENERAL CLINICAL RESEARCH CENTERS

Question. It has been almost 2 years since the NCRR Advisory Council approved the concept of providing "seed money" for GCRC-based pilot projects. This Subcommittee urged you to move forward with this approach in report language accompanying our fiscal year 2000, 2001 and 2002 bills. How many centers have received pilot study support? How many pilot projects been funded? What is the total amount of funding that has been provided for this purpose? Does each GCRC receive an equal amount for pilot projects? If not, how are the funds distributed?

Answer. Pilot studies on GCRCs were phased in during fiscal year 2002 with the intent that all GCRCs would be able to request up to \$100,000 per annum for their support within 2–3 years. We become aware of pilot projects when GCRCs make a specific request for new funds and, in fiscal year 2002, 27 GCRCs made such requests. GCRCs are also permitted to rebudget funds internally to support pilot projects.

Approximately 32 pilot projects were funded in fiscal year 2002 in the 27 GCRCs that applied for new funds for the purpose. A total of \$645,000 was made available in fiscal year 2002, but internal rebudg-

A total of \$645,000 was made available in fiscal year 2002, but internal rebudgeting may allow for the funding of additional pilot projects. The full number will not be known until the Centers submit their annual reports.

No, they do not. The amount received depends first on the participation of the GCRC and on the local approval of the pilot projects by an Advisory Committee. By fiscal year 2003 we anticipate making new funds available for two pilot projects per center. Centers may increase their number of pilot projects beyond this if they are able to rebudget funds internally.

#### GENERAL CLINICAL RESEARCH CENTERS

*Question.* It is my understanding that a number of other programs are funded out of the GCRC appropriation. Could you tell me why this is, what those programs are, and how much money each receives?

Answer. The GCRC program and the research resource provided to clinical investigators have evolved markedly over the past several years. As a consequence, the funding mechanisms used have adjusted to also provide support for career development, loan repayment, research subject advocates, biostatisticians, bioinformatics, and a series of national resources for clinical research. Those include centers for human gene transfer, human islet cell resources, and more. Until a few years ago, one of the NIH centers budget lines had been labeled "GCRCs"—more than 90 precent of the funds in that budget line paid for the GCRC facilities, professional staffing and ancillary costs along with the costs for a unique GCRC clinical associate physician (CAP) program, a research career development program for physicians and dentists. The CAP awards were made as competitive supplements to the parent GCRC grant; the CAP program is undergoing a phase out and is being replaced by the K23 award.

The research careers programs now account for the largest amount of "clinical research" funding through the "other research" budget mechanism. The amount included in the fiscal year 2003 President's Budget request for clinical research careers (including curriculum development) is \$26.6 million. NCRR's clinical loan repayment program will total \$3.5 million in fiscal year 2003; awards will be through a contract mechanism. There are several smaller components of the clinical research budget, including the costs of peer review of clinical research applications, conference grants, and funding for ethics training grants.

*Question.* This past weekend, I met with several children with Diabetes from Wisconsin, as part of the Juvenile Diabetes Research Foundation's Children's Congress. Their parents told me about their children's daily struggle with diabetes, including daily insulin injections and blood sugar checks. They also told me about promising research involving transplantation of insulin-producing cells, which has resulted in dozens of individuals with the disease no longer requiring insulin. Can you update us on the status of this research, and also explain what the Institute is doing to utilize stem cell research in this area?

Answer. The NIDDK has a vigorous research effort on cell-based therapies with the goal of treating diabetes. In juvenile diabetes, the body's immune system mistakenly destroys the pancreatic beta cells, which produce insulin, a hormone critical for life. Beta cells normally exist within groups of pancreatic cells called islets. Recently, researchers, both intramural and extramurally, have obtained encouraging results in transplanting islets into several adult diabetic patients using islets obtained from cadaver pancreases. Researchers in the Immune Tolerance Network are also attempting to replicate the successful islet transplantation procedure developed in Edmonton, Canada, and other research is being vigorously pursued at the clinical level.

While the results of these clinical studies are preliminary, if this therapeutic approach continues to show promise in treating diabetes, then stem cells might one day provide a replenishable supply of beta cells—provided that scientists can develop reproducible ways for "coaxing" stem cells in the laboratory to differentiate into beta cells. I'll highlight some key examples of our efforts in this area.

The work of one research team suggests that the objective of increasing the supply of islets may be realized from pancreatic duct cells from human pancreatic tis-sue that is normally discarded in the process of preparing human islets for transplant. Researchers have shown that these cells can be encouraged to form insulinproducing cells. Although the number of islets generated was small, these findings certainly raise the possibility that, with further optimization, this technique might have major implications for use in islet cell replacement therapy in the future.

In another example, in laboratory experiments on animals, investigators have generated insulin-producing islets from cells isolated from the pancreatic ducts of mice. When they implanted the islets into the kidneys of non-obese diabetic mice, the researchers were able to wean the mice off insulin injections.

In other research, scientists found that human pancreatic islets contain a distinct population of cells that may be adult stem cells. These cells can differentiate into cell types of the pancreas. If researchers can learn how to isolate them in sufficient numbers and control their differentiation, these cells could also potentially be used for therapies for diabetes patients. These studies were performed with animal cells or with human adult stem cells.

We certainly plan to continue funding research on these cells. In addition, new ini-tiatives are now encompassing support for research on the human embryonic stem cell lines eligible for study under federal policy. For example, we are providing an opportunity for supplemental awards to NIDDK grantees who seek to add research on these cells to their work, in cases where such additional research would be with-in the scope of, and would be a relevant extension of, an ongoing project funded through the peer review process. We are also planning support for research training and infrastructure to help investigators commence research on these delicate cells. One major NIDDK initiative is to establish a "Beta Cell Biology Consortium" to fa-cilitate interdisciplinary approaches that will advance our understanding of pancreatic islet development and function in order to build fundamental knowledge that may lead to improved therapies for diabetes. The NIDDK will also extend its progenitor cell genome anatomy project through an initiative to study how adult stem cells and embryonic stem cells lead to the development and maintenance of tissues and organs. Further initiatives that will encompass research on stem cells, as well as other cells, for potential cell-based therapies include: planned support for gene transfer approaches to enhance islet transplantation; a research effort to attract new research talent to type 1 diabetes research; and an effort to develop "benchto-bedside" partnerships between clinical and basic scientists to help extend successful basic research approaches to type 1 diabetes to the point at which they can be tested in animal models or in patients.

#### QUESTIONS SUBMITTED BY SENATOR TED STEVENS

### DEPARTMENT OF DEFENSE RESEARCH ACTIVITIES

Question. The NIH budget includes \$49 million "directed towards collaborative research projects with the Department of Defense." It is unclear from your budget jus-tification just how that money would be used. Funds would be used for electronic laser research (\$11 million), radiation exposure research (\$14 million), and HIV clinical trial research (\$23.2 million). Are you transferring the funds from NIH to DOD? Or are you moving some of the DOD defense science and technology activities to the NIH?

Answer. The White House Office of Management and Budget directed the transfer of oversight and management for the DOD HIV Research and Development Program of the U.S. Army Medical Research and Material Command (USAMRMC) to the NIH in January 2002. NIAID, which has the primary responsibility for HIV/AIDS research within the NIH, will assume responsibility for this program beginning October 1, 2002.

The \$11 million for the free electron laser research effort will be provided to the

Department of Defense. The NIDDK will be providing \$14.3 million directly to the Department of Defense for radiation exposure research through an interagency agreement.

#### OBESITY AND DIABETES

Question. In the U.S. today there are approximately 4.7 million children aged 6-17 who are overweight or obese. Since 1980, the prevalence of overweight children has nearly doubled and the prevalence of overweight adolescents has nearly tripled. You state in your testimony that NIH funded a study showing that millions of over-weight Americans are at high risk for type 2 diabetes and that improved diet and moderate exercise could possibly prevent the disease. You have launched a National Diabetes Education program with the Centers for Disease Control. How does this program help address the obesity problem and is it designed to reach and educate all segments of the population, including parents, teachers, and physicians regarding obesity and its consequences?

Answer. The National Diabetes Education Program (NDEP) is a partnership of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the Centers for Disease Control and Prevention, and more than 200 public and private organizations. The NDEP's objectives are: to increase public awareness of the seriousness of diabetes, its risk factors, and strategies for preventing diabetes and its complications; to improve understanding about diabetes and its control and to promote better self-management behaviors among people with diabetes; to improve health care providers' understanding of diabetes and its control and to promote an integrated approach to care; and to promote health care policies that improve the quality of and access to diabetes care.

To accomplish these goals, NDEP's message is designed to reach people with diabetes and their families (with special emphasis on minority populations disproportionately affected by diabetes), members of the public at risk for diabetes, health care providers, and health care purchasers, payers and policy makers.

Based on the exciting results of the Diabetes Prevention Program (DPP) study that you mentioned, the NDEP is focusing its efforts on preventing type 2 diabetes, and its serious risk factor, obesity. The DPP demonstrated that millions of overweight adult Americans at risk for type 2 diabetes can delay and possibly prevent the disease by improving their diets and engaging in moderate exercise. We are working to get this message to health care providers and to Americans at risk, in the hope of helping millions to avoid developing type 2 diabetes.

In complementary efforts, the NIDDK is also currently funding investigators who are designing a trial to prevent type 2 diabetes in children and adolescents, using a school-based approach that includes lifestyle changes. This initiative will begin in fiscal year 2003. We view these efforts as especially important in light of recent reports of the increase in type 2 diabetes and obesity in children and adolescents, especially in minority populations. Other pilot studies under way are likewise focused on preventing obesity, and some of these also target children and adolescents. As with other trials, once we find interventions that work, we will use the NDEP to disseminate information to those who can benefit. The NDEP's "Diabetes in Chil-dren and Adolescent Work Group" has been established to raise awareness among health care providers about diabetes in children and adolescents and to improve early diagnosis, treatment, and management of children with diabetes, as well as those at risk for diabetes. The Work Group has developed several resources for children with diabetes (www.ndep.nih.gov) including a fact sheet, resource directory, and annotated bibliography. A manual targeted to school personnel, which is designed to encourage optimal management of children with diabetes in the school setting, is under development. The Work Group is continuing its efforts to promote knowledge of the link between diabetes and obesity among children and adolescents. In addition to the NDEP's efforts, the Weight-control Information Network (WIN), another health information program of the NIDDK, is also developing science-based information about the overall health benefits of regular exercise and healthy eating for health care providers and the public, including parents with children who are Another component of the NDEP that is an important corollary to its messages

Another component of the NDEP that is an important corollary to its messages about the benefit of improvements in diet and exercise is its newly launched campaign entitled "Be Smart About Your Heart: Control the ABC's of Diabetes." This campaign is designed to make people with diabetes aware of their high risk for heart disease and stroke and the steps they can take to lower that risk dramatically. The campaign emphasizes managing blood glucose (best measured by the Alc test), blood pressure, and cholesterol. The "ABC" campaign was mentioned in the March 24, 2002, issue of Parade Magazine, which reaches millions of Sunday newspaper subscribers.

<sup>1</sup>Using all of the avenues I have described, the NIDDK and its partners in NDEP are attempting to reach and educate all segments of the population to inform them of the risks of obesity and its dire consequences.

## QUESTIONS SUBMITTED BY SENATOR ARLEN SPECTER

## ANTHRAX VACCINE PURCHASE

*Question.* The NIH budget proposes to spend \$250 million for "anticipated procurement of anthrax vaccines currently under development and testing." If Congress approves this request, it would reduce the biomedical research funding by \$250 million. Vaccine purchase is usually funded through the CDC—not through the NIH.

lion. Vaccine purchase is usually funded through the CDC—not through the NIH. Isn't it unusual for the NIH to be spending \$250 million for the purchase of an anthrax vaccine? Is this request somewhat of a double count—it counts towards your doubling of the research funds and then also counts towards the overall bioterrorism number?

Answer. The nation has an urgent and compelling need to have a second-generation anthrax vaccine product quickly available. At the moment, a second-generation anthrax vaccine still needs to be developed and tested. Due to the accelerated nature needed to do the research, develop, test, and purchase this vaccine in a short time, NIH is taking the lead. Ultimately, the vaccine, when purchased, will be managed by CDC as part of the national stockpile. NIH will not become a stockpile manager for this vaccine.

The request to use \$250 million to develop, test, and purchase a second-generator vaccine product does meet both categories—the development and testing of the product is an integral part of this purchase and the end product is a key tool to help counter a crucial bioterroristic threat.

## SMALLPOX

Question. There was an article in Tuesday's Wall Street Journal that describes the debate surrounding the inclusion of an anti-viral drug known as cidofovir (pronounced—side-off-a-veer) in the National Pharmaceutical Stockpile. The article quotes Dr. James LeDuc of the Centers for Disease Control and Prevention as saying that cidofovir "continues to look good" as a treatment for smallpox. The article also says the CDC backs the idea of stockpiling cidofovir. However, Dr. D.A. Henderson, who is coordinating the Department's Bioterrorism Preparedness activities, is skeptical. Recent press accounts of a variant of cidofovir that is taken orally sound promising. What is your opinion of placing anti-virals, such as cidofovir, in the National Pharmaceutical Stockpile?

Answer. Placing antivirals in the National Pharmaceutical Stockpile is an important tool for the nation to have to combat and neutralize bioterroristic threats and agents of bioterrorism. We believe that the issue of whether to include cidofovir in the National Pharmaceutical Stockpile needs to be addressed; both, for the treatment of smallpox, and for the treatment of the rare complications of smallpox vaccination. Experience with other antivirals suggests that for cidofovir to be effective, the product must be available to administer as soon as possible after infection or after symptoms appear. However, few pharmacies keep more than a few doses of cidofovir on the shelf. With supplies of cidofovir being limited, other organizations, including DOD, are planning purchases. Ultimately, the decision on what products to include in the National Pharmaceutical Stockpile will be determined by the Secretary in consultation with the director of the Office of Public Health Preparedness (OPHP) and the Center for Disease Control and Prevention (CDC). OPHP and CDC are themselves advised by other DHHS experts that includes representatives from NIH.

Research conducted on the oral variant of cidofovir, HDP-cidofovir, looks promising in animal models. Further studies are needed to determine the efficacy in humans before it is made available.

#### BASIC & CLINICAL RESEARCH

Question. This Subcommittee has been NIH's biggest supporter when it comes to providing additional funding for basic research. As a result of that funding, scientists have gained considerable knowledge about human genes and cells. When we reach the doubling goal in October, what is going to become of this investment what is the next step? How do we translate that new scientific knowledge into better treatments and cures for sick people? Answer. The Human Genome Project is providing biomedical researchers with a

Answer. The Human Genome Project is providing biomedical researchers with a vast and unprecedented amount of new biological information. The first draft of the human genome sequence was completed in 2001 and the final sequence is expected to be completed by 2003, well ahead of schedule. The goal of sequencing the human genome is to better understand normal human physiology and, ultimately, to find the root causes of many of our most devastating diseases. The human genome sequence is the first step in this effort.

With this new information scientists must now gain an understanding of the proteins expressed by each gene and the roles such proteins play in all biological processes. The NIH plans to undertake a number of activities, including large-scale efforts to determine the three-dimensional structures of all proteins in nature, as well as the development of innovative research technologies and databases essential to the exploration of protein expression, structure, and function. By using our knowledge about genes, their expressed proteins, and the role they play in disease, future treatments will be based on the underlying causes of disease, rather than its symptoms. Such information will also help classify diseases by subtypes that may respond to different treatments or result in different or varied side effects.

spond to different treatments or result in different or varied side effects. New knowledge about genes and proteins is just one step on the way to improving health. The translation of basic biomedical findings into clinical studies on human subjects and populations helps scientists is the essential link on the road to new and more effective prevention strategies, diagnostics, treatments. To this end, the NIH also plans to engage in new and renewed efforts in clinical research and epidemiology.

The NIH research program spans all aspects of the medical research continuum, including basic research, observational and population-based research, behavioral research, clinical research, and health services research. In addition, the timely dissemination of medical and scientific information is a key part of what we do as is the expeditious transfer of the results of NIH-funded medical research to the broader research community, both public and private, for use in further research and development.

NIH develops and disseminates informational materials to individuals and groups, including medical and scientific organizations, industry, the media, and volunteer and patient organizations. Information dissemination efforts have expedited the translation of NIH's scientific advances and technologies into important diagnostic, preventive, and therapeutic products. In addition, they have brought about major health-enhancing changes in public attitudes and behaviors, such as reduction of smoking and better control of high blood pressure and high cholesterol levels. To effectively reach diverse audiences, whose knowledge of science and health differ, NIH disseminates information ranging from highly technical research advances to the steps individuals can take to improve their own health.

NIH disseminates information on scientific findings and technologies to scientific and other health professionals through various avenues: scientific publications, workshops and symposia, scientific meetings, consensus development conferences, press releases, special physician education programs, and clinical alerts concerning immediate health and safety issues. NIH also provides access to information about scientific articles, NIH research grants, clinical trials and treatment through extensive electronic databases.

Additionally, as a federal R&D agency, the NIH has a statutory mandate to engage in technology transfer activities for discoveries that must be brought to the market by a company in order to benefit the public. The requirement is applied to recipients of NIH research grants and contracts as well as our own intramural research activities. In return for title to inventions developed under NIH support, recipient institutions enter into agreements (licenses) with commercial partners to undertake additional research and development with the invention and ultimately bring a product to market. Internally, we evaluate new research discoveries, seek patent protection if further development is needed, and market the technology to potential licensees. These companies are monitored in their efforts to move the technology to the market place in an expeditious manner.

nology to the market place in an expeditious manner. *Question.* When he was NIH Director, Dr. Harold Varmus called clinical research an "embattled enterprise." He implied that we are not training enough physician scientists, the people who are best equipped to use research to find help for patients. Where do we stand now? Are we attracting enough physician scientists into this field of research? Do you have anyone advising you on the direction clinical research should be going, like an office of clinical research or an advisory board? Answer. The clinical research enterprise has improved. The NIH has made sub-

Answer. The clinical research enterprise has improved. The NIH has made substantial efforts in the training and career development of physician scientists since Dr. Varmus' assessment. He led the development of several programs designed to encourage physician scientists into research careers. For example, the patient-oriented research career development program and the mid-career investigator award in patient-oriented research are products of his efforts. As shown in the data below, since 1998, there has been a steady increase in the number of physicians in the NIH training programs and career development programs:

	Fiscal year <sup>1</sup>	Total numbe	er of MD
1998			3,222

	Fiscal year <sup>1</sup> Total number	er of MD
1999		3,452
2000		3,608

 $^1\rm{Fiscal}$  year 2001 data are not yet available since trainee appointments are made several months after training grants have been awarded.

The NIH is committed to continue its support of physician scientists to ensure that there is a sustainable workforce in this important area of research. The number of physician scientists who are principal investigators in clinical research has increased. In fiscal year 2000, there were 5,562 and in fiscal year 2001, the number has increased to 6,815.

The NIH has an Associate Director for Clinical Research. In addition, each Institute and Center, including the Office of the Director, has a National Advisory Council to provide programmatic advice and guidance to the Institute Director. These councils have clinical researchers as members.

#### CLINICAL RESEARCH

*Question.* What elements need to be in place to move information from the research laboratory into the hands of physicians who are treating patients? Ideally, there should be a balance between basic science and clinical research. How much is NIH devoting to each of these categories? Do you think that's the right balance to get more information into the hands of physicians? Does NIH set aside a certain proportion of grants for clinical research?

Answer. The NIH invests the public's resources and support for medical research in four basic and interrelated ways. First and foremost, NIH supports and conducts medical research. Second, it contributes to the development and training of scientific talent. Third, it participates in the support, construction, and maintenance of laboratory facilities in Bethesda and around the Nation that are necessary for conducting cutting-edge medical research. Fourth, NIH engages in a wide variety of knowledge dissemination activities to help ensure that knowledge gained from NIH supported basic and clinical research will be moved from the laboratory to treatment providers in a timely manner. By focusing its efforts on both basic and disease-specific research, 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 hold the promise of even greater medical advances. In fiscal year 2003, NIH estimates that \$14,454 billion of direct funding will be

In fiscal year 2003, NIH estimates that \$14,454 billion of direct funding will be spent on basic research, and \$11,280 billion on applied research, which encompasses the clinical research program.

NIH does not set aside a certain proportion of grants for clinical 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 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 that might prove relevant to clinical problems important to that Institute's mission.

The NIH does recognize the critical need for increased investment in clinical research, however, and towards that end has created several new programs to foster greater participation by clinicians in research, including the Clinical Research Training and Career Development initiatives, such as the Mentored Patient-Oriented Research Career Development Award (K23), the Midcareer Investigator Award in Patient-Oriented Research (K24), and the Clinical Research Curriculum Award (K30), as well as the creation of the Extramural Clinical Research LRP, and the Pediatric Research LRP. These new programs will help to increase the number of outstanding investigators in clinical research in the future, and hasten the translation of basic research into improved health for all Americans.

*Question.* To what extent are clinical researchers included on review panels that consider applications for clinically-oriented research?

Answer. The Center for Scientific Review (CSR) recently conducted an informal poll of reviewers currently serving on its review committees. The poll indicated that approximately 34 percent of reviewers are engaged in patient care and 27 percent see patients as part of their research activities.

New opportunities to apply the results of basic scientific discoveries to human health problems have generated increased need for reviewers with clinical research experience. CSR has initiated a number of outreach activities to establish closer ties with professional clinical research societies. In addition, CSR staff work closely with funding institutes and centers to identify appropriate clinical researchers to serve on review committees. Finally, CSR recognizes that, because of their other responsibilities, clinical researchers are often quite limited in the time they have available to participate in review activities. We are working to find ways to accommodate the special review service needs of clinical researchers.

#### MINORITY AGING/ALZHEIMERS

Question. By 2030, minorities will represent 25 percent of the elderly, compared with 16 percent today. Some studies are now showing a higher prevalence of Alzheimer's disease in certain minority groups. New evidence suggests that two diseases that are especially common in minority populations-namely diabetes and hypertension-are associated with an increased risk of Alzheimer's disease. Does it have any plans to pursue research in this area in fiscal year 2003? Answer. NIH recognizes the high prevalence of Alzheimer's disease (AD) in racial

Answer. NIH recognizes the high prevalence of Alzheimer's disease (AD) in racial and ethnic minorities and plans to continue research in this area. One important and expanding research focus is on the possible interactions among other health conditions, particularly cardiovascular disease and diabetes, and the risk of developing AD. Both high blood pressure and diabetes are prevalent in some minority populations; and the NIA is funding a number of epidemiological and basic science studies to identify such risk factors, and to analyze their interaction with genetic risk factors in affecting the likelihood of developing AD. A number of NIA-supported epidemiology studies are specifically designed to include minorities, with some emphasizing possible interactions between other organ systems and the brain. For example, in an NIA-funded study published last year, researchers at Columbia University showed an association between diabetes and the risk of AD in a group of patients that were 45 percent Hispanic and 32 percent African-American. Studies on possible mechanisms linking diabetes and cognitive decline and AD are underway.

Increased systolic blood pressure (the "top number" in a blood pressure reading, measuring the pressure on the blood vessel walls as the heart beats) has also been associated with increased risk for AD in several epidemiology studies. The mechanisms by which high blood pressure may contribute to AD brain pathology is being studied in animals and humans. In one study, researchers are comparing patients with vascular dementia (cognitive dysfunction caused by damage to the blood vessels in the brain) and patients with AD. By following these patients using positron emission tomography (PET scans) to study the brain's metabolism, as well as other tests, researchers hope to better understand the mechanisms leading to both conditions, and possible interactions between them. The Institute also recently funded a number of research projects to investigate the relationships among hypertension, aging, cognition and brain pathology The 29 NIA-supported Alzheimer's Disease Centers are conducting research on

The 29 NIA-supported Alzheimer's Disease Centers are conducting research on etiology, pathogenesis, treatment and the effects of the disease on the daily life of patients with AD and their families. Many Centers have set up Satellite clinics in minority neighborhoods to enhance the recruitment of minority subjects into research programs. In recent years minority subjects represented approximately 16 per cent of the patients enrolled in the Alzheimer's Centers. Research is being carried out to determine differences in the age of onset among different patient groups, the differential influence of risk factors that affect development of disease in various racial and ethnic populations, responses to experimental drug treatment, and coping and support strategies used by minority families and communities to deal with the stresses of caring for patients with AD.

The NIA and the National Center on Minority Health and Health Disparities (NCMHD) have worked collaboratively on supporting research efforts on Alzheimer's disease and other aging related conditions affecting minority populations. The NIA and NCMHD are collaborating in two broad program areas, the Nathan Shock Centers of Excellence in Basic Biology of Aging and the Resource Centers for Minority Aging Research (RCMAR).

The Nathan Shock Centers of Excellence in Basic Biology of Aging are designed to stimulate and enhance research into the basic biological processes of aging. Ultimately, research at the Centers is expected to yield breakthroughs in understanding the course of normal aging and the diseases and conditions that affect older people, such as Alzheimer's disease, frailty, and cancer. This program has placed significant emphasis on increasing the expertise of minority investigators and minority-serving institutions in biology of aging research. The RCMAR program represents one of NIH's most focused efforts to build the national research infrastructure for minority aging research. The six RCMAR Centers are actively involved in establishing a research mentoring mechanism in minority health, enhancing professional diversity in minority health research, developing measurement tools tailored to minority populations, and developing strategies for recruiting and retaining minority research participants. RCMAR efforts include research on AD.

## INFORMATION DISSEMINATION

*Question.* Over the past few years, we have seen remarkable strides in understanding Alzheimer's disease. The question is how quickly can some of that new information be put into the hands of physicians and hospitals? Along the same lines, do you feel that there are sufficient clinical researchers trained to translate all of this new knowledge into treatments and better patient care?

do you feel that there are sufficient clinical researchers trained to translate an of this new knowledge into treatments and better patient care? Answer. The National Institute on Aging (NIA) places a high value on sharing our improved understanding of Alzheimer's disease with both the public and medical communities, especially physicians and other health care providers. To accomplish this mission, the NIA has developed a number of programs and products to ensure the transmission of accurate and up-to-date information about Alzheimer's disease. In 1990, the Congress directed the establishment of the Alzheimer's Disease Education and Referral (ADEAR) Center at NIA. Since that time, the ADEAR Center has delivered the latest information about Alzheimer's disease, subjust at professional meetings, and liaison with other NIA programs such as the Alzheimer's Disease Centers (ADCs) program and the Alzheimer's Disease Cooperative Study (ADCS). More recently, NIA has established a web site to provide information 24 hours a day, and worked with the Food and Drug Administration (FDA) and the National Library of Medicine (NLM) to provide up-to-date information about clinical trials being conducted in the field of Alzheimer's disease and other dementias.

Two publications are specifically aimed at the medical community—the annual *Progress Report on Alzheimer's Disease* and the quarterly newsletter *Connections*. The Progress Report details the advances being made in Alzheimer's disease research at NIA and the other NIH Institutes. This report is distributed widely to medical professionals, hospitals, researchers, and interested members of the general public. Through notices in their newsletters and other publications, we are able to help medical professionals keep up-to-date on AD research developments. Copies of the *Progress Report* are provided to the Alzheimer's Disease Centers, who distribute them at local conferences and meetings. Thus, we are able to use one centrally developed publication to share information through many channels. In the past 10 years, the size of the report has more than doubled. The current and past editions of the report are available at the ADEAR web site, and can be downloaded from a pdf file.

In addition to these resources, we provide health professionals, hospitals, Alzheimer's Association chapters, community and voluntary groups, and our grantees with publications to help them educate the public about Alzheimer's disease. To increase the reach of our efforts we have tried to capitalize on the new technologies available to communicate our messages about Alzheimer's disease research. For example, the AD clinical trials database provides the latest information about clinical trials that are being conducted. At the ADEAR web site, physicians and others can locate detailed information about current trials as well as the clinical trial sites located nearest to them. In many cases, direct linkage is provided to the study through an email hot link. In addition, members of the medical community can sign up for automatic email notification when new trials are posted. Last year more than 600,000 individual visits were made to the ADEAR web site.

The NIA has a history of training physician-scientists by using several grant mechanisms—Alzheimer's Disease Centers, Program Project research grants, Leadership and Excellence in Alzheimer's Disease (LEAD) grants, the Alzheimer's disease Cooperative Study and career development awards (K series)—all of which have provided multi-disciplinary training and mentorship to young physicians. To further augment research training for new investigators, the NIA is providing funds for young physician scientists under the Alzheimer's Disease Clinical Research and Training Awards program, (Public Law 106–505, the Public Health Improvement Act) passed during the 106th Congress. Six awards are being made in fiscal year 2002 under this new program and we are in the process of soliciting new applications for fiscal year 2003. The next generation of clinical researchers will be better prepared to translate research advances into clinical practice because of better training in the basic mechanisms underlying the disease process.

#### AUTISM

*Question.* I have been hearing about a great increase in the incidence of autism in America, particularly in California. What can you tell me about that?

Answer. The reported increase in the incidence of autism in California, and elsewhere in the United States, is likely to be the result of a number of factors. There is much more awareness of autism between professionals and parents than there has been in the past, so it is more likely that autistic individuals are identified and diagnosed. Most researchers believe that a large portion of the increase is likely due to improved techniques for diagnosing the disease; increased awareness of the condition; more referrals due to availability of services; and a greater social willingness to identify. Also, autism is now recognized as a spectrum of disorders, so the criteria for classifying an individual as autistic have been expanded. Thus, individuals that, previously, may have been classified with other disorders (e.g., learning impairment) may now be included under the expanded definition of autistic disorder. So, we do not know if there is, in fact, an actual increase in the incidence of autism because accurate assessment of any increase is confounded by changes in the way we define, diagnose, and possibly even report current cases of autism.

*Question.* Tell us how you have implemented the provisions of the Children's Health Act of 2000 with regard to autism.

Answer. Children's Health Act of 2000 (Public Law 106–310) Title I focused on autism. The Act was authorizing legislation requiring major enhancements of research activities at the Centers for Disease Control (CDC) and NIH, as well as mandating the establishment of an Inter-Agency Autism Coordinating Committee (IACC) to enhance communication and effective interaction among the several agencies that support or conduct autism-related research, service, or educational activities. NIMH was designated as the lead among NIH Institutes and Centers (IC) and was also later delegated (from the Secretary, Department of Health and Human Services (HHS) the authority to organize the IACC, except for the appointment of public members, which the Secretary reserved. The NIH activities required by the Act have been coordinated by the NIH level Autism Coordinating Committee, which remains functional and in close communication with the IACC. The Institutes have retained control over their own activities, such as the long-standing Collaborative Programs for Excellence in Autism (CPEAs), a network of sites funded by NICHD and NIDCD.

In November 2001, NIMH led the organization and implementation of the inaugural meeting of the IACC, which included the public members selected by the Secretary of HHS. The date of the second meeting, May 24, 2002, has been set. The IACC is on the schedule to meet twice a year as set forth in the Children's Health Act.

NIH issued an Request For Applications (RFA) to implement, on a fast-track, the requirement of the Children's Health Act that there be established a new center's program for autism research. These comprehensive centers are to be called STAART (Studies to Advance Autism Research and Treatment) Centers. Eleven applications were received in response to this initial RFA and were reviewed in March 2002 for funding in approximately July 2002. A second round of competition will have a deadline for applications of August 2002, with funding of the successful applications in 2003. The participating NIH institutes (NIMH, NICHD, NINDS, NIDCD, NIEHS) have established a pool of \$12 million per year (including \$8 million per year from NIMH) to fund the full cohort of centers that will be established by 2003.

NICHD/NIDCD will competitively renew their long-standing CPEAs—Cooperative Program for Excellence in Autism. The CPEAs program will expand to be essentially the same size as the STAART program, and the NIH commitment to each of these programs will continue for at least the next five years.

The overall commitment of NIH to autism research continues to expand substantially each year. The internal NIH Autism Coordinating Committee continues to be active at the NIH level, and has a strong relationship with the IACC so that NIH activities will be coordinated with those of other agencies. This year the ACC endorsed two RFAs: one for developmental grants for groups intending to submit applications for the STAART competition, and one for innovative research into treatments for autism. For fiscal year 2001, the total NIH commitment to autism research was about \$56 million, with the NIMH contribution being larger than that for any other IC, although this is due, in part, to NIMH being more inclusive in the scope of research included in this total.

Section 105 of the Act calls for an annual report from the Secretary regarding activities of the Federal government on autism. The report for 2001 was drafted by NIMH with input from the FDA, CDC, and other NIH ACC institutes. The report was signed by the Secretary on March 12, 2002 and sent to Members of Congress. In summary, NIMH/NIH are on schedule in terms of implementing the letter and

In summary, NIMH/NIH are on schedule in terms of implementing the letter and the spirit of all of the aspects of the Children's Health Act that fall within their purview.

#### BONE DISEASE AND OSTEOPOROSIS

Question. We understand that bone diseases, such as osteoporosis, affect a lot of people in this country, and that these diseases are debilitating and extremely costly to our Medicare program. In fact it has been reported that osteoporosis and low bone mass are a threat for almost 44 million U.S. women and men aged 50 and over. Doctor, is there a trans-NIH plan currently in place to address bone diseases? Please share the details of the plan with the committee-such information will be helpful as we allocate resources among the various institutes. Answer. The NIAMS is committed to stimulating and supporting research to en-

Answer. The NIAMS is committed to stimulating and supporting research to enhance our understanding of the causes of, and potential treatments for, osteoporosis and related bone diseases. Several years ago, the Institute initiated the Federal Working Group on Bone Diseases, an interagency committee comprised of the NIAMS and ten other NIH components as well as other Federal agencies. This group focuses on osteoporosis, Paget's disease, and other bone disorders and offers a forum for sharing information and facilitating the development of collaborative research activities based on each Institute's mission.

search activities based on each Institute's mission. The NIH Consensus Development Conference on Osteoporosis Prevention, Diagnosis and Therapy is an important example of a trans-NIH activity. This conference, held in March 2000, was sponsored by the NIAMS and the NIH Office of Medical Applications of Research. This three-day conference provided a platform for national and international experts to present and discuss the latest research findings on osteoporosis. The panel recommended several areas for future research including improved diagnosis and treatment of secondary causes of osteoporosis, such as that resulting from the use of glucocorticoids; developing quality-of-life measurement tools that incorporate gender, age and race/ethnicity; and conducting randomized clinical trials of combination therapies to prevent or treat osteoporosis.

There are many other examples of trans-NIH osteoporosis and related bone disease initiatives undertaken by the NIAMS. In 1999, the Institute joined with the National Institute on Aging (NIA) and the National Cancer Institute to support a major study of osteoporosis in men. This 7-year, seven-center study will follow 5,700 men 65 years and older and determine the extent to which the risk of fracture in men is related to bone mass and structure, biochemistry, lifestyle, tendency to fall, and other factors. In 2001, the NIAMS, the NIA and the National Institute of Child Health and Human Development sponsored a solicitation for New Research Strategies in Osteogenesis Imperfecta. As a result, the NIAMS funded several new grants to support research activities ranging from cutting-edge gene and cell therapies to testing drug treatments on animal models. Also in 2001, the NIAMS joined the National Heart, Lung and Blood Institute to support research on bone formation and calcification in cardiovascular disease. Most recently, the NIAMS and the National Institute of Dental and Craniofacial Research released a solicitation for New Research Strategies for Evaluation and Assessment of Bone Quality. This initiative focuses on novel means of assessing bone quality, elucidating relationships among disease- and aging-related changes in bone quality, gender variations in bone quality and increased bone fragility and fracture susceptibility.

In addition to the Institute's support of extramural research in osteoporosis and related bone diseases, there are intramural research efforts underway. For example, the NIAMS is leading a consortium focused on developing a trans-NIH collaboration in musculoskeletal medicine. This trans-NIH effort will build on strengths that are already present and are beginning to be coordinated, enhance research productivity through synergy of the programs, develop new programs, recruit new investigators, coordinate with existing and newly developed clinical programs, and make it possible to create a national resource in this critical and underserved area of research.

Finally, in the area of information dissemination, the NIAMS and five other NIH components support the NIH Osteoporosis and Related Bone Diseases National Resource Center. The resource center collects, develops and disseminates information on a variety of bone diseases. Its mission is to expand awareness and to enhance knowledge of the prevention, early detection, and treatment of these diseases, as well as develop strategies for coping with them.

well as develop strategies for coping with them. *Question.* Dr. Katz, it would appear that NIAMS is the lead NIH institute for bone research. Can you tell the committee what you see for the future of bone research—especially as it relates to women's health? Also, we understand that bone diseases, such as osteoporosis, affect men as well. Is this a serious problem for men?

Answer. The NIAMS has a major interest and investment in research on bone diseases, such as osteoporosis, Paget's disease, and osteogenesis imperfecta. In a recent advance, NIAMS supported researchers have determined that estrogen affects programmed cell death (apoptosis) in cells that are responsible for degradation of bone (osteoclasts). Most recently, scientists have determined that either estrogen or

androgen (a steroid that maintains masculine characteristics) can have this antiapoptotic effect, and that it can be mediated by either estrogen receptors or androgen receptors, regardless of which sex hormone is present. By paving the way for future assessment of whether drugs can also affect the programmed cell death of osteoclasts—thereby making them potentially useful as bone-protecting treat-ments—this discovery represents an exciting link between basic research and tangible patient benefit.

Patient-based research has shown that elderly women who already had several spine fractures at the start of a study experienced the greatest health benefit from calcium supplementation, both in terms of reducing the rate of new spine fractures and stopping bone loss. This finding has clear implications for developing and targeting new preventive strategies.

In 1991, the NIAMS joined the National Heart, Lung and Blood Institute and sev-eral other NIH components in the creation of the Women's Health Initiative (WHI). The WHI is a long-term national health study that focuses on prevention strategies for cardiovascular disease, cancer and osteoporosis in postmenopausal women. The research completed through the WHI will strengthen both osteoporosis prevention and treatment.

In other research on women's health, osteoporosis is also a major complication of systemic lupus erythematosus. The NIAMS continues to support the Safety of Estro-gen in Lupus Erythematosus National Assessment (SELENA) study which examines the effects of hormone replacement therapy on lupus activity in postmenopausal women, and studies the effects of oral contraceptives. In the next few years, researchers will determine the effects of oral contraceptives on osteoporosis.

The NIAMS continues to support research in bone disease as it relates to women's health through several new initiatives. In 2001, the NIAMS joined the National Heart, Lung and Blood Institute to support research on bone formation and calcifi-cation in cardiovascular disease, and with the National Institute of Child Health and Human Development and the National Institute on Aging to stimulate new ap-plications on osteogenesis imperfecta. More recently, the NIAMS has released solici-tations of for New Bergereth Structure for Purplustice and Agency a tations for New Research Strategies for Evaluation and Assessment of Bone Quality, and for proposals on Pilot and Feasibility Trials in Osteoporosis. In addition, the NIAMS continues to support research on combination therapies in the treatment of osteoporosis.

With respect to osteoporosis in men, the NIAMS has joined with the National Institute on Åging and the National Cancer Institute to support a major, multi-center study to better understand the risk factors that predispose aging men to bone fractures and osteoporosis. The study will follow 5,700 men 65 years and older and determine the extent to which the risk of fracture in men is related to bone mass and structure, biochemistry, lifestyle, tendency to fall, and other factors. The project will also try to determine if bone mass is associated with an increased risk of prostate cancer.

We believe that the future is very promising for women of all ages because of our improved understanding of osteoporosis, as well as better diagnostic tools and treat-ments—all as a result of medical research. We are also gaining insights into the in-crease of osteoporosis in men, a growing public health problem as men live longer. The future of bone research has unprecedented opportunities primarily because of the sophisticated research tools now available in medical research that will improve the understanding, diagnosis, treatment and prevention of osteoporosis. *Question.* Briefly describe any initiatives that are currently underway or that you

plan to undertake to learn more about osteoporosis in men.

Answer. Although American women are four times as likely to develop osteoporosis as men, an estimated one-third of hip fractures worldwide occur in men. In addition, men are now much more likely to live into their eighth and ninth decade than 20 years ago. As other causes of early mortality in men are reduced, there is a greater need to focus on chronic disabling conditions such as osteoporosis that can limit independence and affect quality of life. Men tend to get osteoporosis an average of ten years later in life than women, a difference that has been attributed to a higher peak bone mass at maturity and a more gradual reduction in sex steroid influence in aging men. In 1999, the NIAMS launched a major study of osteoporosis in men with the

awarding of a 7-year, 7-center, \$23.8 million grant, in partnership with the National Institute on Aging and the National Cancer Institute. The study is enrolling and following 5,700 men ages 65 and older, and is determining the extent to which the risk of fracture in men is related to bone mass and structure, biochemistry, lifestyle, tendency to fall, and other factors. The study is also trying to determine if bone mass is associated with an increased risk of prostate cancer. Such a relationship is already known to exist between high bone mass and breast cancer in women, another hormonally sensitive condition.

*Question.* What initiatives are currently underway to expand research in Paget's disease? Are you making any progress in understanding the cause of this disease? How large a research investment are you making in finding the cause of Paget's disease?

Answer. Paget's disease is a chronic disorder that typically results in enlarged and deformed bones. The excessive breakdown and formation of bone tissue that occurs in Paget's disease can cause bone to weaken, resulting in bone pain, arthritis, deformities, and fractures. In addition to considerable support for research on basic bone biology—which could have implications for our understanding of Paget's disease—the NIAMS continues to fund a number of projects focused on this disorder, including investigations of the viral and genetic factors contributing to Paget's. For example, current research is working toward the development of an animal model of the disease by introducing viruses or expressing viral genes in mice. Genetic research has linked Paget's disease to chromosome 18q, and through nu-

Genetic research has linked Paget's disease to chromosome 18q, and through numerous grant awards from the NIAMS, researchers are investigating the possibility of the involvement of multiple genes in the predisposition to the disease. Also, several researchers are investigating the occurrence of osteosarcoma in patients with Paget's disease—as well as in individuals not affected by Paget's—in order to evaluate the presence of a genetic link. Osteosarcomas are believed to result from a series of genetic alterations which transform osteoblasts, cells that build up bone, into a malignant state. Research addressing a genetic link between pagetic osteosarcoma and sporadic osteosarcoma will enhance the future development of treatments for both diseases.

In fiscal year 2001, research supported by the NIAMS on Paget's disease totaled \$1.2 million.

## PUBLIC HEALTH NEED

Question. Do you think that there should be more consideration given to public health need when the NIH budget is distributed to institutes and centers? For example, demographic data show that we are facing a huge increase in the number of elderly Americans as the baby boom ages. So, should that be reflected in the budgets of the relevant institutes, such as the National Institute on Aging and the National Institute of Mental Health? We have also seen that the recent WHO/World Bank study has shown that mental disorders are among the leading causes of disability both in developed countries and worldwide, particularly depression, schizophrenia, and obsessive-compulsive disorder (OCD.) Do you think that research at the National Institute of Mental Health ought to be commensurate to this need?

Answer. Public health needs have historically motivated public support of medical research. Public health needs have historically motivated public support of medical research. Public health need is one of five criteria which shape the NIH budget. The allocation of the NIH budget, the formation of Institutes and Centers, and the development of specific research programs and offices reflect Congressional, and therefore public, concerns with the burdens associated with various diseases and conditions as well as with the special needs of the young, the aged, women, and minorities.

as well as with the special needs of the young, the aged, women, and minorities. An over emphasis on the allocation of funds to specific disease or public health need may not, however, be productive, unless there are promising scientific opportunities to pursue. Further, consensus on relative public health need may be difficult to achieve. Rankings will depend on whether need is measured in terms of the number of people who have a particular disease, the number of deaths, the degree of disability, the economic and social costs, or the threat of the growth or spread of the disease in the future.

The NIH Director and the individual Institute Directors gather and receive information and advice for setting research priorities from many sources, including science experts, voluntary organizations, representatives of the public, and members of Congress. Good stewardship of public research funds demands that the NIH leadership seek a balance between public health need and other important considerations, including the quality of research proposals, the pursuit of promising scientific opportunities, the need to maintain a diverse portfolio, and the support of the human capital and material assessments of science. The public will continue to benefit from NIH's stewardship of public funds as long as the Agency continues to appropriately balance this complex array of factors in setting research priorities.

Efforts to prolong and improve the health of the aging baby boom generation will require the efforts of all of the various NIH Institutes and Centers. People are living longer and better, at least partly, as a result of research supported by all parts of the NIH. The last century witnessed victory over many infectious diseases and the improved diagnosis, prevention and treatment of acute conditions. Infectious diseases, heart disease, stroke, and cancer, however, remain major threats to the aging and the elderly. With the longer life and with more people surviving heart attacks, strokes and the diagnosis of cancer, more people must also deal with chronic or relatively slow-progressing conditions. Consequently, research on arthritis, osteoporosis, and diabetes are in order. So is research on cognitive and neurological impairments, impairments of vision, hearing or speech, and other chronic conditions.

A research focus on the elderly is much too limited to improve the functioning and quality of life of elderly in the future. Functioning or general health in old age reflect health habits, assaults to health and quality of care received throughout the life span, including prenatal and early childhood care. As one example, injuries related to childbirth plague some women throughout their lives, and contribute to pain and disability during later years. As another example, eating and swallowing problems associated with poor oral health are linked to malnutrition and physical frailty among the elderly.

Both the National Institute on Aging and the National Institute of Mental Health play vital roles for maintaining and improving the health of the aging baby boomers. The National Institute on Aging supports important research on the aging process and diseases or conditions closely linked with aging such as physical frailty and cognitive impairment. The prevalence and burden of mental illness for the elderly, as well as the general population, has been more extensively documented over the past two decades. However, sustaining and improving the health of the elderly requires contributions from each of the institutes and centers within the NIH.

The burden of mental illness on health and productivity in the United States and throughout the world has long been profoundly underestimated. Data developed by the landmark *Global Burden of Disease* study, conducted by the World Health Organization, the World Bank, and Harvard University, reveal that mental illness, including suicide, ranks second in the burden of disease in established market economies, such as the United States.

Mental illness emerged from the *Global Burden of Disease* study as a surprisingly significant contributor to the burden of disease. The measure of calculating disease burden in this study, called Disability Adjusted Life Years (DALYs), allows comparison of the burden of disease across many different disease conditions. DALYs account for lost years of healthy life regardless of whether the years were lost to premature death or disability. The disability component of this measure is weighted for severity of the disability. For example, major depression is equivalent in burden to blindness or paraplegia, whereas active psychosis seen in schizophrenia is equal in disability burden to quadriplegia.

By this measure, major depression ranked second only to ischemic heart disease in magnitude of disease burden. Schizophrenia, bipolar disorder, obsessive-compulsive disorder, panic disorder, and post-traumatic stress disorder also contributed significantly to the burden represented by mental illness. In the United States, mental disorders collectively account for more than 15 percent of the overall burden of disease from all causes and slightly more than the burden associated with all forms of cancer.

of cancer . NIMH continuously assesses its allocation of research funds to specific areas based on scientific opportunity and public health need. As has been apparent recently, the quality of NIMH-funded research has encouraged growing and receptive attention to the measurable contributions of research to alleviating the public health burden of mental disorders. NIMH research priorities reflect these data. The WHO evidence regarding the immense—and growing—toll of depressive disorders figured prominently in the Institute's decision to select depressive disorders (principally major depression and bipolar disorder) as the focus its first disorder-specific research strategic plan, which will be issued in Summer, 2002. This comprehensive analysis of the state-of-knowledge about mood disorders, including gaps and opportunities, will ensure optimal targeting of research resources to areas of greatest need and likely payoff. In another novel initiative, NIMH has launched a treatment development initiative that aims to discover innovative treatments to address the most incapacitating—and, thus, costly to society—dimensions of schizophrenia and depression. By fostering collaboration among NIMH-funded investigators, the FDA, and the private sector/pharmaceutical industry, the treatment development initiative will leverage increased private sector funding dedicated to development of knowledge generated through publicly funded research. A final example of the Institute's attention to the findings of the WHO study are seen in a series of trials of the clinical effectiveness in actual practice settings of treatments for schizophrenia as well as adolescent depression and adult bipolar disorder and major depression. One of these large trials is examining the effectiveness trials are unprecedented in the size of the participating population samples in the studies, the duration of the trials, and the breadth of the inclusion criteria for determining individuals' eligibility to participate in the trial.

#### TREATMENTS FOR MENTAL ILLNESS

*Question*. While we have come a long way in our treatments for mental illnesses, I know that many people are still suffering. What is the NIMH doing to discover new treatments?

Answer. Somatic and psychological treatments available today for even the most severe mental disorders are highly effective for many patients. For an unacceptably large number of persons with mental disorders, however, extant treatments are inadequate. Too much time often is required for medications to exert therapeutic effect, and many patients do not respond fully to a treatment to achieve full remission from an acute episode of illness or to avoid recurring episodes; for yet others, available treatments simply do not work, for reasons that are not clear. We believe NIMH can play an important role in accelerating the development of new and more effective medications and other interventions to treat mental disorders. The Na-tional Advisory Mental Health Council also attaches high priority to the discovery of novel treatments, and has issued has issued several Council reports—e.g., Bridg-ing Science and Service; Translating Behavioral Science into Action, and Priorities for Prevention Research at NIMH—that call for innovative clinical and systems-level treatment research. We are in the process of updating for immediate reissuance a Program Announcement (PA) meant to encourage development and pilot testing of (1) new mental health interventions and methods of delivering care, (2) adaptations of existing interventions or services to new populations or new settings and (3) novel methods of restructuring the organizational and/or system context in which care is delivered. This PA authorizes the R-21 grant mechanism to provide resources for evaluating the feasibility, acceptability and safety of novel approaches to improving mental health, and for obtaining the preliminary data needed as a pre-requisite to a larger-scale (efficacy or effectiveness) intervention or services study.

The flagship effort in our various ongoing clinical treatment research programs is a new Treatment Development Initiative. This initiative recognizes that common and disabling mental illnesses such as schizophrenia and major depression have a range of symptoms, such as hallucinations, disorganized behavior, lack of motivation, poor social skills, and impaired thinking and problem solving. Currently available medications only target some of these symptoms. As a result, patients are often left with serious residual disabilities. For example, while one medication may be very effective in controlling hallucinations, it may do nothing to alleviate so-called negative symptoms such as lack of motivation. NIMH-funded basic research has yielded intriguing clues about biological and neurochemical processes that mediate different dimensions of mental illness symptoms. Our treatment development program will focus on translating these basic research findings into new and more effective treatments. Specifically, we will: (1) collaborate with private industry in identifying new compounds to reduce particular symptoms that are inadequately treated by available medicines; (2) develop better measures and methods to test the effectiveness of new medications against these symptoms; and (3) work with academic, industry, and regulatory officials to achieve consensus about what dimensions of mental illness symptoms are inadequately remedied by available treatments and therefore represent important targets for new medication development. If regulatory agencies accept inadequately treated clinical symptoms as valid endpoints for drug registration, the pharmaceutical industry will have a powerful economic incentive to focus drug development efforts on these important individual sources of disability.

I would add that the inclusion of non-scientists—and particularly representatives of mental health service consumer groups—on our clinical and treatment-related Initial Review Groups and, of course, our National Advisory Mental Health Council assigns a strong voice to the need for innovative treatment discovery research.

#### NIMH EFFORTS FOLLOWING 9/11

Question. Since September 11th, we have been hearing reports of mental health consequences of the terrorism that shook our country. Recently, the Washington Post carried a story about people experiencing flashbacks and post traumatic stress disorder. What can you tell me about NIMH efforts in this area?

Answer. We have learned from research that the vast majority of those exposed to disasters do not develop a serious mental disorder. We have also learned that many people experience very disturbing symptoms that interfere with their ability to function for a period of time and others will develop quite serious psychobiological disorders (e.g., post-traumatic stress disorder (PTSD) and other anxiety disorders, depression, substance abuse) that can be severe and/or chronic and require treatment. Prior research suggests that widespread mental disorders are not anticipated in the U.S. population as a result of the September 11, 2001 attacks, yet unprecedented levels of mental disorders—particularly in the most affected communities are anticipated, and effective care must be made available to those in need.

A long history of supporting research following natural disasters and humancaused emergencies has allowed NIMH to provide some guidance on how to respond to the 9/11/01 terrorist attack. NIMH immediately established communications with several agencies and departments that were mounting a mental health response on behalf of the Federal government. This included participating in briefings with the Secretary and others within HHS, as well as organizing and delivering educational information to the public and to clinicians, and identifying clinical and training resources around the country. The intramural and extramural programs of NIMH worked with a group of U.S. and international research and clinical experts on violence, traumatic stress, and disasters to share knowledge with the Substance Abuse and Mental Health Services Administration (SAMHSA) and other authorities in Maryland, Pennsylvania, D.C., Virginia, and New York. After consultations with HHS and NIH, useful information for the general public and clinicians lacking trauma experience was posted on the NIMH Website.

The focus of NIMH early post-terrorist guidance fell into three areas: (1) helping the public to recognize that the widespread shock reactions for the vast majority of people in this country were normal and would dissipate with time; (2) providing practical advice on how to reassure one another, particularly young children who needed to understand that responsible people were trying to make things as safe as possible; (3) providing information about seeking professional mental health care if problems persisted and interfered with the ability to continue daily activities. Guidance was provided about who was most at risk and might benefit from mental health services. Finally, information was disseminated about what is known about effective interventions for both acute and long-term mental health concerns.

It was soon evident that much of what is known comes from research on interpersonal violence and trauma or natural disasters. There is not yet adequate knowledge about the potential consequences of terrorist attacks like those of September 11 and how to mount adequate responses. More research is particularly needed on how various risk and protective factors impact the likelihood of adverse outcomes such as anxiety or depression after trauma. More also needs to be known about the neurobiological responses to traumatic stress. This knowledge will be key to developing effective interventions for all those who suffer. A better understanding of the content of interventions and the most appropriate timing for introducing either psychotherapy or medication is also needed.

NIMH has taken steps to foster needed disaster research, recognizing that there is a public health need to learn from these tragedies in a way that is sensitive to the immediate practical needs of trauma victims and their service providers as well as to be better prepared to assist those who need help after mass violence wherever it occurs. Three approaches are being taken: (1) reactivating the Rapid Assessment of Post-Impact Disaster (RAPID) grant program that facilitates research following an unforeseen event http://grants.nih.gov/grants/guide/notice-files/NOT-MH-01-012.html; (2) providing supplemental funding for carefully selected and existing clinical research and epidemiological studies that could generate new information; and (3) adding questions to several nationwide cross-sectional surveys of health and mental health that might provide relevant information. To facilitate these activities, the Institute put together a multi-divisional interdisciplinary working group to review proposals for supplements to existing grants and applications for new research.

view proposals for supplements to existing grants and applications for new research. Several new data collection activities are in place and others will be getting underway soon. (see URL funding page noted above). These projects concern the epidemiology of exposures in children and adolescents in the affected communities as well as in the country as a whole; the settings where people present for care, as well as the health and mental health impact of bioterrorism and its threat; pre- and post-attack effects on a wide variety of psychological and mental health problems; the impact of living with chronic threat and terrorism; the mechanisms by which trauma is linked to illness in children bereaved by the attacks; and whether the development of a chronic disorder after the attacks can be prevented in people already experiencing symptoms of mental illness. NIMH is also supporting a number of ongoing surveys, including a replication of the National Comorbidity Survey and the National Survey of African Americans (adults and adolescents) that collects information on mental disorders, impairments, and disabilities. To be better prepared in the event of subsequent events/attacks, NIMH is exploring how to establish and support disaster mental health research education and rapid response centers to overcome methodological challenges faced by past disaster studies, and how to train new research clinicians and create interdisciplinary research teams for rapid data collection efforts after acts of mass violence, in conjunction with federal, state and local authorities and researchers.

#### NATIONAL DISEASE RESEARCH INTERCHANGE

Question. The fiscal year 2002 report asked for a report on the NDRI and we would appreciate you promptly submitting the report. Please outline what you have done and what you will do to ensure that NCRR will substantially increase its core support' for the National Disease Research Interchange, and what you have done to expand NDRI's support directly from the various institutes at NIH. Please provide actual and expected funding for fiscal year 2002 and fiscal year 2003 by Institute.

Answer. The NDRI has been supported, in part, by the National Center for Research Resources (NCRR) for 11 years through a cooperative agreement entitled "Human Tissue and Organ Resource for Research" (HTOR).

Financial support for this activity is expected to increase over 20 percent during fiscal year 2002, due to an increase in the number of institutes participating in this multi-Institute award. NCRR will provide approximately \$740,000 for NDRI in fiscal year 2002. The National Eye Institute will double its co-funding of the HTOR, from \$100,000 in fiscal year 2001 to \$200,000 in fiscal year 2002.

cal year 2002. The National Eye Institute will double its co-funding of the HTOR, from \$100,000 in fiscal year 2001 to \$200,000 in fiscal year 2002. In fiscal year 2000, National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) agreed to participate in the core support of HTOR, providing \$25,000 annually. This support will increase to \$50,000 in fiscal year 2002. The NIH Office of Rare Diseases (ORD) began its support for HTOR in fiscal year 2000. ORD, which has a mission to address diseases that are within the purview of most other Institutes, has elected to increase its annual contribution to \$30,000 in fiscal year 2002. Fiscal year 2002 also saw the addition of the most recent NIH participant in the HTOR cooperative agreement, the National Institute of Arthritis and Musculoskeletal and Skin Diseases, which has agreed to contribute \$25,000 annually to the core support.

To help meet the needs of the research community in obtaining tissues for human immunodeficiency virus (HIV) research, the National Institute of Allergy and Infectious Diseases (NIAID), with the NCRR, has developed a pilot program to determine if the NDRI can provide a cost-effective method to make appropriately prepared fresh human tissue available for study. This pilot program, costing \$300,000 per year, supports the procurement and processing of fresh tissue from HIV-positive individuals, with the tissues being used to address critical questions such as the origin and maintenance of viral reservoirs, mechanisms of immune reconstitution, and sources of viral diversity. The pilot program will be evaluated in fiscal year 2003 at the end of its planned 3 years, and a full-scale initiative may be considered then.

Representatives of all Institutes that contribute to the support of NDRI participate with NCRR in semi-annual HTOR-NIH Coordinating Committee meetings to facilitate the activities of NDRI. The advice and oversight provided by the participating Institutes is a focused effort to both extend and improve the activity of NDRI in the arenas of many diseases. Other components of the NIH whose investigators utilize the HTOR resources continue to be informed of NDRI's activities to encourage their participation in the HTOR Cooperative Agreement.

age their participation in the HTOR Cooperative Agreement. The table below displays funding for NDRI by IC. This award will be competing for funding in fiscal year 2003, funding levels will be set at this time.

## SUMMARY OF FUNDING FOR NATIONAL DISEASE RESEARCH INTERCHANGE, FISCAL YEAR 2001-2002

Institute/Center	Fiscal year	
	2001	2002
NCRR	\$664,000	\$740,000
NEI	100,000	200,000
NIDDK	25,000	50,000
ORD	20,000	30,000
NIAID	300,000	300,000
NIAMS		\$25,000

# SUMMARY OF FUNDING FOR NATIONAL DISEASE RESEARCH INTERCHANGE, FISCAL YEAR 2001–2002—Continued

Institute/Center	Fiscal year		
	2001	2002	
TOTAL	1,109,000	1,345,000	

#### FOCAL SEGMENTAL GLOMERULOSCELEROSIS

Question. Dr. Spiegel, I am aware that NIDDK is conducting a clinical trial for patients with focal segmental glomerulosclerosis or FSGS. In addition to this clinical trial, I understand that NIDDK is collaborating with the NephCure Foundation on a joint research program involving basic science research. Can you update me on the status of this initiative? Additionally, FSGS disproportionately affects African Americans. Will this study help to identify the prevalence of FSGS?

Answer. In June of 2001, the NIDDK released a Request for Applications (RFA) entitled "Multicenter Clinical Trial of Focal Glomerulosclerosis in Children and Young Adults." This initiative is designed to test the relative effectiveness of various interventions in preventing progression of FSGS. The NephCure Foundation has indicated a willingness to fund some pilot and feasibility studies in conjunction with this RFA and we appreciate this "partnering" approach which can help to synergize and advance research efforts. Applications in response to this RFA are currently undergoing review and awards are anticipated to be made in September 2002.

The planned trial will address new therapies for FSGS, not prevalence of the disease. Determining the prevalence of FSGS is actually a difficult problem, because the disease is relatively uncommon and often silent, and the only early manifestation may be protein in the urine (proteinuria). Proteinuria is considered both a marker of glomerular injury within the kidney and a risk factor for progression to end-stage renal disease. The NIDDK is planning a workshop for October 2002 that will focus on strategies for screening for proteinuria. The development of guidelines for proteinuria screening is a critically important step that should pave the way for studies to assess the prevalence of FSGS and other kidney diseases. You are correct that the impact of glomerular disease is protein in par Gaussian

You are correct that the impact of glomerular disease is greater in non-Caucasian populations. Compared to rates of Caucasians with end-stage renal disease due to glomerular disease, rates in African Americans are more than twice as high, and rates in Native American and Asian American populations are almost twice as high.

## NEUROFIBROMATOSIS

Question. Dr. Kirschstein and Dr. Andrew von Eschenbach, I have long been supportive of Federal funding for Neurofibromatosis. In Fiscal 1992, I included language in the Senate Committee Report asking the National Cancer Institute to initiate a NF research program, and for the past several years this Subcommittee has included report language under the National Cancer Institute, NINDS, and other institutes encouraging those institutes to expand their NF research portfolios. I am concerned that while this Subcommittee has dramatically increased funding for NIH, the Cancer Institute has actually decreased funding for NF from \$6.87 million in fiscal year 2000 down to \$4.5 million in fiscal year 2002. What is the status of NF research overall at NIH? What is the cause of NCI's decreased financial commitment to NF research? Would the NIH and NCI provide the Subcommittee a list of NF research it funds, and the number of NF and NF-related research proposals submitted to NIH overall and NCI specifically, and a figure for the success rate of those NF and NF-related research proposals submitted to NIH and NCI? Answer. Neurofiboromatoses (NF) are genetic disorders that cause tumors to grow

Answer. Neurofiboromatoses (NF) are genetic disorders that cause tumors to grow on nerves and produce other abnormalities such as skin changes and bone deformities. Because NF may affect cognitive functions as well as hearing and sight, these disorders fall within the purview of a number of institutes within NIH, and attempts are being made to coordinate the research effort across NIH.

The NIH investment in Neurofibromatosis (NF) related research in fiscal year 2001 was \$14.2 million. Of that amount, approximately 50 percent was funded by the National Institute of Neurological Disorders and Stroke (NINDS). In May 2000, the NINDS held a two-day workshop to assess the status of NF research and to identify future research opportunities that could be developed in fiscal year 2001. The NINDS has been vigorously engaged in the initiation of a broad spectrum of activities to respond to the needs and pursue the opportunities that were identified at the meeting.

In March 2001, NINDS issued a Request for Applications (RFA) in conjunction with the National Institute on Aging and the National Institute of Mental Health to promote research on the identification of genes that cause or contribute to human neurological and neurobehavioral disease. The participating Institutes intend to commit a total of approximately \$4 million in fiscal year 2002 to fund new grants submitted in response to this RFA; of this amount, NINDS will commit up to \$3 million. This RFA was developed by NINDS as a direct result of the May 2000 workshop, as well as the comments provided by leading NF researchers on the type of directed research solicitations that likely would prove most useful in advancing NF research. This solicitation was designed to encourage applications for genetics research projects to identify the gene or genes that produce disease susceptibility; to identify "modifier" genes that affect disease susceptibility or outcome; and to investigate the relationship between genotype and disease phenotype. These goals are particularly important with respect to NF research. Although the primary genes that cause NF1 and NF2 have been identified—neurofibromin and Merlin/ schwannomin respectively—the modifier genes that contribute to determining the disease phenotype, that is, the clinical manifestations in individual patients, are unknown. In addition, determining the relationship between specific NF1 and NF2 gene mutations carried by patients and their clinical manifestations, known as genotype-phenotype analysis, is of critical importance for the diagnosis and treatment of NF.

A critical bottleneck for NF research has been translating advances in basic research into diagnostic tools and clinical therapies. To accelerate this process, NINDS has developed a broad, overarching concept and series of mechanisms to facilitate translational research. The needs of the NF research and patient communities, as expressed in the May 2000 workshop and subsequent related discussions, served as both the impetus and a coalescing model for its development. NINDS expects to finalize and issue this translational research package by early 2002. NINDS continues its longstanding outreach and support to the NF research and advanced communities.

NINDS continues its longstanding outreach and support to the NF research and advocacy communities. Through a competitively awarded grant, NINDS was the major supporter of the National Neurofibromatosis Foundation (NNFF) sponsored meeting of the International Consortium for the Molecular Biology of NF1 and NF2 held May 20–23, 2001. At this gathering of the world's leading scientists working on NF, new and exciting results were reported by a number of different investigators in studies ranging from animal models to tumors to learning disabilities. The meeting was also structured to attract exceptional new investigators to the field of NF research. NINDS also funded and moderated an NF "satellite" conference as part of a Child Neurology Society meeting in early November, 2001. This conference was extremely well attended, and well received. Finally, NINDS is actively engaged in an advisory capacity in exploring the development, by the NF research community in conjunction with patient advocates, of a strategic plan for NF research, particularly in the area of clinical trials.

The National Cancer Institute (NCI) funds approximately 30 percent of NF Related Research at NIH. NCI efforts continue to build upon the workshop hosted last year by NINDS to assess the status of NF research and to identify future research opportunities. Several priorities were agreed upon at the workshop, including development of more refined animal models for NF1 and NF2; further analysis of the mechanisms of action of neurofibromin and merlin—the proteins whose functions are disrupted in NF1 and NF2 respectively; and the identification of modifier genes that affect the expression of neurofibromin and merlin. NCI supports clinical trials through the pediatric clinical trials cooperative groups

NCI supports clinical trials through the pediatric clinical trials cooperative groups that specifically include children with cancers associated with NF1. Of special concern are the brain tumors associated with NF1 and in particular the low-grade gliomas that develop in children with NF1. The Children's Oncology Group (COG) of the NCI continues accrual to its clinical trial (CCG–9952) for children younger than 10 years of age with progressive low grade astrocytoma. Approximately 200 children have now been entered into this study, and at current rates of accrual, the study should complete patient enrollment in two years. The primary objective of the study is to compare event-free survival in children who are treated either with a regimen of carboplatin and vincristine or with a regimen of 6-thioguanine, procarbazine, CCNU, and vincristine. Accrual is limited to children with disease that is progressive after surgery or those whose risk of neurologic impairment with progression is high enough to require immediate treatment. Children with neurofibromatosis who have radiographic diagnosis of chiasmatic-hypothalamic tumor are eligible for the study after tumor progression is documented radiographically.

NCI Intramural scientists have been studying NF2 since 1987. This disorder is characterized by development of bilateral vestibular schwannomas (VS), which

cause hearing loss and vestibular symptoms in early adulthood. Meningiomas and other benign central and peripheral nervous system tumors are also common. Although NF2 is relatively rare, unilateral VS and meningiomas comprise 30 percent of all brain tumors in adults. The study population has consisted of two major groups: members of multi-generation multiplex NF2 families, and sporadic cases whose parents are unaffected clinically.

In addition, intramural clinical studies have demonstrated a new feature of NF2, the presence of two different types of cataracts at an early age. Studies have also suggested that two major subtypes of NF2 families exist. Patients with severe disease usually develop symptoms before age 20, have many central nervous system tumors in addition to VS, and rapid clinical progression. In contrast, patients with mild disease often are symptom-free until the third decade of life and have few tumors other than VS. In general, affected family members have similar manifestations. To date, 20 different NF2 germline mutations have been identified in 21 of our NF2 families. By comparing the clinical and molecular data in these families, the phenotypic manifestations have been shown to correlate strongly with type of mutation. Mutations that shorted the C-terminus of the NF2 protein usually result in severe NF2, whereas mutations that replace one amino acid with another usually lead to mild disease.

NCI Intramural investigators have begun partnering with extramural investigators to refine the understanding of genotype-phenotype correlations, and to examine the natural history of NF2, beginning with vestibular schwannomas (VS) and spinal tumors. In this regard, NCI Intramural investigators have recently completed a study examining factors that influence the rate of growth of the VS in NF2 patients. In general, VS growth rates were found to be highly variable, but tended to decrease with increasing age at onset of symptoms of NF2, and age at diagnosis of NF2. The rate of growth of the VS was not influenced by either the type of NF2 mutation that the patients had, or by the presence in the patients of other cranial or spinal tumors. Finally, the observed growth rates of VS were found to be highly variable among affected relatives of similar ages from the same family. The implication of this finding is that the clinical course and approach to management of VS in one family member is not likely to be useful in predicting the clinical course or best approach to management of VS in other family members, even when other clinical aspects of NF2 may be similar.

Significant progress has been made in the development of animal models for NF. By generating mice whose hematopoietic system is reconstituted with NF1-deficient hematopoietic stem cells, NCI intramural scientists showed that NF1 gene loss produces a myeloproliferative disease similar to human juvenile chronic myelogenous leukemia, which is observed at increased frequency in juvenile human NF1 patients. They also identified homeobox genes that appear to cooperate with NF1 gene loss in the progression to acute murine myeloid disease. Studies have also shown that mice carrying germ line mutations in NF1 and p53 develop malignant peripheral nerve sheath tumors supporting a causal and cooperative role for p53 mutations in development of tumors. These new mouse models provide the means to address fundamental aspects of disease development and to test therapeutic strategies. The National Eye Institute also funds neurofibromatosis related research. The tu-

The National Eye Institute also funds neurofibromatosis related research. The tumors or neurofibromas, under study, are often subcutaneous but also invade neural and ocular tissues. The ocular involvement may occur as lesions within the eye or surrounding orbital tissue, including eyelids, cornea, conjunctiva, iris, and retina. A severe form of congenital glaucoma is also associated with this disease. The overwhelming majority of NCI's NF related research in terms of dollars has been funded through grants. For a number of years, NCI has supported a grouping of grants, whose original research was considered to be neurofibromatosis related

The overwhelming majority of NCI's NF related research in terms of dollars has been funded through grants. For a number of years, NCI has supported a grouping of grants whose original research was considered to be neurofibromatosis related. The research of these grants focused upon NF1 and NF2 genes. NF1 and NF2 are tumor suppressor genes with a wide range of effects in embryonic and adult tissues. Lately, these grants have focused exclusively upon the relationship of NF1 and NF2 genes and certain types of cancers. The NF1 gene has been found to be associated with some astrocytomas (in persons without neurofibromatosis) and appears also to have a role in epithelial carcinogenesis, including some skin and urinary bladder tumors. The NF2 gene product is essential for normal embryonic development. NF2 mutations have been found in sporadic meningiomas, sporadic schwannomas, and some ependymomas and mesotheliomas, all in persons without neurofibromatosis related for purposes of allocation of dollars, however, they still are research opportunities that can have important implications for NF. In the interim, the relative quality of other grants focusing on NF have not come within the acceptable range (payline) to replace these, so the dollars designated to NCI's NF research amount has decreased.

Attached please find a copy of the project listing of funded NF research by IC. As not all NIH institutes code unfunded applications for specific disease areas, we are unable to provide specific numbers of unfunded NF and NF-related applications and the success rate of NF or NF-related research.

#### PARKINSON'S DISEASE

Question. Dr. Kirschstein, the Fiscal 2002 Senate Labor, Health and Human Services, Education Appropriations Committee Report refers to the Parkinson's Disease Research Agenda, which the NIH developed in cooperation with Parkinson's re-searchers and the Parkinson's advocacy community. The Committee Report states that the Research agenda recommends that a \$143,500,000 increase over the baseline year would be needed to implement year 2 of the agenda (e.g. Fiscal 2002). The report also asks the NIH to hold a series of research consortia with the extramural research community.

The Committee Report requests that the NIH Director report by March 15 of this year on the specific steps that the NIH will take to implement the Research Agenda, and on the research consortia. What is the level of funding for Parkinson's research that the NIH is projected to commit for fiscal year 2002?

Answer. NIH has been actively involved in implementing the Parkinson's Disease (PD) Research Agenda for the past two years. This effort has been remarkable, and has led to the continued support of multiple centers of excellence, new grant applications on important topics, targeted contracts, consortia in several research areas, and research workshops. As a result of these many initiatives, numerous scientific advances have been made, the best new ideas have been funded, and dozens of new projects—including important clinical studies—have been initiated. NIH is fully committed to continued implementation of the Agenda. The estimated NIH funding Gr Parkinson's disease research in fiscal year 2002 is \$198.9 million. *Question.* Furthermore, what is the status of the NIH Director's Report on Parkin-

son's that this Committee requested you to submit by March 15 of this year?

Answer. The initial Consortium meeting was held on January 9-10, 2002. The meeting focused on the scientific opportunities in the field of PD research, and the participants identified a number of research priorities within the context of the original research Agenda. It is my understanding that the requested NIH Director's Report on Parkinson's, which provides a detailed overview of this Consortium meeting, was submitted to this Committee on April 15, 2002.

#### FRAGILE X

Question. Each year since 1995, this Subcommittee has asked the National Institutes of Health to increase and enhance its funding of research "on Fragile X, the most common cause of inherited mental retardation. The National Institute of Children's Health and Human Development has assumed a leading responsibility for this research. Please tell us whether and to what extent the NIH has expanded and enhanced its Fragile X research during the past several years and whether and to what extent it has plans to increase and enhance Fragile X research in future years. Answer. NICHD has a long history of commitment to the support of research rel-

evant to Fragile X Syndrome, having initially supported early studies that led to the isolation of the gene affected in Fragile X, FMR1, in the early 1990s. As a result of recommendations resulting from a 1998, NICHD sponsored "Workshop on Fragile X: Future Research Directions," NICHD issued an RFA, "Neurobiology and Genetics of Fragile X Syndrome" in April 2000. This RFA, supported by funding from NICHD, NIMH, and the FRAXA Research Foundation, resulted in the funding of nine proposals in fiscal year 2001.

The NICHD published a RFA for Fragile X Research Centers that was released in January of 2002. The purpose of this RFA is to establish Fragile X Research Cen-ters affiliated with existing Mental Retardation and Developmental Disabilities Research Centers to stimulate research designed to increase our knowledge base rel-evant to this disorder by encouraging applications that include developmental neurobiology, pathophysiology, genetics, proteomics, epidemiology, structure-function correlations, and clinical, behavioral and biobehavioral studies directly related to Fragile X syndrome. An informational meeting was held in March 2002 for applicants who plan on responding to the RFA.

The NICHD also held a Fragile X investigator's meeting in March of 2002 to bring together researchers currently funded in the field of Fragile X syndrome. These investigators discussed their new research findings in the context of the current state of Fragile X research and future directions. The format of the meeting was thematic and involved presentations by speakers, including RFA awardees, and other investigators who have received new Fragile X grant funding in the past three years. A

report that summarizes the 2 day meeting is currently being prepared. In addition, NICHD participated in a November 2001 workshop on "Mental Health Aspects of Fragile X Syndrome: Treatment Research Perspectives." This meeting, sponsored by the NIMH, brought together investigators currently funded by NICHD to inform program staff at NIMH of the basic and clinical aspects of research of Fragile X syndrome. Biomedical, behavioral, and biobehavioral research were discussed in the context of therapeutic strategies and targeted drug discovery.

## SCHIZOPHRENIA RESEARCH

Question. In 1998, NIMH was reorganized to better address the major public health needs associated with severe mental illnesses. Given the vulnerability of clin-ical research in general, and the many changes underway at NIMH in terms of the funding of clinical research and the clinical research centers how is NIMH moving to ensure that the research base studying schizophrenia is strengthened and expanded?

Answer. Prior to 1998, NIMH had prominent divisions and branches dedicated to specific clinical disorders, while separating basic behavioral and neuroscience research within a discrete division. A reorganization of NIMH in September 1997, established three new operating divisions focused, respectively, on neuroscience and basic behavioral neuroscience research; services and intervention research; and mental disorders, behavioral research, and AIDS. Under the new structure, responsibility for research on mental disorders was assigned to each of these three extramural divisions, with each accountable for the challenge of "translating" new knowledge gained at a given level of analysis into information applicable to clinical- and systems-oriented needs. Urgent need for the translation of knowledge B both in the traditional "basic to clinical" sense and in the sense of moving what is known about the efficacy of interventions to documentation of their effectiveness—was the core justification for the reorganization. The Institute, in consultation with the field, sought to create new opportunities for sustained interactions between basic and clinical researchers, to generate new opportunities for scientists at both ends of the continuum to think about pathophysiology and treatment development for mental disorders. The revamped organizational structure has been very effective in broadening the institutional base of responsibility for research on schizophrenia (and other mental disorders) at a time when the field stands on the verge of a revolution in our understanding of schizophrenia and our ability to treat people who suffer from this devastating illness. With the introduction, first of clozapine, then more recently, a whole series of "atypical" antipsychotics (risperidone, olanzapine, quetiapine, ziprasidone, and soon aripiprazole and iloperidone), new vistas have opened in the pharmacotherapy of schizophrenia. These new antipsychotics seem to allow patients, pnarmacotnerapy of schizophrenia. These new antipsychotics seem to allow patients, families, and their clinicians to focus on coping with illness, rather than just symp-tom control. In fiscal year 2002, an NIMH-sponsored clinical trial (Clinical Antipsychotic Trials of Intervention Effectiveness, CATIE, with sites in 34 different states) is comparing these new antipsychotics, and will define strategies for their optimal use in treating schizophrenia. In addition in 2001, NIMH launched a 4-site, 5-year clinical trial to study the effectiveness of 3 different antipsychotic medica-tions for children and adolescents ( $\Re$ -19 year old) who have schizophrenia tions for children and adolescents (8–19 year old) who have schizophrenia, schizophreniform disorder, or schizoaffective disorder. Both short- and long-term effects will be comprehensively assessed for up to 1 year of treatment. Advances in basic neuroscience, the decoding of the human genome, and develop-

ment of sophisticated neuroimaging techniques strengthen the likelihood that the puzzle of schizophrenia will be solved in the not too distant future. The NIMH has set out to gather a sufficiently large number of families with schizophrenia to pin down the genes that predispose people to developing the illness. Once these are identified and their function in the brain is understood, a whole new generation of specific treatments may become possible. Through sophisticated new techniques to image brain function, we are increasingly able to understand the neural circuitry that underlies the symptoms of schizophrenia. With the development of methods to noninvasively stimulate selected regions of brain, it even may be possible to turn off some of the troubling hallucinations and delusions suffered by patients with schizophrenia. The NIMH program of Silvio O. Conte Centers for the Neuroscience of Mental Disorders are an important and vibrant element in our efforts to bridge basic and clinical research. These Centers support hypothesis-driven, interdisciplinary research encompassing highly interactive and synergistic projects and cores in which clinical research informs, and is informed by, basic research and vice-versa, all addressing specific questions directly relevant to complex mental disorders. Five Conte Centers (at the University of Pittsburgh, University of Pennsylvania, Harvard

University, Yale University, and Washington University) currently are dedicated to research on schizophrenia, with a sixth scheduled for funding this year.

#### BIOPOLAR DISORDER

Question. Bipolar disorder, or manic depression is a serious brain disorder that causes extreme shifts in mood, energy, and functioning. It affects 2.3 million adult Americans, or 1.2 percent of the population. While there is no cure for bipolar disorder, it is a highly treatable and manageable illness. Unfortunately, many of these treatments are palliatives that were originally developed for other disorders such as epilepsy. Maintenance treatment with a mood stabilizer can reduce the number: and severity of episodes for most people, although episodes of mania of depression may occur and require a specific additional treatment. Clearly newer, more effective treatments for bipolar disorder are needed. Can you please update the Subcommittee on progress in implementing the NIMH bipolar disorder research plan?

Answer. The NIMH Strategic Plan for Mood Disorders will be completed by this summer. The document identifies numerous opportunities for developing new pharmacologic and psychosocial interventions. The Plan recognizes that in clinical settings, the effectiveness of more precise and efficacious treatments will be contingent on the accuracy and timeliness of diagnosis and the availability of well-established treatment guidelines and, thus, will call for research in these and related areas.

While the Strategic Plan will accelerate the pace of discovery of new treatments for bipolar disorder, immediate need exists to better understand and use treatments that are currently available. Toward this end, NIMH is funding the Systematic Treatment Enhancement Program for Bipolar Disorder (STEP-BD), a long-term project under contract at a dozen sites around the country. Now in its fourth year, the STEP-BD clinical trial is aimed at maximizing the effectiveness of existing pharmacological and psychosocial treatments for bipolar disorder in naturalistic settings; some 2,000 patients have been enrolled to date, and all will be followed for several years. Related to the STEP project are three additional smaller studies looking at issues specific to women's mental health, including the safety of current treatments and new options for bipolar disorder during pregnancy. Additional investigator-initiated treatment research now underway and directed at bipolar disorder in adults ranges from studies to understand the mechanisms of action of lithium, to the development of new approaches for maintenance treatment, to research on prevention of relapse/suicidal behavior in this long-term, recurrent chronic disorder. The NIMH also supports studies on treatment of bipolar disorder in children.

#### ACCESSING THE NEWEST ADVANCED TREATMENTS

*Question.* In the past decade, many new treatments and services have been developed and proven for severe mental illnesses such as schizophrenia. Yet most individuals with these illnesses receive extremely poor treatment. What efforts are underway (or ongoing) to ensure that the improved treatment interventions being developed now ill be effectively disseminated to providers and made available to the people who so desperately need these treatments?

ple who so desperately need these treatments? Answer. The NIMH has a specific program that sponsors grants to find ways to ensure that effective treatments are implemented in community practice. Ongoing activities in this program include a new program announcement calling for grants in this area; new funding mechanisms to promote this area (including one jointly issued with CMHS on Children's Services); and sponsorship of workshops and conferences to foster new research ideas in this area. Examples of such workshops include one recent workshop focused on implementing evidence-based practices into the public mental health sector.

the public mental health sector. NIMH has collaborated with SAMHSA, especially CMHS, on issues related to improving the implementation of new treatment interventions. CMHS representatives were actively involved in recent workshops and discussions about joint funding of future projects. Other collaborative efforts are underway to foster new research opportunities and implementation strategies.

#### GENERAL CLINICAL RESEARCH CENTERS

Question. It has been almost two years since the NCRR Advisory Council approved the concept of providing "seed money" for General Clinical Research Centerbased pilot projects. How many centers have received pilot study support and how many pilot projects have been funded? How many pilot projects have been funded? What is the total amount of funding that has been provided for this purpose? Does each GCRC receive an equal amount for pilot projects? If not, how are the funds distributed? Answer. Pilot studies on GCRCs were phased in during fiscal year 2002 with the intent that all GCRCs would be able to request up to \$100,000 per annum for their support within 2–3 years. We become aware of pilot projects when GCRCs make a specific request for new funds and, in fiscal year 2002, 27 GCRCs made such requests. GCRCs are also permitted to rebudget funds internally to support pilot projects.

Approximately 32 pilot projects were funded in fiscal year 2002 in the 27 GCRCs that applied for new funds for the purpose. A total of \$645,000 was made available in fiscal year 2002 but internal rebudg-

A total of \$645,000 was made available in fiscal year 2002 but internal rebudgeting by the Centers may result in additional pilot projects. The full number will not be known until the Centers submit their annual reports.

No, each GCRC does not receive an equal amount for pilot projects. The amount received depends first on the participation of the GCRC and on the local approval of the pilot projects by an Advisory Committee. By fiscal year 2003 we anticipate making new funds available for 2 pilot projects per center. Centers may increase their number of pilot projects beyond this if they are able to rebudget funds internally.

#### LOAN REPAYMENT PROGRAM FOR CLINICAL RESEARCHERS

*Question.* I am very pleased that the President's budget would double the funding for the Loan Repayment Program for Clinical Researchers. I have two questions: In the first year, only researchers with NIH support were eligible to apply. But I understand that NIH plans to expand the program eligibility after the first year. When will the details of this expansion be announced? How many applications did NIH receive for the first year of this program? If you have compiled any additional demographic information on the applicants, such as their average tuition loan debt, I would appreciate that as well.

Answer. In fiscal year 2002, the first year of the Clinical Research Loan Repayment Program, the eligibility criteria were designed to allow for the smooth implementation of several Loan Repayment Programs concurrently, using an innovative electronic web-based application process, and to provide a starting point to gain insight into the size and nature of the applicant pool. We are using knowledge gained from this pool of applicants to enhance the process so that we are able to communicate more effectively with a larger and more diverse pool in future years.

Beginning with fiscal year 2003, the eligibility criteria will be expanded to include individuals whose research is supported by foundations, professional societies, and other non-profit sources.

The details of the program expansion will be announced in the NIH Guide to Grants and Contracts and on our Internet home page (www.lrp.nih.gov) no later than May 2002. In addition, we will present information about the programs as widely as possible in other venues, such as annual meetings of professional associations and at educational institutions.

The NIH received 487 Clinical Research Loan Repayment Program applications this fiscal year. Of these, 5.14 percent receive funding under a National Research Service Award for Postdoctoral Fellows (F series), 36.42 percent receive funding under an Institutional Research Training Grant (T series), 38.27 percent receive funding under an NIH Career Development Award (K series), 15.64 percent receive funding under a Research Grant (R series), 26.7 percent receive funding under a Research Program Project Grant (P series), and 1.85 percent receive funding under a Research Project Cooperative Agreement (U series).

The racial and ethnic composition of the applicant pool for the Clinical Researchers Loan Repayment Program is 68.41 percent Caucasian, 11.27 percent Asian, 6.24 percent African-American, 3.02 percent Latino, 0.6 percent American Indian or Alaskan Native, 0.6 percent Native Hawaiian or Other Pacific Islander, and 8.85 percent reported "other" or did not respond. Female applicants constitute 41.68 percent did not respond. applicants constitute 41.68 percent did not respond.

The average educational loan debt (outstanding principal and interest) of the applicant pool for the Clinical Researchers LRP is: \$80,625 for applicants with a K grant, \$99,602 for applicants with a T award, \$64,130 for applicants with an F award, \$97,500 for applicants with a P grant, \$59,012 for applicants with an R grant, and \$59,652 for applicants with a U grant. These averages are tentative and will be adjusted as we continue to verify the total eligible debt of each applicant.

#### NIH DOUBLING

*Question.* Congress has nearly completed the job of doubling NIH funding over five years, and this President has joined Congress in committing to this idea, I would like your analysis for various options for out-year growth.

Please provide for the committee an analysis of the implications of three options on NIH's ability to fund research grants during each of fiscal year 2004–2008: the President's Budget out-years, which projects growth at the following rates: fiscal year 2004, 2 percent; fiscal year 2005, 2.2 percent; fiscal year 2006, 2.3 percent; fiscal year 2007, 2.3 percent and fiscal year 2008, 2.3 percent; a more historically consistent rate of growth from NIH, pre-doubling, of 7.5 percent for each of the next five years. The analysis should also include projections for numbers of new grants, total grants, center grants, intramural, training grants & their stipends, construction, and success rates.

#### EMBRYONIC STEM CELL RESEARCH

Answer. There are currently 78 human embryonic stem cell lines listed in the NIH Stem Cell Registry. The Registry does not make clear how many of these stem cell lines are immediately available to researchers or what intellectual property requirements must be adhered to for use of the lines. Two recent scientific publications in the journal Nature cast doubt on the claim that adult stem cells are so promising that work with embryonic stem cells is unnecessary. The new papers suggest that much of the flexibility attributed to adult stem cells might be the result of bizarre fusions between adult stem cells and other types of cells. If this turns out to be correct, it would be a serious setback to any hope of using adult stem cells to treat disease. (See attached article)

#### NIH STEM CELL RESEARCH FUNDING

#### Stem Cell Research Fiscal Year 2001

Actual Adult	\$265,457,000
Embryonic (Animal only)	40,541,000

NOTE.—No NIH funds have yet been used for human embryonic stem cell research. All of the progress made thus far on human cells has been made with private funds. NIH received only 9 grant applications for the first deadline of November 27, 2001. These applications are currently under review and NIH expects the first grants will be made in June. The second grant application deadline was February 2, 2002, but NIH officials do not yet know how many grant applications for stem cell research they have received. (They received a total of 10,000 applications and have not gone through them all yet). These second round of grants will be made in September.

#### THERAPEUTIC CLONING

Question. Scientists at MIT recently reported the first use of therapeutic cloning in an animal model. The labs of Dr. Rudolf Jaenisch, who testified before this subcommittee in January, and Dr. George Daley used skin cells from a mouse, which was completely immune deficient, to create a cellular therapy that was able to partially restore immune function in the mouse. Dr. Daley says that "Though the immune system wasn't completely restored, there was enough improvement to predict that a comparable result in humans would translate into a significant clinical benefit." It is my understanding that this research was supported in part by the National Cancer Institute and the National Institute of Diabetes and Digestive and Kidney Diseases.

Dr. von Eschenbach and Dr. Spiegel, what are your impressions of this research that your institutes funded?

Answer. Dr. Rudolf Jaenisch is a founding member of the Whitehead Institute and Professor of Biology at MIT. The laboratory of Dr. Jaenisch has been one of the leaders in transgenic science (gene transfer to create mouse models of human disease) and has produced valuable models, which have aided in understanding of cancer and various neurological diseases. One of the areas of exploration in Dr. Jaenisch's laboratory has been the process by which a modification of DNA called methylation plays a role in carcinogenesis. In certain neurological diseases associated with mental retardation (e.g., Prader-Willi syndrome and Angelman syndrome), methylation also appears to play a role in the process referred to as "imprinting" that is abnormal in patients with these diseases. A desire to understand these processes led to interest in mouse cloning since in mouse embryonic stem cells, all marks of methylation are removed. It is postulated that these studies could shed light on cancer since some precancerous cells exhibit diminished methylation and appear to be abnormally prone to mutation and cancer development. Dr. Jaenisch and his colleagues have already demonstrated that alteration in methylation can impact the development of colon cancer in mice with a genetic predisposition to this disease. Since certain drugs and diet can affect methylation patterns, it is important to understand the influence of altered patterns of methylation on carcinogenesis. The work of Dr. Jaenisch on DNA methylation, gene regulation, and cancer is funded by an RO1 grant from the NCI.

Dr. George Daley is also associated with the Whitehead Institute and is an assist-ant professor of medicine at Harvard Medical School. Dr. Daley has also served as Chair of the Whitehead Task Force on Genetics and Public Policy. Dr. Daley and his laboratory study stem cells of the blood in order to define the molecular basis of human leukemia and to understand more fully the development of normal blood. More specifically, Dr. Daley focuses on the BCR/ABL oncoprotein that is responsible for human chronic myelogeneous leukemia. It is through efforts to understand mouse blood cell development that Dr. Daley is working with mouse embryonic stem cells that can differentiate in vitro into a diverse array of cell types including neu-rons, myoblasts, cardiac myocytes, and blood cells. The BCR/ABL gene product is the target for the drug Gleevec (also known as ST1571) that has recently garnered much public attention as a prototype for molecularly targeted therapeutics. Some work by Dr. Delay and his collegement of the second seco work by Dr. Daley and his colleagues relates to use of other classes of therapeutics agents that may be efficacious in cells that are resistant to Gleevec. Dr. Daley's work on therapeutic mechanisms of CML is funded through an NCI RO1 grant, and

work on herapeutic mechanisms of CML is funded through an NCI ROI grant, and his work on hematopoietic stem cells from totipotent stem cell types is funded by an RO1 grant from NIDDK. The NIDDK-funded regular research grant (RO1) to Dr. Daley is on hemato-poiesis—the development of the different blood cell types, including cells of the im-mune system. Dr. Daley's grant was designed to investigate how mouse embryonic stem cells can be "coaxed" to form hematopoietic stem cells in the laboratory, and could then be transplanted into mice and differentiate into blood cell types. Dr. Daley and his calleagues developed a power tochnique for doing this based on expres Daley and his colleagues developed a new technique for doing this, based on expres-sion of a gene called HoxB4. The development of this technique shed light on the molecular mechanisms of hematopoiesis. This technique was used in the study you cited—which is an interesting piece of research combining somatic cell nuclear transfer with gene thereave to correct particular a genetic defect in immune research transfer with gene therapy to correct, partially, a genetic defect in immune response in mice.

Question. How significant an advancement have these investigators achieved?

*Question.* now significant an advancement have these investigators achieved? Answer. In their recent paper published in the journal *Cell*, Dr. Jaenisch and his colleagues demonstrated that nuclei derived from the tail of an genetically immunodeficient mouse when transferred to the egg of a mouse lacking its own nu-cleus could give rise to mouse embryonic stem cells. These stem cells have the same genetic mutation that characterized the mouse from which the nucleus was derived. This defect was "terpend" by a process called hemploreme recursitation. This defect was "repaired" by a process called homologous recombination. Finally, the repaired cells were injected into the mutant mouse and mature and competent immune cells were detected 3-4 weeks after the transplantation of the repaired cells. This work demonstrates that this genetic disorder in the mouse can be treated

by combining nuclear transplantation therapy and gene therapy. In their paper published in the same issue of *Cell*, Dr. Daley and his colleagues report on a mouse model for hematopoietic transplantation therapy. This work largely focuses on the characteristics of definitive adult hematopoietic stem cells and more primitive stem cells derived from the mouse yolk sac or embryo. These authors showed that the expression of a particular gene (called HoxB4) resulted in a switch from the yolk sac or embryonic mouse stem cells to a cell more like the definitive stem cell. These cells like the "repaired" cells of the Jaenisch paper described above were capable of restoring immune functions to a mouse following transplantation. Both papers provide insights into the properties of mouse stem cells. These stud-

ies demonstrate the extraordinary complexity of this process and the importance of exploring these systems in animal model experimentation.

This work, using a mouse genetic model of immunodeficiency, is unique. Previous investigators have created cloned mice using somatic cell nuclear transfer; however, the primary research objective of the present investigators was to test somatic cell nuclear transfer to correct a genetic defect in a living mouse model of disease. Furthermore, other investigators have previously used gene therapy to correct a defect successfully in mouse models, for example in experiments relevant to thalassemia and sickle cell disease. (The reference for this is May C, Rivella S, Callegari J, Heller G, Gaensler KML, Luzatto L, Sadelain M: Therapeutic haemoglobin synthesis in beta-thalassaemic mice expressing lentivirus-encoded human beta-globin. Nature 406: 82-86, 2000.) Clearly, there are multiple approaches to developing therapies for various diseases: cell based therapy, gene therapy, and the combination of both. What is unique about the present work is its combination of approaches. As the re-searchers state, it constitutes the first comprehensive "proof of principle" that com-bines somatic cell nuclear transfer with gene-and cell-therapy to repair, albeit par-tially, a genetic disorder in mice. This research also illuminates an unexpected difficulty in bone marrow engraftment in these genetically-deficient mice, which the investigators managed to overcome using additional strategies. While the present research shows that combining these approaches is feasible and partially effective in mice, it also reveals unexpected biologic processes. As the investigators who did this research point out, further research in mouse models using reprogrammed somatic cell therapy combined with gene therapy will be valuable in providing insights into as yet unknown biological and methodological issues.

## SUBCOMMITTEE RECESS

Senator HARKIN. Thank you all very much. The subcommittee will stand in recess to reconvene at 11 a.m., Thursday, June 6, in room SD-186. At that time we will hear testimony from the Honorable Elaine Chao, Secretary, Department of Labor.

able Elaine Chao, Secretary, Department of Labor. [Whereupon, at 12:27 p.m., Thursday, March 21, the subcommittee was recessed, to reconvene at 11:30 a.m., Thursday, June 6.]

## DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, AND EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR FISCAL YEAR 2003

## THURSDAY, JUNE 6, 2002

## U.S. SENATE,

## SUBCOMMITTEE OF THE COMMITTEE ON APPROPRIATIONS, Washington, DC.

The subcommittee met at 11:35 a.m., in room SD-192, Dirksen Senate Office Building, Hon. Tom Harkin (chairman) presiding. Present: Senators Harkin, Murray, Landrieu, Specter, and Stevens.

## DEPARTMENT OF LABOR

## OFFICE OF THE SECRETARY

## STATEMENT OF HON. ELAINE CHAO, SECRETARY OF LABOR

## OPENING STATEMENT OF SENATOR TOM HARKIN

Senator HARKIN. The Subcommittee on Labor, Health, and Human Services of the Appropriations Committee will come to order. Today we will hear from the Secretary of Labor, Elaine Chao, testifying on budget requests for her department.

Madam Secretary, I must say at the outset I was very glad to see the administration emergency supplemental request for dislocated workers. I congratulate you for your success in securing that request from the Office of Management and Budget. I think the administration's new willingness to support adequate funding for these essential training efforts implicitly includes a recognition that we are all coming to.

Last year, Congress rescinded what we thought was a modest amount of dislocated worker funding based upon as-yet-untested assumptions about carryover funding in a brand-new workforce system. For fiscal year 2003 the administration recommended large cuts in training programs in part based upon these same untested carryover assumptions. Then the administration and Congress found we needed to respond to the substantial and enduring effects of joblessness resulting from the economic downturn, so we worked together, and we are now considering a substantial emergency replenishment of dislocated worker funding. We are taking these actions together now because I think both the administration and Congress recognize the harsh realities that out-of-work Americans face. The continuing, nagging rise in unemployment, now at 6 percent, the highest rate in nearly 8 years, makes it much more difficult for unemployed Americans to return to work. As you know, Madam Secretary, more than 2 million workers have lost their jobs over the past year, and the economic, social, and emotional effects of these job losses typically linger for 2 years or more after economic recovery begins.

I hope the administration's supplemental request represents a recognition that while we might aspire to anticipate every turn in the business cycle, it is not prudent to have an underfunded workforce system at any time. If we want our Governors and the business-led local boards that plan and administer the workforce program to be able to meet the ongoing needs of job-seekers and business and to respond to local, State, and national changes in the economy, you must provide them with reliable and adequate funding over the long term.

And Madam Secretary, I am also pleased that your fiscal year 2003 budget request includes another substantial increase for the Office of Disability Employment Policy, from \$35 million up to \$47 million. My personal thanks to you for leading the effort in doing that. This will result in more than doubling the funding of this office in the 2 years since it was created and, as you know, Madam Secretary, more and more people with disabilities, over the last 12 years since ADA, and now that it has permeated all of our consciousness in our society, more and more people with disabilities are getting higher education, getting better job training, and they are in the workforce. So this office really is a very important factor in helping make sure that they are adequately employed and that they have access to employment, so I thank you for requesting this substantial increase.

However, I must say that there are a couple of things that I am disappointed about in the budget. The recommendation for overall reductions in staffing of the worker protection programs, including OSHA, is one that I am disappointed in. I am disappointed that instead of promulgating a new regulation to protect workers from ergonomic injuries, the Department instead is developing voluntary guidelines.

Further, the Department is recommending deep cuts in programs aimed at reducing child labor throughout the world, and I will have more to say about that after your statement. But your Department has done great work on this over the last several years in really getting up to speed and taking the lead and reducing child labor throughout the world. This budget that you are requesting would reduce some of these programs, and I am very dismayed at that, and we will go over that in our questions and answers.

Also, the budget request totally eliminates a 35-year-old program serving migrants and seasonal farmworkers, so I would like to address the impact of these reductions again in greater detail when we get to questions and answers, Madam Secretary.

At this point, I would leave the record open for any opening statement by my Ranking Member, Senator Specter.

Senator HARKIN. I would recognize Senator Murray for any opening statement.

## OPENING STATEMENT OF SENATOR PATTY MURRAY

Senator MURRAY. Thank you, Mr. Chairman, and thank you, Madam Secretary, for being with us today. I am encouraged by some parts of your budget: increased funding for Job Corps is important, I believe, and the increased funding for the Office of Disability Employment Policy. But I share the chairman's concerns on some other budget cuts that would help at-risk youth and employment and training for dislocated workers and worker safety programs. So Mr. Chairman, I would like an opportunity, after the Secretary speaks, to ask some specific questions on those.

## SUMMARY STATEMENT OF HON. ELAINE CHAO

Senator HARKIN. Thank you, Senator Murray. Well, we welcome Secretary Chao again to this subcommittee. Secretary Chao was sworn in as the 24th Secretary of Labor on January 31, 2001, as the first Asian American woman appointed to the President's Cabinet in U.S. history. Secretary Chao was president and CEO of the United Way Foundation from 1992 to 1996, and served as Director of the Peace Corps and as Deputy Secretary of the Department of Transportation under former President Bush. Most recently, she was a distinguished fellow at the Heritage Foundation.

Secretary Chao received her MBA from Harvard Business School, and her undergraduate degree from Mount Holyoke College.

Madam Secretary, that is an impressive background, and we welcome you again to the subcommittee, and your statement of course will be made a part of the record in its entirety, and you can please proceed as you so desire.

Secretary CHAO. Thank you, Mr. Chairman. I appreciate the opportunity to appear before the committee to present the Department of Labor's fiscal year 2003 budget and, as you mentioned, I would like to submit my written statement for the record.

The administration's 2003 budget necessarily reflects the challenges that our Nation still faces in the wake of September 11, the ongoing war against terrorism, the urgent need to improve homeland defenses, and a struggling domestic economy. This is not a business-as-usual budget. In order to fund pressing wartime obligations we have had to carefully set priorities, consolidate overlapping programs, and delayer our internal bureaucracy.

We also took seriously the President's management directive to integrate performance evaluations into our budgeting process to ensure that we are making the maximum use of taxpayers' dollars. We must do a better job of managing the money given to us by hardworking Americans, which means that programs that do not meet basic performance standards should not be funded. As a result, I believe we have submitted a budget that should be viewed as not smaller, but more effective, not less money, but more bang for the buck.

In OSHA, for example, we are eliminating layers of management in order to put more inspectors on the front line conducting more inspections than ever. In ETA we are consolidating a rifle-shot program approach into the Workforce Investment Act system to reinforce a vision of Congress that States and localities, and not Washington, should be in charge of their workforce development. In PWBA and the Office of Inspector General we are increasing funding to better protect Americans' pensions from mismanagement, fraud, and racketeering influences.

Let me briefly mention three other priority areas for the Department in fiscal year 2003, and some of the important work that is being done in these areas first of all concerns migrant, immigrant workers. The first of these priorities is addressing the needs of immigrant workers.

The Census Bureau tells us that more than 10.5 million Americans speak little or no English. The Bureau of Labor Statistics found that during the last year of the previous administration fatalities among Hispanic workers increased by almost 12 percent, from 730 to 815, so we have got our work cut out for us, and the Department is taking action.

At my direction, OSHA is now translating a broad array of safety materials into Spanish, and is developing partners in the Hispanic community such as civic groups, churches, and Mexican consulates. OSHA is updating its incident-reporting requirements to determine the language skills of injured workers. Our Wage and Hour Division has also targeted nearly one-third of its total reserves toward improving compliance in low-wage industries, where many immigrants currently work. Wage and Hour is also adding more Spanish-speakers on its front lines of investigation and compliance assistance.

Other agencies within DOL, such as Pension Welfare Benefits Administration and the Mine Safety & Health Administration, are developing new approaches to help immigrant workers in this country. We want America to be a safe and fair place to work whether you have full citizenship, a green card, or a temporary work visa.

A second priority for our Department is meeting the needs of working women. In today's economy, women want more flexibility in balancing their careers and families. Right now, our laws and regulations do not really give them very much choice. Women also have unique needs and concerns about retirement, and one of the most significant developments for working women is the rise of female small business owners. Earlier this year, the Department's Office of the 21st Century Workforce hosted a national summit of woman entrepreneurs. This summit brought together over 1,000 small business owners from all across the country. Both the President and I spoke, and we had several interactive sessions where we learned about the interests and needs of this community.

Our Women's Bureau has a partnership with PWBA to help women better prepare for retirement, and one of the fruits of that partnership was seen in this year's Saver Summit, where one of the key elements was meeting the retirement needs of women, both those who work at home, and those who work at a job.

A third priority is addressing the nursing shortage, about which I know, Mr. Chairman, you are concerned. Changes in the health care industry combined with ever-increasing numbers of older Americans have created an urgent demand for trained nurses that is quickly outstripping demand. Within the next couple of weeks we will announce a memorandum of understanding among the Department of Labor, the Department of Education and the Department of Health & Human Services. This MOU will integrate the training, education, and job placement efforts of all three Departments to effectively promote careers in nursing.

In addition to the MOU, our Department has already engaged in a partnership with a private sector health care company, one of the largest, to train and employ more people in this field. This project will provide millions of dollars in scholarships that will be connected to real opportunities to work in the nursing care. We have asked for additional moneys for this partnership as part of our high-growth job-training initiative in the administration's supplemental request. We have also recently launched CareCareers.net, an online job bank sponsored by the Department of Labor that links job-seekers with openings in long-term health care.

## PREPARED STATEMENT

We have sought to integrate these three priorities into a newly emerging workforce that is composed of new participants like immigrant and women's small business owners, and we want to focus on new growth sectors of our economy like health care. We need to make our Department's programs and activities more flexible to meet the needs of a changing workplace and a workforce. We believe that our budget, the fiscal year 2003 budget, moves us in that direction, helping us to better serve and respond to the needs of the 21st Century workforce.

Mr. Chairman, thank you for the time to present my statement, and I will be glad to answer any questions that you may have at this time.

[The statement follows:]

#### PREPARED STATEMENT OF HON. ELAINE L. CHAO

Mr. Chairman, and distinguished Members of the Subcommittee, thank you for the opportunity to appear before you today to present the Department of Labor's fiscal year 2003 Budget. I appreciate the opportunity to be with you again this morning.

As the members of this Committee well know, our Nation since September 11 has had many demands placed upon it for defense and homeland security. Thus, our budget for fiscal year 2003 reflects these new needs and priorities. As Labor Secretary Frances Perkins aptly said in 1942, "One of the things we have tried to do is to become very realistic about requests for any increases in this coming year's budget. We know only too well that the great expenditures should be directly on the war effort."

Every department of the government must take a hard look at all of its programs, especially in times of war. We must provide more funding for those programs that work; reform and revitalize those that can be improved; and cut or eliminate those that have not proven effective, are duplicative of other programs, or are not a great national priority.

I believe we have balanced the goals of meeting the overarching national need of a streamlined budget with the many important goals our Department pursues. For fiscal year 2003, the Department will play a key role in ensuring that President Bush's economic agenda is accomplished. From ensuring that America's workforce is prepared for 21st Century challenges, to providing a secure retirement to the men and women who have worked to provide a better life for themselves and their families, the Department of Labor will be on the job in fiscal year 2003. The Department's fiscal year 2003 budget was developed with the goal of serving

The Department's fiscal year 2003 budget was developed with the goal of serving the needs of the 21st Century Workforce. It reflects the amounts necessary to address the challenges related to a changing economy and workforce while balancing the achievement of three overarching national goals: winning the war against terrorism; strengthening protections of our homeland; and revitalizing our economy and creating jobs. The total request for the Department in fiscal year 2003 is \$56.5 billion in budget authority and 17,179 full-time equivalents (FTE). The request for the Department's discretionary programs is \$11.4 billion.

#### EMPLOYMENT AND TRAINING PROGRAMS

The Department's fiscal year 2003 budget for Employment and Training Programs is \$6.3 billion. Included in this total is \$2.3 billion targeted for employment and training programs for adults, with \$1.4 billion for employment and training activities for dislocated workers. In addition, \$2.6 billion is requested for youth employment and training programs, including \$1.5 billion for Job Corps, which I will address in greater detail in a moment.

Although the overall fiscal year 2003 employment and training budget represents a net decrease in new budget authority of \$545 million from 2002, there will be more than enough money in the system to pay for anticipated employment and training needs. This is because States have not expended approximately \$1.7 billion in funds still available from previous years. I want to be clear, Mr. Chairman: the Administration is committed to meeting employment and training needs. The State carryover can be used in lieu of new budget authority to meet these needs with no diminution of service.

The Administration is also supporting a larger near-term increase in funds for dislocated worker assistance. Helping American workers who have lost their jobs remains a top priority for President Bush. On March 9, the President signed the Job Creation and Worker Assistance Act, which extended unemployment benefits for an additional 13 weeks; gave states \$8 billion in additional funds to improve unemployment benefits and services; and provided new tax incentives to create hundreds of thousands of new jobs. While the economy is showing signs of improvement, some workers are still having trouble finding work, and some communities have been hard hit. That is why the President's fiscal year 2002 supplemental budget proposal is so critical.

#### FISCAL YEAR 2002 SUPPLEMENTAL PROPOSAL

President Bush's \$750 million fiscal year 2002 supplemental request would provide the urgent assistance that is needed now to ensure that affected workers receive the assistance and jobs they so desperately need. There are four main components of the supplemental proposal;

- The proposal restores last year's \$110 million rescission of Federal funds for dislocated workers—making those resources available through the states for employment and training assistance to workers who have lost their jobs; —Recognizing that the economic recovery is taking place more slowly in some
- -Recognizing that the economic recovery is taking place more slowly in some areas than others, it provides \$550 million to replenish and strengthen the National Emergency Grant program to provide fast, flexible assistance targeted to those workers and communities that need additional assistance in recovering from the economic slowdown;
- -It provides up to \$50 million to carry out demonstration and pilot projects, and multi-state and multi-service projects relating to employment of dislocated workers; and
- —It provides \$40 million for transfer to the Secretary of Commerce for the Economic Adjustment Program to help create new jobs in communities that have been hardest hit and to improve coordination of Federal workforce and economic development activities.

This request for supplemental appropriations is intended to address the needs of dislocated workers in those pockets of high unemployment that still exist or where the economic conditions require additional assistance. Moreover, the National Emergency Grant program has always provided a reserve for states who are hit with unexpected natural disasters. Replenishing the national reserve account is essential for this purpose as well.

#### JOB CORPS

The President is requesting \$1.5 billion for Job Corps in fiscal year 2003, an increase of \$73 million (5 percent) above fiscal year 2002. According to a thorough and objective impact evaluation published last year, the dollar value of benefits that Job Corps generates for society is more than twice what the taxpayers invest. The President's fiscal year 2003 request will permit the Job Corps to enroll more than 73,000 new students. In addition, the President's 2003 budget request contains measures to increase teacher pay, support center expansion, and further improve the quality of Job Corps services to disadvantaged young people. Finally, the increased funding will allow Job Corps to fully implement its initiative launched in Program Year

2001 to help all Job Corps centers achieve accreditation to award high school diplomas to Job Corps students.

#### UNEMPLOYMENT INSURANCE AND EMPLOYMENT SERVICE REFORM

The Department's Unemployment Insurance and Employment Service systems provide critical services to unemployed workers. Unemployment Insurance helps workers bridge the gap between jobs while stabilizing the economy during downturns. The Employment Service system helps unemployed workers find jobs and employers find new workers. The Department's 2003 budget proposes strategies to promote flexibility and

The Department's 2003 budget proposes strategies to promote flexibility and strengthen unemployment insurance and employment services to America's workers and businesses. These proposals would make extended benefits more readily available in future economic downturns, reduce Federal unemployment taxes, and give States control of their own administrative funding. During transition, the Administration would help States implement funding changes that would lead to more flexible programs by providing billions of dollars from the U.S. Treasury's Unemployment Trust fund. The fiscal year 2003 request of \$44.0 billion for income maintenance includes \$40.8 billion for benefits paid from the Unemployment Trust Fund.

#### WORKER PROTECTION

I am deeply committed to enforcing the many laws that protect workers' safety and economic security. As you know, Mr. Chairman, I have made expanding and improving compliance assistance one of my major new initiatives at the Department of Labor, but not at the expense of enforcement. The Department has provided targeted increases of \$37 million to its enforcement agencies in fiscal year 2003, while eliminating unnecessary and obsolete activities and functions. I believe the clear winner is the American worker.

In fiscal year 2003, the budget for the Department's Pension and Welfare Benefits Administration is to increase by \$7 million and the Employment Standards Administration's Office of Labor Management Standards by \$4 million. I will momentarily address both of these increases in further detail. Additional Departmental funds are proposed in the President's fiscal year 2003 budget for the Inspector General to help DOL protect pension funds from labor racketeering. These increases will make a real difference in the day-to-day protection of America's workers.

The fiscal year 2003 budget would give the Occupational Safety and Health Administration \$13 million in targeted increases. Our nation now has the lowest occupational injury and illness rate on record in its history—6.1 cases per 100 workers as measured by the Bureau of Labor Statistics. This latest drop in the injury and illness rate was the eighth in a row. Injury and illness rates in more dangerous occupations also continued to drop. Work-related fatalities have also continued a downward trend. Even so, one injury or fatality is too many, and we will strive to do better through the appropriate mix of enforcing health and safety standards and providing compliance assistance, education and training as proposed in our budget.

the better through the appropriate mix of emoting heatin and safety standards and providing compliance assistance, education and training as proposed in our budget. In fiscal year 2003, the Mine Safety and Health Administration would receive targeted increases of \$10 million. While 2001 data show that fatal accidents in America's mining industry have reached the lowest level ever, MSHA issued a challenge to mine operators and workers to join the Department to cut in half, over the next four years, the number of miners killed and amount of time lost as a result of workrelated injuries.

The requests for both OSHA and MSHA also propose offsetting savings through workforce restructuring and the elimination of funding for completed activities.

I have seen reports in the press that our budget may result in less enforcement in areas such as occupational safety and health or wage and hour laws. I must tell you, Mr. Chairman, that these reports are false. We took care to ensure that our enforcement agencies will have the resources they need to maintain enforcement activities at current levels and indeed to increase those activities in several critical respects. Where agencies are to receive less money than in fiscal year 2002, that is because the agencies will eliminate unnecessary bureaucracy and obsolete activities, and because of an adjustment related to pension-related costs. In fact, excluding one-time emergency response funding, the accruals proposal, and our proposal to finance Federal Employees' Compensation Act administration through a surcharge on customer agencies, worker protection agencies are kept at roughly the previous year's level. Mr. Chairman, workers benefit from the appropriate targeting of resources in the agencies that protect them—not unnecessary bureaucracy and adherence to outdated approaches.

So let me be clear: we will vigorously enforce our worker protection laws, as we always have. But we will also look for better, more efficient ways to fulfill our mis-

sion—that is, to help protect workers from risks right now as well as to enforce against past violations.

One important example is my February 1st announcement of a series of initiatives to ensure the safety and promote the prosperity of Hispanics in the workplace. Hispanic or Latino workers accounted for a disproportionate number of workplace fatalities in 2000, 13.8 percent, compared with their proportion of employment, which was 10.7 percent; and, while the number of fatal injuries declined for all workers from 1999 to 2000, there was an 11.6 percent increase in job-related fatalities for Hispanic or Latino workers. Given these troubling statistics, I directed the Occupational Safety and Health Administration to form a task force to reach out and educate Hispanic workers and their families about health and safety on the job. I also called on other Departmental agencies to make unprecedented efforts to increase workplace safety for Hispanics.

One immediate result is OSHA's new Spanish language website, which serves both Hispanic workers and employers. This webpage initially focuses on areas such as OSHA and its mission; how to file complaints electronically in Spanish; worker and employer rights and responsibilities; and a list of resources for employers and workers. It also features highlights from the agency's extensive website and offers one-stop service for Spanish-speaking employers and employees. Additional information will be added in months to come.

#### ERGONOMICS

While not a specific part of the President's fiscal year 2003 budget request, I want to briefly touch on the issue of ergonomics. As you know, Mr. Chairman, on April 5, OSHA unveiled a comprehensive plan designed to dramatically reduce ergonomic injuries through a combination of industry-targeted guidelines, tough enforcement measures, workplace outreach, advanced and coordinated research, and dedicated efforts to protect Hispanic and other immigrant workers.

Our goal is to help workers by reducing ergonomic hazards in the workplace in the most effective way possible and in the shortest time frame possible. I believe this plan is a major improvement over the rejected old rule because it will prevent ergonomics injuries before they occur and reach a much larger number of at-risk workers. I recently announced that the first set of industry-specific ergonomics guidelines is being developed for the nursing home industry, and OSHA expects to release those guidelines in the near future. OSHA has also begun work to develop other industry and task-specific guidelines to reduce and prevent ergonomic injuries that occur in the workplace.

On the question of whether OSHA has sufficient funds for this effort, I can assure you that we have examined OSHA's budget request very carefully and believe we do.

#### RETIREMENT SECURITY

President Bush and I share the priority of ensuring retirement security for our Nation's workers and retirees. To achieve that goal, the Department's Pension and Welfare Benefits Administration protects the integrity of pensions, health plans, and other employee benefits for more than 150 million participants and other beneficiaries in private benefit plans. From ensuring that workers receive the information they need to protect their benefit rights to ensuring that plan officials understand and meet their legal responsibilities to workers, DOL is helping millions of Americans rest a little more soundly at night. For fiscal year 2003, the President's request for PWBA is \$121 million, a \$7 million increase over fiscal year 2002, and 861 FTE.

The President is also proposing legislative changes that would reinforce the American workers' confidence in the security of the private retirement system. The President's Retirement Security Plan, announced on February 1, would strengthen workers' ability to manage their retirement funds more effectively by giving them freedom to diversify, better information, and access to professional investment advice.

The Department's budget also proposes to provide additional resources to the Office of Inspector General to protect pension funds from labor racketeering, as is discussed below.

#### OFFICE OF THE INSPECTOR GENERAL

The President's request in fiscal year 2003 for the Office of Inspector General (OIG) is \$65 million, an increase of \$5 million over fiscal year 2002. This increase will allow the OIG to further its mission of improving the effectiveness, efficiency, and economy of Departmental programs and operations through audits, investiga-

tions, and evaluations. The OIG also serves to detect and prevent fraud and abuse in DOL programs and labor racketeering in the American workplace.

#### OFFICE OF LABOR MANAGEMENT STANDARDS

The Office of Labor Management Standards (OLMS) in the Department's Employment Standards Administration is the Federal agency charged with administering and enforcing most provisions of the Labor-Management Reporting and Disclosure Act of 1959, as amended. This law ensures basic standards of democracy and fiscal responsibility in labor organizations representing employees in private industry. OLMS serves as a key piece of the Department's enforcement strategy and manages 50,000 worker-generated inquiries per year. For fiscal year 2003, the President is requesting an overall increase of \$3.9 million and 40 FTE for OLMS to carry-out this important mission.

#### OFFICE OF DISABILITY EMPLOYMENT POLICY

The President's fiscal year 2003 request for the Office of Disability Employment Policy (ODEP) is \$47 million, an increase of \$9 million, or 24 percent over fiscal year 2002. This level will support ODEP's mission of providing leadership to increase employment opportunities for youth and adults with disabilities. In fiscal year 2003, ODEP will provide technical assistance; identify and develop best practices; expand outreach, education, and constituent services; make policy recommendations, and promote ODEP's mission among employers. The fiscal year 2003 request for ODEP also continues support for the President's

The fiscal year 2003 request for ODEP also continues support for the President's New Freedom Initiative to expand employment opportunities for individuals with disabilities. ODEP requests an increase of \$4.9 million to expand the Olmstead Implementation Grants to provide employment services to support persons with significant disabilities who are moving from institutions into the community. ODEP also requests a \$3.0 million increase for the youth services and training grants programs to assist youth with disabilities in fulfilling their potential in the workforce.

#### BUREAU OF INTERNATIONAL LABOR AFFAIRS

The fiscal year 2003 budget requests \$55 million and 85 FTE for the Bureau of International Labor Affairs. Given that the agency's budget jumped 1,500 percent between fiscal year 1995 and 2001, the fiscal year 2003 request would allow the agency to maintain sensible spending policies and return closer to its core mission and traditional labor advocacy role. In fiscal year 2003, ILAB will continue providing grants to international organizations to reduce exploitative child labor, and finance bilateral technical assistance to support international trade agreements.

ILAB will also continue to coordinate the Department's global responsibilities and provide expert support for many of the Administration's international initiatives. The Bureau's core responsibilities include representing the United States government at the International Labor Organization and on the Employment, Labor, and Social Affairs Committee of the Organization of Economic Cooperation and Development. The fiscal year 2003 request recognizes the importance of promoting international labor standards and reducing child labor throughout the world while managing the growth of this activity.

#### LABOR STATISTICS

The 2003 request includes \$21.5 million in additional funding for the Bureau of Labor Statistics and 2,529 FTE, the same number as fiscal year 2002. Included in fiscal year 2003 is \$5.9 million for modernizing the computer systems of the Producer Price Index and International Price Program, along with continuing other important program improvements.

#### FEDERAL TRAINING AND EMPLOYMENT REFORM

The President's 2003 Budget is launching a long-term reform of the Federal government's overlapping training and employment programs. The Federal government has at least 48 training and employment programs scattered throughout ten agencies. Although the programs vary considerably, their common goal is to improve participants' employment and earnings. However, no consistent measure exists to compare results across these programs. Definitions vary, data quality is uneven, and data are collected using different statistical techniques. Improvements are needed and, as a leader in Federal training and employment policy and programs, the Department supports this reform.

<sup>1</sup> The 2003 Budget begins this multi-year effort to target resources to programs with documented effectiveness and eliminate funding for ineffective, duplicative, and

overlapping programs. The reforms proposed for 2003 would reduce the number of Federal job training programs from 48 to 28. Within DOL, the number would decrease from 17 to nine through some consolidation, the transfer of some veterans employment programs to the Department of Veterans Affairs, and the end of funding for some programs that have not proven effective.

#### VETERANS' EMPLOYMENT AND TRAINING SERVICE

The President's fiscal year 2003 budget request for the Veterans' Employment and Training Service (VETS) is \$212 million and 250 FTE. The 2003 budget adopts the recommendation of the Congressional Commission on Service members and Veterans Transition Assistance to fund the veterans employment grant programs on a competitive basis with clear employment outcomes. In addition, we propose to move these VETS programs from the Department of Labor to the Department of Veterans Affairs. Programs transferred to the Department of Veterans Affairs (VA) will be the Disabled Veterans' Outreach Program (for which the fiscal year 2003 request is \$82 million); the Local Veterans' Reintegration Program (\$17 million). In addition, the Transition Assistance Program, which provides job training, employment assistance, and other transitional services to separating service members, will also be transferred to VA. The total transfer to the Department of Veterans Affairs is \$197 million and 199 FTE.

The transfer proposal is designed to provide the inter-related services of education, training, vocational rehabilitation, homeless veterans reintegration, and employment as part of an integrated, seamless continuum of services. By operating all of these programs in the VA, the duplication of effort can be minimized and services to veterans can be strengthened. Our veterans deserve our attention to their employment needs. I am working closely with Veterans Affairs Secretary Principi on this proposed transfer to ensure that it will be smooth and seamless.

The Department will retain responsibility for the Workforce Investment Act's Veterans' Workforce Investment Program and will continue to enforce veterans' employment and re-employment rights (USERRA) and veterans' preference. The fiscal year 2003 request for these remaining programs is \$14 million and 51 FTE.

#### OFFICE OF THE 21ST CENTURY WORKFORCE

Last year, I announced the creation of the Office of the 21st Century Workforce. The mission of this office is to ensure that all American workers have as fulfilling and financially rewarding a career as they aspire to have, and to ensure that no worker is left behind in the limitless potential of the dynamic, global economy of this new millennium. Much has been done to further this effort.

On June 20, 2001, I hosted the Summit on the 21st Century Workforce. The Summit was a rousing success as President George W. Bush and leaders from business, labor, academia, and government joined me to address the structural changes affecting our workforce and our economy. In January 2002, we hosted a Washington-area Job Fair and, in April, we launched the magazine XXI. The Office also worked with the Department's Women's Bureau to host the "Women's Entrepreneurship in the 21st Century" conference in March.

#### IMPLEMENTING THE PRESIDENT'S MANAGEMENT AGENDA

The Department has instituted a systematic approach to addressing and implementing the President's management reform agenda. The five government-wide agenda reforms—Budget and Performance Integration; Strategic Management of Human Capital; Competitive Sourcing; Improve Financial Performance; and Expanding Electronic Government are teamed with a sixth reform with which the Department has been charged, Faith-based and Community Initiatives.

In August 2001, I established the Department's Management Review Board (MRB) to support the Administration's priorities and to coordinate action on management issues with Department-wide impact that require common solutions. Through the MRB, the Department has in place a management process that complements the President's Management Council, thus facilitating consistency in Departmental decision-making.

The Department's fiscal year 2003 request includes an increase of \$24 million for Information Technology (IT) activities. The increase is for the third year of the Department's efforts to replace previously duplicative and disparate systems with a coordinated and centralized IT investment strategy. The fiscal year 2003 request will support the acquisition of Departmental Information Technology, enterprise architecture, infrastructures, equipment, software, and related needs. These funds will be allocated by the Department's Chief Information Officer in accordance with the Department's capital investment management process to ensure a sound investment strategy for the entire Department. The Department's investment management process has been cited as a "best practice" by the Office of Management and Budget.

#### GOVERNMENT PERFORMANCE AND RESULTS ACT

Initiatives under the leadership of the Management Review Board have advanced the Department's progress during the last year in managing for results and furthered our implementation of the Government Performance and Results Act (GPRA). As a majority of the Department's performance goals now focus on key program outcomes, DOL's attention has turned to developing a management infrastructure that will promote the achievement of these goals, thus ensuring continuous im-provement in the results the Department achieves on behalf of the Nation's working men and women.

The Department recognizes that, to be effective, performance-based management must become an integral part of DOL's daily operational practices. Among its most significant new management practices, the Department has incorporated the respon-sibility for achieving DOL's performance goals into the individual performance agreements or standards for all executives, managers, and supervisors. The Department will also expand the use of program evaluations during fiscal year 2002, with an emphasis on improving the performance of programs not currently reaching their goals and assessing the effectiveness of programs not recently evaluated. The Department's recently-released fiscal year 2001 Annual Report on Perform-ance and Accountability and the fiscal year 2003 Annual Performance Plan provide

detailed information on the Department's results and our ambitious plans for the near-term. I look forward to working with you as these plans continue to unfold.

#### FINANCIAL MANAGEMENT

The Department continues to demonstrate its commitment to responsible stewardship of the resources entrusted to us. This was reflected by the fifth consecutive "un-qualified" or "clean" audit opinion on the Department's financial statements, as well as the Department's receipt of the Association of Government Accountants' Certifi-cate of Excellence in Accountability Reporting. In the Department's recently-re-leased fiscal year 2001 Annual Report on Performance and Accountability, we were also proud to report the successful completion of a multi-year initiative to bring all the Department's financial systems into compliance with the Federal Financial Management Improvement Act of 1996.

#### CONCLUSION

Mr. Chairman, this is an overview of what we have planned at the Department of Labor for fiscal year 2003 within the context of helping achieve the three overarching national goals of winning the war against terrorism; strengthening protections of our homeland; and revitalizing our economy and creating jobs. As I stated, from ensuring a workforce that is prepared for 21st Century challenges to providing a secure retirement to the Nation's workers, the Department of Labor will be hard at work in fiscal year 2003.

I will be happy to answer any questions you may have on the Department's fiscal year 2003 budget request.

Senator HARKIN. Thank you very much, Madam Secretary. Senator Stevens.

## OPENING STATEMENT OF SENATOR TED STEVENS

Senator STEVENS. Mr. Chairman, I hate to interrupt, but I have a bill on the floor and just wanted to make one comment.

Senator HARKIN. I'm sorry. The Senator is recognized for a state-

ment or a question or whatever. Senator STEVENS. There we go again, technology. Madam Sec-retary, I welcome you here, and I do thank you very much for what you are doing with regard to putting into effect the immediate implementation of the program you are developing industry-wide guidelines to prevent injuries, the repetitive stress concepts. I supported delaying the old regulations because I thought there ought to be a better way to do it, and I hope you will continue. I do have

two questions, Mr. Chairman. I would ask my statement in full appear in the record.

Senator HARKIN. Without objection.

Senator STEVENS. I have come particularly because the Department turned down the applications from employees from an oil industry employer in Alaska because they said that the trade adjustment assistance funds would be used only for new job training and education. We are in a situation up there, as the oil industry is literally collapsing in our State, that it requires some concepts of dealing with these people. We know that there is an additional 120 from Anchorage alone that are being laid off, and I have got a question here that I am submitting. I would hope you would take a look at that, because we have to have assistance for these people. They are really displaced workers. Because of the changes in the oil industry, having been denied access to the drilling programs for the Arctic Slope, we are going to see a lot more lay-offs, and I hope that we can find some way to assist them.

## PREPARED STATEMENT

I thank you very much, Mr. Chairman, and I hope that you will put this statement and questions in the record. Thank you. [The statement follows:]

## PREPARED STATEMENT OF SENATOR TED STEVENS

Thank you Mr. Chairman. I'm pleased to be here today to welcome our Labor Secretary Elaine Chao to talk about her agency's budget request for fiscal year 2003. Madam Secretary, you are doing a great job in leading your agency on a number of fronts.

I support your recently announced program to quickly put into effect a new program of incentive-driven compliance by business to protect workers against repet-itive stress, or "ergonomics" injuries.

As I understand it, your new program is developing industry-specific guidelines to prevent such injuries.

It has the advantage of immediate implementation, rather than the years-long wait for new regulations that new legislation on this subject would surely entail.

Businesses will have incentives to keep workers healthy and safe. And, for that small number of businesses that do not maintain safe workplaces, two recent court cases—Beverly Enterprises and Pepperidge Farms—have affirmed that the Labor Department's "general duty" clause gives you the authority to step in and sanction offenders.

I do support measures to protect our workforce from repetitive stress injuries. Your approach deserves to be given the opportunity to succeed, and I support your efforts.

On another matter, the Senate Appropriations Committee's Supplemental Appro-priations legislation, that we are debating on the Senate floor right now, does not provide the full funding of \$550 million for you to use for National Emergency Grants and \$50 million to fund new projects targeted at high growth job areas. Our bill provides a total of \$200 million for both National Emergency Grants and high growth job projects. As this bill moves through the full Senate and to con-ference with the House, we may find a way to increase the level of that funding for your department.

for your department.

After the events of September 11, many people across the country have felt the effects of the economic downturn. We need to have funds that can be made available people back to work in high growth job markets.

Madam Secretary, thank you for the job you are doing with your agency.

Secretary CHAO. I am not aware of that, but I will take a look at it, but I think that also points to the flexibility of the national emergency grants. They are much more targeted and much more flexible, but I will take a look at it. Thank you.

Senator HARKIN. Thank you, Senator Stevens.

Madam Secretary, as I mentioned to you earlier, I would like to now engage with you a little bit in discussion concerning something that I have been involved in for over 10 years. I first introduced a bill here in 1992 regarding child labor and doing something about the introduction into international trade of articles made with abusive child labor, and so it has been a long process, and we have made some strides.

And your Department, beginning just a few years ago, started doing some things on this. First of all, one of the best things the Department did was to compile seven volumes of investigations on the use of child labor around the world, and it is just a seminal work on what is happening with child labor, where it is, what they are doing, how these products intertrade. It was all done by the Department of Labor, so they are down in your shop, and it is really very, very good.

What I said earlier is that we have some tremendous cuts here that you have asked for in your budget, in child labor. Just 2 weeks ago I joined 65 other Senators in supporting the bill to grant President Bush new trade negotiating authority, and the President said in Quebec: "Our commitment to open trade must be matched by a strong commitment to protecting our environment and improving labor standards."

Well, before the Senate approved the bill 2 weeks ago, the Senate adopted my bipartisan amendment to that bill which makes ending the use of the worst forms of child labor in international trade a principal U.S. negotiating objective in all future trade talks. So in light of the President's pronouncement, the fact that at least in the Senate bill U.S. trade negotiators must now pursue an end to the use of child labor in the production of goods flowing in international trade, how can the Department justify the following cuts in the Bureau of International Labor Affairs?

A 100-percent cut and the abolition of a U.S. bilateral program to combat abusive child labor by improving access to basic education for children who are removed from abusive child labor conditions.

A 100-percent cut in funding for multilateral technical assistance.

A 100-percent cut in funding for the U.S. Labor Department to improve monitoring and reporting with respect to internationally recognized worker rights and the core labor standards in foreign countries with whom the United States has international trade agreements, and as required by 14 different U.S. laws enacted since 1993.

And a 33-percent cut in the U.S. contribution to the international program on the elimination of child labor.

Now, these are the cuts. I just have them up on a chart up there. There is also elimination of at least 38 staff positions in the Bureau of International Labor Affairs within DOL. These are big cuts that really go to the heart of the effort that the Department of Labor has been making up to this year, I would say under both Democrat and Republican Presidents up to this year, and being in the forefront of the fight against abusive child labor. Now, again, if I might, 33 Senators just wrote a letter to FIFA, that is the—it is a French word. I cannot speak French, but it is the Federation for International Football, for soccer, asking that the World Cup games now being held in Korea certify that the soccer balls they are using are not made with child labor. I have information from the Global March Against Child Labor that they are, indeed, using soccer balls from countries where it is made with child labor.

Now, there are soccer balls made in countries where they are not using child labor, and so 33 Senators signed the letter to ask them to do that. I personally am asking the U.S. World Cup team, which just had a great victory over Portugal, by the way, to insist that the next game they play, they play with soccer balls that are certified not made with child labor.

And again, I have some charts. I can show you some pictures. These are ones that I have had for some time. Here is a young boy—his name is Tarik. He is 12 years old. He is hand-sewing soccer balls with the Nike swoosh, and he is paid 60 cents a day, and he works over 12 hours a day. And he is 12 years old, making these soccer balls, but that is not bad enough. Here is a little girl. This is Silje. She is 3 years old. She has four sisters, and they make 75 cents a day stitching soccer balls.

Pakistan alone stitches 5 million soccer balls a year just for the United States—just for the United States—and this says right here, Made in Pakistan. I do not care if they are made in Pakistan. That is fine. I just do not think they ought to be made by girls that are 3 years old and boys that are 12 years old.

So these things happen. And Madam Secretary, your Department, along with the Senate and the Congress in the last few years, have been making tremendous strides in both our funding for our contribution to IPEC and for taking leadership in ILAB to reduce this incidence of child labor. And I am just very, very dismayed that this budget makes these tremendous cuts in this effort that we were making.

So any response you might have, Madam Secretary, I would appreciate.

Secretary CHAO. Thank you. Well, the President's budget provides ample resources to meet any reasonable request for technical assistance associated with the free trade agreement, so let me answer that first. I will work through the ILO to assist countries in implementing core labor standards and target funds at countries where there is a clear need for assistance and a willingness among the Government, the employer, and the worker representatives to adhere to the principles of the declaration on—

Senator HARKIN. Madam Secretary, I am sorry, I cannot hear. Can anybody turn up the volume on this thing? I cannot hear a thing. I don't know, is that a bad one, or what?

Secretary CHAO. How about this one?

Senator HARKIN. Ah. Now, much better.

Secretary CHAO. Mr. Chairman, thank you for the opportunity to answer some of your concerns. Let me begin with the free trade agreement. As I say, we believe the President's budget offers ample resources to meet any reasonable request for technical assistance associated with the free trade agreement. ILAB will work through the ILO to assist countries implementing core labor standards, and also target funds at countries where there is a clear need for assistance and a willingness among Government, employer, and worker representatives to adhere to the principles of a declaration on fundamental principles and rights at work.

We are concerned about child labor. We are committed to eradicating and eliminating child labor. But ILAB saw a 1,400-percent increase in appropriations in the past several years for an organization that in 1996 had a budget of \$9 million. For it now to absorb \$147 million is beyond the capacity of this organization. As I have mentioned in the past, the Inspector General has raised concerns over ILAB's management structure, control over the grant programs, and the roles and responsibilities of individual staff to manage this increased level of funding.

We have committed \$3 million to help retrain workers to reenter the economic mainstream in certain countries. We have also had \$5 million to improve access to basic education for children in Pakistan, and perhaps, we believe that the improved access to basic education would be a way to help eliminate abuse of children at this early age.

Senator HARKIN. What was that last statement, Madam Secretary? I'm sorry?

Secretary CHAO. We also have a \$5-million grant to improve basic education for children in Pakistan. We also have a \$1.8-million program to support a program through the ILO to combat, again, child labor issues.

Senator HARKIN. I hate to interrupt, but where did you get that \$5 million? I am looking at my chart here.

Secretary CHAO. It is to provide basic education for children. Then there is a \$1.8-million—

Senator HARKIN. I have got it zeroed out in my budget request from you.

Secretary CHAO. I will clarify this. You are right about that. The child labor IPEC grant is \$30 million.

Senator HARKIN. IPEC is—oh yes, that is \$30 million, that is right, but on the basic education, that was zeroed out. Thank you.

Secretary CHAO. We are concerned about this tremendous increase in funding, and whether the organization, again, has the capacity to be able to effectively manage it, and truly adhere to its core mission.

Senator HARKIN. My time is up, and I apologize to my fellow Senators. I will just finish by saying that in your budget document, quite frankly, you talked about the increase in funding for ILO, IPEC activities, and talked about all of these significant things that were being done with it. There is nothing here that indicates that you were not able to use those funds. In fact, you said that also in fiscal year—listen to this. This is your budget document: "In fiscal year 2001, 25,500 children were actually prevented or removed from exploitative work through ongoing ILO/IPEC projects funded by DOL."

Well, congratulations. I think that is great, and so—and then when you say there has been a 1,400 percent increase, well, I always respond when I hear that, where did we start from? If you start from zero, zero to 1 is an infinite increase. And the fact is that in 1996 we only had one program. That was just this basic ILAB program. This Congress added these other programs, so these are new programs, and we went from fiscal year, basically, in 1998, 1999, 2000, 2001, and 2002. So when you start with a new program, obviously whatever money you have is an infinite increase. You could have said that for basic education, it was an infinite increase, because it went from zero to \$37 million.

Secretary CHAO. Well, in 1996 ILAB had about \$9 million, so it is a big increase.

Senator HARKIN. Well, ILAB had about \$8.9 million in 1996, but that was the only thing we had. I am just saying that these are new programs that we started, so I am not too impressed by the fact that it is a 1,400 percent increase.

Secretary CHAO. It does present a management challenge.

Senator HARKIN. I understand, but your budget document does not say anything about any kind of management challenge whatsoever.

Secretary CHAO. That was an oversight which we should have put in.

Senator HARKIN. You have utilized this very, very well, and I compliment you for that. I just want the budget request different, that is all.

Senator Murray.

Senator MURRAY. Thank you very much, Mr. Chairman. Let me just start by thanking you for your tremendous leadership on the issue of child labor. And I think that the tragic picture you showed of this young girl behind us really underscores the need for us to keep our focus on this. And since I have been here in the Senate you have been a voice for children everywhere who have been lost for a very long time, so I really appreciate your devotion to this subject.

Madam Secretary, following along on focusing on young people and where we are today, I think it is pretty clear that today's workers need more education and training so that they can develop skills that really reflect the changing economy that they are growing up in.

I think the events of September 11, factors like the collapse of the Enron Corporation, the fact that major U.S. companies are continuing to move abroad, really underscore the need for us to make sure our workforce is more adaptable, and I am very concerned that your budget provides \$289 million less for youth employment and training programs in 2002, and I really believe that we should be increasing, not decreasing our investments that focus on one of the most vulnerable sectors of the workforce, and that is our young people here.

I am particularly concerned that you propose to cut the youth opportunity grants by \$181 million, and essentially that guts the program. It goes from \$225 million in 2002 to 44.5. That is going to hurt kids in inner cities and high poverty areas that are trying to transition from school to work, and if you could explain to this committee why you are requesting an elimination of a program that really gives our most at-risk youth some hope that they can be productive members of our society by helping them stay in school and find work when they graduate. Secretary CHAO. We are very committed to helping young people access hope and opportunity. The youth opportunity grants were a pilot program, and what we thought would be a more effective way of helping them is to channel this money through the WIA funding stream.

Senator MURRAY. I am sorry, through-

Secretary CHAO. Streamline this money through the Workforce Investment Act, and let the States have the flexibility of deciding how they want to help the youth in their community.

Senator MURRAY. So have you increased the WIA budget? Secretary CHAO. There is a \$1.7 billion excess overhang.

Senator MURRAY. Is there any directive to the WIA boards to focus on youth?

Secretary CHAO. It is pretty much a block grant. We do not direct them to do very much at all.

Senator MURRAY. Well, I would be very concerned with that, because a lot of our States, like mine, are really having difficulty right now. We have the second highest unemployment in the Nation in the State of Washington, and just block-granting money out to the States, there is real concerns. Of course they love block grants, we all love block grants, but I think at the Federal level we need to continue our focus on making sure that young people across this country, no matter where they are or where they come from, or what the economic opportunities are, have that kind of adaptability, so I am very concerned about this gutting of the youth opportunity grants program.

Secretary CHAO. Senator, let me qualify. There are currently 36 grantees, and they will receive their 5-year funding commitments. Senator MURRAY. Well, the other area, Mr. Chairman, that I am

very concerned about has to do with dislocated workers. And, like I said, my State has the second-highest unemployment in the Nation. We have had a lot of problems with layoffs in our State. The energy crisis precipitated it, the high tech sector deflating a year and a half ago. September 11 made it worse. We have had layoffs at Boeing.

We are a very high-tech State, Boeing-dependent State, and we are really hurting right now. And the recent Department of Labor decision to cut adult employment and training programs by \$39 million, after last year you requested a \$257 million cut, is really going to have an impact on our ability to help those dislocated workers. Can you explain your rationale behind that cut?

Secretary CHAO. We just recently gave your Governor \$15 million in national emergency grants.

Senator MURRAY. But your overall budget request last year was cut \$257 million and this year \$39 million.

Secretary CHAO. We disagree with the characterization that resources will be cut, because again we have \$1.7 billion in excess unused funds. This is going to be a debate that we are going to have next year as well. What I, and I am going to suggest that we work on reauthorization of the Workforce Investment Act, because right now this is a block grant program that goes out to the States. We have very little control over it. And I get very little information. And based on the information that we have received from the States, there is an overhang of \$1.7 billion in excess, unused funds. Now, the States may disagree with that. Not the States, the localities, the individual districts may disagree with that. But we are going to have this discussion every year, and so I would suggest that with reauthorization coming up next year, that we work on this issue in terms of getting better information on where the districts are in terms of their unused funds.

Senator MURRAY. Well, I am happy to work on reauthorization on WIA with you, but the needs are real now. Our unemployment—

Secretary CHAO. We are not compromising the quality of these programs.

Senator MURRAY. With the budget cuts you are requesting—

Secretary CHAO. These are not budget cuts. There is \$1.7 billion in excess, unused funds in the system.

Senator MURRAY. Well, Mr. Chairman, I would like to work with you, and I would like to see your figures and rectify the—

Secretary CHAO. Actually, may I just put the chart up a little bit? Is there a chart here?

It is a matter of carryover funds, so we do not plan, nor expect, any compromises in the quality. We do not expect a decrease in the number of people served due to the carryover funds. You have the budget authority in green, the carry-in—

Senator MURRAY. So you are saying that you had excess funds before; therefore you are coming in at a much lower budget request now because you do not think the States need the money?

Secretary CHAO. It is not a much lower funding request. We had the same discussion last year, and I would love more than anything not to have this discussion again, but we are going to next year. There is this continuing overhang of funds, which go unused.

Senator MURRAY. Well, let me just point out that the economy of the last, whatever, 6 years you have on there is dramatically different than the economy that we are facing today, where again, because of the energy, because of the high-tech drop in employment, because of layoffs, because of September 11, in my home State because of Boeing, those requests for dollars are not going to be decreased this year.

The economy, as I think everybody knew, is in a recession; it still is in my State. And I am very concerned, at a time when our economy is hurting, that we are taking a look back at the last 6 years when everyone was doing well, and then looking at what we need.

Secretary CHAO. And I do not mean to be argumentative or disrespectful, but every State has a surplus.

Senator MURRAY. Well, thank you, Mr. Chairman, and I will continue this discussion. I realize my time is up. I do have other questions. I have to get to another meeting, but I would like to submit them for the record.

Senator HARKIN. Absolutely. Thank you very much, Senator Murray.

Senator Landrieu, I know you wanted to make an opening statement, too, so I would extend the time for you to make an opening statement. Senator LANDRIEU. Well, actually, Mr. Chairman, I would just like to submit my opening statement for the record and just go right into just a couple of questions.

Let me first comment and follow up on both, Mr. Chairman, what you and what Senator Murray said. First, to give my full support to you and to your efforts in terms of child labor.

And particularly as we focus, Madam Secretary, on the new and exciting and wonderful opportunities for trade, more global trade, more international trade, the opportunity to help build a middle class, the opportunity to encourage educational opportunities for all people, not just children but people of all ages, but particularly the children of the world, and to use the enforcement mechanisms and the budgetary strengths that we have as a Nation, I think are crucial in our battle against inappropriate and excessive, or inappropriate child labor. And if the agency that we have tapped is not able to absorb the additional funds, then we could create several other agencies, several other avenues to get these desperately needed funds to help solve a problem that is truly horrific.

And, frankly, no one in the world supports child labor, not Democrats, not Republicans, not people in the United States, and so Senator Harkin, I think even with his great efforts there are a couple of hundred million, or maybe 100 or 150 million. To me, the problem is so great that it would take a lot more money than that. So it is our challenge to create the entities that can use it effectively and to stop these children from sewing soccer balls and everything else they are doing, so I just want to support Senator Harkin and just urge us to not cut funding, but to perhaps reorganize so our work can be more effective.

And what Senator Murray said, let me also say, that I am also concerned and have received quite a few calls, Madam Secretary, from Louisiana about the loss of the youth challenge grants. There seems to be a lot of confusion out there on this budget matter. So perhaps this morning is not the time to get into the details, but I really want to work with your office, because these youth challenge grants have been used effectively. There is some confusion about the zeroing out of that and consolidating it, so I will get back with you on that.

## PREPARED STATEMENT

But one program that came up just last week on the Senate floor, and I wanted to call your attention, as you know or are probably aware, the Louisiana delegation has been very supportive both in the House and the Senate, on helping both the last administration and this administration opening up trade opportunities. We have been more of a pro-trade delegation and are happy to do that. But a recent decision by the administration to improve steel imports has now put hundreds of our maritime workers' jobs in jeopardy, and while we were unable to secure administration help for these workers in the trade bill on the floor, the administration did give us an indication that you, Madam Secretary, might be able to give them some relief through this emergency grant provisions that you have, that the rules are written in such a way that you could give them some relief.

[The statement follows:]

#### PREPARED STATEMENT OF SENATOR MARY L. LANDRIEU

Mr. Chairman, thank you for holding this hearing that, I trust, will guide us in making sound, informed decisions as we enter the 2003 appropriations cycle. I am very pleased to see Secretary Chao here to comment on the Department of Labor's budget. As our economy slowly emerges from recession, and as we contemplate broad Presidential authority to negotiate trade agreements, I believe it is vital that this Department has a budget that will meet the challenges that we place before it.

There is an old Confucian proverb that summarizes my view of the Department of Labor's role in our economy.

#### "He that would perfect his work must first sharpen his tools."

In today's post-industrial economy, the tools that we need for success are not machines, but a educated, trained and skilled workers. Thus, if we are to perfect the workings of this economy, we must first sharpen the quality of our workforce. With that in mind, I believe we should focus our attention on three ideas: job training, job safety, and job security.

In the time since the September 11 attacks, we have transformed our priorities, our actions, and our vocabulary. Today we are focused on our national security. President Bush has called for an economic security plan. And while we will discuss the specifics of his plan in a minute, it is helpful to remember what this means for the average American. It means jobs. What is the most effective way to create jobs for Americans? And how do we keep those jobs both safe and secure.

#### JOB TRAINING

The President has placed most of the job training money for next year's budget into Job Corps, offering an increase of \$73 million. I applaud the President on this initiative. Job Corps centers are an effective resource that deserves our support. I have two Job Corps centers in my state that serve to train hard working young people to become productive members of society. But these Centers are not enough. At any one time, these centers can only serve 375 people. We need to extend Job Training programs in all areas, to reach the greatest possible number of affected people. Some people are simply unable to leave their homes and communities for six months to a year in order to complete residential job training programs.

to a year in order to complete residential job training programs. In my state, programs like Youth Opportunity Grants have led to marked improvements in some of the poorest areas of Louisiana. It seems contradictory to cut funding for job training in these areas while the nation's unemployment rate is near double what it was last year. For three parishes in Northeast Louisiana, East Carroll, Madison, and Tensas, the unemployment rate hovers near 12 percent, almost double the national average. Youth Opportunity grants have served more than 1000 young people in Louisiana. That means 1000 people have access to GED education, Job Training, and College scholarships. Youth Opportunity and similar programs must be given the chance to capitalize on such success stories.

Job Corps has been in existence for nearly 30 years. Its methods have been perfected and its success rate is high. And please don't misunderstand me, I support Job Corps. But I don't think that this program is right for every American in every situation. Other, newer programs are being cut without the benefit of 30 years to achieve real program efficiency. We won't know if a program works until we allow that program to operate. Then we can study it. Then we can tell if the program is effective or ineffective.

#### JOB SAFETY

The President and the Congress are focused on job safety. Last year, the Senate and the House voted to disapprove of the previous administration's ergonomics rule. I agreed with the majority of my colleagues not because I don't believe in ergonomic standards, but because I disagreed with that particular rule.

We need some sort of rules and regulations to protect workers. Its just that simple. Over 5 million people were injured on the job in 2000. These Americans expect and deserve our protection. While the voluntary standards that the Administration is recommending are laudable, they miss the point. Voluntary compliance works for good actors precisely the type of people that are likely to support best practices within the workplace without any government compulsion. Of course, these entities are not the problem. It is the bad actors that need the motivation, and i see no way to provide it short of a regulatory regime.

#### JOB SECURITY

The message of the administration is clear in this area: Every American deserves to be secure in her job. Secretary Chao, you may remember, and my distinguished colleagues will certainly remember, the debate here in the Senate on the Trade Bill last month. This Senate debated long and hard regarding adequate protections for workers who lose their jobs because of the trade practices of Foreign Governments and Corporations. But when workers are hurt by the practices of the United States, they get no help whatsoever. The President's steel tariff has hurt workers at Ports around the country and especially at the Port of New Orleans. It is only fair that the United States compensate workers when its trade practices hurt them.

Soon, the state of Louisiana will apply for a National Emergency Grant, and I urge the administration and Secretary Chao to look favorably upon this application, as my state is in great need for assistance for these workers.

I look forward to hearing your testimony and your answers to our questions.

Senator LANDRIEU. My first question is, is that true, that you were able to give them some relief? Would you be willing to offer assistance and to help work with us in Louisiana and help us to process the applications necessary to tap into those funds?

Secretary CHAO. The short answer is, of course. I might also add again—and I am going to put a plug in for national emergency grants. The TAA process is very cumbersome. It takes a very, very long time to process, and many times it is harder to obtain. The national emergency grants are very targeted, they are very flexible, they are very responsive, and they can be out within a very short period of time, so we would look forward to working with you on that.

Senator LANDRIEU. There are hundreds, Mr. Chairman, of maritime workers that have worked for years on our docks that are being negatively affected because the steel imports, certain steel imports have been diminished because of the tariff. Of course, it was put on to help other workers in other parts of the State, but the maritime workers now have been negatively affected. So this perhaps would be an opportunity to help them get through this very difficult time, and I want to work with you, and I thank you for that.

My second question or comment would be about the ergonomics issue. As you know, I was one of the majority of Senators that suggested that the rule that we had come up with was too broad, too difficult, would have maybe caused more problems than it would have solved. On the other hand, Senator Breaux, Senator Lincoln and myself and some others that objected to the initial rule have been very committed to working with you on a new rule. My question is, have you made a decision that this new rule is going to only be voluntary? And if that is your decision as Secretary, what could you offer today that would make me or other Senators believe that companies that are not engaging in good practices with their workers—what would make them follow a voluntary set of guidelines? And my question is, are you supporting only voluntary and not mandatory and, if so, what would make you believe that companies would follow voluntary guidelines?

Secretary CHAO. We have proposed a comprehensive approach that consists of guidelines, teamed with an aggressive enforcement program, teamed with a third phase, which is an aggressive outreach program for employers and employees to reduce ergonomic injuries, and fourthly, to do additional research. How do we prevent ergonomic injuries? There are three gaps in the science area on ergonomic injuries. So it is a comprehensive approach that relies not just on voluntary guidelines, but it is a very aggressive approach that encompasses outreach, education, and enforcement.

Senator LANDRIEU. So you are saying that you will support mandatory enforcement of certain new rules?

Secretary CHAO. Part of the problem with any sort of mandatory program is that, if it is very prescriptive, it is one-size-fits-all, and it does not allow for the creativity of workers and employers at a particular work site to decide how best to reduce ergonomic injuries. We have had many, many examples of very innovative and creative solutions of employers and workers working together to reduce ergonomic injuries. Part of the reason why the previous rule, which was bipartisan, as you mentioned, was not successful, was that it was prescriptive, and it took a very long time to effect.

The other thing about the previous rule which I was very concerned about was that an injury would have to occur before the process would be triggered And I think under the guidelines approach, and this comprehensive approach, that we be able to prevent injuries before they occur and do so in a very fast manner.

Senator HARKIN. Senator Landrieu, if I could, we have a vote on. Senator LANDRIEU. Oh, I am sorry.

Senator HARKIN. I am sorry to have to cut you off, but Senator Specter wanted to have something.

Senator LANDRIEU. I am sorry. Go right ahead.

Senator HARKIN. We have only got about 8 minutes.

Senator LANDRIEU. Thank you. But let me just say, I look forward to working with you, Madam Secretary. Because I agree that the formal rule—with you. But I do not think that voluntary standards is where we need to be.

Senator HARKIN. I agree with you, Senator. Senator Specter.

## OPENING STATEMENT OF SENATOR ARLEN SPECTER

Senator SPECTER. Thank you, Mr. Chairman. I regret my late arrival, but the Judiciary Committee at this moment is hearing Director Mueller on the terrorism issue, and that is, I do not have to tell you, it is all-consuming.

Next to terrorism, Secretary Chao, your issues are the most important for the country, but they are in second place, behind terrorism.

I have noted your budget, and I know you are under very tight constraints with the Office of Management & Budget, but I am concerned about the cuts in job training and the elimination of training for migrant and seasonal farmers and the cuts in international labor affairs, and the absence of an increase for worker protection.

The ergonomics issue continues to be one of controversy, and I supported, as you know, the congressional action to eliminate the ergonomics bill because it was simply too complicated, and I know you have been working on it for a long time and have come up with the approach of voluntary standards, which I have grave concerns about. I have cosponsored legislation, but candidly, in part to keep your Department moving as to what will be done before there could be legislation. Perhaps if there was an outpouring of voluntariness that really solved the problem, legislation would not be necessary. Candidly, I doubt that there will be that outpouring of voluntariness, but let us see.

But what is happening on the efforts to have voluntary compliance with the problems and issues here on repetitive motion, et cetera?

Secretary CHAO. We actually are doing quite a bit. As I mentioned, we did come out with a comprehensive approach and so it is not just voluntary guidelines. It is also a match-up of our enforcement policy with our legal policy, and we intend to go after the bad actors very aggressively.

Senator SPECTER. What will you do to the bad actors if they do not voluntarily comply?

Secretary CHAO. I think we have been pretty effective in invoking 5(a)(1) with focus and determination, and we have coupled it with our enforcement, and as an example we have settled with Beverly.

Senator SPECTER. How do you do that, Madam Secretary, if you do not have OSHA regulations in place to give guidance to what should be done? What we are looking for is something which gives direction but is not onerous, but at the present time, what do they have to comply with which you would have a basis for enforcement action on?

Secretary CHAO. The OSHA act has a general duty clause which requires employers to provide their employees with employment that is free of recognized hazards that are likely to cause serious physical harm, and to establish a violation there are a certain number of conditions which are evaluated and determined subsequently.

Senator SPECTER. Madam Secretary, we are about to go to a vote. Would you do this, would you provide the subcommittee the specifics?

Secretary CHAO. Sure.

Senator SPECTER. That sounds like such a very generalized standard as to be—

Secretary CHAO. We have been pretty effective in using it, again, with Beverly, and we have said that we are going to have guidelines in the health care industry, and we are going to be announcing two additional industries with which we will have alliances as well.

Senator SPECTER. It sounds like you have been effective. What I would like you to do is submit in writing the specifics.

Secretary CHAO. We will do that.

Senator SPECTER. What enforcement can you undertake from that generalized standard? Give us a dozen illustrative cases as to where you have gone, and how you have been effective, and we will take a look at that.

Thank you very much, Madam Secretary. Thank you, Mr. Chairman.

Senator HARKIN. Thank you, Senator Specter. We have just a little bit of time. I have two last issues, one I think Senator Specter would also be interested in. You are proposing a cut of \$4.7 million and 65 full-time staff from the coal mine enforcement activities in the Mine Safety and Health Administration, yet the number of coal miners killed has increased. 29 were killed in 1998, 34 in 1999, 38 in 2000, 42 in 2001. I think you should take another look at this to make sure there is no reduced effort in enforcement of the Mine Act. My father worked for 20 years in the coal mines, so I have a little bit of interest in this, and to make sure that we do not back down, especially—

Secretary CHAO. We are not cutting back enforcement at all. We are very concerned about that.

Senator HARKIN. You are cutting back 65 full-time staff.

Secretary CHAO. We are reducing the bureaucracy and the layers. It is in the management layers. Also from 1995 to 2001 the number of coal mines in America have reduced by 30 percent, approximately, and the requisite—

Senator HARKIN. The number of mines have gone down, but the number of deaths are going up.

Secretary CHAO. We are concerned about the deaths, of course. Last year we had a horrible accident with a mine in Alabama that I personally visited.

Senator HARKIN. But there is one last thing I have to bring up. In fiscal year 2001 appropriation there was \$500,000 appropriated to the Des Moines Area Community College for the establishment of a manufacturing skills training center. In the same bill, there was \$461,000 for the University of Northern Iowa for a program to integrate immigrants and refugees into the workforce.

I am sorry to say that neither one of these have been awarded by your Department. The funding for the Employment and Training Administration works on a program year, which means its funding will expire in 24 days. I can tell you, Madam Secretary, I will be very unhappy if this funding is not out by then, and I will not be the only one. The money for the \$461,000 for UNI was provided by the chairman of the House Budget Committee, Congressman Nussle. I do not think he would be very happy, either, to have this expire, so I hope you will have your people take a look at this and get this funding out before it expires before the end of June.

Secretary CHAO. I will do so.

Senator HARKIN. Thank you very much. Madam Secretary, thank you, and we look forward to working with you again. There is a lot I like in what you have done. There are some things that we have to work out in the child labor area.

## ADDITIONAL COMMITTEE QUESTIONS

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:]

#### QUESTIONS SUBMITTED BY SENATOR TOM HARKIN

## DOL AND USAID COOPERATIVE AGREEMENT

*Question.* Is DOL now party to or has it ever been party to a cooperative agreement with USAID, using the Economy Act or otherwise, as part of an inter-agency agreement to implement some of the bilateral projects designed to help reduce abusive child labor by improving access to basic education. If so, please provide copies of pre-existing or current cooperative agreements. If not, why not?

Answer. A cooperative agreement does not exist between DOL and USAID on international child labor. Consistent with the language in the appropriations bill, DOL regularly consults with USAID in the development of spending plans for the Child Labor Education Initiative. USDOL officials have also held consultations with USAID staff in the field during country needs assessments conducted to ascertain the extent and nature of exploitative child labor and its impact on children's school attendance. DOL is currently collaborating with USAID and the ILO's International Program on the Elimination of Child Labor (ILO-IPEC) on the development of a joint project to address child labor, trafficking, and rural development in West Africa.

#### ENFORCEMENT OF CHILD LABOR LAWS

Question. Since 1983, the Congress has enacted 14 different laws linking U.S. trade, investment, and aid benefits to compliance with child labor and related worker rights laws in foreign countries, not to mention the applicable international law. How is your Department stepping up to the challenge of securing effective enforcement of these laws and what have you done in this regard to make certain that Labor Department findings and recommendations are taken more seriously and acted upon by the USTR, State, Commerce, and Treasury Departments in the Interagency Trade Policy Committee?

Answer. DOL is an active participant in the interagency process that is responsible for applying U.S. laws conditioning trade, investment, and aid benefits for foreign countries on their adoption and implementation of internationally recognized worker rights. Within the interagency process, the Department of Labor plays a lead role in developing materials and documenting the extent to which labor laws and practices in foreign countries meet the standards set out in U.S. law. In recent times, these efforts have included, for example, extensive analysis of worker rights in potential beneficiaries of the United States-Caribbean Basin Trade Partnership Act (CBTPA) and the African Growth and Opportunity Act (AGOA), as well as detailed follow-up research pursuant to their continued eligibility in these programs. For example, the United States self-initiated a labor review of Guatemala in 2000

For example, the United States self-initiated a labor review of Guatemala in 2000 pursuant to the Generalized System of Preferences (GSP) and DOL conducted a large part of the research connected with this case. As part of the GSP review, DOL staff traveled to Guatemala as part of an interagency team in April 2001. The United States' review led to significant improvements in worker rights in Guatemala, including a major reform of the national labor code. DOL has also participated in consultations between the United States and other CBTPA and AGOA beneficiaries.

DOL has also actively pursued labor aspects of U.S. investment and aid policies. The Deputy Secretary of Labor is a member of the Board of Directors of the Overseas Private Investment Corporation (OPIC). DOL provides regular input to the Treasury Department to help implement statutes that require U.S. representatives to international financial institutions to adopt programs and policies in support of internationally recognized worker rights.

#### COMBATING CHILD LABOR

Question. In the fiscal year 2002 Act, our Subcommittee incorporated virtually every request you made to provide flexibility and to equip your Department to more efficiently and responsively administer all ILAB's activities. We also gave you more tools to use to strengthen and extend ILAB's internal capacities and to affirm its growing importance vis-a-vis other federal agencies. Accordingly, how many and which countries, for example are now waiting in line at the doors of DOL and the ILO respectively in search of assistance and resources to implement projects and programs to combat the worst forms of child labor by improving access to basic education?

Answer. According to the ILO, approximately 211 million children between the ages of 5 and 14 were working around the world in 2000. Given the extent of the child labor problem, many countries have requested assistance from the ILO's International Program on the Elimination of Child Labor (ILO-IPEC). Since fiscal year 1995, the U.S. has provided approximately \$112 million to IPEC to fund projects that provide viable alternatives to child labor in over 40 countries; the U.S. is currently the largest contributor to IPEC. However, it is clear that the magnitude of the child labor problem around the world easily exceeds the availability of funding from all donors to address the situation.

In both fiscal year 2001 and fiscal year 2002, DOL received \$37 million with a two-year obligation authority to fund child labor basic education projects in countries with a high incidence of child labor and lack of access to quality basic edu-

cation. On the basis of carefully developed pre-selection criteria, nine countries will be funded with fiscal year 2001 funds. As of April 2002, \$19 million out of the \$37 million appropriated in fiscal year 2001 had been obligated for projects in India, El Salvador, Nepal, and Tanzania. The remaining funds will be used for programs in Bolivia, Pakistan, Peru, Togo and Zambia and will be obligated by September 30, 2002. In addition, \$5 million of fiscal year 2001 funding has been earmarked for a global Education Innovations grant that will provide funds for organizations proposing grassroots innovations for the education of child laborers and for identification and dissemination of best practices in community-based education initiatives. It is planned that at least seven more countries will be funded by September 30, 2003 with the \$37 million appropriated to DOL in fiscal year 2002.

#### OBLIGATIONS OF FISCAL YEAR 2001 AND FISCAL YEAR 2002 FUNDS

*Question.* Why has DOL been so slow in obligating all of the fiscal year 2001 and fiscal year 2002 funds appropriated to provide such assistance?

Answer. DOL has undertaken a systematic process for programming the funds which included extensive consultation with USAID and U.S. Embassies in 22 countries, strategic planning, in-country needs assessments, and drafting and signing of letters of understanding with concerned ministries in countries where projects have been planned. A joint DOL-USAID spending plan identifying target countries was completed in February 2002. All of these time-consuming steps have been carried out in order to establish strong foundations before granting implementation awards to eligible organizations.

## AVAILABILITY OF FUNDING FOR CHILD LABOR BASIC EDUCATION PROJECTS

*Question.* Even now, why is it that DOL has failed to define and post to the Federal Register clear guidelines for interested employer groups, trade unions, and NGOs to submit project proposals in this regard and get timely decisions?

Answer. To inform interested parties and provide advanced notice about the availability of funding for child labor basic education projects, USDOL published in the Federal Register on April 18, 2002 a notice of intent to solicit applications for grant applications for awards to be given before September 30, 2002. Four Solicitations for Grant Applications (SGAs) have already been published in the Federal Register (Togo, Education Innovations, Pakistan and Peru/Bolivia). Each of these SGAs gives very clear and precise instructions to potential applicants on the requirements and guidelines to receive the awards. These four SGAs have either already closed or will close by July 9. A final SGA for Zambia will close July 31. DOL expects all awards for fiscal year 2001 funds to have been obligated by August 2002.

## NAFTA SUPPLEMENTARY AGREEMENT ON LABOR STANDARDS

Question. Pursuant to the NAFTA Supplementary Agreement on Labor Standards, what specific actions has DOL taken following the Ministerial Consultations of the ITAPSA and Han Young health and safety complaints, which were combined and supposed to have been "resolved" by August 2001? Answer. Under a Ministerial Consultations Joint Declaration signed in May 2000

Answer. Under a Ministerial Consultations Joint Declaration signed in May 2000 to address the ITAPSA and Han Young submissions, the United States and Mexican labor departments agreed, among other things, to hold a government-to-government session for experts from the two countries to exchange information on techniques and policies to promote compliance with safety and health laws and regulations. Due to scheduling difficulties, this session has not yet taken place. On June 11, 2002 Secretary of Labor Elaine L. Chao and Mexican Secretary of Labor Carlos Abascal established an ongoing bilateral occupational safety and health working group tasked with reviewing safety and health issues raised in the submissions, formulating technical recommendations, and developing technical cooperation projects. The working group will be co-chaired by the U.S. Assistant Secretary for Occupational Safety and Health and the Mexican Director General for Occupational Safety and Health and will hold its first meeting in early July. The establishment of this working group will create a continuing forum for addressing occupational safety and health issues with the Government of Mexico and offers a stronger commitment than the previously agreed to government-to-government session.

# EVALUATION COMMITTEE OF EXPERTS REQUEST BY PETITIONERS IN THE CUSTOMTRIM/ AUTOTRIM CASE

*Question.* Recently, DOL denied a request by the petitioners in the Customtrim/ Autotrim case for an Evaluation Committee of Experts. Why should these petitioners be denied this request when the prior Ministerial Consultations on health

and safety have literally taken years and have resulted in no substantial improve-ments in the implementation of Mexican laws? Answer. The Auto Trim/Custom Trim submission was filed with the U.S. National Administrative Office on July 3, 2000, and was accepted for review on September 1, 2000. The NAO issued a public report on April 6, 2001, and Secretary Elaine L. Chao requested ministerial consultations on June 25, 2001, which were accepted by Mexican Secretary of Labor Carlos Abascal on July 24, 2001. When, in early 2002, the petitioners requested that Secretary Chao seek an Evaluation Committee of Ex-perts (ECE), we were engaged in ministerial consultations with the Government of perts (ECE), we were engaged in ministerial consultations with the Government of Mexico. As was explained to the submitters, a request for an ECE at that time would not have been appropriate and would not have furthered the objectives of the North American Agreement on Labor Cooperation or the interests of the U.S. Gov-ernment. The consultations continued and, on June 11, 2002, Secretary Chao signed a Joint Declaration with Mexican Labor Secretary Carlos Abascal addressing the issues in the Auto Trim submission. In addition to the establishment of a bilateral occupational safety and health working group as described above, the Government of Mexico committed to outreach efforts to inform workers about the status of cases related to prevention of and compensation for occupational injuries and illnesses, the right to file complaints and to appeal decisions, and the availability of free legal advice and assistance offered by government entities to assist workers in assuring their work place rights. We believe that these efforts, as well as additional cooperative programs and technical assistance projects that result from the continuing dia-logue between our labor departments, has and will continue to lead to safer and healthier work places.

#### MIGRANT AND SEASONAL FARMWORKERS

Question. Over the last 5 years, the non-profit and public agencies that receive grants via Section 167 of WIA have helped over 30,000 migrant and seasonal farmworkers obtain good jobs outside of agriculture. In each of those years, the average hourly wage of those workers has increased. Last year, the average wage of the nearly 6,000 beneficiaries who were trained and placed was \$8.04 per hour. That translates to over \$16,000/year, quite a step up from the less than \$10,000/year that most farmworkers earn from all sources. Most of these workers also got job-related benefits for the first time, experienced steady work, and enjoyed some measure of job security. Some of these farmworkers have bought homes for the first time and have been able to keep their kids in school by settling down instead of constantly migrating to find work. What is ineffective about these results in helping arguably the most vulnerable and impoverished subset of the American work force?

Answer. The Department has evaluated programs and processes to reduce in-stances of ineffective and duplicative efforts and to streamline the delivery of services to all of our workforce customers. Each of the required partners of the One-Stop delivery system is required to serve all customers equitably. The elimination of the WIA 167 means that farmworkers will have the same ac-

cess as other customers to the WIA program services available at local One-Stop centers. Effectively, this change provides farmworkers full access to the entire network of services available from all the partners of the One-Stop delivery system. This will expand the range of services provided for farmworkers beyond the current levels of utilization by farmworkers.

The 2003 Budget proposes to end this program because it has not succeeded in significantly improving participants' employment and earnings. It provides little job training. Nevertheless, the Administration recognizes the importance of support services to this population. DOLs' transition from a primary-source service provider to the One-Stop center's multiple-source system of service providers will require a reasoned and strategic process that promotes the recognition and support of farm-workers by all the partners. We are committed to bringing these partners together to ensure migrant and seasonal farmworkers continue to receive quality services.

Also, other Departments have programs to address the needs of migrant workers and their families. For example, the Women, Infants, and Children (WIC) and Head Start programs provide targeted assistance to migrant worker families. In addition, two Department of Education programs are available to help migrant students com-plete high school and succeed in college. The budget requests \$23 million for the Migrant High School Equivalency Program (HEP) and \$15 million for the College Assistance Migrant Program (CAMP).

#### NATIONAL FARMORKER JOBS PROGRAM

Question. I understand now that most of the Section 167 WIA-funded agencies do participate in the one-stop centers as mandated partners. The farmworkers they serve have significant unique barriers to employment. Most participants in the existing National Farmworker Jobs Program (NFJP) did not finish high school and have limited English language and reading skills. The 167 agencies typically have bilingual staff, flexible hours, and operating offices in rural areas near fields where farmworkers work. They also provide outreach to labor camps, fields, churches, health clinics, and wherever else migrant and seasonal farmworkers congregate. All of these services not only assist farmworkers who often work 12 hours/day during harvesting, but they also assist employers and growers because they greatly reduce "down" time that growers would otherwise experience. Do one-stop centers typically provide this fully array of services? If not, how will migrant and seasonal farmworkers, agricultural employers, and growers be assisted in FT 2003 and beyond of the Section 167 WIA-funded agencies are no longer part of the one-stop network?

Answer. The 2003 Budget proposes to end this program because it has not succeeded in significantly improving participants' employment and earnings. It provides little job training. Nevertheless, the Administration recognizes the importance of support services to this population.

The Workforce Investment Act has created a system of local One-Stop Career Centers for individual communities to design a workforce delivery system responsive to the needs of its customers. The WIA 167 program is the One-stop partner that is currently recognized for assisting farmworkers. That arrangement will change to a system where all the One-stop partners recognize farmworkers as their customers, and the partners possess the capacity to respond to the needs of farmworkers. The Department will assist in the transition from the old system, which primarily depended on one partner to serve farmworker customers, to the system envisioned by WIA where all the partners recognize and accept eligible farmworkers as their customers. The services available at a local One-Stop career center must be made available to farmworkers equitably with other customers. It is incumbent upon the state and Local Workforce Investment Boards to ensure that local One-Stop center partners facilitate the delivery of the center's services to the farmworker population in their community. This could be achieved through, or in coordination with, other community service providers including the staff of the former NFJP partner agency in the state.

Also, other Departments have programs to address the needs of migrant workers and their families. For example, the Women, Infants, and Children (WIC) and Head Start programs provide targeted assistance to migrant worker families. In addition, two Department of Education programs are available to help migrant students complete high school and succeed in college. The budget requests \$23 million for the Migrant High School Equivalency Program (HEP) and \$15 million for the College Assistance Migrant Program (CAMP).

#### MIGRANT AND SEASONAL FARMWORKER SUPPORT SERVICES

*Question.* The Bush Administration has taken the position that most NFJP beneficiaries only receive employment-related assistance (including emergency services) and that these services should be provided by state welfare offices, private agencies, or churches instead of through a federally-funded program to help farmworkers find non-agricultural jobs.

Given that migrant and seasonal farmworkers have very special needs and confront multiple barriers to employment such as having to travel long distances between jobs, living and working in very remote areas, and subsisting on very low wages, why are you proposing to eliminate altogether the very modest safety net of support services available nationwide for those farmworkers who wish to stay in farmwork instead of training for a different type of job?

Answer. We concur that the supportive services available for farmworkers from the National Farmworker Jobs Program, such as temporary housing, food, emergency transportation and child care, are important. We also believe that the workforce investment system should serve businesses, especially small businesses such as family farms. To grow and thrive, farmers require a rural economy that delivers an adequate workforce when and where it is needed.

However, the supportive services used by farmworkers are also offered through other federal programs (such as the Department of Health and Human Services) and through community service agencies, some of which are partners at local One-Stop career centers.

We will work with the states to develop further the organizational culture among the partners that leads to a full appreciation and recognition of the importance of providing supportive services to farmworkers. By our doing so, farmers will be served and farmworkers will have access to a more comprehensive range of partners and services, including partners with the capacity to provide supportive services to farmworkers. *Question.* When you and your staff are promoting the one-stop concept for the rest

*Question*. When you and your staff are promoting the one-stop concept for the rest of America's workers, why are you discouraging this one-stop approach that employment-related assistance provides for migrant and seasonal farmworkers all across the country?

Answer. We support the continuation of supportive services (Related Assistance Services) to farmworkers through the various federal programs. Supportive services help farmworkers stay employed in farmwork, help educate their families and help provide farmers and agricultural growers with an adequate supply of workers when and where they are needed.

DOL recognizes the value of the services to farmworkers by non-profit and public agencies. These organizations have built an excellent network of resources, enabling them to specifically meet the needs of the migrant and seasonal farmworkers. The result of this, however, is a focus on a single subset of the workforce population (farmworkers) versus the capacity of the One-Stop centers to serve the universe of populations.

<sup>1</sup> DOL's proposal will hold the entire network of One-Stop partners responsible for serving farmworkers. By setting the expectation for each partner to recognize a farmworker as a potential customer, farmworkers' access to One-Stop services will grow, not diminish. DOL strives to build One-Stop delivery systems that identify and serve all customers of the workforce investment system equitably and efficiently.

*Question.* How do you plan to answer the agricultural employers and growers who have written to me and other Senators who believe maintaining current services are essential to their ability to secure a stable, reliable workforce to harvest their crops?

Answer. At present, farmers and the other agricultural employers use the One-Stop system to access available labor. Farmworkers who are seeking agricultural employment use the One-Stop system to identify available agricultural jobs. For all other services needed by farmworkers, referrals are made to the NJFP in the local area. Elimination of the WIA section 167 will streamline the coordination and delivery of labor-exchange services to farmers and supportive services to farmworkers.

#### EMPLOYMENT OF CHILDREN IN PROCESSING OCCUPATIONS

Question. It is my understanding that American children under 18 are prohibited from working in certain hazardous jobs. For example, there exists a Hazardous Order pertaining to their employment in meat-packing plants, pursuant to 29 CFR, Part 570, Subpart E, because the nature of that work and conditions under which it is performed are such that children under 18 have no place there. Nevertheless, child under 18 are allowed to work in poultry processing, the fastest growing and largest employer in the meat industry. (54 percent of all meat workers are now employed in the poultry industry.) Over the past 20 years, the percentage of food workers who work in the meat industry has more than doubled. At the same time, I understand that the injury and illness rate in this industry is now more than twice the national average. Am I correct that children under 18 are allowed to work in this industry? What restrictions, if any, are placed upon them by law or regulation?

derstand that the injury and illness rate in this industry is now more than twice the national average. Am I correct that children under 18 are allowed to work in this industry? What restrictions, if any, are placed upon them by law or regulation? Answer. Child Labor Regulation No. 3 (Subpart C of Regulations, 29 CFR Part 570) specifically prohibits the employment of minors less than 16 years of age in any processing occupation, including poultry processing. Although there is no Hazardous Occupations Order (HO) that specifically prohibits youths 16 and 17 years of age from working in the poultry processing industry, several of the existing HOs limit the types of jobs that such minors may perform in that industry. For example: —HO 2 prohibits any occupational driving by youths under 17 and limits the type

-HO 2 prohibits any occupational driving by youths under 17 and limits the type and frequency of driving by 17-year-olds.

- -HO 7 prohibits minors under 18 from operating power-driven hoisting equipment such as forklifts and tiering trucks.
- -HO 12 restricts minors under 18 years of age from operating and unloading balers and compactors and provides restrictions on the loading of such equipment by 16- and 17-year-olds.

-HO 14 prohibits workers under 18 years of age from operating power-driven circular saws, band saws, and guillotine shears on carcasses.

*Question.* Why aren't children under 18 who work in the poultry industry covered under existing Hazardous Orders?

Answer. Children under 16 years of age are prohibited from employment in the poultry processing industry by Child Labor Regulation No. 3. The 17 existing Hazardous Occupations Orders (HOs) for non-agricultural employment were first issued between 1939 and 1963 and amended over the years. While Hazardous Order No.

10 prohibits the employment of youths under 18 years of age in most meat proc-

essing occupations it does not include poultry, seafood, or small game processing. In fiscal year 1999, the Department entered into an inter-agency agreement with the National Institute for Occupational Safety and Health (NIOSH) to review occupational fatality and injury data and make recommendations regarding the current HOs, and the creation of new HOs. From the onset of this review, it was understood that NIOSH would examine both the poultry and seafood processing industries. The Department is continuing its analysis of the NIOSH report and has begun the process of prioritizing the recommendations with the aim of balancing the benefits of employment opportunities for youth with the need to ensure their safety on the job. The recommendations regarding youth employment in the poultry processing indus-try—as with the other recommendations—will be carefully evaluated.

#### REVIEW OF HAZARDOUS WORK ORDERS

Question. Did DOL conduct and complete a review of all existing Hazardous Work Orders in 2001 with a view to assessing current workplace hazards pertaining to children under 18?

Answer. In fiscal year 1999, the Department entered into an inter-agency agree-ment with the National Institute for Occupational Safety and Health (NIOSH) to conduct a review of occupational fatality and injury data and make recommendations regarding the current HOs, and the creation of new HOs, to ensure today's youths continue to receive adequate workplace protections while not being denied access to those positive jobs which they can safely perform. The report is now available to the public.

#### POULTRY INDUSTRY HAZARDOUS ORDERS

Question. Did DOL consider bringing children under 18 who are employed in the poultry industry under the scope of any Hazardous Orders? What decision was made and why?

Answer. Children under 16 years of age are currently prohibited from employment in the poultry processing industry by Child Labor Regulation No. 3. Youth 16 and 17 years of age who work in the poultry industry are protected under existing HOs that limit the types of jobs that minors may perform in that industry. In 1994, the Department sought public comment on the feasibility of restricting youth employment in poultry processing and fish and seafood processing. A small number of comments were received on this issue.

In fiscal year 1999, the Department entered into an inter-agency agreement with the National Institute for Occupational Safety and Health (NIOSH) to review occupational fatality and injury data and make recommendations regarding the current HOs, and the creation of new HOs. From the onset of this review, it was understood that NIOSH would examine both the poultry and seafood processing industries. The Department is continuing its analysis of the NIOSH report and has begun the process of prioritizing the recommendations with the aim of balancing the benefits of employment opportunities for youth with the need to ensure their safety on the job. The recommendations regarding youth employment in the poultry processing indus-try—as with the other recommendations—will be carefully evaluated.

*Question.* Did DOL spend at least \$750,000 pursuant to Inter and Intra-Agency Agreements #99–08–01M2 entered into between DOL and NIOSH to conduct such a review? Please provide a copy of the results of that review, including the findings regarding whether children under 18 who work in the poultry sector deserve greater

protections from workplace hazards. Answer. The Department entered into an inter-agency agreement with the Na-tional Institute for Occupational Safety and Health (NIOSH) in fiscal year 1999. In each of the three fiscal years (1999, 2000 and 2001), the Department provided \$750,000 to NIOSH to fund the inter-agency agreement. Pursuant to the agreement, NIOSH has completed a review of occupational fatality and injury data and made recommendations regarding the current HOs and the creation of new HOs.

#### PROTECTION OF RETIREMENT SAVINGS OF AMERICAN WORKERS

Question. One of the most important policy questions facing the country today is how to protect the retirement savings of American workers. Therefore, I was particularly disturbed by a recent report issued by the Department of Labor's Inspector General on cash balance pension plans, "PWBA Needs to Improve Oversight of Cash Balance Plan Lump Sum Distribution." The report found that cash balance plans were underpaying workers millions of dollars of their hard earned pension benefits. Can you comment on the report?

Answer. I agree that protecting Americans' retirement security should be-and is-a top legislative and regulatory priority for this Administration. President Bush believes that "government must support policies that promote and protect savings' because "the American Dream includes a sound pension plan."

In fact, the President's 2001 tax legislation, the Economic Growth and Tax Relief Reconciliation Act of 2001 (EGTRRA), implemented important changes in the laws impacting cash balance plans. EGTRRA amended Code section 4980F and ERISA section 204(h) to replace the 15-day advance notice requirement with a "reasonable time" notice requirement. The Treasury Department's draft regulations provide for 45 days advance notice for most plans, 15 days advance notice for small plans and mergers, and adequate advance notice where the plan provides choice. Other important changes include requiring notification of a reduction in the rate

of early retirement subsidies; requiring that a plan administrator must provide writ-ten notice to affected plan participants of an amendment that provides a significant reduction in the rate of future benefit accruals; and the imposition of a tax of \$100 per day per affected participant up to \$500,000 where there is a failure to provide the notice.

The new law also permits the Secretary of the Treasury to provide for a simplified notice for plans with fewer than 100 participants. And, in the case of an egregious failure to comply with these provisions, a participant may be entitled to the greater of the benefits they would have been entitled to without regard to the amendment or the new benefits.

On the regulatory side, the Department of Labor and the Pension and Welfare Benefits Administration (PWBA) take very seriously the responsibility to safeguard, through both stronger voluntary compliance and enforcement, the retirement assets of 200 million workers, their families, and retirees.

Recoveries from enforcement efforts for all investigations in 2001 resulted in total monetary recoveries of \$652.4 million consisting of nearly \$330 million as a result of prohibited transactions corrected, \$139 million in plan assets restored, \$114 million in future losses, and \$69 million in benefits restored directly to participants. As transactions become more sophisticated and complex, we are committed to providing the most effective technical and human capital resources needed to protect American workers and their families. In March 2002, the GAO issued a report entitled, "Pension and Welfare Benefits

Administration: Opportunities Exist for Improving Management of the Enforcement Program." It noted that PWBA is a relatively small agency facing a daunting challenge of safeguarding the economic interests of millions of Americans by overseeing the providers of employee benefits plans. The report observed that over the years, PWBA has taken steps to strengthen its enforcement program and leverage its resources by placing the majority of its resources into its enforcement program, decentralizing its investigative authority to its regions, and making improvements in technology. The GAO summarized its findings by stating that all these actions "contributed to what is, overall, a well-run program.

GAO identified areas in which PWBA could further improve its enforcement pro-

gram; we are now addressing these recommendations. Also, as referred to in the question, in March 2002, the DOL's Inspector General's Office (IG) issued a report titled "PWBA Needs to Improve Oversight of Cash Balance Plan Lump Sum Distributions." The report examined the actions of 60 compa-nies that converted from traditional defined benefit to cash balance plans and found that in 13 of 60 cases, employees who left the company before normal retirement age "did not receive all of the accrued benefits to which they were entitled." The report suggested that PWBA "direct more resources to protecting cash-balance plans participant benefits and that it initiate specific enforcement action on the 13 plans that are putatively underpaying some workers

Since our regulation and enforcement of ERISA's Title I provisions are coordinated with the Internal Revenue Service (IRS) and the Pension Benefit Guaranty Corporation (PBGC) on related provisions, we are currently working closely with these agencies to address the issues that were raised in the Report.

It should be noted that the OIG's report does not take into account the division of authority regarding enforcement and regulation of cash balance plan conversions and distributions among PWBA, the Department of Treasury and the IRS.

#### CASH BALANCE PENSION PLANS

Question. Among other things, the OIG recommended that PWBA provide additional oversight, intervention, and guidance with respect to cash balance pension plans. But, in her response to the OIG's report, Assistant Secretary Ann Combs re-fused to increase oversight and enforcement of cash balance plan benefit calculations. Instead, Secretary Combs chose to argue with the OIG over the sampling methodology and assumptions used by the OIG's audit team. Can you comment on this extraordinary lack of concern for workers?

Answer. We respectfully differ on the characterization of Assistant Secretary Combs' response. She did not refuse to increase oversight and enforcement of cash balance plan benefit calculations, rather, Assistant Secretary Combs immediately referred the findings of the OIG report to the IRS and the Department of the Treasury, and stands ready to take appropriate action after these agencies have com-pleted their review of the OIG audit report and provided analysis to PWBA.

In sum, the OIG report fails to recognize the division of authority regarding enforcement and regulation of cash balance plan conversions and distributions be-tween PWBA, the Department of Treasury and the Internal Revenue Service (IRS). As soon as the OIG communicated its conclusions to PWBA, the agency requested an expedited review of the identified cases by the IRS, and will work diligently to develop a coordinated response once the IRS has provided guidance. PWBA takes pride in its enforcement of benefit protections that are so important

to American workers, retirees and their families.

First, in analyzing the OIG's conclusions, it is important to understand the limitations on PWBA's regulatory and enforcement authority in this area. There are two major limitations under current law. First, under Reorganization Plan No. 4 of 1978 (codified in notes to 29 U.S.C. 1001), the authority of the Department of Labor to issue regulations, rulings, opinions, variances and waivers with respect to the ben-efit accrual, forfeiture, and related provisions of ERISA, was transferred to the Sec-retary of the Treasury. Although the Reorganization Plan provides that the Secretary of Labor may continue to enforce compliance with these provisions of ERISA, the Department is bound by regulations and interpretations issued by the Secretary of the Treasury.

Second, Federal ERISA law further restricts the Department's ability to initiate enforcement actions regarding alleged violations related to plan participation, vesting, and funding. When a plan is qualified or pending qualification under the Inter-nal Revenue Code, the Labor Secretary may exercise her authority with respect to a violation relating to participation, vesting, and funding only if requested to do so by the Secretary of the Treasury, or if one or more participants, beneficiaries, or fiduciaries of such plan make such a request in writing. If a participant makes a request, the Secretary may exercise her authority only if she determines that such violation affects, or such enforcement is necessary to protect, claims of participants

and beneficiaries to benefits under the plan. In light of these restrictions on PWBA's interpretive authority and enforcement oversight, the agency concluded that the official view of the IRS was necessary regarding the alleged violations identified in the OIG report in order to properly evaluate the recommendations and properly respond to the report. Furthermore, in formulating the conclusions regarding the 13 plans, the OIG itself relied on the IRS, specifically Notice 96–8 addressing certain requirements of Code sections 411 and 417 (and the parallel provisions in Title I of ERISA) as applied to present value cal-

417 (and the parallel provisions in Title I of ERISA) as applied to present value cal-culations of lump sum distributions from cash balance plans. Therefore, on February 7, 2002, PWBA forwarded a copy of the OIG report and supporting work papers to the IRS for its review and comments. We have asked the IRS to expedite its review and we anticipate receiving its written response in the near future. Once these comments are received and discussed with the IRS, we will immediately determine an appropriate course regarding the 13 plans identified in the report. We look forward to working with the IRS and the Treasury Department to develop additional guidance for plan sponsors and others in the regulated commu-nity on calculating lump sum distributions of accrued benefits in cash balance plans. nity on calculating lump sum distributions of accrued benefits in cash balance plans. We will also review our enforcement resources

However, in reviewing the plans identified by the OIG, PWBA examined the cash balance issues that do fall within its enforcement authority, such as whether plan administrators provided cash balance plan participants the necessary disclosures re-quired under ERISA. As you may know, the Department supported legislation to strengthen ERISA's disclosure requirements, and worked with both House and Senate leaders to include these improvements in pension legislation enacted as part of EGTRRA. Also, PWBA has developed general guidance on cash balance plans for plan participants that can be found on our web site, www.dol.gov/pwba. PWBA recently initiated an enforcement project in certain regions to determine if expenses are being improperly paid by the plan in connection with the conversion of a tradi-tional defined benefit plan to a cash balance plan. Since fiscal year 1999, PWBA has opened 30 investigations of cash balance plans involving the improper allocation of expenses and recovered \$789,000 on behalf of participants and beneficiaries. *Question.* Secretary Combs asserted in her response to the OIG that she had asked the Department of Treasury for its review and comments on the OIG's report. Yet, in a May 10th letter from Treasury's Benefits Tax Counsel, Bill Sweetnam asserts that Treasury has not received any such communication. Can you explain this discrepancy?

Answer. PWBA's request for assistance was sent on February 7, 2002, to Paul Schultz, Director, Employee Plans Rulings & Agreement, Internal Revenue Service. A copy of the letter is attached.

U.S. DEPARTMENT OF LABOR, PENSION AND WELFARE BENEFITS ADMINISTRATION, Washington, DC.

Re Department or Labor's Office of Inspector General's ("OIG's") Audit of Cash Balance Plans.

PAUL T. SHULTZ,

Director, Employee Plans Rulings & Agreements, Internal Revenue Service, T:EP:RA, 1111 Constitution Ave., NW, Washington DC.

DEAR MR. SHULTZ: As part of the OIG's oversight responsibilities of the PWBA's enforcement program, OIG reviewed 60 cash balance plan conversions to determine if violations of ERISA were occurring, either during or after the plan converted to a cash balance plan. The review disclosed that 13 of the plans contained in the sample may have miscalculated the lump sum distributions pursuant to IRC sections 411 and 417(e) and did not comply with the guidance set forth in IRS Notice 96–8. Notice 96–8 proposes guidance concerning the applications of IRC sections 411 and 417(e) to single sum distributions under defined benefit pension plans that are cash balance plans. OIG has asked the PWBA to comment on their findings. The PWBA cannot respond adequately to the OIG without reviewing these findings with the IRS.

According to Reorganization Plan No. 4 of 1978, Sec. 101 Fed. Reg. 47713, sole authority over benefit accruals, forfeitures and related provisions of ERISA is transferred from the Secretary of Labor to the IRS. While the Secretary of Labor may continue to enforce compliance with these provisions of ERISA, the Department of Labor is bound by the regulations, rulings, opinions, variances, and waivers issued by the IRS pursuant to the transfer of authority. We are requesting the assistance of the IRS in reviewing the OIG's audit work

We are requesting the assistance of the IRS in reviewing the OIG's audit work papers and a summary chart, which the OIG prepared, of their findings to determine if the IRS concurs that these plans are in violation of IRC sections 411 and 417(e). The OIG intends to issue their draft report no later than February 20, 2002. We would appreciate if you could expedite your response in light of the OIG's issuance date. In the interim, we would like to meet with you and your associates, and Ralph McClane, Assistant Regional Director for Audit for the San Francisco Regional office of the OIG, to discuss the OIG's findings.

Thank you for your prompt attention to this matter. If you have any questions, please contact either Joseph Canary or Catherine Suttora. Their numbers are (202) 693–8531 and (202) 693–8450, respectively. Alternatively, Mr. McClane has stated he would be available to review the work papers with you. His number is (415) 975–4030.

Sincerely,

## VIRGINIA C. SMITH, Director, Office of Enforcement.

#### PWBA'S OVERSIGHT OF CASH BALANCE PLAN FIDUCIARIES

Question. In her letter to the OIG, Secretary Combs also asserts that the Department of Labor's ability to regulate and enforce pension plans is restricted by the Reorganization Plan. However, under the Reorganization Plan the Department of Labor has the ability and duty to enforce the fiduciary provisions of ERISA, including the provision that requires plan fiduciaries to discharge their duties solely in the interest of plan participants and to use plan assets for the exclusive purpose of paying benefits to plan participants. How can the PWBA improve its oversight of cash balance plan fiduciaries?

Answer. PWBA is committed to discharging its responsibility to enforce the benefit protections that are so important to American workers, retirees and their families, and works in coordination with other enforcement agencies. The agency is confident that it can continue to appropriately address fiduciary issues in cash balance plans.

As noted in the response above, the authority of the Department of Labor to issue regulations, rulings, opinions, variances and waivers with respect to the benefit ac-

crual, forfeiture, and related provisions of ERISA, was transferred to the Secretary of the Treasury. Although the Reorganization Plan provides that the Secretary of Labor may continue to enforce compliance with these provisions of ERISA, the Department is bound by regulations and interpretations issued by the Secretary of the Treasury.

In addition, under ERISA when a plan is qualified or pending qualification under the Code, the Labor Secretary may exercise her authority with respect to a violation relating to participation, vesting, and funding only if requested to do so by the Secretary of the Treasury, or if one or more participants, beneficiaries, or fiduciaries of such plan make such a request in writing. If a participant makes a request, the Secretary may exercise her authority only if she determines that such violation affects, or such enforcement is necessary to protect, claims of participants and beneficiaries to benefits under the plan.

ficiaries to benefits under the plan. As indicated above, we have asked the IRS to expedite a review of the 13 plans identified by the OIG report and once these comments are received and discussed with the IRS, we will immediately determine an appropriate course regarding the 13 plans. PWBA looks forward to working with the IRS and the Treasury Department to develop additional guidance concerning how to calculate lump sum distributions of accrued benefits in cash balance plans.

13 plans. PWBA looks forward to working with the IRS and the Treasury Department to develop additional guidance concerning how to calculate lump sum distributions of accrued benefits in cash balance plans. PWBA recently initiated an enforcement project in certain regions to determine if expenses are being improperly paid by the plan in connection with the conversion of a traditional defined benefit plan to a cash balance plan. Since fiscal year 1999, PWBA has opened 30 investigations of cash balance plans involving the improper allocation of expenses and recovered \$789,000 on behalf of participants and beneficiaries.

#### GUIDANCE FOR SPONSORS OF CASH BALANCE PLANS

Question. Secretary Combs has asserted that she is working with the IRS to develop improved guidance for sponsors of cash balance plans. However, the HELP Committee held hearing on this issue almost 3 years ago, and no guidance has been announced either by the Treasury, the IRS, or the Department of Labor? When do you expect that this guidance will be provided?

Answer. Again, it is important to note that under Reorganization Plan No. 4 of 1978, DOL's authority to issue regulations, rulings, opinions, variances and waivers with respect to the benefit accrual, forfeiture, and related provisions of ERISA, was transferred to Treasury. Assistant Secretary Combs has—and will continue—to provide PWBA's input and perspective as Treasury drafts additional guidance on cash balance plans, which we understand will be issued in the near future.

## OFFICE OF DISABILITY EMPLOYMENT POLICY (ODEP)

Question. What is the Office of Disability Employment Policy (ODEP) currently doing and what are its long-term goals? Will it offer programs to the disabled community or create policy? Answer. The Office of Disability Employment Policy was created to provide na-

Answer. The Office of Disability Employment Policy was created to provide national leadership to increase employment opportunities for adults and youth with disabilities while striving to eliminate barriers to employment. ODEP's long-term goal is to promote policy that will increase opportunities by expanding access to training, education, employment supports, assistive technology, community-based employment, and entrepreneurial and small business development. To achieve its long-term goal, ODEP is focused on policy development. As you are even a very a people and adult with disabilities accounter similar the primer to the primer to achieve the super second adults and the primer to access the second secon

To achieve its long-term goal, ODEP is focused on policy development. As you are aware, young people and adults with disabilities encounter significant barriers to employment. Our strategy for policy analysis and development relies upon a strategic plan that will include several components. Although ODEP is finalizing its fiscal year 2003 strategic plan and related goals and objectives, the general direction for the plan is emerging.

First, we are working to expand our partnerships with our critical stakeholders: individuals with disabilities and their families, private employers, Federal, state, and local government, educational and training institutions, disability organizations, and providers of employment and training service. These partnerships are crucial for understanding and exploring these persistent employment barriers, conducting research and evaluation into employment alternatives, performance effectiveness, validating best practices, and providing outreach, dissemination, and technical assistance to effect systemic change.

Second, we are working with our partners to increase the capacity of the workforce development system to serve people with disabilities. Our strategy is to leverage our resources, including \$23 million in fiscal year 2002, to test and validate best practices and to conduct research and evaluation that result in the development of alternative policy solutions for the workforce development system. Our resources are strategically leveraged to enhance partnerships among our stakeholders such as the workforce development system, including One-Stop Career Centers and youth services at the state and local levels, researchers and trainers, and the disability community to test models for increasing the capacity of the system to better serve and benefit people with disabilities. For example, our Customized and Innovative Youth initiatives are targeted to increasing the capacity of the workforce development system by linking the system to stakeholders with an understanding of needs of people with disabilities and potential research-based practices for addressing these needs. We also support Congressional and White House initiatives to increase the em-

We also support Congressional and White House initiatives to increase the employment of people with disabilities through policy development. For example, in fiscal year 2002 Congress asked us to develop, test, and disseminate best practices and policy development for promoting telework/telecommuting as an employment alternative for people with significant disabilities through Federal agencies that have telework initiatives. The Department is also actively supporting the President's New Freedom Initiative through such policy development initiatives as the Olmstead Community Initiative, and the Ticket-to-Work, Work Incentives Improvement Act Initiative.

With these research and best practice initiatives in place, our task is to take the lessons learned from our initiatives and conduct policy analysis and development. ODEP policy staff conducts analysis and develops policy options for the workforce development system.

The third component emerging through our strategic planning process is replicating and implementing the research-based best practices and policy alternatives throughout the workforce development system. This is achieved through extensive outreach and technical assistance to our critical stakeholders.

Finally, evaluating our performance is a critical component of our emerging strategic plan. Currently, we have established intermediate milestones to measure our progress and anticipate finalizing our fiscal year 2003 strategic plan this summer. Measuring our performance and learning from these measures position ODEP to provide national leadership in policy direction and guidance in order to integrate people with disabilities into the workforce, promote their economic and social independence, and enhance their inclusion in communities throughout this nation.

#### DIVERSITY WITHIN LEADERSHIP, MANAGEMENT AND RANK-AND-FILE OF ODEP

*Question.* Leadership and management positions at the ODEP are currently being filled. Is it important to you that people with disabilities—who acknowledge their disabilities—are in visible leadership or management positions: Does diversity in the leadership of this new office matter to you? Will you give your word to this Committee that you are committed to diversity within the leadership, management and rank-and-file of this new office?

Answer. The Office of Disability Employment Policy (ODEP), along with the entire Department of Labor, is committed to recruiting, developing, and retaining a diverse workforce that includes individuals with disabilities. Our nominee for the Assistant Secretary of ODEP is a step in this direction. Individuals with disabilities are and will continue to be an important part of that diversity.

#### LUMP SUM DISTRIBUTIONS OF ACCRUED BENEFITS

Question. I have been very involved in conversations over cash balance plan conversions, with specific regard to their effect on aging workers, and have also been concerned with the distribution of lump sum for workers in defined benefit plans. To address the latter, I crafted an amendment to the HELP Committee pension legislation that was added in committee markup in late March that would require Treasury to draft rules requiring employers who offer a lump sum instead of a regular annuity in defined benefit plans to provide a clear statement of the relative values of the two options using standard interest and mortality rates. This is in response to a letter that I sent to both Treasury and Labor in January of 2000. What is the Labor Department doing on this front, and what resources can be provided to assist in your progress in this area?

Answer. As noted previously, DOL's authority to issue regulations, rulings, opinions, variances and waivers with respect to the benefit accrual, forfeiture, and related provisions of ERISA, was transferred to Treasury.

PWBA looks forward to working with the IRS and the Treasury Department to develop additional guidance for plan sponsors and others in the regulated community concerning how to calculate lump sum distributions of accrued benefits, as well as other issues, regarding cash balance plans.

#### ERISA ENFORCEMENT

Question. Similarly, I read with interest the Inspector General's investigation of the Pension Welfare Benefits Administration's oversight of cash balance pension plan lump sum distributions in an audit dated March 29, 2002. I have a three-part question involving this issue.

The IG stated that additional enforcement resources should be directed to this issue, and PWBA's response was that the IG's sampling methodology may be in error. However, assuming that a broader study had occurred and the conclusions of the audit are correct, what kinds of additional resources would be needed to take appropriate enforcement action?

Answer. PWBA is committed to the enforcement of benefit protections that are so important to American workers, retirees and their families, and works in coordination with other enforcement agencies. The agency is confident that it can continue to appropriately address fiduciary issues in cash balance plans.

In areas where the agency does have jurisdiction, PWBA has devoted considerable resources to issues related to plan design, age discrimination and disclosure to participants. In addition, PWBA has spent significant resources on educating partici-pants about cash balance plans, and recently initiated an enforcement project in certain regions designed to determine if the expenses incurred in connection with converting a traditional defined benefit plan to a cash balance plan have been improp-erly paid from plan assets. During fiscal year 2001, PWBA spent 88 staff days inves-tigating cash balance plans and for the first 7 months of fiscal year 2002 spent 126 Staff days. PWBA intends to continue this effort. *Question*. What actions have PWBA taken since the audit was released?

Answer. As stated earlier, on February 7, 2002, PWBA forwarded a copy of the OIG report and supporting work papers to the IRS for its review and comments. We have asked the IRS to expedite their review and after these comments are received and discussed with the IRS, PWBA will immediately determine an appropriate course regarding the 13 plans.

## PATIENT'S RIGHTS

Question. Recently, I understood Members of the House sent a letter to you asking you to make immediate changes to the Department of Labor's patients' rights claims procedure rule. I am very concerned about this request because I know that this rule provides important patient protections to consumers in private, job-based health plans, ensuring that the health plan's process for making benefit decisions and hearing appeals is fair and timely. This rule is scheduled to go into effect July 1 of this year. It has already taken nearly five years for this rule to be implemented.

Is your Department considering any further delays or changes that would take away from these important protections for consumers?

Answer. As you are aware, the Bush Administration and, in particular, this Department are committed to protecting the rights and benefits of American workers and their families. Few benefits are more important to today's workers than affordable, quality health care coverage. This is why the President has long supported enactment of a Patients' Bill of Rights.

The new claims procedure regulation went into effect as scheduled and will be applied to health claims for plan years beginning on or after July 1, 2001. We are fo-cusing our efforts on providing the technical guidance and compliance assistance necessary to facilitate a smooth and efficient transition to the new requirements. Most recently, the Department released, via its website, answers to a set of "fre-quently asked questions" that are intended to address implementation and other issues raised with the Department since the publication of the final regulation.

#### RESOURCES FOR LABOR-MANAGEMENT REPORTING AND DISCLOSURE ACT (LMRDA) ENFORCEMENT

Question. Your budget request includes an additional \$3.4 million and 40 additional full-time employees dedicated solely to ensure that unions comply with the Labor-Management Reporting and Disclosure Act (LMRDA). At the same time, you propose cutting 253 full-time employees from the Department of Labor, including 83 employees in OSHA, 46 employees in the Mine Safety and Health Administration, and 39 employees in the Employment Services Administration, which is the part of the Agency that protects the nation's workers from wage and overtime violations. It appears that you are seeking to target labor unions at the expense of the safety and health of the nation's workers.

How do you justify asking for such a substantial increase in resources for LMRDA enforcement, while at the same time you are proposing to significantly reduce the number of Department staff members who are dedicated to protecting the safety of workers and protecting workers' rights under wage and hour laws? Answer. As Deputy Secretary Findlay indicated in his April 10, 2002, testimony

Answer. As Deputy Secretary Findlay indicated in his April 10, 2002, testimony before the House Subcommittee on Employer-Employee Relations and the Subcommittee on Workforce Protections of the Committee on Education and the Workforce, the LMRDA is one of a number of important statutes that have been enacted over the years to safeguard the rights of workers. For example, the Occupational Safety and Health Act protects worker safety, the Fair Labor Standards Act protects certain labor standards the Employee Retirement Income Security Act protects worker pensions, and the LMRDA protects the rights of union members. As Secretary of Labor, I take very seriously the Department's responsibility to enforce each of these statutes.

The request for an additional \$3.4 million and 40 additional full-time employees for the Office of Labor-Management Standards (OLMS), the DOL agency that enforces the LMRDA, is a first step toward reversing the steady reductions that have hindered the enforcement of the LMRDA in recent years. OLMS compliance audits have fallen from a high of 1,583 in 1984 to only 238 in 2001. Today, ten of the largest national unions have never been audited. This deterioration in the level of compliance review and enforcement would not be tolerated with respect to OSHA, Wage and Hour, or PWBA. It should not be tolerated under the LMRDA either. The LMRDA is a worker protection statute like any other that we are charged with enforcing at the Department of Labor.

Question. It appears that your decisions to propose a substantial cut in your staffs that safeguard workers' occupational safety, mine safety, and rights to receive wages and overtime pay owed to them, while proposing a massive increase—40 new full-time employees and \$3.4 million—to do nothing but ensure that labor organizations file annual financial reports, could be interpreted as being strongly against workers and their unions, and strongly in favor of the interests of employers and big business. Viewing your proposed budget in light of your Department's performance on the issue of ergonomics over the past year and a half, what can you say in reply to the charge that you are simply acting in the interests of big business and against America's workers?

Answer. The reporting requirements of the LMRDA are at the heart of the protections accorded to union workers by that law, and, as stated previously, the vigorous enforcement of those requirements is in keeping with a sound worker protection strategy. During testimony before the House Labor Committee in June 1959 prior to passage of the LMRDA, AFL-CIO President George Meany himself recognized the importance of reporting when he said "if the powers conferred [in the LMRDA] are vigorously and properly used, the reporting requirements will make a major contribution toward the elimination of corruption and questionable practices." However, in report year 2000 over 34 percent of unions either were late in filing their statutorily required annual financial reports or failed to file at all.

The 40 new full-time employees in the budget request will support agency efforts to secure timely and accurate union financial reporting and enable an increase in audits of unions under the OLMS Compliance Audit Program (CAP) and International Compliance Audit Programs (I-CAP). These audits are conducted to verify the reports filed by unions, detect financial mismanagement and embezzlement, and provide compliance assistance to union officers. As a result of the 30 percent decrease since 1992 in the staff responsible for enforcing the LMRDA, the number of compliance audits has dropped from a high of 1,583 in 1984 to only 238 in 2001. OLMS cannot effectively enforce the statutory rights and interests of union workers at this funding level. The staff increase would provide additional front-line investigators, auditors, and support positions for ensuring greater compliance with the reporting and union financial integrity standards in the LMRDA.

Question. What led you to seek such a large increase in resources to enforce the LMRDA? Has there been an increase in complaints by union members about their unions, and do you have statistics that show an increase in complaints? Or is this budget request a response to conservative elements who are not themselves union members, but whose goal is to weaken the labor movement?

Answer. The increase sought for OLMS is a modest attempt to reverse some of the dramatic staff reductions the agency has suffered in previous years. This increase is critical because of the 30 percent decrease since 1992 in the staff responsible for enforcing the LMRDA.

OLMS frequently receives complaints from union workers about union reporting, handling of funds, elections of officers, and similar maters, but does not formally track the number of such complaints.

The LMRDA was enacted to eliminate union corruption and to protect union members' right to democratic participation within their unions. It is DOL's responsibility to enforce the law that guarantees democracy to union workers.

Since the new that guarantees democracy to union workers. Question. Your budget request includes an additional \$3.4 million and 40 addi-tional full-time employees dedicated solely to ensure that unions comply with the Labor-Management Reporting and Disclosure Act (LMRDA), as well as an addi-tional \$2 million for electronic filing and Internet posting of the yearly reports sub-mitted by labor organizations. The LMRDA also imposes reporting obligations on employers and management consultants, yet your budget request includes no addi-tional funding to ensure greater compliance by these parties. How do you justify sin-gling out unions for compliance? Answer While the Department's fiscal year 2003 budget request includes an  $add^{\pm}$ 

Answer. While the Department's fiscal year 2003 budget request includes an addi-tional \$3.4 million and 40 FTE for the LMRDA program, it does not include an enhancement over the prior year in the level of funding earmarked for electronic re-porting and Internet disclosure. The Labor Organization Annual Financial Reports (Forms LM-2, LM-3, and LM-4) account for most of the reporting and disclosure activity under the LMRDA. Approximately 30,000 unions are required to file these reports with OLMS each year.

The Act also requires unions to file Form LM-1, Labor Organization Information Report, and Forms LM-15, LM-15A, and LM-16, trusteeship reports. When com-bined, these reports total about 1,300 each year. Consequently, in the normal course of business, unions and their members will be the constituents primarily affected by OLMS policies and processes.

Under certain circumstances, reports are also required from labor relations con-sultants (Forms LM-20 and LM-21), employers (Form LM-10), surety companies (Form S-1), and union officers and employees (Form LM-30). However, these "other" reports make up only about 2 percent of the reports filed with OLMS every year. But while there are significantly fewer of these reports filed, OLMS's oversight remains the same.

To implement the President's E-Government Initiative, in fiscal year 2003 OLMS will continue efforts to facilitate electronic filing, and public access to LMRDA reports. Electronic filing and Internet disclosure have been implemented for the Labor Organization Annual Financial Reports (Forms LM–2, LM–3, and LM–4), and OLMS plans to provide for electronic filing and Internet disclosure of the other re-ports filed by unions, labor relations consultants, employers, surety companies, and union officers and employees.

#### LEGISLATIVE SAVINGS

Question. There are two major portions of your budget that depend upon enactment of authorizing legislation to generate fees to replace appropriations: \$138 mil-lion for processing employers' applications for permanent foreign labor certifications; and \$86 million for administration of the workers' compensation program. That's

\$224 million that may not materialize to fund programs in your fiscal 2003 request. What would you recommend the Appropriations Committee do if these legislative savings are not available?

savings are not available? Answer. One near-term option that the Appropriations Committee could consider would be to authorize the Secretary of Labor on a one-time basis to redirect \$110 million of the unobligated H-1B technical skill training grant fund balances for pur-poses of reducing the permanent labor certification backlog and providing prevailing wage services. This would provide the needed funds while the Congress acts on the Administration's legislation to terminate the ineffective H-1B training grant pro-gram. Transferring \$110 million on a one-time basis to the permanent labor certifi-cation program would not adversely affect the H-1B technical skill training grant program because there would still be sufficient funds available for new awards of program because there would still be sufficient funds available for new awards of technology training grants.

*Question.* Which of your requested increases could be scaled back? Answer. The Administration is proposing a reduction of existing funds for the permanent foreign labor backlog rather than a funding increase. Transferring \$110 mil-lion of the H-1B technical skill training grant balances, on a one-time basis, would cover the needs of reducing the permanent labor certification backlog, and no other funding would be requested. A redirection of funds for one year's worth of backlog processing would equal \$57.1 million. However, this would require a similar redirection or appropriation in fiscal year 2004 in order completely process the backlog.

#### FAITH-BASED INITIATIVE

Question. You recently announced a \$14.9 million Faith-Based and Community-Based Initiative, setting aside funds appropriated for One-Stop Career Centers for these grant awards. There does not appear to be any mention of this initiative in your budget request.

Can you tell us more about this initiative, and the rationale for utilizing funds appropriated for One-Stop Centers, without requesting a reprogramming?

Answer. ETAs fiscal year 2002 One-Stop/America's Labor Market Information System budget proposal outlined several proposed investments to promote and ex-tend "universal access for customers" under the One-Stop system. With our state and local partners, ETA has recognized that there are identifiable populations in urban and rural areas that can benefit from the core, intensive and training services which the local One-Stop Centers provide. These populations, however, have lacked knowledge of the existence of these services or may have encountered impediments in their use (e.g., transportation distance or difficulty). In January 2001, President Bush issued Executive Order 13198 which created the

Office for Faith-Based and Community Initiatives in the White House and centers in the departments of Labor, Health and Human Services (HHS), Housing and Urban Development (HUD), Education (ED), Justice (DOJ). President Bush charged the Cabinet centers with identifying barriers—statutory, regulatory, and bureau cratic—that stand in the way of effective faith-based and community initiatives, and to take steps that these organizations have equal opportunity to compete for federal funding and other support.

With the "universal access" principle as a major touchstone for our discussions, ETA and the Department's Center for Faith-Based and Community-Based Initiatives (CFBCI) developed a number of strategies. These strategies were intended to provide additional opportunities for the Federal-state-local partnerships under WIA to engage the faith-based and community-based organizations in service delivery, while providing more "points of entry" for customers into the One-Stop system. In April 2002, ETA announced the availability of funds under three separate competitions to award grants to states, intermediaries, and small faith-based and community-based non-profit organizations. These investments have several important objectives, which were uniformly conveyed in all three solicitations:

-To expand the access of faith-based and community-based organizations' clients and customers to the services offered by the nation's One-Stops ("the universality principle");

-To increase the number of faith-based and community-based organizations serving as committed and active partners in the One-Stop delivery system; and

-To identify, document, showcase and replicate successful and innovative instances of faith- and community-based involvement in our system-building.

Through these grant awards announced in June, ETA has reaffirmed its continuing commitment to those customer-focused reforms instituted by state and local governments. These reforms help Americans access the tools they need to manage their careers through information and high quality services, and to help U.S. companies find skilled workers. These solicitations also reflect the interest in creating new avenues ("access zones") through which qualified grass-roots organizations can more fully participate under WIA while bringing their particular strengths and talents in service provision to our customers. Since the universal access goal expressed in the budget proposal was addressed by both the design and objectives of this FBO/CBO *Question.* Do you plan to continue this effort in fiscal year 2003, and, if so, with

what funding

Answer. The agency has also not yet made a final decision on what proportion funds might help support the exemplary grantees who receive fiscal year 2002 funding, and what proportion will be dedicated to the award of new grants.

#### LOCAL SURVEY OF SPENDING

Question. The National Association of Counties has conducted a survey indicating that most local workforce investment areas have "legally obligated" more than 85 percent of their available dislocated worker funds, and a majority have "legally obli-gated" nearly 100 percent of their funds. "Legally obligated" funds are those funds that are no longer available for use either because they have been expended or because they have been designated for a specific activity through a legally binding con-tract with a service provider or individual training account. This data seems to contradict the Labor Department's estimates of large, unspent balances of job training hinds throughout the nation.

What is your reaction to this data?

Answer. We would not dispute these findings. The Department has never questioned state and local claims that these funds are legally obligated, only claims that they are, therefore unavailable for services. We have questioned the nature of these obligations and the unprecedented levels of unspent funds in some states and communities, whether obligated for future spending or unobligated. We contend that if large amounts are obligated but not spent, according to state reports, for services over the next two years, then large amounts remain available to provide services to people who need them and small reductions in 2003 allotment levels can be absorbed with no adverse impact. Likewise, we would challenge state and local program managers to reexamine these obligations to determine their continued necessity or whether they could be financed by a future year's allotment rather than through a commitment of current year's money.

#### ONE-YEAR TARGETED TRAINING GRANTS

Question. In addition to longer term institutional competency grants, there's another group of new one-year grants that you awarded last year, after first canceling their five-year program days before the programs were to begin. One of these grantees is Kirkwood Community College from Iowa. When these grants were awarded, DOL told these grantees that, "If first year performance is satisfactory and funds are available, grants may be renewed for an additional 12 month period." My understanding is that in the past, these programs have always been funded for a second year. Well, funds are available; we appropriated them in the fiscal year 2002 budget. We have seen no indication that performance of most of the grantees is anything but satisfactory. Yet in your April 26 letter, you indicated to us that you may make these grantees start all over and recompete once again for their funding.

Is this a suitable way for the Department of Labor to treat its grantees that are performing satisfactorily?

Answer. I believe there is some misunderstanding about OSHA's plans for the Susan Harwood Training Grant Program in fiscal year 2002. OSHA published a new Harwood grant solicitation on May 22, announcing two different grant categories for fiscal year 2002: Targeted Topic grants for training programs addressing ergonomic hazards and homeland security issues; and Institutional Competency Building grants.

In addition, OSHA has reserved some of its fiscal year 2002 grant funds to offer second-year grant renewals to the 28 current targeted training topic grantees, such as Kirkwood Community College, that were funded in fiscal year 2001. Renewal grant applications will be mailed to eligible grantees as soon as the Harwood fiscal matters are resolved. Second year renewal funding will be available to targeted training grantees that apply for a second year and are performing satisfactorily. *Question.* What if Congress treated you like that? Promised you money for mul-

*Question.* What if Congress treated you like that? Promised you money for multiple years, then, without warning, took it away despite good performance and adequate funding?

<sup>1</sup> Answer. OSHA's May 22 Federal Register notice did announce that OSHA reserved some of its fiscal year 2002 grant funds to offer second-year grant renewals to the current targeted training grant topic grantees. OSHA's efforts with regard to the funding and renewal of these grants were intended to improve the process for the disbursement of funds, and to assure more effective performance under the grants.

#### OSHA REORGANIZATION AND STANDARDS BUDGET

*Question.* On April 23, OSHA announced a proposed restructuring of National Office operations and functions. One proposal is to merge the Directorate of Safety Standards and the Directorate of Health Standards and Guidance. This new Directorate will not only be responsible for developing safety and health standards, but will also have responsibility for developing and managing non-regulatory approaches.

Currently, the Directorate of Technical Support is responsible for developing guidelines, technical information bulletins and non-mandatory documents. Are you proposing to reprogram the money and personnel allocated for this work in the Technical Support Directorate to the new combined standards and guidance directorate and, if so, how much money and how many people will be reprogrammed from technical support to the standards directorate in your fiscal year 2002 budget and in your fiscal year 2003 request? If you are not proposing to reprogram money, how can you justify spending money that was requested and appropriated for setting mandatory safety and health standards for another purpose?

ting mandatory safety and health standards for another purpose? Answer. The proposed reorganization and merger of the Directorate of Safety Standards and Directorate of Health Standards into one Directorate of Standards and Guidance will not require a reprogramming. The Safety and Health Standards and Technical Support budgets would continue to fund the same activities. Currently, the existing directorates are funded under the Safety and Health Standards budget activity. When the reorganization is approved, the merged Directorate of Standards and Guidance will also be funded under the Safety and Health Standards budget activity that would continue to finance the promulgation of standards and development of other non-regulatory products, such as voluntary guidelines. Funding for the Technical Support budget activity will continue to support activities such as technical information bulletins, electronic compliance assistance tools, and the agency's Technical Information Retrieval System. It should be noted that the Safety and Health Standards Directorates have been involved in the development of guidance documents in the past, so this is not a new function for these directorates.

ance documents in the past, so this is not a new function for these directorates. *Question.* The President's fiscal year 2003 budget proposal cuts the budget for OSHA standard setting by \$1.3 million and 10 FTEs. It requests \$14.2 million for standard setting in fiscal year 2003. This represents about 3 percent of the \$437 million requested for OSHA in fiscal year 2003. This compares to \$60 million for compliance assistance and \$20.2 million for technical support activities. Setting health and safety standards is one of OSHA's major responsibilities. How can the Administration justify cutting the OSHA standard's budget when the current resources for standards are so small?

sources for standards are so small? Answer. Safety and health standards are one of the tools the agency uses to improve the working conditions of the Nation's workers. The fiscal year 2003 budget proposed for Safety and Health Standards is sufficient to support the proposed regulatory agenda and develop other non-regulatory approaches to rulemaking. The budgets for the Technical Support and Compliance Assistance Federal budget activities support a variety of critical activities in the agency, including training at the OSHA Training Institute; the development and delivery of outreach and assistance to employers and workers; voluntary and partnership programs such as the Voluntary Protection Programs; sample analysis at the Salt Lake City Technical Center; the development of electronic compliance assistance tools; and equipment repair and calibration. All these activities work in concert with standards setting to improve occupational safety and health and achieve the goals of the Department and OSHA.

*Question.* What final standards will the Department issue in fiscal year 2002 and in fiscal year 2003? And which standards will be delayed as a result of the proposed cuts in the fiscal year 2003 budget?

Answer. The Regulatory Agenda was published in the Federal Register on May 13, 2002 (67 FR 33342–55). A copy of the relevant portions is attached. Unlike past practice, we have reviewed the agenda commitments carefully, and only included those that we can meet during the 12 month period following its publication. For many years, OSHA included many items in its regulatory agenda that were not being actively worked on, and which had little chance of being completed during the time period the agenda addressed. We believe it is more important to be realistic about what can be accomplished, and to notify the public of those areas OSHA actually intends to address in the coming year. The agenda does not address all of fiscal year 2003, but only the next 12 months,

The agenda does not address all of fiscal year 2003, but only the next 12 months, and decisions have not been made regarding all of the work commitments that may be completed during that fiscal year. Adjustments will be made as necessary in six months when the agenda is published next. Our proposed fiscal year 2003 budget fully supports our regulatory agenda.

*Question.* Two OSHA standards that have been proposed and have gone through the public comment and hearing process are the standard on tuberculosis and the standard that requires employers to pay for personal protective equipment required by OSHA standards. When will OSHA issue final standards on TB and payments for personal protective equipment?

for personal protective equipment? Answer. The record on the TB standard was re-opened on March 25, 2002, to allow the public to comment on a new study as well as risk assessment issues. The comment period closed on May 24, 2002. The May 13 Regulatory Agenda indicates that OSHA will determine the next step in this rulemaking by the end of October 2002.

Similarly, the agency continues to review the issue of employer payment for PPE, and will make a determination on that issue by the end of October 2002 as well. This too is reflected in the current Regulatory Agenda.

Question. The Department of Labor's December 2001 Regulatory Agenda removed dozens of OSHA and MSHA regulatory actions from the agenda including standards on perchlorethylene, updating permissible exposure limits for toxic chemicals, metalworking fluids, and covering reactive chemicals under the process safety management standard. There was a recent report that the next Regulatory Agenda, due out in June, will cut back further on planned OSHA standards. Can you tell me which standards that are currently on your regulatory agenda will be eliminated in the new regulatory agenda?

Answer. The regulatory agenda is intended to reflect those items that will be completed during the next twelve months. The most recent regulatory agenda was published on May 13, 2002. Only regulatory actions published previously in the Federal Agenda in the proposal or post-proposal stages were withdrawn from the agenda announced on May 13, 2002. Other items removed from the agenda had not reached the proposal stage and could be resurrected if resources and priorities permit. These include indoor air quality (withdrawn December 2001), and four out-of-date proposals in the shipyard industry (withdrawn March 2002).

#### ERGO ADVISORY COMMITTEE

Question. As part of your comprehensive ergonomics program you have proposed to establish yet another advisory committee on ergonomics that you have said will look at questions of research needs.

Are you aware that in recent years the Congress appropriated more than \$1.4 mil-lion for two NAS studies on the question of the science and research needs on ergonomics and that NIOSH also conducted a major review and study on the same issue?

Answer. The Department is aware of the NAS and NIOSH studies and agrees with their primary findings-that injuries related to ergonomic hazards are real. It is important to note, however, that the NAS studies did not make any policy rec-ommendations and concluded that there are still gaps in the research. To quote from the NAS study: "In the course of its review, the panel identified several impor-tant gaps in the science base." These gaps included a need to develop "better tools for exposure and outcome assessment as well as further quantification of the rela-tionship between exposures and outcome . . . " as well as further research into "tis-sue mechanobiology, biomechanics, psychosocial factors and stress, epidemiology, and workplace interventions." The presence of these gaps is one reason we devel-oped a multi-faceted plan that will help drive research and development to fill these gaps, working with NIOSH. This will be OSHA's first effort at using an advisory committee solely to evaluate and make recommendations about specific research, guidance, and outreach relating to ergonomics in the workplace.

Question. Isn't it true OSHA itself already has a number of advisory committees? Answer. OSHA has four general advisory committees: the National Advisory Com-mittee on Occupational Safety and Health (NACOSH), the Advisory Committee on Construction Safety and Health (ACCOSH), the Maritime Advisory Committee on Safety and Health (MACOSH), and the Federal Advisory Committee (FACOSH). This list does not include advisory committees that are established to conduct nego-tiated rulemaking on a specific standard. OSHA currently has one advisory committee working on a negotiated rulemaking for fire protection in shipyards, and the Agency will be publishing shortly a notice of its intent to establish a negotiated rulemaking advisory committee for cranes and derricks in construction.

*Question*. You have NACOSH, the National Advisory Committee on Occupational Safety and Health, as well as a Construction Advisory Committee, both statutorily required committees. Both of these committees have done extensive work on

ergonomics. Are you going to use them to advise you on the ergonomics issue? Answer. We have, and will, continue to seek advice from all stakeholders on the ergonomics issue, including all our current advisory committees.

Question. You also have a Maritime Advisory Committee and a Federal Agency Advisory Committee, both of which have also done work on ergonomics. Why aren't all of these currently existing OSHA advisory committees adequate to provide you with advice on ergonomics? Answer. While the present OSHA advisory committees can and do provide general

policy advice to the agency, they were not constituted to assist in the specific areas that we identified in our announcement of intention to establish this new committee. As explained in our Federal Register notice (May 2, 2002, 67 Fed. Reg. 22121), OSHA's Ergonomics Committee will advise OSHA about issues related to ergonomics-including ergonomic guidelines, research, and outreach and assistance. In particular, OSHA intends to seek advice from the Committee on the Department's comprehensive approach to ergonomics, including:

 Information related to various industry or task-specific guidelines;
 Identification of gaps in the existing research base related to applying ergonomic principles to the workplace;

(3) Current and projected research needs and efforts;

(4) Methods of providing outreach and assistance that will communicate the value of ergonomics to employers and employees; and

(5) Ways to increase communication among stakeholders on the issue of ergonomics.

Identifying research gaps, consequently, is only one of the areas to be addressed. Members of the new committee also will have more specific expertise and experience in the areas of ergonomics than do members of existing OSHA advisory committees. The new committee, therefore, will be able to advise OSHA in more depth about guidelines, research, outreach, and assistance. *Question.* Meanwhile, at NIOSH, there is the National Occupational Research

*Question.* Meanwhile, at NIOSH, there is the National Occupational Research Agenda (NORA) which has a musculoskeletal disorders team that has broad representation from the ergonomics community and whose mission it is to develop a comprehensive research agenda, facilitate development of partnerships directed at implementing successful control strategies and to provide a framework for increasing funding for research.

In addition to the NORA ergonomics team, NIOSH also has a Board of Scientific Counselors, established under the Federal Advisory Committee Act, which provides oversight and advice on all NIOSH research initiatives, including ergonomics.

Can you explain to me what your new committee is going to do that all of these other committees have not already been doing for a number of years?

Answer. While NIOSH's Board of Scientific Counselors does provide advice to the Secretary of Health and Human Services on research initiatives, it does not focus solely on ergonomic matters. Rather, its focus is on a much wider range of occupational safety and health issues and it is supported by a membership drawn from varied scientific disciplines. As explained in our Federal Register notice, the OSHA Ergonomics Committee's members will have skills specialized to address ergonomic issues and will be able to advise the Secretary of Labor on specific ergonomic research needs. In addition, as explained above and in our Federal Register notice, the OSHA Committee will advise the agency on several other issues, including the need for, and effectiveness of, various industry- or task-specific guidelines, methods of providing outreach and assistance to employers, and ways to improve communication between stakeholders on the issue of ergonomics. The Committee's advice will help OSHA to better fulfill its statutory responsibilities.

While it is true that the NORA musculoskeletal disorders team focuses strictly on ergonomics, their efforts to date have been limited to research needs generally. The team does not address many of the specific areas where OSHA needs information.

Of course, NIOSH is, and will continue to be, the principal organization to conduct research in occupational safety and health. We believe our approach will complement NIOSH's and NORA's roles by looking for practical solutions and applied results. We expect to collaborate closely with both NIOSH's Board of Scientific Counselors and the NORA team and, where OSHA Ergonomics Committee recommendations involve research efforts, OSHA will forward such recommendations to NIOSH.

*Question.* The OSHA Act states that NACOSH "be composed of representatives of management, labor, occupational safety and occupational health professions, and of the public." The other advisory committees have similar criteria. I see no such requirements for this new ergonomics advisory committee in the Federal Register Notice. Can you tell me why not?

Answer. While not explicitly stated in the Federal Register notice, the agency is seeking membership from the broadest possible range of stakeholder interests, including all the categories mentioned in your question. I can assure you that membership on the committee will be balanced. We will make every effort to include individuals with knowledge or expertise on the issues to be addressed, representing a wide range of backgrounds and interests.

*Question*. Can you tell me which groups and interests will be represented on this committee and how this committee will have balanced representation?

Answer. At this time, I am unable to state exactly which of the many and diverse interested parties will actually be invited to serve on the Committee. To date, the Agency has received over 200 individual nominees. The nominees come from a wide range of backgrounds, and represent the medical, scientific, labor, academic, and industrial communities, as well as the professional societies and the general public. Every attempt will be made to ensure that the individuals selected for the Committee collectively represent the viewpoints of all of these diverse interests. As stated in the Federal Register notice announcing the establishment of the Committee, OSHA will select members based on their specific knowledge of ergonomics, their knowledge of the scientific research and gaps in that research, their ability to discuss the value of ergonomics in the workplace, and their ability to advise the Secretary about how to disseminate ergonomics information to all involved stakeholders.

#### EXPENDITURE RATE TRENDS

#### Question. How well are States spending their WIA allotment?

Answer. Although state spending has increased over recent months, only recently has spending reached the level included in the budget. We expect that PY 2001 total spending will be less for the complete year that had been projected when the PY 2003 request was provided to the Committee. We believe the reductions in new budget authority requested for Program Year 2003 remains appropriate and allow for significant increases in participation. We do not expect PY 2002 and PY 2003 spending to increase to a level where the large carryover will be significantly reduced.

*Question.* What is the range of expenditure rates and Treasury draw-downs among States in the current program year?

Answer. For the second quarter, ending March 31, 2002, the "Fund Utilization Rate" for the three WIA state programs combined averaged 44.8 percent nationally and ranged for states from a high of 75.9 percent to a low of 26.1 percent. This rate represents total spending during the current program year as a percent. We estimate that at the end of the year this rate will be 69 percent.

*Question.* Do you see any changes in the expenditure rates between program year 2000 and program year 2001?

Answer. As previously indicated, we have seen increases in this spending rate. For Program Year 2000, the Fund Utilization Rate for the combined programs was 56.7 percent, compared to the projected rate at the end of the year of 69 percent.

Question. How do the expenditure rates observed under WIA compare with those under JTPA?

Answer. Expenditure data for all Job Training Partnership Act programs was not sufficiently complete or reliable to provide meaningful comparisons. The JTPA Dislocated Worker program did have a reallotment requirement based on expenditure. For the last two years where a reallotment was required, states spent all of their funds carried into the year plus 84.8 percent (Program Year 1996) and 84.3 percent (Program Year 1997) of current program year funds.

*Question.* What do you consider to be a "good" expenditure rate for a State and what portion of States have met that benchmark?

Answer. We believe that rate of 80 percent would be satisfactory. A state that carried over 25 percent of its prior year allotment and spent 75 percent of its current year award would attain this 80 percent. A state on target to reach this 80 percent would be at approximately 60 percent at the end of the March quarter. Only six states were at this combined rate as of March 31, 2002.

*Question.* What is the basis of that benchmark and do you consider it to be reasonable given the fundamental way in which WIA has changed employment and training?

Answer. This rate is the same as the threshold required for reallotment under JTPA Dislocated Workers. We believe this is reasonable, even in light of changes in WIA.

*Question.* How does the structure of the WIA program affect expenditure rates such as the way in which the 15 percent set-aside is appropriated, how service contracts are procured, and how participants are registered for programs?

Answer. We do not believe these requirements or other WIA requirements impose such a burden that would require that large amounts remain unspent and be carried forward to a subsequent year. There may be changes from requirements under JTPA, but procedures also must be adapted to ensure the timely and effective spending of resources provided on people who need services.

Question. What is Labor doing to address low expenditure rates?

Answer. ETA has conducted an on-going program of evaluation to determine state and local partner progress in implementing WIA. The seven ETA regional offices routinely conduct on-site visits with our partners to determine success against the implementation objectives reflected in the state strategic plan. The regional offices file a quarterly report on outstanding issues in governance, performance measurement and a number of other key issues, noting both progress and remaining problems. The ETA's emphasis on identifying the major operational issues that impede complete implementation remains an important priority. The agency has also enlisted outside contractors—including Social Policy Research Associates—to assist in the process evaluation of WIA implementation. Both these Federal and contractor findings become valuable, continuing input into technical assistance strategies that are developed for states. Our negotiation of state performance measures has also been mindful of the Administration's emphasis on the Government Performance Results Act and the requirement to set high targets of accomplishment for those customers served by the Adult, Dislocated Worker and Youth funding streams under WIA.

ETA hosts both national and regional conferences, which organize presentation agendas and workshops around "solutions to problems".

ETA also issues Training and Employment Guidance Letters to the workforce system on a routine basis to provide clarification on WIA policy, technical assistance materials, "questions and answers" and other advisories that will assist our partners.

ETA staffs have also conducted an analysis of quarterly financial reports to determine the various dimensions of the under expenditure issue, and the combination of causal factors contributing to the reported low outlays. The problem is more acute in some states than in others. Early implementation was certainly marked by significant under expenditure in a subset of states as they moved from JTPA to WIA.

The examination of financial reports led to the development of a diagnostic line of inquiries that has been used by our line staff and political leadership in conversations with the states. These questions probe state knowledge, experience, and intent. Among them:

- -What information do you have at the state level on local workforce investment area obligations?
- What is the nature of these obligations? Are they obligations attached to specific customers for training, such as Individual Training Accounts, and/or specific services? Are they obligations to service providers to assist customers over the next few immediate months? Or are they obligations made from one administrative entity to another for services and training over a longer extended period?
- —Spending for statewide activities has lagged considerably behind local spending. Why is this? If you have large balances in statewide activities, have you discussed reducing the amount reserved for these services to provide a greater proportion of the funds to areas that lack resources to meet demands for training and services?
- —Are there particular obstacles—statutory or regulatory—that have restricted the timely expenditure of these funds?

The pursuit of this issue has also focused on the arguments made by many local One-Stop operators that funds have been obligated at the local level, but have not been reflected in the state reports (differences in "closing dates" for account structures, etc.).

Both the analysis of reports and our ongoing conversations with the states have translated into "action items" for all levels of WIA governance. We believe the states are working extremely hard to fully implement the law and realize the goals and objectives outlined in their respective strategic plans. The effort to fully enlist all the partners in the day-to-day operation of the One-Stop delivery system has certainly been a difficult and time-consuming process in many communities, a contributing factor to the under spending during this period. The time and energy to deal with the documentation requirements necessary to certify eligible training providers for a period of, "subsequent eligibility" was also perhaps not fully anticipated at the outset of WIA implementation.

We have convened state and local partners in a series of "WIA readiness" sessions across the country, gathering their viewpoints on what has worked (and what has not worked). These workgroups were charged with suggesting strategies to assist the system in addressing implementation issues in four areas—One-Stop service delivery, adult and dislocated worker services, youth services, and attracting and retaining employer involvement on workforce boards. Their commitment and work yielded a series of recommended actions that were shared with the workforce development system in November 2001.

Our collective stewardship of these WIA resources is a mutually recognized one; ETA is fully committed to working with our state and local partners to ensure that employers and jobseekers are provided the assistance they need in all the local workforce investment areas. The agency is moving to issue new policy (or restate existing policy) where clarity in the Federal position is needed.

*Question.* To what does Labor attribute these low expenditure rates? Are they an indicator that States are not effectively managing their WIA allotment in order to maximize services to eligible participants?

maximize services to eligible participants? Answer. We do not generally believe that the low spending in many states is the result of poor program management. The transition from JTPA to WIA brought considerable change to state and local workforce development system that had the effect of slowing spending. As previously indicated, ETA and our state and local partners worked very closely to identify and respond to these issues. Also, many states and locals told us that with the legislated change to the Dislocated Worker program that based the reallotment of funds on obligations rather than expenditures, their focus shifted from spending to contracting for the services. This contributed to lower spending and reduced service levels during the first two years of WIA.

Question. Has Labor provided guidance and technical assistance?

Answer. As previously indicated, ETA dedicates considerable time and resources to providing guidance and technical assistance to our partners. This guidance comes in part through regular and frequent policy guidance and ongoing communications. Technical assistance is provided through national and regional conferences and workshops, on-site expert visits and publications.

Question. Is Labor monitoring States' financial management systems and practices?

Answer. DOL does not routinely monitor state financial systems and practices. In the past, ETA has relied upon the Single Audit Act to audit these systems and has supplemented these audits only when problems or issues have been identified.

the past, ETA has relied upon the Single Audit Act to audit these systems and has supplemented these audits only when problems or issues have been identified. ETA has published a Request for Proposal to procure additional contractor assistance from CPA firms to assist the agency in examining grantee financial systems and providing specialized assistance. This is financed through an increase received in the fiscal year 2003 budget.

#### QUALITY OF WIA EXPENDITURE DATA

*Question*. What do you know about the quality of information that Labor uses to track States' WIA expenditures?

Answer. From conversations with states and their sub-recipients we are increasingly concerned about the quality of the information reported. Both the GAO and the OIG are conducting independent reviews of state spending. We hope to get feedback from them that will assist us in addressing financial system shortcomings.

Question. How are States defining expenditures? Obligations?

Answer. The WIA regulations include definitions for obligations and the Department's grants administration regulations define expenditures. We have no evidence that states or their sub recipients are using different definitions. However, while expenditures reflect the cost of actual services and training delivered and are intended to be recorded concurrently on Federal, state and local books when incurred, obligations represent a legal commitment to provide future services and are recorded at different times, depending on the funding processes of the entity. For example, the Federal obligation occurs when the allotment is provided to the state on the first day of the funding period. A state, in turn, obligates the funds when providing them to the sub recipient. The sub recipient might obligate the funds when contracting with a service provider. And finally, a service provider may not obligate the funds until a participant is enrolled in a specific training program. Because of this, obligations have many meanings, depending on the entity that is reporting, are not comparable between similar entities and can be misleading when discussing the availability of funds.

*Question.* We have reason to believe that the definitions differ widely among States. What is Labor doing to facilitate consistency in collecting and reporting the data?

Answer. We intend to review the findings of our own review efforts and those of GAO and Labor's OIG, to provide additional assistance to states and their sub-recipients.

*Question*. Describe Labor's efforts to validate expenditure data.

Ånswer. DOL does not validate expenditure data. We rely on the Single Audit Act to review state systems and determine whether state records and spending reports accurately reflect activity occurring.

*Question.* Do Labor's expenditure reports accurately reflect States' available funding?

Answer. The reports that we provide to the Committees and share with the states reflect reports submitted to us by the states. Because WIA allows the states to pool spending for a number of different state and local activities, some allocations among funding streams are required. OIG auditors reviewed these allocations as part of the annual audit of our own systems and financial statements this past year. They provided no criticism of our methodology.

*Question*. Does Labor's calculation of expenditures and available funds include States' obligations?

Answer. Labor's reports reflect only expenditures. As previously indicated, we do not display obligations by state because they are of questionable value nationally and may not be comparable among states. Labor does recognize that not all obligations will be liquidated during the year and that monies will be unspent at yearend. The concern that we have expressed is the extent to which funds have remained unspent, whether obligated or not.

Question. If not, how is Labor adjusting for these obligations when deciding whether funding cuts are justified or warranted?

Answer. Labor does not adjust for these obligations. Instead we recognize that funds will be unspent and that when these levels approach the high levels that have been experienced recently, small cuts in new authority should be considered since they can be made with no reduction in services.

Question. We understand that, while local workforce investment areas are required to report expenditures, they are not required to report obligations. Yet obligations are an important indicator of local spending activity. Given this, does Labor have a good understanding of the amount of funds available in local areas?

Answer. As previously stated, we question the usefulness of any local obligation data for the reasons stated above.

#### ISSUES RELATED TO STATE AND LOCAL SPENDING

Question. You proposed budget reductions of States' WIA funds in both fiscal years 2002 and 2003 citing large amounts of unspent funds. What impact do you think these shifts in funding levels have on the ability of States and localities to plan and develop a stable and comprehensive workforce investment system?

Answer. We believe these reductions in budget requests have had a positive effect on the workforce investment system. Both the Department and our partners have had a positive and meaningful dialogue on the causes of lower spending and what can and should be done to address the problems and issues identified, fully utilize available resources and maximize service to those in need. The requests themselves, while drawing much attention, have been small relative to the total resources available for the program. The requested reduction in new budget authority to state pro-grams for fiscal year 2003 for WIA Adult is 5.3 percent, for WIA Youth it is 11.3 percent and for the WIA Dislocated Worker programs it is 10.7 percent.

However, when these new resources are combined with the Large unspent balances in these programs, the President provides more than enough new resources to support a substantial increase in assistance to adults, youth, and dislocated work-The budget for these programs includes \$5 billion in total resources—which is ers. \$1.1 billion, or 30 percent, more than the estimate of what states will spend in 2002. This resource total includes \$3.3 billion in new budget authority and \$1.7 billion in unspent balances for state formula grants that will be carried into Program Year 2003.

Question. States have three program years within which to spend their allotment, including the year in which funds were received. Thus, funds received in program year 2000 must be spent by the end of program year 2002. Is it reasonable to reach conclusions about WIA spending and make decisions about future program funding

conclusions about WIA spending and make decisions about future program factors before the three-year period is up? Answer. Yes, it is reasonable. To date, we still have seen no significant and sustained departure from the trend since WIA implementation of tower than estimated spending on participants. Given the totals that were unspent at the end of the last program year and the amounts projected to be carried into 2003, we do not believe the small proposed reductions in new budget authority will have adverse impact on the program or those seeking the training and services it offers.

Question. Will Labor be recapturing unspent WIA funds in light of the low ex-

penditure rates you are observing? Answer. Under WIA, the Department has no authority to recapture unspent amounts retained by states. Such authority was available under the Job Training Partnership Act Dislocated Workers program and spending rates were significantly birther The Department only her the other interaction of the little of the states of higher. The Department only has the authority to reallot unobligated funds in excess of 20 percent of the year's allotment. Since obligating funds is a relatively simple task, states can easily avoid recapture of funds.

Question. Do you have plans to recapture unspent funds from States that have not met their target spending levels and reallocate them to other States that have already spent their allotment?

Answer. As indicated previously, under WIA, the Department has no authority to reallocate unspent funds available to states

*Question.* How many States are in jeopardy of having their funds recaptured? Answer. No states are in jeopardy of having funds recaptured. WIA does provide the Secretary with the authority to reallot unobligated funds in excess of 20 percent of the year's allotment. Since obligating funds to avoid a reallotment is a relatively simple task, we expect that no states will have WIA funds recaptured at the end of the current program year.

Question. Have any States recaptured unspent funds from their local areas? Answer. The Department has not collected this information from the states.

Question. Madame Secretary, Congress provided an fiscal year 2002 increase of \$8.9 million for community service employment programs for older Americans. Effective with the program year beginning July 1, 2002, twenty five percent of this increase will go to private sector grantees funded directly to the Department and seventy five percent will be granted to states. Can you tell us the current status of plans for this increased funding?

of plans for this increased funding? Answer. On July 1 we will provide these funds for the Senior Community Service Employment Program to support part-time community service positions. The funds will be distributed in accordance with the authorizing legislation. First, a small setaside is provided for the territories. Then, funds will be set-aside for the national Indian and Asian/Pacific groups. The balance of the appropriation will be distributed according to the formula prescribed in the law. It will be divided so that 25 percent of the increased funding will be provided to the national private sector grantees and 75 percent will be provided to the state agencies that operate this program.

*Question.* Additionally, this Committee provided guidance in last year's Report regarding the Department's plans to increase the SCSEP unsubsidized placement goal. The Committee requested certain assurances from the Department regarding available WIA training funds for older workers in light of anticipated increases in this goal. The Committee has not yet received such assurances and so we again request them.

quest them. Answer. Based on the Committee's request, we are preparing a report that will respond to that inquiry. The report will address the level of JTPA and WIA services provided to persons age 55 or over.

Question. Finally, on April 11, 2002 Chairman Harkin, Senator Specter and four Senators who are members of the authorizing committee wrote the Secretary regarding our concern that the bipartisan agreement on the reauthorization of Title V be implemented in a way that complies with the Congressional intent that competition for SCSEP grants be conducted in a fashion that ensures currently successful grantees continue to receive funding. We look forward to receiving your assurances in that regard.

Answer. A response to the April 11, 2002 letter will be mailed shortly. The letter mentioned Senate report language in the context of commenting on the GPRA goal of 37 percent for unsubsidized placement of SCSEP participants.

A later paragraph in the letter states that the group of five Senators, "looking forward to receiving your assurances that competition requirements will maintain continuity and stability at the national level by ensuring that successful grantees continue to receive funding."

In response, we note that Federal acquisition regulations require that grants and contracts are awarded through a competitive process where possible. The Procurement Review Board at the Department of Labor has reviewed the national sponsor portion of the SCSEP and recommended that it be subject to competition. The Department is committed to seeing that older Americans receive the best services. Therefore, we are looking at the option of competing the National grantee share of the SCSEP. While we wholeheartedly support accountability sanctions for poor performance, we believe that the best interests of participants are served by taking steps to improve services in the first instance rather than sanctioning poor performance, which has already negatively impacted participants. If such a competition were to take place, we would do everything in our power to insure that it does not unnecessarily disrupt current participants and provides a fair opportunity for all eligible organizations to be national SCSEP grantees. We would expect that high performing grantees would be in an excellent position to compete for grants, although it would be a competition in name only if the results were guaranteed ahead of time.

#### NURSING SHORTAGE

Question. As you know, our country is facing a nationwide nursing shortage. Not only are people choosing not to enter the nursing profession, but they are leaving the profession in alarming rates as well. In a recent study released by the Division of Nursing at HHS, the Division found that 500,000 licensed registered nurses have chosen to leave nursing. In the fiscal year 2002 Labor-HHS-Education conference report, the Committee di-

In the fiscal year 2002 Labor-HHS-Education conference report, the Committee directed the Departments of Labor and HHS to convene a national panel to examine the education and training requirements for all nursing care occupations—including nurses aides, orderlies, LPNs, registered nurses with all levels of educational preparation, and advanced practice nurses. This panel was tasked with providing specific recommendations on the education, training, continuing education, and professional development for all levels of nursing care providers. This initiative is very important, especially in light of the nursing shortage that is plaguing our country. Our citizens need to be assured that they have the most appropriate provider giving their nursing care at whatever level of acuity their health care needs may be. The panel was to host its first meeting by March of this year. I would like to know the progress of this very critical effort. What are your plans to have a report to the Congress within a year? What are some other efforts that the Department of Labor is undertaking to address the severe shortage of registered nurses and other nursing care providers?

Answer. The Departments of Labor (DOL) and Health and Human Services (HHS) have had initial conversations as to how best to assemble the national panel on nursing. Both departments are enthusiastic about establishing the panel and we are continuing to work on this important effort.

We at DOL have a number of initiatives to address the national shortage of nurses and other workers in related health care professions. For example, staff from DOL, HHS, and the Department of Education have drafted and agreed upon a broad-based strategy that will guide the joint work of the three agencies in addressing the shortage of nurses and related occupations. These strategies will better link existing recruitment, career guidance, training and education, job referral and placement efforts.

Other efforts DOL has undertaken include a public-private partnership with HCA, Inc., the nation's largest manager/owner of hospitals and other health care facilities. The DOL-HCA partnership will offer scholarships and certification to workers dislocated as a result of September 11th who choose to pursue careers as RNs, LPNs, Certified Nursing Assistants (CNAs), and radiological or surgical technicians. DOL and HCA are each contributing \$5 million.

DOL has also partnered with the American Health Care Association and the American Association of Homes and Services for the Aging to provide a web-based clearinghouse that includes a searchable database on caregiver jobs (http:// www.carecareers.net/). DOL is also working on a project using ETA's electronic tool kit and the One-Stop Career Center infrastructure to help health care providers fill worker shortages by recruiting displaced workers from the hospitality industry.

Other DOL activities include: "sectoral" projects to address health care shortages while assisting dislocated workers; Job Corps training in fifteen specialty areas including CNA, Medical Assistant and Physical Therapy Assistant, producing 4,700 new workers annually; the Apprenticeship Health Care Outreach Initiative to encourage hospitals, nursing homes and other health care facilities in establishing apprenticeship programs for such occupations as CNAs, LPNs, radiology technicians, and home health aids; and competitive Welfare-to-Work grants provided for projects preparing public assistance recipients and other low income individuals for entrylevel health care jobs

#### LIFTING OF ERGONOMIC STANDARD'S AFFECT ON HEALTH CARE PROFESSION

Question. Much attention has been given to the lifting of the ergonomics standard last year and the potential effects this decision could have on the nation's workforce. Of particular concern to me is the effect on our health care system. For example, America's nurses have both seen and experienced the devastating effects of repetitive lifting, forceful exertions and inadequate prevention measures. These conditions are contributing to the shortage of health care workers, including nurses, who are willing to work in fast-paced, repetitive, stressful and dangerous environments. The health care occupations of nurses' aide and registered nurse rank first and

The health care occupations of nurses' aide and registered nurse rank first and sixth, respectively, among U.S. occupations at risk for strains and sprains, outranking construction laborers and stock handlers. And, although effective control measures exist to reduce these risks, few health care employers have voluntarily implemented them.

The absence of enforceable ergonomics regulations is also putting an even greater strain on the nation's health care industry, which is already facing a nursing shortage that is fast reaching crisis proportions. And many nurses view the potential for disabling injuries as a major contributing factor in their decision to leave the profession. In an American Nurses Association survey conducted last year, 60 percent of nurses surveyed cited a disabling back injury as ranking among their top three health and safety concerns. Additionally, nurse respondents stated that more than half the facilities in which they worked did not have lifting and transfer devices readily available for moving patients. Without a federal mandate, how can our health care workforce be protected from these injuries? Answer. OSHA has a number of options with regard to actions it can take to address injuries related to ergonomic conditions in the workplace. Secretary Chao's comprehensive strategy for ergonomics, includes four elements:

-Industry-specific and task-specific guidelines

-A strong and effective enforcement strategy

-Extensive outreach and assistance

-Research

The nursing home industry has been selected as the first one in which to develop industry-specific guidelines. This will help protect the health care workforce in an area that currently has many work-related injuries related to ergonomic hazards. Given that concerns such as patient lifting are similar in other parts of the health care industry, it may be anticipated that these guidelines will have a positive impact in sectors other than nursing homes. Combined with the other three elements of the strategy, effective protection can be achieved.

#### CARRYOVER IN A FEW STATES

*Question.* I understand that the majority of the carryover in Workforce Investment Act funds is found in a handful of States, while the majority of States and local areas are spending their WIA funding allocations at or above rates in past years. Does this correspond with your understanding of the situation?

Answer. While spending is considerably lower in a few states, many of the states have substantial carryover. In fact, with three quarters of the program year over through March 31, only 5 states have spent more than 60 percent of the total funds available for the program year for all three WIA state formula programs.

*Question.* How would the President's proposed cuts affect those States and local communities that are fully spending their funding allocations who would not have excess carry-over funds to cushion funding reductions?

Answer. A reduction in the amount appropriated for any program will result in reduced allotments for all states and locals. However small these reductions at the local level, to the extent that Governors elect, they could provide additional resources to local areas from statewide WIA balances available to them. Likewise, where major dislocations occur, applications for National Emergency Grants can be submitted for the department's expeditious consideration.

*Question.* What have these states and localities told you about the effect that these cuts would have on their ability to deliver services?

Answer. Some states and localities have expressed concerns about the proposed reductions. Again, however, the reductions in new budget authority are small relative to the large amounts unspent, and planned services will not be adversely affected.

In the 2003 Budget, the President provides more than enough new WIA grant resources to support a substantial increase in assistance to adults, youth, and dislocated workers. The budget for these programs includes \$5 billion in total resources—which is \$1.1 billion, or 30 percent, more than the estimate of what states will spend in 2002. This resource total includes \$3.3 billion in new budget authority and \$1.7 billion in unspent balances for state formula grants that will be carried into Program Year 2003.

*Question.* Could you submit for the record, an analysis of the funding allotments on both a state by state and local workforce investment area by local workforce investment area basis (using the current year's formula), which takes into account the reductions proposed in the Administration's budget?

Answer. Attached are tables that display state allotments at the Program Year 2002 appropriated level and at the Program Year 2003 request level. States do not provide the Department with local area allocation information so a local analysis is not possible. However, the overall reduction should approximate the overall percentage reduction requested.

#### EMPLOYMENT AND TRAINING ADMINISTRATION, ADVISORY SYSTEM, U.S. DEPARTMENT OF LABOR

#### TRAINING AND EMPLOYMENT GUIDANCE LETTER NO. 13-01

To: All State Workforce Liaisons; all State Workforce Agencies; all State Worker Adjustment Liaisons; all One-Stop Center System Leads

From: Emily Stover DeRocco, Assistant Secretary

Subject: Workforce Investment Act (WIA) Allotments for Program Year (PY) 2002; Wagner-Peyser Act Preliminary Planning Estimates for PY 2002; Reemploy-ment Services Allotments for PY 2002; and Workforce Information Grants to States for PY 2002.

#### 1. Purpose

To provide states and outlying areas with WIA title I Adults and Dislocated Workers and Youth Activities allotments for PY 2002; preliminary planning estimates for PY 2002 public employment service (ES) activities, as required by Section 6(b)(5) of the Wagner-Peyser Act, as amended; Reemployment Services allotments for PY 2002; and the Workforce Information Grants to States for PY 2002.

#### 2. References

Wagner-Peyser Act, as amended (29 U.S.C. 49 et seq.; Workforce Investment Act of 1998 (WIA), (29 U.S.C. 2801 et seq.) Public Law 106–113; Planning Guidance and Instructions for Submission of the Strategic Five-Year State Plan for Title I of the Workforce Investment Act of 1998 and the Wagner-Peyser Act (64 F.R. 9402 (February 25, 1999); State Unified Planning Guidance (65 F.R 2464 (January 14, 2000); Training and Employment Guidance Letter (TEGL) No. 11–98; TEGL 3–99, dated January 31, 2000; TELL 12–00, dated March 6, 2001; and TEGL 22–00, dated May 23, 2001 23, 2001.

#### 3. Background

The WIA allotments, the Wagner-Peyser Act preliminary planning estimates, the Reemployment Services allotments, and the Information Grants to States allocations are part of the fiscal year 2002 funds appropriated in the Departments of Labor,

Health and Human Services, and Education, and Related Agencies Appropriations Act, 2002, Public Law 107–116, January 10, 2002. This appropriation includes: *Youth Activities*—\$1,353,065,000—a decrease of \$24.9 million, or 1.8 percent below PY 2001 (including the \$25 million supplemental), composed of (1) Formula funds—\$1,127,965,000; and (2) Youth Opportunity Grants—\$225,100,000; *Advid Activities* \$000,000 the gene level of PV 2000;

Adult Activities—\$950,000,000—the same level as PY 2001; Dislocated Workers Activities—\$1,549,000,000—a decrease of \$41,040,000, or 2.6 percent below the PY 2001 level;

Wagner-Peyser Act (preliminary planning estimates)-\$761,735,000-the same as the PY 2001 level;

Reemployment Services—\$35,000,000—the same level as PY 2001; and Workforce Information Grants to States—\$38,000,000—the same level as PY 2001. The WIA allotments for states are based on formulas defined in the Act. The allotments for outlying areas are based on a discretionary formula as authorized under WIA title I. These allotments and preliminary planning estimates were published in the Federal Register on March 8, 2002. Comments are being invited from the public on the formula used to distribute outlying areas funds only.

#### 4. Outlyine Areas Funds for Youth Activities, Adult Activities, and Dislocated Worker Activities

A. Total funds for outlying areas.—The total funds available for the outlying areas for each program were reserved at the maximum 0.25 percent of the full amount appropriated for each program in accordance with WIA provisions. For Youth Activities, this calculation was done on the total appropriation including \$225.1 million for Youth Opportunity Grants. The calculation resulted in \$3,382,663, a decrease of \$124,750, or 3.6 percent, from the PY 2001 level. The total available for the outlying areas for the Adult Activities program is \$2,375,000, the same level as PY 2001. Outlying areas' total funds for Dislocated Worker Activities are \$3,872,500, a de-crease of \$102,600 for the areas from PY 2001.

WIA section 127(b)(1)(B)(i)(IV) provides that the Freely Associated States (Marshall Islands, Micronesia, and Palau) are not eligible for funding for any program year beginning after September 30, 2001. However, section 3 of Public Law 106–504, (November 13, 2000), supercedes this section of WIA, and provides that the Freely Associates States remain eligible for funding until negotiations on the Compact of Free Association is complete and consideration of legislation pursuant to the compact is completed. Accordingly, the Freely Associated States are provided funds for PY 2002.

B. Competitive Grants.—The WIA provisions for competitive grants from all three programs for the outlying areas expired after PY 2001, this no competitive grant funds are available in PY 2002.

C. Formula Grants.-For the Youth Activities and Adult Activities programs, the funds were distributed among all outlying areas by the same formula as used for these programs for PY 2001, i.e., based on relative share of number of unemployed with a 90 percent hold-harmless of the prior year share, a \$75,000 minimum, and a 130 percent stop-gain of the prior year share. Data used for the relative share calculation in the formula were the same as used for PY 2001 for all outlying areas, essentially 1995 Census data from special surveys. Updated 2000 special Census data are expected to be available for next year's allotment calculations. The Dis-located Worker Activities funds for grants to all outlying areas were distributed by the methodology previously used, i.e., based on the same pro rata share as the areas received for the PY 2002 WIA Adult Activities program. For amounts determined for outlying areas, see Attachment I for Youth Activities, Attachment II-A for Adult Activities, and Attachment III-A for Dislocated Workers Activities

#### 5. State Youth Activities Funds: Title I—Chapter 4—Youth Activities

A. State and Native Americans Allotments .-- PY 2002 Youth Activities funds appropriated under WIA total \$1,353,065,000 (including \$225.1 million for Youth Op-Youth Activities program allotments by state for PY 2002 and provides a compari-son of these allotments to PY 2001 Youth Activities allotments for all states, out-lying areas, Puerto Rico and the District of Columbia.

The total amount available for Native Americans is 1.5 percent of the total amount for Youth Activities excluding Youth Opportunity Grants, in accordance with WIA Section 127. This total is \$16,919,475, the same level as the PY 2001 Youth Activities and the PY 2001 Youth Activities level (including the supplemental appropriation) for Native Americans

After determining the amount for the outlying areas (discussed in item 4 above) and Native Americans, the amount available for allotments to the states for PY 2002 is \$1,107,662,862, a nominal increase of \$124,750 from the PY 2001 level (including the supplemental appropriation). This total amount was above the required \$1 billion threshold specified in Section 127(b)(I)(C)(iv)(IV); therefore, as in PY 2001, the WIA additional minimum provisions were applied: 1. Minimum 1998 dollar (not percentage) (JTPA II-B and II-C combined) allot-

ment, and 2. Two-tier small state minimum allotment (.3 percent of first \$1 billion and .4 percent of amount over \$1 billion), rather than .25 percent. These provisions were in addition to the traditional provision of a 90 percent hold-harmless from the prior year allotment percentage. Also, as required by WIA, the provision applying a 130 percent stop-gain of the prior year allotment percentage was used. The three for-mula factors required in WIA use the following data for the PY 2002 allotments:

(a) the number of unemployed for areas of substantial unemployment (ASU's) are averages for the 12-month period, July 2000 through preliminary June 2001;

(b) the number of excess unemployed individuals or the ASU excess (depending on which is higher) are averages for the same 12-month period used for ASU unemployed data; and

(c) the number of economically disadvantaged youth (age 16 to 21, excluding college students and military) are from the 1990 Census. (2000 Census data are not expected to be available for use until PY 2004 allotment calculations.)

B. Notices of Obligation (NOOs) and State Plans.—Pursuant to WIA section 189(g)(1)(B), youth allotments will be issued on April 1, 2002. In preparation for this action, states will be receiving grant documents shortly. Those states who plan to receive their Youth Allotments by April 1 should complete and return their new WIA Annual Funding Agreements by mid-March. This will allow for the timely execution of the new WIA Annual Funding Agreements and Youth allotments by April 1.2002

C. Within-State Allocations .- Youth Activities funds are to be distributed among local workforce investment areas (subject to reservation of up to 15 percent for statewide workforce investment activities) in accordance with the provisions of WIA section 128 and according to the approved state plan.

D. Transfers of Funds.—There is no authority for local workforce investment areas to transfer funds to or from the Youth Activities program.

E. *Reallotment of Funds.*—Reallotment of Youth Activities formula funds, as provided for by WIA section 127(c), will be based on completed program year financial reports submitted by the states. Reallotment of funds among states under WIA will occur during PY 2002 based on obligations made during PY 2001 (20 CFR § 667.150 of the WIA interim final regulations). There were no recapture/reallotment of WIA funds in PY 2001.

#### 6. State Adult Employment and Training Activities Funds: Title I—Chapter 5— Adult and Dislocated Worker Employment and Training Activities

A. State Allotments.—The total Adult Employment and Training Activities appropriation is \$950,000,000, the same level as PY 2001. Attachment II-A shows the PY 2002 Adult Employment and Training Activities allotments and comparison to PY 2001 allotments by state.

After detaining the amount for the outlying areas (discussed in item 4 above), the amount available for allotments to the states is \$947,625,000, the same as PY 2001. Unlike the Youth Activities program, the WIA minimum provisions were not applied for the PY 2002 Adult Activities allotments because the total amount available for the states was below the \$960 million threshold required for Adults in section 132(b)(1)(B) (iv)(IV). Instead, as required by WIA, the JTPA section 202(a)(3) (as amended by section 701 of the Job Training Reform Amendments of 1992) minimums of 90 percent hold-harmless of the prior year allotment percentage and 0.25 percent state minimum floor were used. Also, like the Youth Activities program, a provision applying a 130 percent stop-gain of the prior year allotment percentage was used. The three formula factors use the same data as were used for the Youth Activities formula, except that data for the number of economically disadvantaged adults (age 22 to 72, excluding college students and military) from the 1990 Census were used. (2000 Census data are not expected to be available for use until PY 2004 allotment calculations.)

allotment calculations.) B. NOO's.—For PY 2002, Congress appropriated funds for this program in two portions: \$238 million available for obligation on July 1, 2002, and \$712 million available for obligation on October 1, 2002 (fiscal year 2003). Allotments to states will be prorated based on these amounts and two NOO's will be issued: one for July 1, 2002, under the PY 2002 WIA grant agreement, and the other for October 1, 2002, (also under the PY 2002 WIA grant agreement) (see Attachment II-B). C. Within-State Allocations.—Adult Activities, funds are to be distributed among local washforms investment areas (subject to reconvision of up to 15 percent for

C. Within-State Allocations.—Adult Activities, funds are to be distributed among local workforce investment areas (subject to reservation of up to 15 percent for statewide workforce investment activities) in accordance with the provisions in WIA section 133 and according to the approved state plan.

section 133 and according to the approved state plan. D. Transfers of Funds.—WIA Section 133(b)(4) provides the authority for workforce investment areas, with approval of the Governor, to transfer up to 20 percent of the Adult Activities funds to Dislocated Workers Activities, and up to 20 percent of Dislocated Workers Activities funds to Adult Activities.

E. *Reallotment of funds.*—Reallotment of Adult Activities formula funds, as provided for by WIA section 132(c), will be based on completed program year financial reports submitted by the states. Reallotment of funds among states under WIA will occur during PY 2002 based on obligations made during PY 2001 (20 CFR § 667.150 of the WIA interim final regulations). There were no recapture/reallotment of WIA funds in PY 2001.

#### 7. State Dislocated Worker Employment and Training Funds: Title I—Chapter S— Adult and Dislocated Worker Employment and Training Activities

A. State Allotments.—The total Dislocated Worker appropriation is \$1,549,000,000, a decrease of \$41,040,000, or 2.6 percent from the PY 2001 pre-rescission level. The total appropriation includes 80 percent allotted by formula to the states, while 20 percent is retained for National Emergency Grants, technical assistance and training, demonstration projects, and the outlying areas Dislocated Worker allotments (outlying areas are discussed in item 4 above). Attachment III-A shows the PY 2002 Dislocated Worker Activities fund allotments by state.

The amount available for allotment to the states is 80 percent of the Dislocated Workers appropriation, or \$1,239,232,000, a decrease of 2.6 percent from the PY 2001 pre-rescission level. Since the Dislocated Worker Activities formula has no floor amount or hold-harmless provisions, funding changes for states directly reflect the impact of changes in number of unemployed. The three formula factors required in WIA use the following data for the PY 2002 allotments:

(1) the number of unemployed are averages for the 12-month period, October 2000 through September 2001;

(2) the number of excess unemployed are averages for the 12-month period, October 2000 through September 2001; and (3) the number of long-term unemployed are averages for calendar year 2000.

B. NOO's.—For PY 2002, Congress appropriated fields for this program in two portions, \$489,000,000 available for obligation on July 1, 2002, and \$1,060,000,000 available for obligation on October 1, 2002 (fiscal year 2003). Allotments to states will be prorated based on these amounts and two NOO's will be issued: one for July 1, 2002, under the PY 2002 WIA grant agreement, and the other for October 1, 2002, (also under the PY 2002 WIA grant agreement) (see Attachment III-B). C. Within-State Allocations.—Dislocated Worker Activities funds are to be distrib-

C. Within-State Allocations.—Dislocated Worker Activities funds are to be distributed among local workforce investment areas (subject to reservations for Rapid Response and statewide workforce investment activities) in accordance with the provisions in WIA section 133 and according to the approved state plan.

D. Transfers of Funds.—WIA Section 133(b)(4) provides the authority for workforce investment areas, with approval of the Governor, to transfer up to 20 percent of the Dislocated Workers Activities funds to Adult Activities, and up to 20 percent of Adult Activities funds to Dislocated Workers Activities.

E. Reallotment of Funds.—Reallotment of Dislocated Worker Activities formula funds, as provided for by WIA section 132(c), will be based on completed program year financial reports submitted by the states. Reallotment of funds among states under WIA will occur during PY 2002 based on obligations made during PY 2001 (section 667.150 of the WIA interim final regulations). There were no recapture/reallotment of WIA funds in PY 2001.

#### 8. Wagner-Peyser Act Grants to States Preliminary Planning Estimates

The public employment service program involves a Federal-State partnership between the U.S. Department of Labor and the State Workforce Agencies. Under the Wagner-Peyser Act, funds are allotted to each state to administer a labor exchange program responding to the needs of the state's employers and workers through a system of local employment service offices that are part of the One-Stop service delivery system established by the state. Attachment IV shows the Wagner-Peyser Act preliminary planning estimates for PY 2002. These preliminary planning estimates have been produced using the formula set forth at section 6 of the Wagner-Peyser Act (29 U.S.C. 49e). They are based on monthly averages for each state's share of the civilian labor force (CLF) and unemployment for the 12 months ending September 2001. Final planning estimates will be published in the Federal Register, based on calendar year 2001 data, as required by the Wagner-Peyser Act.

State planning estimates reflect \$16,000,000, or 2.1 percent of the total amount appropriated, which is being withheld from distribution to states to finance postage costs associated with the conduct of Wagner-Peyser Act labor exchange services for PY 2002.

The Secretary of Labor is required to set aside up to three percent of the total available funds to assure that each state will have sufficient resources to maintain statewide employment service (ES) activities, as required under Section 6(b)(4) of the Wagner-Peyser Act. In accordance with this provision, the 3 percent set-aside funds, \$22,372,050, are included in the total planning estimate. The set-aside fiends are distributed in two steps to states which have lost in relative share of resources from the previous year. In Step 1, states which have a CLF below one million and are also below the median CLF density are maintained at 100 percent of their relative share of prior year resources. All remaining set-aside funds are distributed on a pro-rata basis in Step 2 to all other states losing in relative share from the prior year but not meeting the size and density criteria for Step 1.

Under Wagner-Peyser Act section 7(b), ten percent of the total sums allotted to each state shall be reserved for use by the Governor to provide performance incentives for public ES offices, services for groups with special needs, and for the extra costs of exemplary models for delivering job services.

#### 9. Reemployment Services

The purpose of these funds is to ensure that all Unemployment Insurance (UI) claimants receive the necessary services to become re-employed. The total fluids available for PY 2002 are \$35 million, the same as in PY 2001. The allocation figures for the distribution of the \$35 million in Reemployment Services fiinds for each state for PY 2002 are listed in Attachment V. The remaining fluids were allocated using the following method: each state received \$215,000; the remaining funds were distributed using each state's share of first payments for fiscal year 2001 to UI claimants. There will be a slight increase in funds to the states this year as there was no deduction in PY 2002 for an evaluation of services provided through these fluids. Guidance on the use of these fiends will be provided in a separate TEGL.

#### 10. Workforce Information Grants to States

Total PY 2002 finding for Workforce Information Grants to States is \$38,000,000, the same as for PY 2001. Funds are allocated by formula to the fifty states, the District of Columbia, Guam, Puerto Rico and the Virgin Islands. Part of the allotment formula is based on the relative share of the CLF for each entity. Slight year-toyear changes in the size of the CLF in each area resulted in insignificant increases and decreases to PY 2002 allotments, as compared to PY 2001 allotments. Guidance on the use of these funds will be provided in a separate TEGL.

#### 11. Reporting

For the WIA programs, states will be required to submit one WIA quarterly report for each of the fund sources received (including a separate report for each of the funding periods for Adults and Dislocated Workers—July 1 fluids and October 1 fiands). This report will be divided into six separate sub-reports detailing statewide activities; statewide rapid response (Dislocated Workers Activities); local area administration; local area Youth program activities; local area Adult program activities; and local area Dislocated Workers program activities.

#### 12. Inquiries

Questions regarding these allotments, preliminary planning estimates and planning requirements may be directed to the appropriate Regional Office. Information may also be found at the website—http://usworkforce.org

#### ATTACHMENTS

I. Youth Activities Allotments, PY 2002 vs PY 2001

II-A. Adult Employment and Training Activities Allotments, PY 2002 vs PY 2001 II-B. Adult Employment and Training Activities Allotments, July 1 and October

1 Funding III-A. Dislocated Worker Employment and Training Activities Allotments, PY 2002 vs PY 2001

III–B. Dislocated Worker Employment and Training Activities Allotments, July 1 and October 1 Funding

IV. Wagner-Peyser Act Allotments, PY 2002 Preliminary Planning Estimates vs PY 2001 Final

V. Reemployment Services Allotments, PY 2002 vs PY 2001

VI. Workforce Information Grants to States, PY 2002 vs PY 2001

#### ATTACHMENT I

#### U.S. Department of Labor Employment and Training Administration WIA Youth Activities State Allotments Comparison of PY 2002 vs PY 2001

State	PY 2001 With Supplemental	PY 2002	Difference	% Chang
Fotal	\$1,127,965,000	\$1,127,965,000		0.009
Alabama		20.901.613	1 595 557	8 269
1770na	20 080 561	10 774 004	(1 2/5 477)	<
Arkansas	10 919 676 '	10 068 513	49 997	0 4 60
alifornia	181 546 639	174 357 054	(7 102 695)	2 0 4 8
olorado		7 246 178	0	0.00%
onnecticut			0	0.009
Jelaware	3 430 152	3 430 651	400	0.010
District of Columbia	4.593.113	4 134 267	(458 846)	0.000
londa	41 077 500	10 260 848	(907 4 63)	1 070
Jeorgia			(2.303.391)	-9 999
1awan			(612 541)	_0 009
daho	4 294 868	4 707 720	413 953	0 (10
linois		57 523 690	7 475 009	14 049
ndiana	13,604,901	13.604.901		0.00%
owa		4.026.670	0	0.000
Cansas		6,190,812	1,429,185	30.019
entucky	17 117 753	17 117 752	0	0.000
Jouisiana			4 197 450	18 029
Maine			0	0.009
faryland		13,734,681	(248,764)	1.789
Assachusetts		16,005,091	0	0.009
Aichigan			8,936,976	
Ainnesota			1,344,881	13.539
Aississippi Aissouri		17,273,760	(564,249)	3.169
Aontana	4 272 845			
Vebraska	3 420 152		(244,105)	5./19
vevada	4 577 695			
vew Hampshire	3 430 152			
lew Jersey	29 273 666	20 272 666		
lew Mexico	10 733 667	10 271 220	(263 427)	
lew York	87 084 035	78 384 460	(8 600 575)	
orth Carolina	18.056.932	23 476 656	5 410 774	20 010
Iorth Dakota	3 430 152	3 430 651	400	0.010
Dhio		46.654.314	(3 975 350)	-7 859
Jklahoma		9.427.216	(1 046 289)	
Dregon		13.507.227	(1 499 113)	_0 009
ennsvlvania	38,152,152	39 258 866	1 106 714	2 00%
uerto Rico			(4 242 176)	-7159
chode island			499	0.019
outh Carolina		14,935,516	0	0.00%
outh Dakota		3 430 651	499	0.019
ennessee			1.622.659	8 339
exas		91.315.821	(10 134 775)	_0 00%
Jtah				10.879
ermont				
/irginia		16,534,311	0	0.009
Vashington		30,638,767	6,754,939	
Vest Virginia		10 601 615	(1 176 631)	-0.009
Visconsin		12.972.896	2.994.869	30 019
Vyoming		3 430 651	490	0.019
State Total		1,107,662,862	124,750	0.019
merican Samoa			(9.452)	-6 659
Juam		1,297,603	(92,385)	6.65%
larshall Islands				
licronesia		534,840		
orthern Marianas			52,854	
'alau	82 150	76 600	(5 460)	6 6 5 9.
rgin Islands			(59.175)	6.65%
Jullying Areas Competitive			(222 535)	-100.00%
Outlying Areas Total			(124,750)	3.56%
Nauve Americans	16 919 475	16 010 475	0	0.000

#### ATTACHMENT II-A

#### U.S. Department of Labor Employment and Training Administration WIA Adult Activities State Allotments Comparison of PY 2002 vs PY 2001

State	PY 2001	PY 2002	Difference	% Chang
Total	\$950,000,000	\$950,000,000	\$0	0.00
Alabama	17 044 406	18 567 669	1 522 262	8.04
Alaska	3 728 842	3 627 608	(101 224)	
Arizona	17 300 190	16 247 051	(1 162 120)	( ( ))
Arkansas	9 622 728	0 709 232		0.02
California	156 375 879	150 741 436	(5 624 442)	
Colorado	5 768 432	5 101 590	(576 947)	10.000
Connecticut	6 7 3 7 6 7 5	6 063 008	(672 767)	10.000
Delaware	2 369 063	2 360 063		-10.00
District of Columbia	3 971 309	2 574 179	(207 121)	
Florida	37 761 854	35 900 699	(1 061 166)	
Georgia	20.011 763	18 010 597	(2 001 176)	10.000
Hawaii	5 444 869	4 900 382	(2,001,170)	-10.00
daho	3 712 025	4 104 697		10.00
Illinois	44 094 693	51 107 312	7 012 620	
ndiana	10 825 762	9 743 186	(1 092 576)	10.00
owa	2 888 253	2 100 999	211676	10.70
Kansas	4 279 240	5 563 012	1 292 772	20.000
Kentucky	15 183 245	14 301 853	1,283,/72	
Louisiana	20 294 120			
Maine	3 301 429			19.13
viarviand	12 196 915	12 516 336	210 421	2 6 2 1
Massachusetts	11 235 182	10 111 664	(1 107 519)	
Michigan	24 550 144	21 015 197		-10.00
Minnesota.	7 877 780	0.026.029		
Mississippi	14 744 150	14 494 502		
Missouri	12 359 685	14 220 577		1./0
Montana	3 056 597	2 752 106	(202,401)	
Nebraska	2 360 063		(203,481)	5.14
Nevada	4 007 022		449 700	
New Hampshire	2 360 063	2 360 063		
New Jersey	2,505,005		······································	
New Mexico	0 202 772			10.00
New York	80 628 707	77 545 974	(322,900)	
North Carolina	16 154 202	21 000 504		-10.00
North Dakota	2 360 063			
Dhio	45 060 209			0.00
Oklahoma	0 235 640		(3,351,100)	1.44
Dregon	12 460 527		(923,363)	
ennsylvania	13,400,527		(1,346,053)	10.00
uerto Rico.	52 746 221			
thode Island	2 260 062		(3,382,838)	6.79
South Carolina	2,509,005			0.00
South Dakote	12,098,373		(1,269,837)	10.00
South Dakota	16 206 020			0.00
ever	10,300,939			17.00
exas	80,570,009			10.00
Jtah	2,4/8,4/5			15.87
/ermont	2,369,063			0.00
/irginia	12,4/8,418	11,230,576	(1,247,842)	
Vashington			6,243,318	29.69
Vest Virginia	10,558,659		(1,055,866)	10.00
Visconsin	8,782,497	11,417,246	2,634,749	
Vyoming			0	
State 1 otal			0	0.00
American Samoa		115 594	2 881	2 54
uam		499 361	55 922	12.61
Aarshall Islands			6,120	2.56
Aicronesia				12.61
orthern Marianas	100 536	205 597	06 061	40.14
Palau	75,000		1.917	2 56
rgin Islands			74 909	12.61
Dutiving Areas Competitive	290 780	0	(200 280)	100.00
Out 1	2,375,000	0.000.000		

#### ATTACHMENT II-B

#### U.S. Department of Labor Employment and Training Administration WIA Adult Activities PY 2002 State Allotments

State	Total	7/1/02	10/1/02
Total	\$950,000,000	\$238,000,000	\$712,000,000
Alabama		4,651,689	
A Jaska		908 811	2 718 70
Arizona		4 070 314	12 176 727
Arkansas		2 432 168	7 276 06/
California		37 764 606	· 112 076 74
Lolonado		1 300 630	3 800 050
Connecticut		1.519.169	4 544 730
Jelaware		503 513	1 775 550
Jistrict of Columbia	3 574 178	905 474	2 670 76
lorida		8 969 014	26 831 67/
Georgia		4,512,126	13 408 461
lawan	4 900 382	1 227 675	2 (72 70)
daho	4 104 697	1 009 222	207/201
llinois	51 107 313		
ndiana	0 7/2 196		
	3 100 000		
/			
Kansas			4,169,331
Centucky			10,786,315
Louisiana		6 056 990	18 120 070
Vlame	2 071 204	744 397	2 224 002
Maryland		3 135 672	0 380 66/
Michigan	31 915 187	7 005 504	22 010 502
viinnesota			7 439 454
/119515510D1	14.484.593	3 628 772	10 855 821
Aissouri	14 329 577		10 730 641
Aontana	3 753 106		2 012 05
Jehraska	2 360 062		
levelo	A 455 812	1,116,298	
lew Hamnehire	2 260 062		
low lessour	10 0 44 005		1,775,550
New Jersey			14,123,828
low Verk			6,648,448
Wew TOR			54,386,185
North Carolina		5,261,201	15,739,393
North Dakota			1,775,550
Лю		10,449,212	
JKIanoma			6 229 689
Drepon	12 114 474	2 024 004	0.070.490
ennvivania	36 183 794	0.064.002	77 110 001
uerto Kico	49 163 463	12 216 741	26 046 722
chode Island			1 775 550
outh Carolina	11 478 536		0 565 20"
outh Dakota	2 369 063		
ennessee	10 078 725		1,773,330
evas	77 010 002		
ltab			
/an			2,152,316
ermont			1,775,550
nginia			
Vashington		6 833 007	20 441 603
Vest Virginia			7 122 093
Visconsin			8 556 924
Vyoming		593 513	1 775 550
State Total			710 219 990
merican Samoa	115 504	26.020	96.626
juam	499 361	125 103	274 250
farshall Islands	245 520		184.011
dicronesia	473 102		
Inthern Marianas	205 597		
alan			
arau.			
ing in islands		167,582	

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#### ATTACHMENT III-A

#### U.S. Department of Labor Employment and Training Administration WIA Dislocated Worker Activities State Allotments Comparison of PY 2002 vs PY 2001

State	PY 2001 (Pre-Rescission)	PY 2002	Difference	% Chan
Total	\$1,590,040,000	\$1,549,000,000	(\$41,040,000)	,
Alabama	15 068 548	22 896 031	7 979 292	61.06
Arkansas		7.550.450	446 794	6 20
California	273 301 437	218 507 541	(64 002 00/)	20.00
Colorado	8 255 862	7 279 905	(077.067)	10.00
Delaware	7 (84 6)7	2 554 637	270 020	14.04
District of Columbia	8 433 050	8 827 001	402 102	4 7 9
riorida	30 311 417	10 106 950	706 442	2.07
Jeorgia	20 930 127	10 020 241	(1 900 994)	0.02
Hawaii	6477632	4 242 014	(2 224 610)	24.00
daho	3 898 217	6382042	2 402 026	(2.75
1111018		91 853 295	50 277 002	120.03
nglana	10 582 428	12 270 152	1 597 774	14 04
owa	5 437 368	4 837 782	(500 584)	
Cansas	5 502 565	6 205 111	000 646	
Centucky	11 735 435			
ouisiana	23 158 418	44 343 003	21 106 406	01.40
Maine	3 214 045			
faryland	17 550 765		153,430	
Assachusetts	15 124 262		(597,129)	3.40
dichigan				18.59
dinnesota				
Aississiani		11,439,858		9.23
Aississippi		19,710,556	(10,990,921)	35.80
Aissouri		15,805,346		
Aontana			(3,793,526)	53.55
Vebraska			(222,676)	
Vevada		6,647,377	1,313,320	
lew Hampshire		2,261,165		20.4
lew Jersey	30,498,439		(3,982,857)	13.06
New Mexico		17,696,491		19.28
orth Dakota	1 279 725	1 109 227	(91 200)	<i>c</i> 2
/11/0		34 226 768	(82 350)	0.2
Jkianoma			(83 798)	-1 29
Dregon		29,731,969		
ennsvivania	38 706 830	41 662 107	2056 222	
uerto Kico		122 346 374	(43 755 302)	26.20
outh Carolina		11 995 901	50 644	0.60
Jtah		4.334.469	(95.662)	
ermont	1 740 882	1 306 704	45 012	5 31
/irginia,	12 424 713	11 111 264	(1 212 240)	
Vashington	27 110 437			10.5
Vest Virginia	25 473 072	15 221 429		
Visconsin	17 800 253			40.09
Vyoming	1 662 175			
State Total	1 272 022 000	1,283,343	(377,030)	
marican Samoa		1,239,200,000		2.58
merican Samoa			(172)	0.09
iuam				9.70
farshall Islands		400,327		0.09
ficronesia				9.70
orthern Marianas	333 969	481 963	147 004	44 21
alau	125 530	125 415	(116)	0.00
irgin Islands	994 210	1 000 600	06 490	0.70
Area Competitive Grants	486 685	0	(492 295)	100.00
Outlying Area Total	3 975 100	2 072 600	(100 (00)	0.50

#### ATTACHMENT III-B

#### U.S. Department of Labor Employment and Training Administration WIA Dislocated Worker Activities PY 2002 State Allotments

State	Total	7/1/02	10/1/02
Total	\$1,549,000,000	\$489,000,000	\$1,060,000,0
Alabama		7 228 276	15 669 6
Alaska		3 053 173	6 6 19 2
Arizona	12,606,123 ,	3 070 506	
Arkansas			
California			
Calamda			
Contrado			5,049,4
Connecticut	5,384,702		
Delaware			
District of Columbia		2 789 756	6 047 3
rionda	40 106 859	12 661 226	27 445 6
Georgia		6 010 451	13 028 7
Hawan	4.243.014	1 339 467	2 002 5
Idaho		2 014 731	1 267 2
Illinois		29 004 040	
Indiana		2 972 674	
Tourse tours			
lowa	4,837,782	1,527,227	
Kansas			
Kentucky			
Louisiana	44 343 003	12 009 919	20 246 04
Maine		1 063 354	2 305 0
Maryland		5 354 893	11 607 7
Massachusetts		3 889 638	8 431 51
Michigan		8 737 606	19 000 67
Minnesota		2 611 421	
Mississinni			
Missouri			13,488,17
Wilssouti			10,815,79
Montana			
Nebraska			1,898,98
Nevada		2 098 494	4 548 89
New Hampshire			1 547 34
New Jersey		8 370 639	18 144 94
New Mexico	17 696 491	5 596 567	10 100 02
New York		21 268 106	46 102 64
North Carolina		9 500 7/7	
North Dakota			
Ohio			
011-1		10,804,964	
			4,433,02
Oregon			20,345,95
Pennylvania	41,663,107		
Puerto Rico	122 346 374	38 673 776	92 712 1
Rhode Island			1 834 35
South Carolina		3 786 056	
South Dakota		210.075	
Tennessee	12 027 456		
Tevae			
10,403	59,784,453		40,911,24
Utan	4,334,469	1,368,338	
vermont		412 539	804 24
Virginia		3.507.719	7 603 64
Washington			46 865 54
West Virginia		4 808 435	10 423 10
Wisconsin	15,314,830	4 834 701	10 400 10
Wyoming		405 021	
Stata Total	1 220 200 000		
American Comer			
American Samoa			
ouan			
Marshali Islands		126 378	273 94
Micronesia		243 523	577 81
Northern Marianas		152 150	370 81
Palau		30 507	
Virgin Islande			
T T T T T T			
remitory rotal		1,222,499	
	205 027 500	04 CMM 601	

## ATTACHMENT IV

#### U.S. Department of Labor Employment and Training Administration Employment Service (Wagner-Peyser) Allotments Comparison of PY 2002 Preliminary vs PY 2001 Final

State	PY 2001 Final	PY 2002 Preliminary	Difference	% Change	
Total	\$761,735,000	\$761,735,000	\$0	0.00%	
Alabama	10,959,154	10 930 782	(28 372)	0.76	
Alaska	8 106 495	8 106 405	0	0.000	
Arizona	11 647 788	11 604 206	(42 402)	0.270	
Arkansas	6 349 907	£ 20£ 071	(43 03()	0.000	
Colorado	10 324 433	10 245 432	(70.001)	0 776	
Connecticut	8 314 954	0 040 250	(354 (05)	2.0/0	
Delaware		2 082 068	(234,093)		
Florida		26 054 696		3.06%	
Georgia					
Hawaii			(125,258)	0.64%	
Idaho	6,754,153		(78,080)	2.42%	
Illinoir		6,/34,133	0	0.00%	
Indiana			610,797	1.91%	
lowa		14,196,089	(120,715)	0.84%	
/	6,980,905	6,915,792	(65,113)	0.93%	
Kansas	6,671,747	6,658,405	(13,342)	0.20%	
Louisiana	11,075,973	11,000,879	(75,094)	0.68%	
viaine		4 016 631	0	0.000	
Maryland	13,703,736	13,595,498	(108,238)	0.79%	
Massachusetts		15 144 482	(180 221)	1 1 00/	
Michigan		25 655 401	1 207 801	5 2 2 9/	
Minnesota.	12 471 659	12 607 891	126 000	1 000	
Mississippi	7 309 108	7 150 544	(150 664)	2 1 70	
VUSSOUT	13 680 001	12 770 247	00 357	0 700	
viontana		5 5 19 529	0	0.00%	
Nevada		5 277 141	(88 422)	1 6 50/	
New Hampshire		2 988 940	(4 774)	0169/	
New Jersey		20.852.518	(277 652)	1 3 194	
New Mexico	6 193 882	6 102 892	•	0.000/	
New York	47 277 511	46 260 225	(009 194)	1.000	
vorun Carolina		19 702 435	1 093 607	5 9 9 0 /	
NORTH Dakota	5 620 532	5 620 522	•	0.000/	
Лю	28 306 057	28 180 402	(116 665)	0 410/	
Klahoma	8 125 646	7 904 634	(001 100)		
Jregon	9 557 836	0/127 200	(70 626)	0 7 40/	
ennsvivania	30 125 489	30.010.064	(106 425)	0 2 5 0 /	
	10 329 110	10 103 210	(225 000)	3 108/	
Chode Island	2 594 102	7 557 657	(40.450)	1.000	
South Carolina	9 751 406	0 724 715	(96 701)	0.070/	
South Dakota	5 194 66 3	5 104 662	A	0.000/	
ennessee			U		
Fras				0.19%	
Itah				0.32%	
/embont			(312,916)	3.06%	
Vincinia			0	0.00%	
Vashinatan	15,820,479	15,736,646	(83,833)	0.53%	
vasungton		16,209,660		0.19%	
vest virginia		5.945.805	0	0.00%	
visconsin	13,675,955	14,254,511			
Vyoming	4,030,272	4,030,272	0	0.00%	
Juam		348 947	· •	0.00%	
rgin Islands		1.468.896	0	0.00%	
ostage.		16 000 000	Δ		

#### ATTACHMENT V

#### U.S. Department of Labor Employment and Training Administration Reemployment Services Allotments Comparison of PY 2002 vs PY 2001

State	PY 2001	PY 2002	Difference	% Chang
Total	\$35,000,000	\$35,000,000		0.00
Alabama			(21 147)	-3.25
A Jaska		378 830	(36 606)	10.049
Arizona		465.550	13 946	3 00
Arkansas	475.622	486 834	11 212	2 26
California		3 786 773	(200 000)	
Colorado		413 300	22 414	0.00
Connecticut		550 475	2 245	J./J
Delaware		285 842	(17.047)	
District of Columbia		262 811	(17,947) (8.110)	
Florida		055 872	(11 250)	
Georgia		865 424		
Hawaii		280 505		
Idaho		252 667	(14,247)	
Illinois				3.91
Indiana				
lowa				17.76
Kansas				2.06
Kentucky				
Control on the second s				1.40
Maine			(23,705)	5.25
Maryland				
Massachueette			(31,165)	5.84
Michigan	1,329,035			0.66
Ainmesoto				12.429
Micciccinni				
Missonri				3.04
Viissouri			(21,953)	3.29
Nebeceke			(16,452)	5.479
Neurada				0.949
Vevada			(30,355)	6.92
New Frampshile			15,097	5.81
New Jersey			(105,299)	10.009
New Mexico			(12,315)	3.95
New TOR	1,614,071	1,626,347		0.769
North Carolina	1,014,309	1,117,194		10.149
Nonn Dakota			(6,468)	2.54
	1,006,822	1,104,374	97,552	9.69
Jkianoma			11,726	3.39
Jregon			(21,725)	3.079
ennsylvania		1,514,175	(29,940)	1.949
ueno Kico				10.589
chode Island			(22,161)	6.439
outh Carolina		592,943		10.33
South Dakota			1,289	0.549
ennessee				
exas		1.311.777	(16 519)	.1.249
Jtah		351 075	1 740	0.500
ermont		270 142	(2.550)	0.049
Virgin Islands		218 774	(98)	0.049
Virginia		551 293	18 627	2 500
Washington		856 127	(44 902)	4 099
West Virginia		351 524	(22 825)	-6.109
Wisconsin		1.008 827	50 356	5 250
Wyoming		245 177	(4 617)	1 950
State I otal			0	0.009
			······································	

## ATTACHMENT VI

#### U.S. Department of Labor Employment and Training Administration Workforce Information Grants to States Comparison of PY 2002 vs PY 2001

State	PY 2001	PY 2002	Difference	% Change
Total	\$38,000,000	\$38,000,000	\$0	
Alabama	618,961	-615 467	(2 404)	0 5 6 9
Alaska		313 087		0.30%
Arizona		660 644	7 1 2 5	1 0.0%
Arkansas	478 432	477 041	(1 201)	0 208/
California		2 948 503		0.29%
Lolorado	642 148	612 126	1 200	0 200/
Connecticut		544 272	(7 200)	1 2 49/
Delaware		346 773	(1 105)	
District of Columbia		325 186	(1,195)	-0.54% 0.50%
lorida		1.478 885	19 140	1 3 1 9/
Jeorgia		923.001	(7 200)	0 77%
lawaii	375 013	276 049	195	0.040/
dabo	386 621	299 701	0.170	0.5/0/
llinois		1 252 163	(12 527)	
ndiana	761 616	758 085	(2 521)	0 4/0/
owa		528 771	2 400	0 6 69/
ansas		502 144	(4 760)	0.049/
Centucky.		588 413	(7,137)	
ouisiana		506 706	(2,137)	0.30%
/laine	380 002	297 027	(10(5)	0 500/
Marvland	726 672	721 061	(4 711)	0 ( 60)
Aassachusetts		794 878	2 262	0.03%
Aichigan.	1,088,586	1 092 260	(6 217)	
Ainnesota		714 447		0.3/%
Aississippi		194,006		0.03%
dissouri		732 722	(6 201)	
Iontana		255 457		0.85%
Vebraska			(2,198)	0.61%
vevada	439 128	142 615	4 497	1 0 0 0 /
lew Hampshire		390 223	······ 4,407	
lew Jersey	038 083	022 670	(6 212)	0.578/
lew Mexico		A13 074		0.3/%
ew York	1,669,359	1 644 015	(25 2 44)	0.0/%
North Carolina		909 050		
North Dakota		334 743	(1 625)	
)hio	1,191,106	1 184 810	(6 206)	0.49%
)klahoma		541 220		0.53%
regon		£54 950		
ennsylvania		1 208 800		
uerto Rico		492 804		0.05%
hode Island		360 192	(1964)	0.17%
outh Carolina		590 401	(1,004)	0.51%
outh Dakota		245 412		
ennessee		722 027		U.10%
exas		1 911 467		
Itab			······	0.94%
ermont		437,555	(130)	0.03%
irvinia.			(/54)	0.22%
ashington				0.82%
Vest Virginia			(1/,474)	2.30%
lisconsin				
Vyoming				
State Total			(322)	0.10%
Jam			(75,813)	0.21%
firgin Islande			(38)	0.06%
Ingin Ioldinis			(149)	0.12%
usuage				

# Workforce Investment Act Title I Adult Employment and Training Activities

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## State Tables

## (\$ in Thousands)

<ul> <li>A second sec second second sec</li></ul>	State 1 adies		1243 <u>2</u>
VEL DET HER MET AND ALL A	(\$ in Thousand		
State	NT	s SI ARLING, the larg	
STATE STATE AND A STATE OF	<u>PY 2001 Actual "</u>	PY2002 Estimate 1/2	PY 2003 Estimate ""
Alabama	····· \$17.044	\$17 175	an station chan said
Alaska		2 707	1 (00
Arizona			
Arkansas	9.623		
California	1. 1. 1. 1. 1. 1. 1. 1. 1. 1. 1. 1. 1. 1	159 664	
Colorado	5 768	6 100	· · · · · · · · · · · · · · · · · · ·
Connecticut	6718	····· 5,192	4,670
Delaware	7360		
District of Columbia		••••••	2,244
Florida			3,473
	102	37,968	
Georgia	20.012	<b>00.000</b>	n na stariante en s
Hawaii	20,012 5 445	20,120	19,154
Idaho	····· J,445		4,863
Illinois	44.005	3,/49	3,572
Indiana	10.926	44,632	42,543
	10,820	10,831	10,301
Iowa	2 888	2 021	
Kansas	4 270		2,766
Kentucky	15 192	4,200	4,055
Louisiana		15,177	
Maine	2 201	20,396	19,414
Maryland	12 107	10.077	e de la comercia de la
Massachusetts	11 225	10,977	
Michigan	24 550	10,112	8,622
Minnesota	7 970		23,291
Mississippi	14 744		7,388
	14,/44	15,070	14,357
Missouri	12 240		and the state of the
Montana	12,300	11,124	· · · · · · · 9,485
Nebraska		3,977	3,786
Nevada	2,309	2,369	2,244
Nevada	4,00/	4,043	3,851
New Hampshire	2,369	2,369	2,244
New Jersey	20.020		
New Jersey	20,939	21,162	20,169
New Mexico		9,492	9,045
New York	80,629	81,546	77,717
North Carolina	16,154	16,196	15,409
North Dakota	2,369	2,369	2,244
		· · · · ·	

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## Workforce Investment Act Title I Adult Employment and Training Activities

### State Tables (\$ in Thousands)

<u>State</u>	PY 2001 Actual <sup>1/</sup>	PY2002 Estimate 1/2/	PY 2003 Estimate "
Ohio	\$45,060	\$45,629	\$43.497
Oklahoma	9,236	8.312	
Oregon	13,461	13.638	13 002
Pennsylvania		29.442	28 017
Puerto Rico	52,746	53,224	50,698
Rhode Island	2 360	2.260	
South Carolina	12 609	2,509	
South Dakota	12,098	12,/98	12,189
Tennessee	2,309	2,369	
	10,307	10,138	15,359
Texas	80,377	87,546	83,432
Utah	2,478	2,432	2,309
Vermont	2,369	2,369	2,244
Virginia	12,478	12,509	11,902
Washington	21,031	21,329	20,338
West Virginia	10,559	10,677	10,175
Wisconsin	8.783	8 764	8 331
Wyoming	2.369	2 369	2 244
American Samoa		116	00
Guam		499	
Marshall Islands	239		200
	•		
Micronesia		473	453
Northern Marianas			
Palau			
Virgin Islands			
Competitive Grants to Outlying Areas .			
	••••••••••••• 471 •••••	· · · · · · · · · · · · · · · · · · ·	· · · · · · · · · · · · · · · · · · ·

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<sup>1/</sup> Includes \$712,000 actually available for obligation in the following year.
 <sup>2/</sup> Based on current data available.

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### Workforce Investment Act Title I Dislocated Worker Activities

#### State Tables (\$ in Thousands)

<u>State</u>	<u>PY 2001 Actua</u>	PY 2002 Estimate	<sup>3/</sup> PY 2003 Estimate <sup>1/3/</sup>
Alabama	\$15,069	\$14.690	#13.10F
Alaska			
Arizona		11,101	
Arkansas		12,347	
California		0,920	
		200,335	
Colorado		8.042	
Connecticut		8,043	
Delaware		/,210	6,443
District of Col	umbia	2,128	
Florida			
		•••••••••••••••••••••••••••••••••••••••	
Georgia			
Hawaii		20,390	
Idaho		0,310	5,634
Illinois			3,391
Indiana		40,502	
		10,407	9,292
Iowa	5,437	C 007	
Kansas		5,297	4,729
Kentucky			4,786
Louisiana		11,433	10,208
Maine		22,561	
		3,132	
Maryland		17.104	
Massachusetts		1/,106	
Michigan		14,/44	13,164
Minnesota			
Mississinni		10,203	
minoriosippi		29,909	
Missouri	12,375 .	10.055	
Montana	·····	12,055	10,764
Nebraska		6,902	
Nevada	····· 5,334 .	2,920	2,607
New Hampshir	·····	5,196	4,640
reew manipani	e 1,878 .	1,829	1,633
New Jersey	20.400		
New Mexico		29,711	
New Vork 2		21,358	
North Carolina		102,835	
North Dakets		16,521	
North Dakota		1,247	1,113

## Workforce Investment Act Title I Dislocated Worker Activities

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#### State Tables (S in Thousands)

	 	 ,	

State	PY 2001 Actual 1/2/	PY 2002 Estimate 1/ 3/	PY 2003 Estimate 1/ 3/
Ohio	\$24 200	\$22 4 <b>3</b> 4	\$20 942
Oklahoma	\$34,309	····· \$33,424 ·····	
Oregon			
Pennsylvania	28 707	37,708	
Puerto Rico	166 102	161 014	
	100,102	101,014	
Rhode Island	2 886	2,811	2 510
South Carolina		2,011	
South Dakota	1 284	1 251	
Tennessee	12 772	12 442	
Texas	63 747	62,102	
I CAUS		02,102	
Utah	4 430	1 316	2 962
Vermont	1 241	1 200	
Virginia	12 425	12 104	10 907
		26,419	
West Virginia			
Wisconsin	12 880	12 548	11 202
Wyoming			
American Samoa			
Guam			
Marshall Islands			
Micronesia	703		
Northern Marianas			
Palau			
Virgin Islands			
Competitive Grants to Outlying Areas			
Secretary's Reserve			
Rescission 4	(177,500)		0
Total	\$1,437,540	\$1,549,000	\$1,383,040
			and another and
<sup>17</sup> Includes \$1,060,000,000 available for o	bligation in the following ye	ear.	
2/ Includes \$25 million of emergency resp			"2001 Emergency
Supplemental Appropriations Act for Re			
2001.	-		Mew York
<sup>37</sup> Based on current data available.	aot.,;	and and a second se	
4' Reflects rescission of fiscal year 2001 fi	nds available July 1, 2001,	to June 30, 2002, enacted by I	P.L. 107-20, "Supplemental
Appropriations Act, 2001", July 24, 200			

## Workforce Investment Act Title I Migrant and Seasonal Farmworker Programs

#### State Tables (\$ in Thousands)

.

State State	PY 2001 Actual	PY 2002 Estimate "	PY 2003 Estimate <sup>2</sup>
Alabama	\$703		
Alaska		\$833	••••• \$0
Arizona		0	0
Arizona	1,/09	1,798	0
Arkansas	1,167	1,228	0
California	16,802	17,677	0
Colorada			
Colorado			0
Connecticut			0
Delaware			0
District of Columbia	0		0
Florida	4,631	4,873	0
Georgia	1,712	1,801	0
Hawaii			0
Idaho		1,048	0
Illinois	1,435	1,510	0
Indiana			
-			
Iowa	1,314	1,383	
Kansas		859	Δ .
Kentucky	1.353	1 423	٥
Louisiana	796		0
Maine	327		
Maryland	346		
Massachusetts	351	369	٥
Michigan		1.000	•
Minnesota	1,275	1.341	0
Mississippi	1,449	1.525	
Missouri	1,095	1.152	0
Montana	667	702	0
Nebraska	895	942	0
Nevada	201		
New Hampshire	113	118	
New Jersey	477	502	٥
New Mexico		729	····· U
New York	1 851	1 047	•
North Carolina	3 006	1,947	····· 0
North Dakota	526	····· 2,103 ·····	
			0

## Workforce Investment Act Title I Migrant and Seasonal Farmworker Programs

#### State Tables (\$ in Thousands)

<u>State</u>	PY 2001 Actual	PY 2002 Estimate 1/	PY 2003 Estimate
Ohio	\$1,044	\$1.099	\$0
Oklahoma			0
Oregon	1,248	1.313	0
Pennsylvania	1,392	1.465	0 0
Puerto Rico	2,939	3,092	····· 0
Rhode Island	4	e	
South Carolina	1 080		
South Dakota	602	1,130	
Cennessee	058		0
ſexas	6 718	7.008	0
	0,/10		····· 0
Utah	277		
Vermont	213		0
Virginia	1,036	1.090	0
Washington	1,955	2,057	
West Virginia	219		0
Wisconsin	1.229	1 203	•
Wyoming	227	220	
Fechnical Assistance/Housing	4 606	A 846	
			•••••••••••••••••••••••••••••••••••••••
Fotal	76 770	80.770	•
			····· 0
		•	
<sup>1</sup> Based on current data available.			
No funds requested for FY 2003.			

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## Workforce Investment Act Title I Youth Activities

#### State Tables (\$ in Thousands)

<u>State</u>	<u></u>	Y 2001 Actual <sup>1/</sup>	PY 2002 Estimate <sup>2</sup>	PY 2003 Estimate 2/
Alabama	•••••	\$19 306	\$10.202	
Alaska	••••••	4 108	\$19,595	\$17,625
Arizona	••••••	20.000	4,218	3,895
Arkansas	•••••••••••••••••••••••••••••••••••••••	10.020	20,181	18,398
California	••••••	181 547	10,969	
		. 101,547	182,385	167,209
Colorado	•••••••••••••••••••••••••••••••	7 246	7.046	
Connecticut	•••••••••••••••••••••••••••••••••••••••	9 512		5,790
Delaware	•••••••••••••••••••••••••••••••••••••••	3 430		
District of Colum	nbia	4 503		
Florida	••••••	41 077	41.262	3,691
			41,203	37,446
Georgia	•••••••••••••••••••••••••••••••••••••••	23 057	22.161	<b>AA A C</b>
Hawaii	•••••••••••••••••••••••••••••••••••••••	6 132	5 510	20,962
Idaho	••••••	4 295		4,998
Illinois	•••••••••••••••••••••••••••••••••••••••	50 049	4,314	3,928
Indiana	•••••••••••••••••••••••	13 605	12 605	45,994
Iowa	•••••••••••••••••••••••••••••••••••••••	4.027	4 027	2 210
Kansas	•••••	4.762	4,027	
кепшску		17.118	17 118	16.000
Louisiana	* * * * * * * * * * * * * * * * * * * *	23.291	23 396	21 166
Maine	•••••••	3.836	3 836	2 225
Maryland	•••••••	. 13,983	12.586	10.058
massacnusetts	********************	16.005	16 005	12 790
Michigan	* * * * * * * * * * * * * * * * * * * *	29.775	29 775	35 883
Minnesota	************************	9,942	9.942	8 020
Mississippi		. 17,838	17.919	16 281
Missouri	••••••	14,919	14.919	11 921
Montana	• • • • • • • • • • • • • • • • • • • •	4.274	4 203	2 804
Nedraska	• • • • • • • • • • • • • • • • • • • •	3.430	3 431	2 741
ivevada		4.523	4 530	4 126
New Hampshire	••••••••••••••••••••••••••••	3,430	3.431	2 741
New Jersey	•••••••••••••••••••••••••••••••••••••••	. 29,274	29,274	
New Mexico	• • • • • • • • • • • • • • • • • • • •	. 10.734	10 783	0.925
New FOR		. 87.084	87 485	80.160
North Carolina .	• • • • • • • • • • • • • • • • • • • •	. 18,057		16 267
North Dakota	•••••••••••••••••••••••••••••••••••••••	3,430	3,431	2.741
				···-•

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## Workforce Investment Act Title I Youth Activities

#### State Tables (\$ in Thousands)

State	PY 2001 Actual 1/	PY 2002 Estimate 2/	PY 2003 Estimate <sup>2</sup>
Ohio	\$50,630	\$50.863	\$46 584
Oklahoma	10.473	9.427	7 533
Oregon	15.006	15.076	13 825
Pennsylvania	38.152	38.152	30 486
Puerto Rico	59.290	59 561	54 245
Rhode Island	3.430	3 4 3 1	2 741
South Carolina	14.935	14 935	12 145
South Dakota	3.430	3 431	2 741
Tennessee	19.488	19 488	16 227
Техаз	101.451	101 914	02 027
Utah	3.430	3 431	2 964
Vermont	3.430	3 4 3 1	2 741
Virginia	16.534	16 534	13 212
Washington	23.884	23 994	22 012
West Virginia	11.778	11 832	10 818
Wisconsin	9.978		8 975
Wyoming	3.430		2 741
American Samoa			80
Guam	1,390		864
Marshall Islands			200
		/	
Micronesia		535	445
Northern Marianas	,	209	201
Palau			75
Virgin Islands			679
Competitive Grants to Outlying Areas			0
		•••••••••••••••••••••••••••••••••••••••	••••••
Native Americans	16,920	16,919	15,014
Total	\$1.127.965	\$1,127,965	\$1 000 965
	·····		··· ψ1,000,202

<sup>17</sup> Includes \$25 million supplemental enacted by P.L. 107-20, "Supplemental Appropriations Act, 2001", July 24, 2001.
 <sup>27</sup> Based on current data available.

### Community Service Employment for Older Americans<sup>1/</sup>

#### State Tables (\$ in Thousands)

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State see	PY 2001 Actual	PY 2002 Estimate 2/	PY 2003 Estimate <sup>2/</sup>
Alabama		\$7 994	\$7 049
Alaska	1.874	1 806	1 974
Arizona	5 715	7 400	
Arkansas	7 922	7 969	
California			
Colorado	4.349		4 340
Connecticut	4.721	4 736	1 771
Delaware	1.874	1 896	1 974
District of Columbia		2 483	····· 1,0/4
Florida	25 372	27 / 405	
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Georgia	9.535		0 535
Hawaii	1.874	1 896	1 974
Idaho	2.039	2 107	2 020
Illinois	16 724	16 124	
Indiana	11 259	11 205	
			····· 11,259
Iowa	5,508	5.526	5.508
Kansas	4,406	4.285	4 406
Kentucky	8.154		8 154
Louisiana		6 995	BOMGES 099722
Maine	2 654	2 662	
	and the second second second		indext din Tilletinoh
Maryland	5,916	5.935	5.916
Massachusetts	9.349		0 340
Michigan	14.335		14 335
Minnesota	10.200	10.069	10 200
Mississippi		5 325	5 209
Missouri	10,637	10,435	
Montana	2,682		2.682
Neoraska			3 200
Nevada			2 153
New Hampshire	1.953	2.197	1.052
	1. AS\$2. A	land diacement to be adaptive and the	He add we had been as
New Jersey	12,153		12 153
New Mexico		2 850	2 425
New York		27 895	28 422
North Carolina		11.526	11 252
North Dakota	2.582	2.591	2 582

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## Community Service Employment for Older Americans $^{\prime\prime}$

#### State Tables (\$ in Thousands)

State	PY 2001 Actual	PY 2002 Estimate 2/	PY 2003 Estimate <sup>2/</sup>
Ohio		18 816	19 765
Oklahoma	6 924		
Oregon	6 323	6 2 <i>4</i> 4	
Pennsylvania	22 000		
Puerto Rico	5 908	····· 22,/14 7 457	
Rhode Island	2 289	2 202	2 200
South Carolina	5 858	2,303 6 273	
South Dakota	2 983	2742	
Tennessee	8 78A	2,/42	
Texas	23 855	····· 0,019	
	23,035		
Utah	2 868	2 979	2.979
Vermont	2,000	2,0/0	
Virginia	9 320	0 164	
Washington	6 357	····· 9,104	
West Virginia			
		4,801	4,835
Wisconsin	11.016	10 770	11.016
Wyoming	2 020		
American Samoa		1 000	
Guam		1,002	991
Northern Marianas			
			330
Virgin Islands	990	1.001	000
Sec 502(e) Projects <sup>3/</sup>	2 204		
	2,290	2,290	2,296
Total	\$440 200	£446 100	
	·····	····· \$445,100	

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<sup>17</sup> Based on the Older Americans Act Amendments of 2000 provisions for the Community Service Employment for Older Americans program.
 <sup>27</sup> Using current data available.
 <sup>37</sup> Funds for conducting experimental projects designed to assure career training and the placement of eligible individuals in employment opportunities with private business concerns, as authorized in section 502(e) of the Older Americans Act of 1965, as amended by the Older Americans Act Amendments of 2000.

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## Employment Service State Tables (\$ In Thousands)

#### <u>State</u> PY 2001 Actual 2002 Estimate " PY 2003 Estimate" Alabama.....\$10,959 .....\$10,959 .....\$10,959 Alaska. Colorado .....

## **Employment Service**

## State Tables (\$ in Thousands)

State	PY 2001 Actual	2002 Estimate "	PY 2003 Estimate"	
Ohio	\$28,306	\$28,305	\$28,305	
Okialioilla			8 112	
Oregon			9 5 5 4	
i cinisyivama			30 113	
Puerto Rico			10,315	
Rhode Island	2.594	2 592	2 502	
South Carolina		9 748	0 747	
South Dakota		5 195		
1 010100000		13 716	12 716	
Texas	51,499			
Utah		10 197	10 103	
Vermont		2 433	2 133	
virginia		15 808	15 905	
wasnington		16 194	16 200	
West Virginia	5,946		5,946	
Wisconsin			13 688	
w yoming			4 030	
Guam		349	3/0	
Virgin Islands		1.469	1 469	
Postage				
Total	\$761,735	\$761,735	\$761,735	

1/ Based on current data available.

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## Reemployment Services State Tables (\$ In Thousands)

State	PY 2001 Actual	PY 2002 Estimate"	PY 2003 Estimate	
Alabama	\$651	0751		
Alaska	365		\$651	
Arizona	452			
Arkansas	лт. лт.		452	
California	2 576			
			3,576	
Colorado	201			
Connecticut.				
Delaware				
District of Columbia				
District of Columbia				
Florida			967	
Georgia				
Georgia Hawaji				
Hawaii				
Idaho				
	1 230	1 220	1	
Indiana			606	
lowa Kansas			486	
Nalisas	384	204		
KCHLUCKY		570	680	
Louisialla		451	461	
Maine			307	
Maryland		534	524	
viassaciiuscus		907	007	
viicingan	1 2 2 0	1 000		
minesota		567	e ( =	
Aississippi	406			
Aissouri	669	(())		
Iontana	201		668	
Vebraska				
Nevada				
New Hampshire				
New Hampshire				
Jew Jersey				
New Jersey			1,053	
**** INICAICO		211		
NEW TOIK		1 614	1 / 1 /	
or ur Caronna		1 014		
North Dakota			255	

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**Reemployment Services** 

State Tables (\$ in Thousands)

State		PY 2001 Actual	PY 2002 Estimate "	PY 2003 Estimate	
Ohio	Transiti 1001 ( i	\$1,007.db	\$1,007	\$1.007	
Ukianoma		246			
Oregon		768	700	700	
Pennsvivania	e e construir d'Aller e a charachaire ann an	1 544	1 5 4 4		
Puerto Rico	24		612		
	2.7.8a	· · · · · · · · · · · · · · · · · · ·	and the second	1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 - 1997 -	
Rhode Island				245	
South Carolina			537	537	
South Dakota					
Tennessee	•		773	772	
Texas		1,328		1,328	
Utah	and a gate	349		210	
Vermont					
Virginia				522	
Washington				001	
West Virginia					
Wisconsin		958		050	
Wyoming		250			
Virgin Islands		210			
Undistributed					
			\$35,000		

1/ Based on current data available.

#### IMPACT OF WORKFORCE CUTS ON EMPLOYERS

Question. What effects will continue budget cuts to the workforce investment sys-

*Question.* What effects will continue budget cuts to the workforce investment system have on the building of business leadership and support for the new system? Such support was a major goal of the Congress in developing the Workforce Investment Act, and I fear that instability of funding, particularly at the local level, will undermine the important work that has been done to ensure the relevance of the job training system to business needs, to instill confidence with employers, and to build this vital support.

Answer. The Department of Labor is working to strengthen business connections with the public state and local workforce investment system. Under the Workforce Investment Act (WIA) of 1998, business leaders, as members of state and local Workforce Investment Boards, have the opportunity to develop state and local strategies to address skill shortages based upon their assessment of local and regional labor market needs. Businesses in need of workers can learn about and gain access to workforce investment system information and services and as a result, workers should find expanded employment opportunities.

The Department of Labor request recognizes that unspent WIA funds remain available to maintain or increase services and continue building the workforce investment system. At the same time, it proposes to eliminate programs that did not live up to their promise or that duplicate other efforts. We believe this is sound business practice and should encourage confidence among business leaders as well as American taxpayers. Most states and local communities have high levels of unspent carryover funds in their WIA formula allotments, so the Department does not expect the decrease in the fiscal year 2003 budget request to have an adverse impact on the services provided to American workers or U.S. companies. While we recognize that major dislocations or unemployment could result in increased demand for workforce services in some communities, resources are available for under National Emergency Grants to respond to major dislocations that may result in increased demand for workforce investment services in particular communities.

The Department of Labor is continuing to develop closer connections among business and state and local public workforce systems to better meet business' needs for skills by equipping American workers with knowledge and skills employers are seeking in the 21st century. The Department of Labor also is working to reform the unemployment insurance and employment service programs, making them more responsive to business and worker needs, providing states more flexibility, and promoting economic growth. We believe that these efforts will strengthen business partnerships with the state and local workforce investment system, building long-term confidence that the system will be able to respond quickly to meet skill needs.

#### H-1B PROGRAM

Question. The Bush Administration proposes to transfer \$138 million from H–1B training programs into clearing up the backlog in permanent foreign labor certification requests. Yet H–1B training was part of a commitment made to American workers as part of the quid pro quo in raising the number of H–1B (foreign guest worker) visas.

Why is the Administration abandoning this national commitment to training workers in skill shortage occupations jobs so suddenly, particularly since the Department only began awarding these grants in 2000 and most of the projects funded thus far have barely begun implementation?

Answer. The H–1B technical skill grant training program was authorized to help American workers acquire the skills to fill jobs for which skills shortages caused U.S. companies to hire high-skilled foreign workers. The Department of Labor started awarding H–1B training grants in 1999, and a number of these grants are nearing conclusion. There is no evidence that these grants will have a measurable national impact on American business' demand for temporary, highly-skill foreign workers. Indeed, little DOL-supported training is sufficient to adequately train workers at the level of H–1B visa holders, 97 percent of whom have at least a Bachelor's or Professional degree and most of whom are information technology systems analysts or programmers, engineers, professors, physicians, surgeons or architects.

Given this, the Department of Labor plans to redirect the H–IB fees paid by employers that currently finance these training grants to reduce the backlog of pending applications for the permanent certification program at the state and federal levels. Many workers admitted under the H–IB program apply for permanent residency, contributing to these backlogs. The Department of Labor has worked with our state partners to improve processing these applications and while productivity has nearly doubled, the volume of incoming applications has outpaced productivity gains. These redirected funds will serve the customers of employment-based immigration programs and resolve the backlog problem.

American workers can access information through the existing network of One-Stop Career Centers about career opportunities and available education and training resources that may help them acquire the skills business is demanding. Among these training resources are funds for eligible dislocated and other adult workers under the Workforce Investment Act of 1998. We believe the H–1B training program is duplicative of these resources.

Question. If government and the private sectors don't work together to partner on the kind of community-based job training initiatives envisioned under the H–1B training program, how are we ever going to decrease our reliance on foreign guest workers?

Answer. Enhanced employment opportunities for American workers and increased business prosperity continue to result from private sector and public sector partnerships. The Workforce Investment Act (WIA) of 1998 established a broad framework to begin to meet the needs of the Nation's businesses and Americans seeking work or wanting to further their careers. Under WIA, business leaders have the opportunity to develop state and local strategies to address skill shortages based on their assessment of local and regional labor market needs. Businesses in need of workers can learn about and gain access to the public workforce investment system and as a result, workers should find expanded employment opportunities. The Department of Labor will continue to develop closer connections among businesses experiencing skill shortages and state and local public workforce investment systems to better meet businesses' needs for skills by equipping American workers with the knowledge, skills and abilities sought after in the 21st century.

*Question.* If we eliminate this program, how are incumbent American workers going to get the training they need to qualify for those employment opportunities that are said to be going begging because we apparently don't now have sufficiently-trained U.S. job seekers?

Answer. We need to help American workers make better use of available training and education resources to qualify for current and future jobs that meet business needs for skilled workers. The Workforce Investment Act (WIA) of 1998 provides the framework for a public, state and local workforce preparation and employment system designed to meet both the needs of businesses and the needs of workers. In the 2003 budget the President provides \$2.0 billion in new budget authority for the WIA Adult and Dislocated Worker State Grant Program, which when combined with an estimated \$1 billion in unspent balances represents an increase of 27 percent over what states will spend on these programs in 2002. We are encouraging this state and local system to more effectively partner and connect with business and with public and postsecondary education systems to help workers take advantage of career opportunities in high-growth sectors of the modern economy.

WIA established the network of state and local One-Stop Career Centers where workers can access information about a wide array of public job training, education, and employment services. Through these One-Stop Centers, workers wishing to upgrade their skills can learn about training and education resources for which they are eligible, including WIA-financed training, federal student financial aid, and other financing opportunities such as Lifetime Learning and HOPE tax credits. We need to encourage workers to make good use of this information in managing their careers.

Question. Please provide any formative evaluations that the Department has undertaken on H-1B programs along with all summative evaluations.

Answer. The H–1B technical skill training grants program is comparatively new. Thus, the evaluation activities funded by ETA to date provide early snapshots of how the grants are being implemented rather than information on their impact on the number of H–1B visa holders being hired by U.S. companies.

The Department of Labor sponsored an early review of six H–1B training grant sites by Dr. Stephen Baldwin of the KRA Corporation in August 2001. This study largely focused on initial grant implementation along the various dimensions, such as targeting participants and occupations, determining the level and intensity of skill training, and obtaining business engagement and the collaboration of other community entities. The Department of Labor sponsored a second short-turnaround study of six other grantee sites that was completed by Dr. Burt Barnow of the Institute for Policy Studies of Johns Hopkins University. The objectives of this study were to compare and contrast approaches undertaken across the six sites and to highlight interesting practices that might be replicated by current and future grantees. Interested individuals can access both studies through the Department of Labor's Employment and Training website: www.doleta.gov. (Copies of the studies are also attached for the Subcommittee's use.)

The Department of Labor has commissioned a longer-term, in-depth study of the H–1B technical skills training grant program. This three-year effort is being undertaken by Bruno Associates in association with WESTAT, Inc. as the result of a competitive process. Now in its early phases, the study will encompass a process evaluation; collect quantitative administrative data; and assess the feasibility of conducting an impact study.

The Department's Office of the Inspector General is conducting audits of several grantees and has published one of them. A copy may be accessed at www.oig.dol.gov.

#### CLEANING UP THE GREEN CARD BACKLOG

*Question.* Your budget proposes shifting all current and future H–1B training dollars into faster processing of the backlog of pending employer applications for permanent labor certifications. Are you really going to need every single current and future H–1B training dollar that's nearly one half billion dollars (that will be generated by new and extended H–1B visas over the next several years to clear up the green card backlog?

Answer. The President's Budget proposes to redirect the portion of H–1B fee revenues that go for training grants to eliminate the backlog of permanent program applications at the State level. The H–1B fee is scheduled to sunset on September 30, 2003, at which time the cap reverts back to 65,000 visas. The number of H–1B fee paid petitions processed by INS has not kept pace with earlier projections. The 195,000 cap was not reached in fiscal year 2001, and based upon recent fee revenues received, it does not appear the cap will be reached in fiscal year 2002. The Immigration and Naturalization Service (INS) reported that H–1B visa petitions are down 48 percent compared to the first six months of fiscal year 2001, which will substantially reduce the current and future balance level.

There are approximately 300,000 pending permanent labor certification applications in the states and the DOL regional offices. Over 200,000 of these applications were received as a result of the Congress enacting the Legal Immigration Family Equity (LIFE) Act. The Immigration and Nationalization Service (INS) receives revenue from a \$1,000 fee to process LIFE Act applications. DOL does not receive any resources specifically for LIFE Act application processing. Employer applicants have cause to expect their applications will be processed within a reasonable time. Processing times today, depending upon the state, can take more than 5 years.

The budget proposes shifting the H–1B training grant funds to support processing of the applications under the current regulation. Approximately, 15 percent–25 percent of these applications are believed to be high-skilled H–1B visa holders who desire to remain permanently employed in their current jobs. Based upon a management review conducted by Pricewaterhouse Coopers (PwC), we estimate it will take approximately 2–2<sup>1</sup>/<sub>2</sub> years for these backlogged cases to be processed.

Concurrent with the processing of backlogged applications under the current regulation, the Department plans to implement the proposed Permanent Employment in the United States (PERM) regulation in Spring, fiscal year 2003. This new regulation is expected to significantly streamline the processing of newly submitted permanent labor certification cases. The budget does not propose shifting the H–1B training grant funds to implement the proposed streamlined PERM regulation, only for processing applications under the current regulation.

*Question.* Have you developed a budget for exactly how all of this money is going to be spent to clear up the backlog?

Answer. The Employment and Training Administration (ETA) engaged Pricewaterhouse Coopers (PwC) to conduct a management review of the permanent labor certification program to determine where processing efficiencies may be realized and the necessary resources to clear out the backlog. ETA is using PwC's budget estimate and evaluating several PwC recommendations on where processing efficiencies may be realized. Once this evaluation is concluded, an exact budget, including how much is needed and how the redirected H–1B training grant balances would be used, will be developed.

*Question.* At a time of high levels of unemployment, particularly in the high tech sector, do you think it makes sense for the government to be taking steps to accelerate the entry of even more foreign workers into the United States?

Answer. In the vast majority of cases, the alien beneficiary is already working for the U.S. employer at the time an application for alien employment certification is filed. Hence, eliminating the current backlog will not have an appreciable effect on the U.S. labor market. Further, it should also be clearly understood that under the permanent labor certification program the Secretary certifies the job opportunity, not the alien beneficiary of the labor certification. The labor certification regulations require, pursuant to section 212(a)(5)(A) of the Immigration and Nationality Act, a test of the labor market to determine that there are not sufficient American workers who are able, willing, qualified and available, and the employment of the alien beneficiary will not adversely affect the wages and working conditions of workers in the United States similarly employed.

#### ERGONOMIC HAZARDS

Question. In a recent survey of nurses conducted by the American Nurses Association, 60 percent stated they feared a disabling back injury. Fewer than half of the facilities (46 percent) where these nurses were employed made lifting and transfer devises readily available. Currently, since no federal ergonomics standard exists, facilities are not required to provide such devices. What is the Department doing to address the concern of nurses and other health care workers about such problems as back injuries?

Answer. OSHA is in the process of implementing a comprehensive plan to address ergonomic hazards. This plan combines enforcement measures, industry guidelines, outreach, and research to reduce the incidence of injuries related to ergonomic hazards in the workplace.

In this regard, OSHA has developed, and is preparing to implement, a National Emphasis Program (NEP) to focus on injuries from resident lifting and transfers in Nursing and Personal Care Facilities. The purpose of this enforcement effort is to encourage employers to minimize manual lifting, as the majority of lost workday injuries in nursing homes are a result of resident transfer and lifting. For each year of this NEP, OSHA anticipates conducting inspections at approximately 1,000 Nursing and Personal Care Facilities with the highest injury and illness rates. OSHA is optimistic that through this enforcement effort, employers throughout the nursing and health care industry will implement the use of effective and feasible controls to address back injuries and other musculoskeletal disorders.

OSHA also provides annual training to our Compliance Officers in the recognition of hazards in the health care industry, including ergonomic stressors. Back injuries and other musculoskeletal disorders are recognized hazards in the health care in-dustry. Even the absence of a specific OSHA standard to address this hazard, employers retain a positive duty to protect their employees from work related injuries and illnesses. The OSH Act of 1970 allows OSHA to cite under the "General Duty Clause" when employers are not fulfilling this obligation.

In addition to this enforcement activity, the agency is moving forward with guidelines for Nursing and Personal Care Facilities, and other specified industries. ÖSHA also has numerous outreach materials on its website (www.osha.gov), including a graphical menu to identify hazards and controls found in the Hospital and Health Care Industry, an e-tool for Nursing and Personal Care Facilities, reference material, and fact sheets addressing hazards, including ergonomic hazards in these industries.

The goal of these efforts is to address the hazards and the concerns of nurses and nursing staffs and to reduce the injury and illness rates within the health care industry.

#### JOB TRAINING TECHNICAL ASSISTANCE

Question. Secretary Chao, you talked about the slow spending of Workforce In-vestment Act resources at last year's hearing, over a year ago. There is an obvious need for services nationally during difficult economic times, especially for dislocated worker finding as exemplified by the Administration's supplemental request.

What sort of technical assistance for states and localities have you ordered to help improve Workforce Investment Act spending rates in States and localities across the country?

Answer. ETA attributes low spending, in part, to the implementation of the new WIA program. ETA has conducted an on-going program of evaluation to determine state and local partner progress in implementing WIA. The seven ETA regional offices routinely conduct on-site visits with our partners to determine success against the implementation objectives reflected in the state strategic plan. The regional offices file a quarterly report on "outstanding issues" in governance, performance measurement and a number of other key issues, noting both progress and remaining problems. ETA's emphasis on identifying the major operational issues that impede complete implementation remains an important priority. The agency has enlisted outside contractors, including Social Policy Research Associates, to assist in the process evaluation of WIA implementation. Both these Federal and contractor findings become valuable, continuing input into technical assistance strategies that are developed for states. Our negotiation of state performance measures has also been mindful of the Administration's emphasis on the Government Performance Results Act and the requirement to set high targets of accomplishment for those customers served by the Adult, Dislocated Worker and Youth funding streams under WIA.

ETA hosts both national and regional conferences that organize presentation, agendas, and workshops around solutions to problems. ETA also issues Training and Employment Guidance Letters to the workforce sys-tem on a routine basis to provide clarification on WIA policy, technical assistance materials, questions and answers, and other advisories that will assist our partners.

ETA staff have also conducted an analysis of quarterly financial reports to determine the various dimensions of the underexpenditure issue and the combination of causal factors contributing to the reported low outlays. The problem is more acute in some states than in others. Early implementation was certainly marked by sig-nificant underexpenditure in a subset of states as they moved from JTPA to WIA.

The examination of financial reports led to the development of a diagnostic line of inquiries that has been used by our line staff and political leadership in conversations with the states. These questions probe state knowledge, experience, and intent. Among them:

What information do you have at the state level on local workforce investment area obligations?

What is the nature of these obligations? Are they obligations attached to specific customers for training, such as Individual Training Accounts, and/or specific services? Are they obligations to service providers to assist customers over the next few immediate months? Or are they obligations made from one administrative entity to another for services and training over a longer extended period?

Spending for statewide activities has lagged considerably behind local spending. Why is this? If you have large balances in statewide activities, have you discussed reducing the amount reserved for these services to provide a greater proportion of the funds to areas that lack resources to meet demands for training and services?

Are there particular obstacles-statutory or regulatory-that have restricted the timely expenditure of these funds?

The pursuit of this issue has also focused on the arguments made by many local One-Stop operators that funds have been obligated at the local level, but have not been reflected in the state reports (differences in "closing date" for account structures. etc.).

Both the analysis of reports and our ongoing conversations with the states have translated into "action items" for all levels of WIA governance. We believe the states are working extremely hard to fully implement the law and realize the goals and objectives outlined in their respective strategic plans. The effort to fully enlist all the partners in the day-to-day operation of the One-Stop delivery system has certainly been a difficult and time-consuming process in many communities and a contributing factor to the underspending during this period. The time and energy to deal with the documentation requirements necessary to certify eligible training providers for a period of "subsequent eligibility" was also perhaps not fully anticipated at the outset of WIA implementation.

We have convened state and local partners in a series of "WIA readiness" sessions across the country, gathering their viewpoints on what has worked (and what has not worked). These workgroups were charged with suggesting strategies to assist the system in addressing implementation issues in four areas: One-Stop service delivery, adult and dislocated worker services, youth services, and attracting and retaining employer involvement on workforce boards. Their commitment and work yielded a series of recommended actions that were shared with the workforce development system in November, 2001.

Our collective stewardship of these WIA resources is a mutually recognized one. ETA is fully committed to working with our state and local partners to ensure that employers and jobseekers are provided the assistance they need in all the local workforce investment areas. The agency is moving to issue new policy (or restate existing policy) where clarity in the Federal position is needed.

Question. How have you addressed this continuing problem?

Answer. ETA dedicates considerable time and resources to providing guidance and technical assistance to our partners. This guidance comes in part through regular and frequent policy guidance and ongoing communications. Technical assistance is provided through national and regional conferences and workshops, on-site expert visits, and publications.

#### YOUTH OPPORTUNITY GRANTS

Question. I share the pride that many of my colleagues feel in the success of the Job Corps program, in which a five-year study of the Job Corps program, conducted by Mathematica Policy Research, Inc., recently found that \$2.01 was returned to society for every dollar spent on the program. The success of the Job Corps did not happen overnight in fact efforts were made on the floor of the Senate to disband it as a national program as late as 1995. We were able to preserve Job Corps and give it the chance to achieve success. That is what concerns me so greatly about your proposed cuts to the Youth Opportunity Grants the grants were awarded only two years ago, and are providing intensive services to at risk youth in 36 of the poorest communities across the nation.

How is this consistent to leaving no child behind, particularly in a recession? Answer. Since the Youth Opportunity Grants (YOG) started, the Department has urged grantees to develop plans for sustaining the activities and services under these grants after completion of federal funding. The President's 2003 Budget completes five-year funding for existing grantees but does not initiate new grants. Instead, youth will continue to be served through Workforce Investment Act (WIA) Youth Activities and Job Corps. The 2003 Budget includes about \$3 billion in resources for these programs, including an estimated \$398 million in unspent balances that states will carry into Program year 2003.

The Administration is concerned about mismanagement by certain YOG Grantees and is actively working to correct all identified problems. The Department will work with YOG grantees to ensure that all instances of mismanagement are completely corrected while the program activities are completed. Where appropriate, the Department will work with YOG grantees to maintain and formalize their relationships with existing partners, connect them with the local workforce investment system in their communities, and sustain relationships that they have developed with the youth.

#### OSHA ENFORCEMENT BUDGET

*Question.* You are proposing to cut OSHA's enforcement budget by \$918,000, and 64 full time equivalent staff. I understand you plan only to cut management staff, not inspectors. Instead of getting rid of these managers, why don't you make them into inspectors?

Answer. OSHA has submitted what it believes is a sound, responsible budget that will support OSHA's mission and the way it does business. (Excluding the one-time terrorism related supplemental funding OSHA received for this activity in fiscal year 2002, the proposed reduction in OSHA's Federal Enforcement is \$548,000). Staff proposed for elimination in fiscal year 2003 are managers and other administrative support positions that are not involved in the delivery of front-line safety and health in the workplace. The reassignment of staff would not be feasible, as inspection work demands different and relatively technical skills. The fiscal year 2003 budget would allow OSHA to continue to vigorously enforce the laws that protect the Nation's workers.

#### NEED TO EXPAND JOB TRAINING SERVICES

*Question.* Your budget states that you will be able to retain the current level of job training services of about 2 million participants, despite cuts in funding, due to the assumed availability of unspent funds from prior years.

Even assuming this is correct, since the number of unemployed has grown by more than 2 million in just the last year, shouldn't we now be expanding the level of job training services?

Answer. In the 2003 Budget, the President provides more than enough new resources to support a substantial increase in assistance to adults and dislocated workers, when combined with large unspent balances. The budget for Workforce Investment Act (WIA) adult and dislocated worker programs includes \$3 billion in total resources—which is \$623 billion, or 27 percent, more than the estimate of what states will spend in 2002. This resource total includes \$2.0 billion in new budget authority and about \$1 billion in unspent balances for state formula grants that will be carried into Program Year 2003.

Additionally, the Administration recognized the dislocation impact of the events of September 11, 2001 on the nation's workforce as well as the consequences of a continuing downturn in the economy. In an effort to quickly address these issues in the short term, the President proposed and has continued to be a strong supporter of additional resources to help the nation's unemployed and dislocated workers. In October 2001, the President proposed a "Back to Work Relief Package," which included extended unemployment benefits and an additional \$3 billion for National Emergency Grants (NEGs) to target resources to dislocated workers and communities that were struggling during the economic downturn. Although the Housepassed economic stimulus bill included \$4 billion for NEGs, the final legislation did not provide additional resources for this critical program. However, the enacted economic stimulus package did include \$8 billion in Reed Act transfers to States, which are available to provide employment services and unemployment insurance benefits to unemployed workers. Nevertheless, again in March 2002, the President proposed a \$750 million supplemental budget request, which included \$550 million for targeted assistance to dislocated workers through NEGs.

Although Congress ultimately did not adopt the President's supplemental request, another source of assistance for dislocated workers and other adults recently became available. From the fiscal year 2002 appropriation, the Department of Labor will allocate almost \$2.2 billion in state formula grants for adult and dislocated worker assistance, and approximately \$265 million for additional NEGs. These resources will help achieve the President's goal of returning dislocated workers and other adults to work as quickly as possible.

#### CUTS IN YOUTH TRAINING PROGRAMS

Question. Your budget submission cuts over \$360 million in youth programs other than Job Corps. As a result of the recession, over one million young people lost jobs in the past year. The old adage "last hired first fired" proved true once again. With this in mind, is it the right time to make such damaging cuts in programs designed to serve disadvantaged youth just when we were beginning to see some very positive outcomes in these programs?

—Cutting the Youth Opportunity Grant Program by 80 percent;

-Eliminating the Youth Offender Program; and

-Cutting the Youth formula program by \$126 million.

This appears to be especially risky in light of the President's pledge to "leave no child behind" as these are the only programs geared to these young people who have already fallen between the cracks of our educational system.

Answer. The President and the Department of Labor remain committed to helping young people in need. We also are committed to making smart investments on behalf of the American people. To do so, we are reducing requests for new money when unspent balances remain available to maintain or increase spending and ending programs that are expensive relative to the benefits they provide, ineffective, and/or duplicative of other efforts.

In the 2003 Budget, the President provides more than enough new resources to In the 2003 Budget, the President provides more than enough new resources to support a substantial increase in assistance to youth, when combined with large unspent balances. The budget for the effective Job Corps program is \$1,532 million, a \$73 million (5 percent) increase over fiscal year 2002. This increase will be used to support center expansion, increase teachers' pay, and obtain accreditation of Job Corps' curriculum so that it may award high school diplomas. The budget for WIA youth state formula grants includes \$1.4 billion in total resources—which is \$223 willion to a support center with the strength of the teactor will be used million, or 19 percent more than the estimate of what states will spend in the pro-gram year 2002. This resource total includes \$1.0 billion in new budget authority and about \$400 million in unspent balances for state formula grants that will be carried into Program Year 2003.

The Department of Labor continues to bolster opportunities for young people who participate in youth workforce training programs to acquire the knowledge and aca-demic and work skills and behaviors that can help them successfully transition to further education or training or to employment. Most states and communities have significant funds in their youth activities formula allotments from last year, so we don't expect the decrease in new budget authority to have adverse impact.

Youth Opportunity grants were intended to concentrate large amounts of funds into high poverty areas to bring about community-wide change in the long-term employment rate of youth growing up in these areas. Given the cost of replicating the Youth Opportunity approach and the uncertainty of future local funding beyond fedreal funding, the Department decided to complete existing grants and not award new grants. We will share useful information learned from the Youth Opportunity grantee with state and local workforce investment boards. Finally, the Department of Labor initiated a multi-phased Youth Offender demonstration to help meet the reentry needs of ex-offenders and youth at risk of court or gang involvement. The approach allowed the Department to develop and test an effective youth offender public management model and with fiscal year 2002 funds, begin transitioning the demonstration to local communities. The Department plans to use evaluation findings on the youth offender demonstration to inform state and local workforce investment systems about what works best and what does not to help them integrate these services into mainstream programs targeted to at-risk youth.

#### POCKETS OF UNDERSPENDING

Question. We have difficult choices to make in this Subcommittee and I think we all agree that the overriding principle needs to be fairness in making funding deci-sions. While implementation of the Workforce Investment Act is progressing in most areas of the country, there are a few States and local areas that lag significantly behind. In some cases these under expenditures are so dramatic that they distort the cumulative expenditure rates for entire States, and for the entire system. What is the Department doing to ensure that areas with significant under ex-

penditures are kept to a minimum? Answer. The Department has been working with our partners to identify issues confronted nationwide while implementing WIA that might be impacting spending and services. We are also working with individual states and communities where spending is particularly low. Through technical assistance and clarification of WIA rules and requirements, we hope to see turnarounds and spending increases commensurate with amounts allocated for programs.

Question. What type of technical assistance is being provided to such areas, as demand for employment and training services has always outstripped available resources to provide such services?

Answer. ETA attributes low spending, in part, to the implementation of the new WIA program. ETA has conducted an on-going program of evaluation to determine state and local partner progress in implementing WIA. The seven ETA regional offices routinely conduct on-site visits with our partners to determine success against the implementation objectives reflected in the state strategic plan. The regional offices file a quarterly report on "outstanding issues" in governance, performance measurement and a number of other key issues, noting both progress and remaining

problems. ETA's emphasis on identifying the major operational issues that impede complete implementation remains an important priority. The agency has also en-listed outside contractors, including Social Policy Research Associates, to assist in the process evaluation of WIA implementation. Both these Federal and contractor findings become valuable, continuing input into technical assistance strategies that are developed for states. Our negotiation of state performance measures has also been mindful of the Administration's emphasis on the Government Performance Re-with a det and the requirement to act heir target of accomplicement for those guilts. sults Act and the requirement to set high targets of accomplishment for those cus-tomers served by the Adult, Dislocated Worker and Youth funding streams under WIA

ETA hosts both national and regional conferences that organize presentation, agendas, and workshops around solutions to problems. ETA also issues Training and Employment Guidance Letters to the workforce sys-

tem on a routine basis to provide clarification on WIA policy, technical assistance materials, questions and answers, and other advisories that will assist our partners. ETA staff have also conducted an analysis of quarterly financial reports to deter-mine the various dimensions of the under expenditure issue and the combination of causal factors contributing to the reported low outlays. The problem is more acute in some states than in others. Early implementation was certainly marked by sig-nificant under expenditure in a subset of states as they moved from JTPA to WIA. The examination of financial reports led to the development of a diagnostic line

of inquiries that has been used by our line staff and political leadership in conversa-tions with the states. These questions probe state knowledge, experience, and in-

- tent. Among them: —What information do you have at the state level on local workforce investment area obligations?
  - What is the nature of these obligations? Are they obligations attached to specific customers for training, such as Individual Training Accounts, and/or specific services? Are they obligations to service providers to assist customers over the next few immediate months? Or are they obligations made from one administrative entity to another for services and training over a longer extended period?
  - Spending for statewide activities has lagged considerably behind local spending. Why is this? If you have large balances in statewide activities, have you discussed reducing the amount reserved for these services to provide a greater pro-portion of the funds to areas that lack resources to meet demands for training and services?

Are there particular obstacles-statutory or regulatory-that have restricted the timely expenditure of these funds?

The pursuit of this issue has also focused on the arguments made by many local One-Stop operators that funds have been obligated at the local level, but have not been reflected in the state reports (differences in "closing dates" for account structures. etc.).

Both the analysis of reports and our ongoing conversations with the states have translated into "action items" for all levels of WIA governance. We believe the states are working extremely hard to fully implement the law and realize the goals and objectives outlined in their respective strategic plans. The effort to fully enlist all the partners in the day-to-day operation of the One-Stop delivery system has certainly been a difficult and time-consuming process in many communities and a con-tributing factor to the under spending during this period. The time and energy to deal with the documentation requirements necessary to certify eligible training pro-viders for a period of "subsequent eligibility" was also perhaps not fully anticipated at the outset of WIA implementation.

We have convened state and local partners in a series of "WIA readiness" sessions across the country, gathering their viewpoints on what has worked (and what has not worked). These workgroups were charged with suggesting strategies to assist the system in addressing implementation issues in four areas: One-Stop service delivery, adult and dislocated worker services, youth services, and attracting and retaining employer involvement on workforce boards. Their commitment and work yielded a series of actions that were shared with the workforce development system in November 2001.

Our collective stewardship of these WIA resources is a mutually recognized one. ETA is fully committed to working with our State and local partners to ensure that employers and jobseekers are provided the assistance they need in all the local workforce investment areas. The agency is moving to issue new policy (or restate existing policy) where clarity in the Federal position will accelerate expenditures.

If areas are significantly under spending and carrying out large balances from year to year, we would be hard pressed to argue that the demand for services outstrips available resources.

Question. If these under spending communities do not improve their expenditure rates, are there plans to reallocate resources to areas where funding is being spent well and is desperately needed?

Answer. Unlike predecessor programs such as the Dislocated Workers formula program under the Job Training Partnership Act, the Workforce Investment Act does not provide the Department authority to reallocate monies between states when large amounts remain unspent. Our authority to reallocate resources is limited only to instances where over 20 percent of a year's allotment has not been obligated. In many instances obligations recorded are for services that will not be provided until a subsequent year.

#### ERGONOMICS BUDGET

Question. On April 5, 2002, after months of delay and inaction, the Department announced its plans on ergonomics. The plan consists of four parts—voluntary guidelines, enforcement under the general duty clause, outreach and compliance assistance, and a research advisory committee. It does not include the development of a new mandatory standard.

You have said that your approach will be more protective than the previous ergonomics standard and provide protection faster than a new ergonomics standard. According to the Bureau of Labor Statistics, there were more than 577,000 ergonomic injuries that resulted in time off work reported by employers in 2000. OSHA has estimated that there are more than 1.8 million total musculoskeletal disorders each year. How many ergonomic injuries and illnesses will your ergonomics plan prevent in 2002? How many will it prevent in 2003, 2004?

Answer. The Department's goal is to help workers by reducing ergonomic hazards in the shortest possible time frame. This comprehensive approach is the best way to get protections into place quickly. In addition, our plan is a major improvement over the rescinded rule because it will prevent injuries caused by ergonomic hazards before they occur and will reach a much larger number of at-risk workers. We expect to see significant declines in injuries in those industries that will be the focus of our efforts.

Voluntary industry efforts have been successful in reducing the injury and illness rates related to these disorders. For example: carpal tunnel illness rates fell by 30 percent from 1992 to 2000; the rate of strains and sprains fell by almost 41 percent between 1992 and 2000; back injury rates fell by 24 percent between 1992 and 2000.

In the meatpacking industry, using industry-specific guidelines and focused OSHA enforcement, we have seen even greater progress. Since 1992, there has been a 73 percent decline in the rate of carpal tunnel illnesses, a 76 percent decline in the rate of strains and sprains and a 63 percent decline in the rate of back injuries. Our measurement of success is very simple—significant and sustained reductions

in the number of injuries.

*Question.* The first element of your plan is voluntary guidelines. Can you tell me how many ergonomic guidelines will the Department of Labor develop and issue in 2002, and for what industries?

Answer. OSHA has announced that it is working on guidelines in three industries: nursing homes, retail grocery stores, and poultry processing. We expect to complete draft guidelines for these three industries during calendar year 2002. *Question*. How many guidelines will the Department of Labor develop and issue in 2003 and for what industries?

Answer. We have not yet made decisions regarding what industries will be addressed through guidelines beyond the three already mentioned for 2002.

Question. The next element of your plan is enforcement. Can you tell me how many enforcement actions has OSHA conducted under the general duty clause against ergonomic hazards in the past year? How many inspections on ergonomics hazards does OSHA plan to conduct in fiscal year 2002 and fiscal year 2003?

Answer. During the past year OSHA routinely examined ergonomic hazards during its inspections, but did not issue any General Duty Clause citations for ergonomics. OSHA focuses its inspection resources on complaints, referrals, and workplaces with high overall injury and illness rates. In fiscal year 2002, Federal OSHA plans to conduct 36,400 inspections, and in fiscal year 2003 we plan to do 37,700. Ergonomic hazards will be addressed where they are identified in the course of programmed (planned) inspections, including about 3,600 Site-Specific Targeting inspections that are scheduled in the nation's most hazardous workplaces. Work-places are included on the SST targeting list because of the high injury and illness rates the employers have reported to OSHA. Likewise, workplace complaints and referrals that allege ergonomic hazards will be treated under OSHA's normal procedures, including inspections and investigations. Thus, where OSHA finds ergonomic hazards in the course of its enforcement activity, the agency will address them appropriately. Finally, OSHA is creating a National Emphasis Program that will direct enforcement efforts to industries where ergonomic hazards are present.

Question. What level of funding has been targeted to support your "comprehensive approach" to ergonomics in the current fiscal year 2002 budget? Now let me turn to your fiscal year 2003 request. How much money is included in your budget request for the development of ergonomics guidelines? For enforcement of ergonomic hazards under the general duty clause? For training and compliance assistance on ergonomic hazards? For your proposed research advisory committee?

Answer. OSHA does not specifically earmark funds to address any particular workplace hazard. However, budgets in both years include the necessary resources to support the Secretary's comprehensive plan to address ergonomic hazards.

*Question.* How many staff at OSHA and the Department have been assigned to work on your ergonomics initiative?

Answer. OSHA personnel throughout the agency have been assigned responsibilities in carrying out each prong of the comprehensive approach. The agency is working directly with the Office of the Solicitor to fashion the enforcement aspect of the plan. In addition, staff from the field and national office are involved in developing and delivering the outreach and assistance portion of the plan. As part of the effort, OSHA is hiring individuals with specific knowledge and expertise in ergonomics.

#### ERGONOMICS ENFORCEMENT

*Question.* After you issue ergonomic guidelines, will you use these guidelines for enforcement purposes under the general duty clause? If not, why won't you use them for enforcement purposes?

Answer. OSHA will use the General Duty Clause to cite employers for ergonomic hazards. The OSH Act's General Duty Clause requires employers to keep their workplaces free from recognized serious hazards, including ergonomic hazards. This requirement exists whether or not there are voluntary guidelines. We understand that many employers have implemented their own measures that would meet this requirement. If an employer with ergonomic hazards has instituted measures that effectively identify and reduce ergonomic hazards and injuries, there is unlikely to be any basis for a Section 5(a)(1) citation. OSHA intends the guidelines to provide information to help employers identify ergonomic hazards in their workplaces and implement feasible measures to control such hazards. An employer's failure to implement guidelines, however, is not in itself a violation of the General Duty Clause of the OSH Act.

Question. You have cited the Pepperidge Farm case and Beverly nursing home case as examples of the successful litigation the Department has undertaken in the past on ergonomics enforcement under the general duty clause. Each of these cases took 10 or more years to complete, during which time no abatement of hazards was required. Could you tell me what was the total cost of these cases to the Department, from beginning to end, including the inspection, review before the ALJ, the Review Commission and in the Beverly case, resources devoted to reaching the settlement?

Answer. The Pepperidge Farm and Beverly cases were indeed successes for the Department. In both cases, the Commission determined that the General Duty Clause could be used to address ergonomic hazards. The Beverly settlement also demonstrates how successful the general duty clause can be in protecting a large number of workers. Initially OSHA issued general duty clause citations in five nursing home facilities. The Beverly settlement, however, applies to approximately 270 nursing home facilities nationwide.

It is true that in both the Beverly and Pepperidge Farm cases the employers were not required to abate the hazards until the case was completed. However, this is the case when OSHA issues any citation, whether for a standard or under the General Duty Clause. Under the OSH Act the employer does not have to abate the hazard until a final Commission decision is issued.

Regarding the 10-year time frame, it is important to note that these types of "groundbreaking" cases generally take longer to litigate the first time around. Future cases should not take nearly as long to litigate. Furthermore, there is no reason to believe that cases brought under the rejected ergonomics standard would have taken any less time than the Beverly or Pepperidge Farm cases. The agency cannot provide the full costs of the Beverly and Pepperidge Farm

The agency cannot provide the full costs of the Beverly and Pepperidge Farm cases as many records are no longer available, because they were disposed of in accordance with relevant Federal records retention policies. In addition, the Department does not have a cost accounting system that tracks expenses to that level of specificity. However, the Department has attempted to estimate the cost of expert witnesses, travel, and other expenses from the Beverly cases based upon a review of available documents. The total estimate of these costs is approximately \$278,000. In addition, the case required approximately 7.5 Full Time Equivalent (FTE) of attorney time.

Question. What does the Department estimate that it will cost to bring and litigate a major ergonomics enforcement case under its new plan, and what level of funding is included in your fiscal year 2003 budget request for this purpose? How many large enforcement cases on ergonomics will the Labor Department be able to handle in fiscal year 2003?

Answer. It is extremely difficult to estimate how much it will cost to litigate an ergonomics case under the General Duty Clause because the scope and number of contested issues will vary considerably from case to case. In any case litigated by the Department, the Department could incur costs for expert witnesses, travel, ste-nography, and attorney time. In addition, most cases are settled. OSHA is not requesting new funding specifically for litigation of 5(a)(1) cases, as this has never been a specific line-item request in either the Department's or OSHA's budget. Both OSHA's and the Department's budgets are sufficient to support the effort required to implement the comprehensive ergonomics approach and make it successful.

#### OLDER WORKERS

Question. A bipartisan group of Senators, including myself, sent a letter to Assistant Secretary Emily DeRocco on April 11, 2002, seeking assurances that the Labor Department would follow Senate Report language designed to ensure that successful grantees, under the Senior Community Service Employment Program, would continue to receive funding.

Will you look into this matter and expedite a response? Answer. A response to the April 11, 2002 letter will be mailed shortly. The letter mentioned Senate report language in the context of commenting on the GPRA goal of 37 percent for unsubsidized placement of SCSEP participants.

A later paragraph in the letter states that the group of five Senators ". . . . look forward to receiving your assurances that competition requirements will maintain continuity and stability at the national level by ensuring that successful grantees continue to receive funding."

In response, we note that Federal acquisition regulations require that grants and contracts are awarded through a competitive process where possible. The Procurement Review Board at the Department of Labor has reviewed the national sponsor portion of the SCSEP and recommended that it be subject to competition. The Department is committed to seeing that older Americans receive the best services. Therefore, we are looking at the option of competing the National grantee share of the SCSEP. While we wholeheartedly support accountability sanctions for poor per-formance, we believe that the best interests of participants are served by taking steps to improve services in the first instance rather than sanctioning poor performance which has already negatively impacted participants. If such a competition were to take place, we would do everything in our power to insure that it does not unnecessarily disrupt current participants and provides a fair opportunity for all eligible organizations to be national SCSEP grantees. We would expect that high performing grantees would be in an excellent position to compete for grants, although it would be a competition in name only if the results were guaranteed ahead of time.

*Question.* What is your rationale for cutting the appropriation request for this older worker program by \$4.9 million in fiscal year 2003?

Answer. Due to overall budget considerations, we did not include the additional \$4.9 million that Congress provided in last year's appropriation. Our request is a return to the status quo, not a cut, as Congress appropriated the additional funds for a single program year.

#### OSHA TRAINING GRANTS

Question. In 2000, as part of the Susan Harwood Grant program, OSHA awarded a number of Institutional Competency Building training grants that were to be funded for five years assuming "satisfactory performance and the availability of funds." These grants were awarded to non-profit groups, including the National Safety Council, unions, universities and immigrant worker groups to build safety and health training programs with particular focus on underserved workers and high risk groups. Last Fall, without any warning to the grantees, OSHA cut the 2nd year of these grants by 25 percent and announced that the program would be terminated due to reductions in funding proposed in the President's fiscal year 2002 budget request.

This committee provided an additional \$3 million in the OSHA fiscal year 2002 budget and instructed the Labor Department to use that additional funding to "restore the institutional competency building training grants."

In a letter sent to OSHA Assistant Secretary Henshaw in January, Senator Specter and I requested information on the agency's progress and, in case our instruction in the Report language was not clear enough, clarified that we expected OSHA to restore the 25 percent cut made last Fall AND "fully fund the third year of this program for all grantees who have performed satisfactorily."

Yet, in a letter sent to us on April 26, Mr. Henshaw informed us that instead of doing as the Committee instructed, OSHA plans to terminate your commitments to these grantees, and open competition for a new, one-year round of grants that you are calling "Institutional Competency Building 'transitional' grants."

Amount of the same name as the old program, and then claim that you are doing what we told you to do?

Answer. The May 22 Federal Register notice announced that the Department is making available approximately \$5.5 million for new Institutional Competency Building Grants (ICB), a significant portion of the overall \$11.175 million available for Susan Harwood Training Grants. The Department also announced that these grants would be available, through competition, to any eligible organization, include the 17 organizations that have received ICB grants in the past.

*Question.* Why would you terminate an existing program that is successful, reaching high-risk workers and providing much needed training and education to workers?

Answer. The agency hopes to attract new grantees with new and innovative ideas. Preference will be given to organizations that would develop, evaluate and validate training materials for OSHA to distribute to the public. All current fiscal year 2000 ICB grantees are eligible, and are encouraged, to apply for these grant funds in fiscal year 2002. By recompeting these grants OSHA will be able to fund 21 ICB grants, as opposed to the 17 currently funded.

#### MIGRANT JOB TRAINING

Question. Madam Secretary, the \$80 million Migrant and Seasonal Farmworker Program is slated for elimination in the Department's fiscal year 2003 budget proposal. But, Madam Secretary, I wonder whether the Department has examined the real life difficulties of providing training and related services to farmworker families and how such a program elimination would actually affect them. A look at a local agency providing services under this program may be instructive. This program enables the California Human Development Corporation to serve

This program enables the California Human Development Corporation to serve migrant and seasonal farmworkers throughout Northern California. Without these funds, more than thirteen local farmworker services offices would close with the loss of job training and a broad range of other services to more than 10,000 farmworker families. These offices also provide outreach for the Labor Department's One Stop System whose offices are not located in farmworker communities and usually do not have bilingual staff.

My own State of Iowa receives \$1.3 million to provide a broad range of services including housing for migrant workers, family self-sufficiency services, opportunities for migrant youth, emergency assistance programs, energy services such as home weatherization and assistance with utility bills, citizenship and naturalization services, and domestic violence reduction and prevention.

How does the Department intend to ensure availability of these needed services without these funds?

Answer. The 2003 Budget proposes to end this program because it has not succeeded in significantly improving participant's employment and earnings. It provides little job training. Nevertheless, the Administration recognizes the importance of support services to this population. DOL's transition from a primary-source service provider to the One-Stop center's multiple-source system of service providers will require a reasoned and strategic process that promotes the recognition and support of farmworkers by all the partners. We are committed to bringing these partners together to ensure migrant and seasonal farmworkers continue to receive quality services.

Also, other Department's have programs to address the needs of migrant workers and their families. For example, the Women, Infants, and Children (WIC) and Head Start programs provide targeted assistance to migrant worker families. In addition, two Department of Education programs are available to help migrant students complete high school and succeed in college. The budget requests \$23 million for the Migrant High School Equivalency Program (HEP) and \$15 million for the College Assistance Migrant Program (CAMP).

#### JOB CORPS EXPANSION IN WISCONSIN

Question. I am glad that in the fiscal year 2002 and now fiscal year 2003, the President's budget for the Job Corps program includes funds for Job Corps expansion. As you know, the State of Wisconsin is interested in developing a new Job Corps center to train our youth with the academic and vocational skills they need to succeed in the 21st century workforce. Currently, Wisconsin is last in terms of per capita participation in Job Corps.

Will the new round of expansion focus on expansion in under served areas like Wisconsin?

Answer. The Department recently published a notice in the Federal Register to solicit applications from communities that are interested in providing a site for a new Job Corps center. One of the criteria that the Department will use to select the two winning applications will be the degree of need for a new Job Corps center in the state in terms of eligible youth population versus the number of Job Corps

training slots now located in the state. *Question.* What steps can we take to ensure another Job Corps center comes to the State of Wisconsin?

Answer. One important step is to encourage responsible state and local officials to submit responsive applications that fulfill or exceed all of the criteria reflected in our recent Federal Register notice.

Question. At the Blackwell center in Northern Wisconsin, one of the main trades being taught is business and clerical. However, the equipment at the center is quite outdated and does not allow for students to use technology that they would use in the workplace. Also, each vocational classroom only has one computer with Internet access, which is not enough. Part of the curriculum is job searching on-line and posting your resume on-line and students are unable to fulfill this with only one Internet access computer.

The Blackwell Job Corps Center in my state has done a tremendous job of educating our youth with the technological tools they need to enter the workforce, but continuing upgrades are needed to keep pace with industry

What provisions does this budget make for Job Corps technology upgrades?

Answer. Job Corps is advancing a long-term strategy for the use of technology in its student training programs. In support of that strategy Job Corps' budget request, which is an increase of \$73 million (5 percent) above the 2002 level, includes provisions for the development of online and computer instruction in its academic and vocational classrooms. Primarily this will include funding to pilot web-based high school programs, or "virtual high schools," to increase students' opportunities to obtain their diplomas. It will also involve online professional development courses for instructors and training to enable staff to upgrade their information technology (IT) instructors and training to enable staff to upgrade their information technology (11) skills in order to help students more effectively. Job Corps is undertaking this initiative in partnership with the Department of Education as a part of the June 2001 Memorandum of Understanding to improve literacy and academic achievement in training programs for youth and adults. In addition, Job Corps' budget provides for continued investment in its computer-based training efforts that have been initiated over the past three years. These efforts include:

forts include:

enhancing Job Corps' program to teach students basic IT skills in the first 60 days that they are on centers;

-developing information technology vocational training offerings including computer repair service and network cable installation;

infusing IT training in all other Job Corps vocational training programs; and establishing working relationships with employers such as Cisco Systems, AT&T, and Sun Microsystems to develop on-center training programs, workbased learning opportunities and to gain information on industry skill requirements.

To support Job Corps' use of technology in training, Job Corps will continue to invest in its technology infrastructure. Job Corps has completed wiring and installation of computers in all academic and services trades classrooms. It has installed Learning Resource Centers in all Job Corps centers to provide students and staff with opportunities for customized, cost-effective training through Internet access, video conferencing and distance learning. In addition, Job Corps is establishing a comprehensive computerized Center Information System to gather student information, track student progress in the program and follow-up on students' placement and support after they leave Job Corps.

#### PARTNERSHIPS BETWEEN JOB CORPS CENTERS AND INFORMATION TECHNOLOGY EMPLOYERS

Job Corps Center-Sargent Shriver, Edison, Phoenix

Location—Devens, Massachusetts; Edison, New Jersey; and Phoenix, Arizona Employer Partner—Sun Microsystems; AT&T; and Cisco Systems

*Question.* How will those funds help the Blackwell center in Wisconsin?

Answer. We cannot tell you this far in advance what the exact impact will be at the Blackwell Job Corps center. These resources will be available for use starting in July, 2003. Around that time, program managers and staff will undertake a process that will identify and prioritize the needs for equipment upgrades in classrooms at all Job Corps centers. The fund allocations to Blackwell and all other Job Corps centers will be based on the results of this process.

*Question.* Is there anything the Department of Labor can do to help them upgrade their equipment and software?

Answer. We can assure you that the IT equipment and software needs at Blackwell will receive equitable consideration in the fund allocation process. Since July 1998 through the current program year (2001) Blackwell Job Corps Center has received \$193,587 in modernization funds. A large portion of these funds supported the purchase of computers, workstations, and related equipment for both the academic classes and vocational programs, in particular the Business/Clerical program. Starting in the new program year that will begin July 2002, Blackwell is scheduled to receive an additional \$2,028,000 in modernization funds. These funds have been allocated for an addition/renovation to the Academic Education Building, which will include wiring to support the technological infrastructure and \$129,000 for the purchase of equipment and computers.

#### QUESTION SUBMITTED BY SENATOR ERNEST F. HOLLINGS

#### NATIONAL SKILL STANDARDS BOARD

Question. Madame Secretary, thank you for appearing before the Subcommittee today. I want to seek clarification of comments made about the National Skills Standards Board (NSSB) on page 221 of the President's budget. In particular, the President attempts to justify eliminating funding for the NSSB because of standards developed to train busboys how to clear tables and prevent manufacturing employees from stealing. While I certainly would not want additional federal funds spent in this manner, it is my understanding that the Departments of Labor and Education issued these standards, not the NSSB. In fact, I have been told that these standards were released before the Board was even seated. Could you please clarify who in fact was responsible for the standards discussed on page 221 of the President's budget?

Answer. The skill standards example on page 221 of the President's fiscal year 2003 budget was the result of early work to develop skill standards by industry under a grant by the Department of Labor.

The decision to eliminate the funding for the NSSB in the President's fiscal year 2003 budget was not made based on this or any other anecdotal example. The decision was made largely because the NSSB was not conceived as a continuous Federal investment. Legislation authorizing the Board included a sunset date of September 30, 1999. It is clear that the legislation envisioned the completion of skills standards for all industry clusters by that date. The complete skill standards have not been achieved as of 2002 despite provision of \$45 million to NSSB.

#### QUESTIONS SUBMITTED BY SENATOR PATTY MURRAY

#### YOUTH PROGRAMS

Question. Today's workers need more education and training to develop skills that reflect our changing economy. September11th, the collapse of the Enron Corporation, and recent actions by major U.S. companies to move abroad, underscore the need for our workforce to be more adaptable. I am concerned that your budget provides \$289 million less for youth employment and training programs than in 2002. We should be increasing not decreasing our investments that focus on one of our most vulnerable sectors of the work force, young people. I am particular concerned that you propose to cut the Youth Opportunity Grants by \$181 million, from \$225 million in 2002 to \$44.5 million. That essentially guts this program. Your cut won't help children from inner cities and high poverty areas make transitions from school to work.

Secretary Chao, why are you requesting an elimination of a program that gives our most at-risk youth hope that they can be productive members of our society, by helping them stay and school and find work when they graduate?

Answer. The Youth Opportunity grants were intended to be five-year grants, with the final year of funding from PY 2003 funds. The Department intends to complete 5-year funding to the 36 current sites. The 36 sites were funded under a declining dollar amount formula, beginning with year 3. Remaining funds from PY 2001 and PY 2002 are being used to forward fund sites. Under current appropriations and with the PY 2003 budget request, we expect that there will be a relatively small reduction, amounting to only about \$200,000 per grant site.

*Question.* Do you provide adequate funding for programs aimed at helping children from poverty finish school and find work somewhere else in your budget?

Answer. The youth formula-funded grant program is continued at a slightly reduced level of new budget authority in the fiscal year 2003 budget. Under this program, states and local areas will continue to provide a comprehensive array of services to assist at-risk youth achieve academic and employment success. Despite the reduction in new budget authority proposed in the fiscal year 2003 budget for the program, it is expected that the same level of participants will be served in PY 2003, due to the amount of unexpended funds carried forward to 2003 estimated to be about \$400 million. Approximately 465,000 youth will be served in 2003. With unspent balances, we estimate that another 88,000 youth could be served.

Also, we expect that more out-of-school youth and special populations, such as youth offenders, will be served by local One-Stop systems in fiscal year 2003, through increased outreach activities, by providing a broader array of age-appropriate services for older youth and young adults, and establishing close working relationships with a wider range of youth program partners that can meet the special needs of the out-of-school population, youth offenders, and homeless youth, among others.

#### DISLOCATED WORKERS

*Question.* While there are signs of economic recovery, many sectors of our economy are still ailing. My state currently has the 2nd highest unemployment in the nation. Dislocated worker and training programs help support workers who find themselves out of a job unexpectedly. These programs help them get the training and assistance they need to transition to a new job. In the last few years, my area of the country has had particular problems with large-scale lay-offs and the energy crisis. September 11 made it worse. The slowdown in the tech sector has also impacted Washington State, as we are one of the more tech dependent areas of the country. Recently, the Department of Labor has helped workers get the training and assistance they need to find another job. My constituents and I appreciate your help. However, your budget cuts adult employment and training programs by \$39 million from the 2002 numbers. Last year you asked for a \$257 million dollar cut from the previous year.

Secretary Chao, what measures do you propose to help workers who find themselves suddenly unemployed?

Answer. In the 2003 Budget, the President provides more than enough new resources to support a substantial increase in assistance to adults and dislocated workers, when combined with large unspent balances. The budget for Workforce Investment Act (WIA) adult and dislocated worker programs includes \$3 billion in total resources—which is \$623 million, or 27 percent, more than the estimate of what states will spend in 2002. This resource total includes \$2.0 billion in new budget authority and about \$1 billion in unspent balances for state formula grants that will be carried into Program Year 2003.

Additionally, the Administration recognized the dislocation impact of the events of September 11, 2001 on the nation's workforce as well as the consequences of a continuing downturn in the economy. In an effort to quickly address these issues in the short term, the President proposed and has continued to be a strong supporter of additional resources to help the nation's unemployed and dislocated workers. In October 2001, the President proposed a "Back to Work Relief Package," which included extended unemployment benefits and an additional \$3 billion for National Emergency Grants (NEGs) to target resources to dislocated workers and communities that were struggling during the economic downturn. Although the Housepassed economic stimulus bill included \$4 billion for NEGs, the final legislation did not provide additional resources for this critical program. However, the enacted economic stimulus package did include \$8 billion in Reed Act transfers to States, which are available to provide employment services and unemployment insurance benefits to unemployed workers. Nevertheless, again in March 2002, the President proposed a \$750 million supplemental budget request, which included \$550 million for targeted assistance to dislocated workers through NEGs. Although Congress ultimately did not adopt the President's supplemental request,

Although Congress ultimately did not adopt the President's supplemental request, another source of assistance for dislocated workers and other adults recently became available. From the fiscal year 2002 appropriation, the Department of Labor will allocate almost \$2.2 billion in state formula grants for adult and dislocated worker assistance, and approximately \$265 million for additional NEGs. These resources will help achieve the President's goal of returning dislocated workers and other adults to work as quickly as possible.

Furthermore, I am pleased to report that through the NEG funds, the Department was able to respond to the worker dislocations in Washington State related to the September 11 events by providing a grant of up to \$15 million for airline and associated layoffs.

The Department of Labor continues to work with states and local communities to strengthen the services provided through their One-Stop Career Center system by providing technical assistance to help them continue to improve services to dislocated workers. In this regard, the Department has developed new tools to help state and local programs improve Rapid Response services to workers prior to their unemployment. As you know, Rapid Response provides early intervention help to workers while they are still employed with the goal of reducing their unemployment or eliminating it entirely through immediate entry into new employment. In addition, we recently convened over 150 experimental dislocated worker demonstration project grantees to distill "promising practices" from their experiences for dissemination to the broader workforce community.

broject grantees to disting produces from their experiences for discontinuation to the broader workforce community. We are confident that a mix of new funding, carryover balances, TAA, technical assistance, national emergency resources, and improvement through implementation of pilot project lessons learned, presents a strong set of measures to effectively help America's dislocated workers.

*Question.* Do you think it is wise to cut finding for these programs in a time where the economy is unpredictable? Answer. In the 2003 Budget, the President provides more than enough new re-

Answer. In the 2003 Budget, the President provides more than enough new resources to support a substantial increase in assistance to adults and dislocated workers, when combined with large unspent balances. The budget for Workforce Investment Act (WIA) adult and dislocated worker programs includes \$3 billion in total resources—which is \$623 million, or 27 percent, more than the estimate of what states will spend in 2002. This resource total includes \$2.0 billion in new budget authority and about \$1 billion in unspent balances for state formula grants that will be carried into Program Year 2003. In addition, National Emergency Grant funds may provide additional assistance

In addition, National Emergency Grant funds may provide additional assistance in response to applications from states with insufficient resources, including dislocated worker formula allotted funds, to respond to unexpected or community-wide events such as mass layoffs, plant closures, and workers indirectly or indirectly affected by foreign trade or national disasters.

Question. Does the administration care about workers who have lost their job and are now trying to learn the skills necessary to find a new one? If you read your budget requests since taking office I think it points to the conclusion that dislocated American workers aren't a priority of this administration. Answer. To the contrary, the Administration has made, and continues to make,

Answer. To the contrary, the Administration has made, and continues to make, training and jobs for American workers one of its most important goals. In the 2003 Budget, the President provides more than enough new resources to support a substantial increase in assistance to adults and dislocated workers, when combined with large unspent balances. The budget for Workforce Investment Act (WIA) adult and dislocated worker programs includes \$3 billion in total resources—which is \$623 billion, or 27 percent, more than the estimate of what states will spend in 2002. This resource total includes \$2.0 billion in new budget authority and about \$1billion in unspent balances for state formula grants that will be carried into Program Year 2003.

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In addition, early in my role as Secretary, I launched the 21st Century Workforce Initiative. Its mission is to ensure that all American workers have the opportunity to equip themselves with the necessary tools to succeed in their careers and in whatever field they choose in this new and dynamic global economy. This is a time of tremendous economic change across the country. These changes include a fundamental transformation for all industries and increasingly require higher skill sets and higher education. The Department of Labor cannot and must not simply react to changes. We must anticipate them, thus helping all workers to have as fulfilling and financially rewarding careers as they aspire to have and to ensure that no worker gets left behind. In March 2001, I created a new Office of the 21st Century Workforce to direct this effort.

One of the goals of the Department's One-Stop Career Center system is to assure that all workers have universal access to workforce information and services. The Department's Employment and Training Administration has established a Toll-Free Help Line as well as America's Service Locator on the Internet to provide additional information and locations of One-Stop offices where many services might be obtained. Information on health and pension benefits is also available at the Department's Pension and Welfare Benefits Administration Web site.

In addition, we are preparing new materials for workers and for employers. Some of these materials more fully explain the Worker Adjustment and Retraining Notification Act and directly address each constituency's concerns. These materials will also be available in Spanish. As other language needs become apparent, additional translations will be made available. We have also developed new materials to help state and local programs improve Rapid Response services to workers prior to their unemployment. This service focuses on providing early intervention services to workers while they are still employed, with the goal of reducing their unemployment or eliminating it entirely through immediate entry into new employment.

These reflect just a few of the ways by which dislocated workers can receive help and are being empowered to help themselves: Lifelong learning; increased userfriendly information through technology; better understanding of rights, responsibilities and benefits; and up front intervention before layoffs occur.

Another experimental approach we have undertaken is what we are calling "Partnerships for Jobs" with large-scale employers like HCA Healthcare, Toys R Us, and Home Depot. In the case of HCA, we have matched \$5 million in corporate scholarship funds with \$5 million in additional WIA funds provided to States and local Workforce Investment Boards to work with the company to hire and train dislocated workers (primarily those displaced by the economic fallout of September 11) and others into health care careers with an upwardly mobile future.

#### DEALING WITH DOL ON PETITIONS

Question. Programs, like Trade Adjustment Assistance, have helped Americans deal with transitioning from a job that has been taken away due to no fault of their own to an occupation that provides a livable wage. A problem with getting the needed assistance under these programs is the Department of Labor has frequently missed statutory time lines, failed to make contact with many petitioners, and have even mistaken the subject matter being investigated. One investigator of a petition in my state failed to understand the difference between wood pulp and paper, and that the product to be investigated was paper not pulp. What resulted were numerous appeals, letters and an on-site investigation by a DOL investigator. The petitioner eventually won the trade act certification after 18 months of struggle that could have been resolved with one phone call.

Secretary Chao, what measures are you taking to ensure that those handling petition for assistance in your department are communicating better with the petitioner?

Answer. Establishing good lines of communication are a key part of successfully completing actions on trade petitions. Through internal meetings with investigators and internal memoranda, we will re-emphasize the need to communicate timely and effectively with petitioners, companies and customers. Also, in the past year, we have hired and trained 10 contract staff to assist in the investigation process due to the huge increases in caseload experienced in the past year and a half. These actions will undoubtedly improve our ability to effectively manage and complete petition caseload.

Question. Can you assure me that situation like I've mentioned will be the exception and not the norm?

Answer. Yes. I can assure you that the situation mentioned is an exception and not the norm, and we will work diligently to minimize such exceptions.

#### ASBESTOS

Question. Secretary Chao, last year when you testified before this Subcommittee, I asked you about MSHA's efforts to protect miners and their families from exposure to asbestos. Specifically, I am interested in what steps MSHA has taken to implement the recommendations outlined in the Inspector General's March 22, 2001 report.

Can you please update me on MSHA's progress?

Answer. Yes, I can. MSHA published an Advanced Notice of Proposed Rulemaking in the Federal Register on March 29, 2002. This Notice requested information from the public on three major issues from the OIG's report:

1. Whether MSHA should lower its existing Permissible Exposure Level of 2 fibers per cubic centimeter to a more protective level;

2. Whether MSHA should use a more sensitive analysis method called Transmission Electron Microscopy to quantify fibers in our samples, rather than the cur-rent method called Phase Contrast Microscopy; and

3. Whether take-home asbestos contamination is a problem and, if so, how MSHA should address the problem.

As part of the public comment phase, MSHA is holding seven public meetings to solicit further comments from the public on these three issues. So far, six public meetings have been held in the following locations: Pittsburgh, Pennsylvania; Spokane, Washington; Vacaville, California; Canton, New York; Phoenix, Arizona; and Virginia, Minnesota. The last meeting will be held on June 20 in Charlottesville, Virginia.

The information submitted to MSHA in connection with these meetings is being

posted on the MSHA web site for the public to access. *Question.* Does MSHA have a time-line for implementing these recommendations? Answer. The public comment period closes June 27, 2002. MSHA will evaluate the information submitted to the record to determine the next appropriate action on each of these issues and will publish its decision in the October 2002 Unified Agen-da of planned regulatory actions.

#### JOB CORPS AND TECHNOLOGY

Question. Overall the digital divide has narrowed, but the disparity between the haves and have not has been widening in some communities. Regardless of the truth, the use of computers in our academic and vocational classrooms is important to the skills our youth take with them to higher education or employment. Some Job Corps Centers have done a tremendous job of educating our youth with the technological tools they need to enter the workforce successfully. We all agree that strong IT skills are necessary for success in today's marketplace.

Secretary Chao, are there provisions in the Job Corps' budget request for technology upgrades at our Centers?

Answer. Job Corps is advancing a long-term strategy for the use of technology in its student training programs. In support of that strategy Job Corps' budget request, which is an increase of \$73 million (5 percent) above the 2002 level, includes provisions for the development of online and computer instruction in its academic and vocational classrooms. Primarily this will include funding to pilot web-based high school programs, or "virtual high schools," to increase students' opportunities to obtain their diplomas. It will also involve online professional development courses for instructors and training to enable staff to upgrade their information technology (IT) skills in order to help students more effectively. Job Corps is undertaking this initiative in partnership with the Department of Education as a part of the June 2001 Memorandum of Understanding to improve literacy and academic achievement in training programs for youth and adults. In addition, Job Corps' budget provides for continued investment in its computerbased training efforts that have been initiated over the past three years. These efforts include:

-Enhancing Job Corps' program to teach students basic IT skills in the first 60 days that they are on centers;

- —Developing information technology vocational training offerings including computer repair service and network cable installation;
- -Infusing IT training in all other Job Corps vocational training programs; and -Establishing working relationships with employers such as Cisco Systems, AT&T, and Sun Microsystems to develop on-center training programs, workbased learning opportunities and to gain information on industry skill requirements.

To support Job Corps' use of technology in training, Job Corps will continue to invest in its technology infrastructure. Job Corps has completed wiring and installation of computers in all academic and services trades classrooms. It has installed Learning Resource Centers in all Job Corps centers to provide students and staff with opportunities for customized, cost-effective training through Internet access, video conferencing and distance learning. In addition, Job Corps is establishing a comprehensive computerized Center Information System to gather student information, track student progress in the program and follow-up on students' placement and support after they leave Job Corps.

## OSHA NATIONAL OFFICE RESTRUCTURING

*Question.* On April 23, OSHA announced a proposed restructuring of National Office operations and functions. One proposal was to merge the Directorate of Safety Standards and the Directorate of Health Standards into the new Directorate of Standards and Guidance.

Will this new position be responsible for developing the ergonomics guidelines that OSHA announced in April?

Answer. In the past, the Standards Directorates have been involved in the development of guidance documents though other Directorates may have issued the guidelines. The new guidelines are being developed in the Directorates of Health and Safety Standards at present, and development will continue in the new Directorate of Standards and Guidance when the restructuring is implemented.

#### OSHA BUDGET REQUEST

*Question.* You have requested \$14.2 million for standards development. Isn't this funding for developing mandatory standards that are different than voluntary guidelines?

Answer. Funding requested for the Safety and Health Standards budget activity provides not only for the development, promulgation, review and evaluation of safety and health standards, but also other non-regulatory products that include voluntary guidelines and informational materials.

*Question.* million for federal compliance assistance. Isn't this the budget category that is funded to develop voluntary guidelines? Answer. The Federal Compliance Assistance budget activity funds a variety of ac-

Answer. The Federal Compliance Assistance budget activity funds a variety of activities, including general outreach and technical assistance, partnerships and voluntary programs, and other compliance assistance guides. However, it does not fund the development of voluntary guidelines. These activities are funded in the Safety and Health Standards budget activity.

#### OSHA STANDARDS

*Question.* What standards will you issue in fiscal year 2002 and fiscal year 2003? Answer. The Department of Labor's regulatory agenda was published on May 13, 2002 (67 FR 33308). OSHA's regulatory agenda may be found on pages 33342 through 33355.

#### OSHA REGULATORY AGENDA

*Question.* There was a recent report that the next Regulatory Agenda, due out in June, will cut back further on planned OSHA standards. Can you tell me which standards that are currently on your regulatory agenda will be eliminated in the new agenda?

Answer. The regulatory agenda is intended to reflect those items that will be completed during the next twelve months. Some of the items withdrawn in the May 13, 2002 Federal Agenda had been previously published in the Federal Agenda in the proposal or post-proposal stages. Other items withdrawn from the agenda had not reached the proposal stage and could be resurrected if resources or priorities permit. As already noted, the current regulatory agenda is the one published on May 13, 2002. A new agenda is published every six months, so there is no new agenda due in June. The only items withdrawn from the agenda were published in the Federal Register prior to publication of the agenda. Indoor Air Quality was removed from the agenda in December 2001 (66 FR 64946). In March of this year, OSHA published a notice removing four out-of-date proposals addressing shipyards (67 FR 13177). These were the only ongoing OSHA rulemakings that were actually eliminated when they were removed from the Regulatory Agenda. Most of the rulemakings that OSHA has removed from the last two Regulatory Agendas were removed because OSHA's Regulatory Agenda now includes only projects for which the Agency expects to complete some important regulatory step within twelve months. Removal of an agenda item, in and of itself, does not mean that the Agency has either stopped work on, or eliminated, that project.

#### OSHA ENFORCEMENT BUDGET

*Question.* I would like some clarification on the OSHA enforcement budget. Isn't it true you are cutting the OSHA enforcement budget?

Answer. While the fiscal year 2003 budget includes some reductions, they reflect workforce restructuring (including the elimination of unnecessary management and administrative positions) and elimination of obsolete and one-time activities—all of which are intended to improve the way OSHA does business. They do not reflect a move away from enforcement. OSHA is not cutting any inspectors in fiscal year 2003. In fact, OSHA plans to conduct an additional 1,300 inspections next year.

*Question.* Instead of getting rid of these managers, why don't you make them into field inspectors? Especially, considering it would take federal OSHA 119 years at its current pace to visit every workplace in the United States under its jurisdiction?

Answer. OSHA has submitted what it believes is a sound, responsible budget that will support OSHA's mission and improve the way it does business. The proposed reduction of staffing in Federal Enforcement does not impact the safety and health of America's workforce. Staff proposed for elimination in fiscal year 2003 are managers and other administrative support positions that are not involved in the delivery of front line safety and health in the workplace. The reassignment of these staff would not be feasible, as inspection work demands different and relatively technical skills. The fiscal year 2003 President's Budget would allow OSHA to continue to vigorously enforce the laws that protect the Nation's workers.

#### QUESTIONS SUBMITTED BY SENATOR TED STEVENS

#### TRADE ADJUSTMENT ASSISTANCE

Question. British Petroleum recently submitted an application for Trade Adjustment Assistance (TAA) for 120 employees who are in the process of being laid off in Alaska. An additional three employees who were already laid off from BP because of declining oil production in the state applied on their own for trade adjustment assistance through your Department, but their applications were denied. The TAA funds would be used directly by the displaced workers for new job training and education. It is essential that they develop new skills if they are to find work. I am told that your Department until August or September will not make the decision on the application for the additional 120 employees. I am hopeful that your department can come to a decision sooner on this application so that these 120 employees can get the money necessary to get additional training for other employment, and that when the three already displaced workers appeal your Department's decision they can get some sort of assistance.

Answer. Decisions on petitions are made when all the necessary information is gathered and analyzed in order to determine whether the Trade Act criteria are met for certification. We began working on the latest BP petition mid-May and would expect to have a decision on the petition soon. Regarding the denied BP petition, the appeal (request for reconsideration) came to us on May 30. We are reviewing the information provided carefully and will determine if there was anything that may have been overlooked in making our earlier decision. We would expect a decision on this request for reconsideration by late June, or early July. As you are probably aware, the Dislocated Worker Program under the Workforce

As you are probably aware, the Dislocated Worker Program under the Workforce Investment Act is available to dislocated workers in Alaska. Dislocated workers can pursue opportunities for training and other supportive services through this program. *Question.* I have been contacted by the manager of a Safeway store and several constituents in Kodiak, Alaska concerning a Department of Labor review on the status of Postal substations in grocery stores. I am told only 10 Safeway stores nationwide are renting space to the Postal Service, but that your Department may classify the entire Safeway chain as a government contractor because of the USPS presence. This would subject nearly 1,500 Safeway stores nationwide to cumbersome reporting and government audits, even though most of the stores are not housing postal substations.

In many rural areas, the co-location of the post office with other community-centered enterprises is essential to maintaining reasonable cost structures and providing reliable service. I am told by executives at Safeway's headquarters that if your Department persists in this interpretation that they will have no choice but to cancel their contracts with the Postal Service, leaving my constituents in Kodiak and other rural Americans without access to some postal services. I have been told by the Postal Service that they disagree with your Department's current position on this issue, and that this will create serious problems for them in the future in terms of service options.

I am hopeful you can help find a solution to this situation that is beneficial for all involved parties without burdening an entire grocery chain.

Answer. The Department is well aware of constituents' concerns regarding these postal services. At present, Safeway has requested OFCCP to grant an exemption to its stores with current Postal leases, or alternatively, an exemption to its other retail outlets on the basis that they are separate and distinct establishments from those that have contracts with the Postal Service. OFCCP officials met with Safeway representatives to discuss their request. As a result of this meeting and information Safeway has provided to OFCCP, we believe that Safeway will be able to retain its postal facilities without triggering significant burdens under OFCCP regulations. Safeway is a large food retail chain, with approximately 1,500 retail locations. OFCCP requires covered federal contractors to develop and maintain an affirmative action program for each of their individual facilities.

In fiscal year 2001, OFCCP sent out 50,000 EO Surveys. Safeway complained about the aggregate burden of developing and maintaining affirmative action programs for each of its 1,500 stores and for having to complete nearly 500 EO Surveys. According to Safeway, it decided to terminate many of its contracts with the government to avoid these burdens. One of the types of government contracts that Safeway began to eliminate was leases to operate postal service centers in ten of its stores. Safeway terminated contracts as to 8 of the 10 postal service centers. As we understand the facts, at two Safeway locations with postal service centers, Tumwater, Washington and Kodiak, Alaska, customers complained vigorously about the proposed closing of the postal facilities. Safeway encouraged these customers to contact their Congressional representatives. In March, 2002, Safeway submitted a formal request for an exemption to OFCCP. Beginning around May, 2002, the Department began receiving correspondence from members of Congress inquiring about the Safeway situation and relating their constituents' concern over loss of postal services.

In July, 2002, OFCCP met with Safeway representatives and within the next several weeks obtained all the information necessary to evaluate Safeway's request for an exemption. OFCCP is working on a decision memorandum that will assess Safeway's exemption request and make a final determination. OFCCP's action will allow Safeway to maintain its postal service centers without incurring the more burdensome aspects of OFCCP's regulations.

#### CONCLUSION OF HEARINGS

Senator HARKIN. Thank you all very much for being here, that concludes our hearings.

[Whereupon, at 12:30 p.m., Thursday, June 6, 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 2003

## 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 THE HARBORVIEW MEDICAL CENTER

As per our prior correspondence, we very much need your help in maintaining funding for our Project With Industry within the Rehabilitation Act. This is a very effective and efficient program with tight evaluative criteria and close ties to business.

At the Harborview Medical Center, we are on track to place into competitive employment, 112 individuals with epilepsy, traumatic brain injury, and multiple sclerosis. Nore than half of our client base are already on Social Security and yet have the desire for competitive employment. We could not accomplish our goals without the commitment of company representatives from Microsoft, CSG Openline, Alaskan Copper and Brass, and other's who have a real commitment to our program. Please work to maintain or increase federal funding for PWI within the Rehabili-

tation Act.

#### PREPARED STATEMENT OF THE INTER-NATIONAL ASSOCIATION OF BUSINESS, INDUSTRY, AND REHABILITATION

We would like to bring to your attention what we consider to be a serious error in judgment in the President's Budget Request for fiscal year 2003. The President's request would eliminate funding for a number of discretionary programs authorized under the Rehabilitation Act of 1973, as amended. Specifically, four line items would be zero-funded: Projects with Industry (PWI), Supported Employment (SE) State Grants Migrant Farm Workers, and Recreation Projects. We urge you to restore and increase funding for these programs. We recommend that PWI be funded at \$50 million for fiscal year 2003 and that Supported Employment be funded at \$75 for fiscal year 2003.

year 2003. This statement is being made by the Inter-National Association of Business, In-dustry and Rehabilitation (I-NABIR) and is submitted for the record. I-NABIR is made up of 111 organization members. They include major international corpora-tions, local rehabilitation service organizations, state and regional programs, na-tional and local labor organizations, state rehabilitation agencies, national trade as-sociations, school transition programs, disability specific organizations, mental health centers, and organizations created just to provide PWI services. Members run the gamut of organizations providing employment related services to persons with disabilities, but the business and labor communities are active members as well. I-

NABIR represents most of the programs funded under the Projects with Industry program.

The Administration appears to think these separate line items are unnecessary or that they provide services that "overlap" or duplicate the services funded by State Vocational Rehabilitation (VR) program funded through Section 110 of the Rehabilitation Act. The assumption seems to be that if these services are not funded with federal dollars, the states will automatically pay for them. Currently, most states are in the process of cutting their budgets and do not have the capacity to pay for these services. In addition, rather than being duplicative or overlapping, the discretionary programs funded under the Rehabilitation Act are complementary, often providing services which are substantively different than the services provided by State VR agencies. Rather than providing statewide services like VR does, these discretionary projects are often designed to meet specific service needs (e.g., providing a business partnership model of placement services or recreational services) or to address the needs of individuals with the most severe disabilities (e.g., supported employment projects). Some discretionary projects are designed to meet the needs of specific astor of the population which are significantly underserved by the State VR agencies.

Rather than de-funding, and thus ending these discretionary programs, we believe that they, along with the Public VR program, need and deserve significant increases in funding for fiscal year 2003. The Consortium for Citizens with Disabilities (CCD) has recommended that PWI funding be increased to \$50 million and Supported Employment to \$75 million along with a very substantial increase in Title I funding. We agree with these recommendations and urge them to be incorporated in the Senate bill.

Projects With Industry was created in 1968 as part of the Rehabilitation Act. Its purpose is to develop cooperative arrangements between rehabilitation organizations and private employers in building competitive employment placement programs for persons with disabilities. According to the US Department of Education, approximately 13,000 persons with disabilities obtained jobs through Projects with Industry programs in 2000 at an average cost per placement of \$1,700. The PWI program is currently funded at \$22.1 million. It has been level funded since 1994.

Thirty-seven State VR agencies are under an order of selection for fiscal year 2002. State VR agencies are more likely to use any additional funding to meet the needs of individuals applying for VR services, rather than initiating new programs or funding existing PWI or supported employment projects. In fact, the Council of State Administrators of Vocational Rehabilitation (CSAVR) and the National Organization of Rehabilitation Partners (NORP), the organizations representing State VR agencies across the country are opposed to the President's proposal to roll the funding for these important and complementary discretionary into the federal appropriation for the Public VR program.

At a minimum, the President's budget request to defund PWI and Supported Employment should be delayed and examined in context of the upcoming reauthorization of the Rehabilitation Act in 2003. Policy changes of this magnitude should be part of a reauthorization process, not part of the appropriations' process. There are many important issues that need to be thoroughly reviewed and addressed by Congress over the next year as part of the reauthorization process. In de-funding these four discretionary programs, the Administration is actually amending the Rehabilitation Act through the appropriations' process. We feel this is not the proper way to address these important legislative issues.

One particular concern is the fact that elimination of the Projects with Industry and Supported Employment State Grant Programs would have a negative impact on the success of the new Ticket to Work program that is intended to assist Social Security disability beneficiaries in securing employment and getting off the disability rolls. Existing PWI and supported employment projects are viewed as critical players as employment networks in the Ticket to Work program. While the President calls for timely implementation of the Ticket to Work program, his budget request will have a definite negative impact on such implementation. The Advisory Panel on the Ticket Program has written President Bush expressing their strong opposition to his budget proposal to end federal funding for PWI and supported employment.

#### PROJECTS WITH INDUSTRY

Projects With Industry was created in 1968 as part of the Rehabilitation Act. Its purpose is to develop cooperative arrangements between rehabilitation organizations and private employers in building competitive employment placement programs for persons with disabilities. According to the U.S. Department of Education, approximately 13,000 persons with disabilities obtained jobs through Projects with Industry programs in 2000 at an average cost per placement of \$1,700. The PWI program is currently funded at \$22.1 million. Individual PWI's must match the federal funds with 20 percent of their own funds or donated goods or services. In some cases, the match made available to a PWI project is well above 20 percent. PWI differs from other placement services in several respects. First and foremost, business is recognized as a full partner in the process. Business Advisory Councils (BAC) are key to every aspect of the program from determining labor market needs to designing training that will meet employer needs. It is recognized that employers are customers of PWI projects, as are the individuals with disabilities seeking placement services. It is understood that successful placements will not occur if the needs of employers are not being met. There are over 2,500 businesses that currently serve

PWI is business and results oriented with stringent performance standards. This is the type of program that should be valued and increased—not eliminated.

#### PWI IS NOT A DUPLICATION OF THE STATE VOCATIONAL REHABILITATION (VR) PROGRAM

PWI's are not a duplication of the State VR program, or of other job training or placement programs. The business partnerships make PWI services fundamentally unique and different from VR services. Most of the projects provide job training as well as placement services. Often the job training is done in conjunction with the members of the BAC. These members also contribute a great deal in goods and services to the services available to job seekers, creating a match for the federal dollars that range from the required 20 percent to 100 percent, with an estimated average match of almost 40 percent. PWI's have served as a bridge between the VR system and the business commu-

PWI's have served as a bridge between the VR system and the business community. They have served well as partners to VR. As businesses themselves (or by operating in a business outcome-based model), PWIs have a thorough understanding of the needs of the business community and have proven to be effective and efficient in meeting those needs. Many employers cite this as the critical different that justifies a separate PWI program.

#### PWI NEEDS TO BE A FEDERAL PROGRAM

Many PWI projects are national or multi-state in nature. Job prospecting and client placements don't end at the state lines. The job prospecting moves along industry lines.

Try lines. With PWIs operating as Federally funded projects, a peer review, competitive grant process is used to select the most qualified from a national pool of applicants. This national competitive process helps to assure quality and openness of opportunity.

PWI organizations also work in strong partnership with a broad variety of other programs from School to Work, TANF, One-Stops, Workforce Development Boards,

Ticket to Work, Business Leadership Networks, and many locally based programs. Choice is a major concern among people with disabilities, advocates, and policy makers. Job seekers with disabilities which are barriers to employment need to be able to choose from an array of providers and PWI offers an excellent alternative.

#### FEW, IF ANY, PWI'S WOULD SURVIVE UNDER THE ADMINISTRATION'S PLAN

If the Administration's budget proposal is implemented, few, if any, current PWI's will survive. Even if states were to decide to continue funding the existing PWI's (which is doubtful) it would be too late since most PWI's will end their current grant cycle in September 2002.

Most states are so strapped financially that they will need any additional funds to address other priorities. If the PWI funds are rolled into the VR funding, states will have to match these additional funds. As a separate funding stream, PWI funds are already being matched with private resources.

#### THE RESEARCH TRIANGLE INSTITUTE SHOULD COMPLETE THE PWI EVALUATION

The Administration should not take this drastic step of ending a program that has been successful for more than 30 years without thoroughly studying the matter and receiving input from a variety of interested parties. The Research Triangle Institute (RTI) in North Carolina was granted a 2-year contract beginning October 1, 2000 to conduct a through evaluation of the PWI program. Activities RTI is undertaking to fulfill the purposes of this study include: (1) a comprehensive review of grantee documents; (2) collection of survey data from the universe of PWI grantees; and (3) site visits to 30 nationally representative PWI projects. These site visits will involve interviews with PWI project directors, state VR agency staff, Business Advisory Council members, and local Workforce Investment Board members. RTI has a survey instrument ready to send to the various audiences noted above; however, questions from the Office of Management and Budget have delayed implementation of the survey. RTI's evaluation was to have been completed by September 2002 so the results could be used in the reauthorization of the Rehabilitation Act in 2003. We think it is imperative that the Administration postpone any final decision on the PWI program until the RTI evaluation has been completed and the findings of the evaluation have been analyzed.

# ANY CHANGES TO THE PWI PROGRAM SHOULD BE MADE THROUGH THE REAUTHORIZATION PROCESS

The appropriate means to consider changes to programs under the Rehabilitation Act is through the reauthorization process. The Rehabilitation Act is up for reauthorization in 2003. The reauthorization process is the appropriate time for the Administration to put forth major policy changes related to the Rehabilitation Act.

#### CONGRESS SHOULD INCREASE FUNDING FOR PWI

PWI has a proven track record over more than 30 years of placing persons with disabilities into competitive jobs in the community. It has proven to be a most effective means of involving the business community in the rehabilitation process. PWI provides a bridge between the private business community and government supports for people with disabilities. In every nationwide PWI competition conducted during the last 15 to 20 years, the number of qualified applications has far exceeded the available funding. Rather than cutting PWI funding, we believe additional funding should be made available so that more individuals with disabilities can be placed through PWI projects We recommend that the Projects with Industry program be funded at \$50 million for fiscal year 2003.

#### LETTER FROM THE INTERNATIONAL ASSOCIATION OF MACHINISTS CENTER FOR ADMINITERING REHABILITATON AND EMPLOYMENT SERVICES, Arlington, TX.

## Senator KAY BAILEY HUTCHISON,

Washington, DC.

This letter is being written to encourage positive participation in the fate of the Projects With Industry Grant Programs for People with Disabilities. IAM CARES, Inc. (International Association of Machinists-Center for Admin-

IAM CARES, Inc. (International Association of Machinists-Center for Administering Rehabilitation and Employment Services) is a 501(c)3 national organization that has been in the Fort Worth Dallas area since 1984 serving people with disabilities and helping them to find jobs. During the course of these years, IAM CARES— Texas has placed approximately 2,000 persons into competitive positions earning good wages and paying taxes.

Many of our national offices operate, as does Fort Worth Dallas, under these PWI programs. They are the single most influential programs in the country affecting thousands of lives of the people we serve. IAM CARES has placed over 25,000 people across the nation while serving mostly under the PWI programs.

Because of your position as a member of the Senate Appropriations Subcommittee for the Departments of Education-HHS-Labor, IAM CARES-Texas would like to encourage you to think favorably about the funding levels for the next year for Project With Industries (PWI) programs. These DOE/RSA grants are designed to help people with disabilities find jobs by bringing together Business, Industry, and Rehabilitation.

This is accomplished through a Business Advisory Council representing IAM CARES and is comprised of seventeen local and area representatives of businesses, District #776 Machinists union, the Texas Rehabilitation Commission and the Texas Workforce Commission. It is the only program of its kind in the country, as far as I know.

The basic message to get across at this time is: (1) PWI is important to people with disabilities and businesses in Texas. (2) I would like to request that, as a member of the Senate Appropriations Subcommittee, you help maintain federal funding for PWI and the other discretionary programs in the Rehabilitation Act as well as the basic state grant program and (3) Funding for PWI at \$50 million for next year (fiscal year 2003).

Thank you for your time and consideration to this important matter.

#### R.A. WADE, Area Project Director, PWI: IAMCARES.

#### PREPARED STATEMENT OF ROBBIE ARRINGTON

The Honorable Kay Bailey Hutchison: Please accept this statement as support for funding PWI programs at \$50 million for next year (fiscal year 2003). Please review the attached Houston PWI Program stats.

PWI is important to people with disabilities and businesses in Texas. People with disabilities gain meaningful and gainful employment while employers receive the benefit of pre-screened applicants and assistance in working with people with disabilities (ADA issues).

I am also requesting that as a member of the Senate Appropriations Subcommittee you will maintain federal funding for not only PWI but the other discretionary programs in the Rehabilitation Act as well as the basic state grant program.

	10/97-9/98	10/98-9/99	10/99–9/00	10/00-9/01
Number of Customers Served	224	250	245	233
Number of Customers Served/w Significant Disabilities	140	115	137	199
Total Number of Customers Placed	83	105	104	139
Average Hourly Wage	\$8.35	\$8.46	\$8.82	\$8.66

#### PREPARED STATEMENT OF THE ASSOCIATION OF UNIVERSITY PROGRAMS IN OCCUPATIONAL HEALTH AND SAFETY

Thank you for the opportunity to present testimony to the Subcommittee in support of funding for the National Institute for Occupational Safety and Health (NIOSH) and for the NIOSH-funded Education and Research Centers (ERCs). My name is Jacqueline Agnew, and I am the Director of the Education and Research Center at Johns Hopkins University.

Center at Johns Hopkins University. I am testifying on behalf of the Association of University Programs in Occupational Health and Safety (AUPOHS), the organization that represents 16 multi-disciplinary, NIOSH-supported, university-based Education and Research Centers (ERCs). The ERCs are regional resources for all parties involved with occupational health and safety—industry, labor, government, academia, and the general public. The ERCs play the following roles in helping the nation reduce losses associated with work-related illnesses and injuries:

-Prevention Research.—Developing the basic knowledge and associated technologies to prevent work-related illnesses and injuries.

- *Research Training*.—Preparing doctoral-trained scientists who will respond to future research challenges and who will prepare the next generation of occupational health and safety professionals.
- tional health and safety professionals. —Professional Training.—Graduate degree programs in Occupational Medicine, Occupational Health Nursing, Safety Engineering, and Industrial Hygiene to provide qualified professionals in essential disciplines.
- -Continuing Education.—Short courses designed to enhance professional skills and maintain professional certification in occupational health and safety disciplines. These courses are delivered on-campus at the 16 ERCs as well as through distance learning technologies.
- -Regional Outreach.-Responding to specific requests from local employers and workers on issues related to occupational health and safety.

#### THE SCOPE OF THE PROBLEM OF OCCUPATIONAL INJURY AND ILLNESSES

The many causes of occupational injury and illness represent a striking burden on America's health and well-being. On an average day, the nation suffers the following losses:

—137 Americans die from work-related illnesses

—17 Americans die from work-related injuries

-9,000 workers sustain injuries on the job resulting in temporary or permanent disabling conditions

This is an especially tragic situation because most work-related fatalities, injuries and illnesses are preventible with effective, professionally directed, health and safety programs. Although we have our nation has made tremendous progress in reducing occupational illnesses and injuries during the past 30 years, leading to a decline in the rate of total recordable cases from 11.0 to 7.1 cases per 100 full-time workers between 1973 to 1997, the burden of occupational illnesses and injuries remains unacceptably high.

Furthermore, we do not live in a static environment. The rapidly changing workplace continues to present new health risks to American workers that need to be addressed through occupational safety and health research. For example, by the year 2005, an estimated 33 percent of the U.S. workforce will be 45 years or older. Work-injury fatality rates begin increasing at age 45, with rates for workers 65 years and older nearly three times as high as the average for all workers. Despite being the primary federal agency for occupational disease and injury prevention in the nation, NIOSH receives only about \$1 per worker per year for its mission of research, professional education and outreach.

# THE NEW ROLE OF OCCUPATIONAL SAFETY AND HEALTH PROFESSIONALS IN HOMELAND SECURITY

The tragic events of September 11, and the new threats faced by emergency responders, mail handlers, and other workers, illustrate the great concern for workplace health and safety needed in the ongoing war on terror. The NIOSH ERCs play a crucial role in preparing Occupational Safety and Health (OSH) professionals to identify and ameliorate vulnerabilities to terrorist attacks and other workplace hazards.

Thanks to the Subcommittee's support for occupational health and safety research, NIOSH last year developed more effective methods to test for anthrax contamination in congressional offices. These procedures are now being used by the Coast Guard, the FBI, and Government Building Contractors.

In addition, occupational health and safety professionals have worked for several years with emergency response teams to minimize losses in the event of a disaster. NIOSH took a lead role in protecting the safety of emergency responders in New York City and Virginia, with ERC-trained professionals applying their technical expertise to meet immediate protective needs and conducting ongoing activities to safeguard the health of clean-up workers.

In the face of the growing concerns surrounding homeland security, ERCs have rapidly upgraded research coordination and expanded training opportunities, including sponsoring national and regional forums on response to bioterrorism and other disasters.

#### THE NEED FOR OCCUPATIONAL SAFETY AND HEALTH MANPOWER

The NIOSH ERCs were reviewed by the DHHS Office of the Inspector General in 1995. The resulting report affirmed the efficacy of the ERCs in producing graduates who pursue careers in occupational safety and health. Since the ERCs are regional, they are ready to respond to various trends in industries throughout the country. And because they provide training that is multi-disciplinary, ERCs graduate professionals who can protect workers in virtually every walk of life. Despite the recognized success of the ERCs in training qualified occupational health and safety professionals, the country continues to have ongoing shortages. The manpower needs are especially acute for doctoral-level trained professionals who can conduct biomedical research and help in implementing the National Occupational Research Agenda.

In May 2000, the Institute of Medicine issued its final report on the education and training needs for occupational safety and health (OSH) professionals in the United States. This report concluded that "the continuing burden of largely preventable occupational diseases and injuries and the lack of adequate OSH services in most small and many larger workplaces indicate a clear need for more OSH professionals at all levels." Specific needs identified by the IOM report include:

- -An insufficient number of doctoral-level graduates in occupational safety, thus limiting the nation's capacity to perform essential research and training in traumatic injury prevention.
- —An inability to attract physicians and nurses into formal OSH academic training programs, thus limiting the resources needed to deliver occupational health services.

#### FUNDING RECOMMENDATION FOR FISCAL YEAR 2003

Mr. Chairman, AUPOHS supports Congress' goal to double funding for biomedical research through support of the National Institutes of Health (NIH). We also believe that investment in biomedical research to prevent, treat, and rehabilitate occupational injuries and illnesses is an equally wise investment. NIOSH, which is part

of the Centers for Disease Control and Prevention, does not have a research counterpart in NIH. Therefore, efforts to address occupational health and safety research needs should be appropriately funded by Congress and led by NIOSH.

NIOSH and its partners in the private and public sector have developed the National Occupational Research Agenda (NORA) to guide occupational safety and health research into the next decade. Our nation's universities, through AUPOHS, have participated with industry, labor, and professional organizations to help NIOSH develop this coordinated research agenda for the nation.

The implementation of NORA requires increased NIOSH funding. While other federal research bodies have experienced growth in their budgets during the past two decades, NIOSH has lost research capacity at a time when it is needed more than ever. This erosion of research capacity is recognized by university researchers and has negatively impacted new research initiatives. NIOSH is fully integrated into the NIH system for funding research grants. All submitted proposals are peer reviewed by a standing NIH study section. For most of the 1990s, research proposals submitted to NIOSH had a funding success rate of between 15 and 20 percent, compared to a success rate of about 28 percent for NIH overall. The relatively low success rate, which is directly tied to low levels of research funding, has led some investigators to refocus their research priorities into other areas, leading to a shrinkage in grant submissions. Additional support for ERCs would expand the pool of qualified researchers and ensure that critical research needs are addressed. Thanks to the Subcommittee, and the Chairman in particular, Congress has taken

Thanks to the Subcommittee, and the Chairman in particular, Congress has taken a first step to reversing this trend by providing \$2 million to ERCs in fiscal year 2002 for research activities as part of an overall NIOSH increase of \$16 million. Given the expanded need for both research and training in response to the heightened threat of terrorism, we hope to work with the committee to expand federal support for NIOSH and the ERCs.

AUPOHS requests \$5 million for ERCs, and we are supporting a \$60 million total increase over fiscal year 2002 for NIOSH.—Given that most of NIOSH's extramural research program is carried out by our institutions, sustaining the academic infrastructure provided by the ERCs is essential to the success of NORA. Our recommendation would ensure that our nation's universities have the capacity and manpower to implement NORA and expand training programs to improve the health and productivity of American workers. Funding for NIOSH and the ERCs would reduce the staggering burden of occupa-

Funding for NIOSH and the ERCs would reduce the staggering burden of occupational illnesses and injury on the American economy. In 1992, the direct and indirect costs of work-related injuries and illnesses totaled \$171 billion. To put this number in perspective, these costs dwarf the \$33 billion for AIDS and the \$67 billion for Alzheimer's Disease, and they are comparable to the \$164 billion economic cost for all circulatory diseases and the \$171 billion cost of cancer. Yet federal support for occupational safety and health research pales in comparison for example, cancer research receives 15 times as much federal funding.

Indeed, total funding for ERCs alone remained essentially flat throughout the 1990s, despite the growth in the number of ERCs. In real dollars, the average ERC has suffered a 35 percent reduction in funding since 1980. This erosion in real dollar support seriously threatens our ability to implement the NORA agenda through university-based research and training and respond to the ever-changing needs of the American workplace.

Thank you for the opportunity to testify of the great need for research and training in occupational safety and health.

#### NIOSH-SUPPORTED EDUCATION AND RESEARCH CENTERS (ERCS)

The University of Alabama (Birmingham) and Auburn University, Deep South Center for Occupational Health and Safety; University of California at Berkeley and University of California at San Francisco, Northern California Education and Research Center; University of California at Los Angeles and University of Southern California, Southern California Education and Research Center; University of Cincinnati, Institute for Occupational and Environmental Health; Harvard University, Harvard Education and Research Center; The University of Illinois, Great Lakes Center for Occupational and Environmental Health; The University of Iowa, Iowa Education and Research Center; Johns Hopkins University, Johns Hopkins Education and Research Center; The University of Michigan Center for Occupational Health and Safety Engineering; The University of Minnesota, Midwest Center for Occupational Health and Safety; Mt. Sinai Medical Center, New Jersey Institute of Technology, and Hunter College, New York-New Jersey Education and Research Center; The University of North Carolina Education and Research Center; The University of South Florida, Sunshine Center for Occupational Safety and Health; The University of Texas at Houston, Southwest Center for Occupational and Environmental Health; The University of Utah, Rocky Mountain Center for Occupational and Environmental Health, and The University of Washington, Northwest Center for Occupational Health and Safety.

#### PREPARED STATEMENT OF THE NATIONAL TREASURY EMPLOYEES UNION

My name is Colleen M. Kelley and I am the National President of the National Treasury Employees Union (NTEU). NTEU represents more than 150,000 federal employees across 25 agencies and departments of the federal government, including employees in a number of HHS agencies.

NTEU represents employees in the Health Resources and Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA), Administration for Children and Families (ACF), Administration on Aging (AoA), Office of the Secretary (OS), Office for Civil Rights (OCR), Program Support Center (PSC) and the National Center for Health Statistics (NCHS). NTEU also represents employees in the Social Security Administration's Office of Hearings and Appeals (OHA).

The tragic events of September 11 showed the world that civil servants at every level of government are hard-working men and women committed to doing the best possible job in spite of often difficult circumstances. The need to hire and maintain a highly trained and skilled federal workforce has never been more clear. Yet, due to inadequate pay and benefits, the federal government often loses the battle for the best employees to state and local governments and private sector employers.

As the Chairman knows, for too long, too little attention and too few resources have been spent on the federal government and its employees. The human capital crisis the federal government faces will only be solved when we begin to treat federal employees as assets to be valued, not costs to be cut. Adequate and stable agency funding coupled with appropriate pay, benefits and incentives are key to ensuring that the government is able to attract and retain the federal employees it needs.

Unfortunately, funding has been severely constrained at most federal agencies for quite some time. Agencies have been left with inadequate resources to accomplish their missions and insufficient funding to reward their employees. They have been hamstrung by restrictive appropriations levels and forced to shuffle resources between competing priorities and from one account to another.

Fiscal year 2003 will be no different. According to the Congressional Budget Office (CBO), once funding for homeland security and defense is removed from the discretionary spending figures suggested in the President's fiscal year 2003 budget, discretionary spending declines by 1 percent. The funding levels suggested by the President will not even permit agencies to keep pace with inflation. The Administration's fiscal year 2003 budget request for program management at

The Administration's fiscal year 2003 budget request for program management at the Health Resources and Services Administration (HRSA) is \$161 million, a reduction of \$2 million from the fiscal year 2002 funding level. HRSA's role is to insure equal access to quality health care, particularly for our low-income and uninsured populations as well as those with special needs. The essential services this agency provides are desperately in need of expansion, yet the agency faces a funding reduction of \$2 million. HRSA cannot accomplish its mission with fewer employees and reduced resources.

The President's proposal for program management funds for the Substance Abuse and Mental Health Services Administration (SAMHSA) is \$80 million. This figure represents a reduction of \$15 million and 28 full time equivalent employees from the agency's fiscal year 2002 funding level. As the Chairman knows, SAMHSA's mission is to constantly improve the quality and availability of services to help those suffering from substance abuse and mental illness. This will not be accomplished by squeezing agency funding levels and NTEU hopes the Committee will restore this much needed funding.

The Administration for Children and Families (ACF) is not slated to receive any funding increase over its fiscal year 2002 level for program administration under the Administration's fiscal year 2003 budget request. Given the array of programs this agency oversees to help strengthen families and develop supportive communities, it is difficult to understand the President's recommendation for no new funding. Funding restrictions in past years have already hampered ACF's ability to fulfill its complex and important mission. This is truly an agency that cannot continue to provide quality services to low-income families and individuals without additional resources.

NTEU is also troubled by proposals the Administration has made to shift the Head Start Program from the Department of Health and Human Services to the Department of Education. The Head Start Program has a long tradition of delivering comprehensive family services—not just early learning experiences for young children, but an array of services that support the learning environment for low income families and parents. The Head Start Program's ability to address the range of issues often facing low-income children and their families is what has made Head Start the premiere program it is today. Proposals to transfer oversight for Head Start from HHS to the Department of Education ignore the comprehensive nature of the program. NTEU believes such proposals also risk destroying what most agree is one of the federal government's most successful programs. NTEU urges this Committee to reject proposals to move Head Start to the Department of Education.

For fiscal year 2003, the budget request for program administration at the Administration on Aging (AoA) is \$19 million, an amount identical to the agency's fiscal year 2002 funding level. Helping older Americans remain independent and productive is one of the Administration on Aging's key goals. The agency operates nutrition programs, caregiver support programs and preventive health programs. There is little question that AoA will be called upon to continue and expand its work in the coming years; their funding level needs to reflect this reality.

NTEU also represents employees in the Office of the Secretary of HHS. The President's budget request for departmental management is \$13 million above the fiscal year 2002 funding level, a reflection of the important work accomplished by the Office of the Secretary. Employees of the Office of the Secretary administer and oversee the organization, programs and activities of the entire Department of Health and Human Services. NTEU hopes the Committee will support this proposed increase.

The Administration's budget request for the Office for Civil Rights (OCR) for fiscal year 2003 is \$2 million above their fiscal year 2002 funding level. As you know, HHS's Office of Civil Rights provides critical oversight in insuring that all individuals have equal access to the services and programs HHS provides. OCR employees are responsible for enforcing civil rights statutes that prohibit discrimination in federal health and social services programs. In many years, OCR's funding level has not reflected the agency's critical mission and NTEU urges the maximum possible appropriation for the Office for Civil Rights. For the National Center for Health Statistics (NCHS), the Administration has re-

For the National Center for Health Statistics (NCHS), the Administration has requested a small increase over the agency's fiscal year 2002 funding level. The work undertaken by NCHS employees is critical to assessing the effectiveness of health care programs and determining appropriate public health practice. It is shortsighted not to provide the NCHS with the funding necessary to accomplish their mission. The Department of Health and Human Services' Program Support Center provides an array of support services to both HHS and other federal agencies. These

The Department of Health and Human Services' Program Support Center provides an array of support services to both HHS and other federal agencies. These services include human resource and financial management supports as well as a range of administrative services. For fiscal year 2003, the Administration has recommended an increase in appropriations, yet calls for a reduction of 51 full time equivalent employees. NTEU urges the Committee to question the Administration's plans for the PSC in the coming fiscal year and provide the highest possible funding level for the important work accomplished by this HHS division.

NTEU also represents employees in the Office of Hearings and Appeals (OHA) of the Social Security Administration. As the Committee knows, OHA is charged with providing claimants who have been found ineligible for disability benefits with a fair and timely hearing of their cases. Today, the growing backlog of cases before OHA prevents a fair and timely hearing for these individuals. The fundamental problem is that OHA lacks sufficient decision makers to handle its rapidly growing workload.

Since the mid-1990's, SSA's disability program has been in crisis. In 1995, SSA introduced a program called the Senior Attorney Program that was instrumental in reducing the backlog and improving processing times. In every respect, the Senior Attorney Program was a success. The agency's experienced staff attorneys were given the authority to decide and issue fully favorable decisions—without the time and expense of a full hearing—in those cases where the evidence clearly identified an individual as disabled. It materially improved both the quality and timeliness of service to the public. The OHA backlog fell from over 550,000 pending cases to a low of 311,000 at the end of fiscal year 1999.

Unfortunately, SSA chose to terminate this innovative program as it undertook its Hearing Process Improvement (HPI) plan, a plan even SSA now agrees was not successful. Once again, the backlog of cases before OHA has climbed to record numbers. By March of 2002, the backlog stood at more than 486,000 pending cases and SSA projects that by the end of fiscal year 2002, the backlog will rise to 546,000 cases.

The Senior Attorney Program benefitted more than just those claimants who received their disability benefits sooner than would have otherwise been the case. Administrative Law Judge time was more wisely spent on cases that required a hearing, thereby reducing processing times for those cases as well! NTEU urges the Committee to closely review the original Senior Attorney Pro-

NTEU urges the Committee to closely review the original Senior Attorney Program. Not only was it a resounding success, it materially improved the quality of service to the public and resulted in administrative and program cost savings. With an inevitable increase in disability applications expected as the "baby boomers" age, the time to address the situation is now. The Senior Attorney Program worked. It did not consume additional resources, nor did it require the hiring of hundreds of new Administrative Law Judges. The Senior Attorney Program provides an answer with proven results. Its termination was short sighted and NTEU urges this Committee to carefully consider it as a potential solution to the growing backlogs facing the Office of Hearings and Appeals.

Mr. Chairman, thank you again for this opportunity to share our views on the fiscal year 2003 funding needs for the agencies within the jurisdiction of your Committee.

#### PREPARED STATEMENT OF THE CONSORTIUM FOR CITIZENS WITH DISABILITIES EMPLOYMENT AND TRAINING TASK FORCE

The Consortium for Citizens with Disabilities Employment and Training Task Force, a coalition of national organizations writes to bring to your attention a serious concern we have with the President's fiscal year 2003 budget request. The President's request would eliminate funding for a number of discretionary programs authorized under the Rehabilitation Act of 1973, as amended. Specifically, four line items would be zero-funded: Supported Employment (SE) State Grants, Projects with Industry (PWI), Migrant Farm Workers, and Recreation Projects.

The Administration appears to think these separate line items are unnecessary or that they provide services that "overlap" or duplicate the services funded by State Vocational Rehabilitation (VR) program funded through Section 110 of the Rehabilitation Act. The assumption seems to be that if these services are not funded with federal dollars, the states will automatically pay for them. Currently, most states are in the process of cutting their budgets and do not have the capacity to pay for these services. In addition, rather than being duplicative or overlapping, the discretionary programs funded under the Rehabilitation Act are complementary, often providing services which are substantively different than the services provided by State VR agencies. Rather than providing statewide services like VR does, these discretionary projects are often designed to meet specific service needs (e.g., providing a business partnership model of placement services or recreational services) or to address the needs of individuals with the most severe disabilities (e.g., supported employment projects). Some discretionary projects are designed specifically to meet national or regional needs, while others are designed to meet the needs of specific segments of the population which are significantly underserved by the State VR agencies.

Although the President's budget encourages State VR agencies to continue funding these discretionary projects, it is very unlikely that this will happen since the funds available to State VR agencies are inadequate to meet the many challenges already facing the program. Thirty-seven State VR agencies are under an order of selection for fiscal year 2002. This means that these State Agencies have determined that the State and Federal funds available to the program are insufficient to meet the needs of the potentially eligible individuals with disabilities in the state who are likely to seek assistance from VR during fiscal year 2002. This being the situation, State VR agencies are more likely to use any additional funding to meet the needs of individuals applying for VR services, rather than initiating new programs or funding existing PWI or supported employment projects. In fact, the Council of State Administrators of Vocational Rehabilitation (CSAVR), the organization representing State VR agencies across the country is opposed to the President's proposal to roll the funding for these important and complementary discretionary into the federal appropriation for the Public VR program. CSAVR still maintains that the Public VR program is sorely under-funded to address its mandates in the Rehabilitation Act and the challenges facing the program due to changes in the environment, e.g., passage of the Workforce Investment Act of 1998 and the Ticket to Work and Work Incentives Improvement Act of 1999.

At a minimum, the President's budget request should be delayed and examined in context of the upcoming reauthorization of the Rehabilitation Act in 2003. Policy changes of this magnitude should be part of a reauthorization process, not part of the appropriations' process. There are many important issues that need to be thoroughly reviewed and addressed by Congress over the next year as part of the reauthorization process. In de-funding these four discretionary programs, the Administration is actually amending the Rehabilitation Act through the appropriations' process. We feel this is not the proper way to address these important legislative issues.

Of particular concern is the fact that elimination of the Projects with Industry and Supported Employment State Grant Programs would have a negative impact on the success of the new Ticket to Work program that is intended to assist Social Security disability beneficiaries (i.e., people on SSDI and SSI) in securing employment and getting off the disability rolls. Existing PWI and supported employment projects are viewed as critical players in the Ticket to Work program. Many of these projects will be applying to the Social Security Administration (SSA) to be approved to function as employment networks and provide services to eligible beneficiaries who want to go to work. One of the underlying principles of the ticket legislation is to increase the universe of service providers who will make their services available to Social Security beneficiaries with disabilities. While the President's New Freedom Initiative calls for timely implementation of the Ticket to Work program, his budget request will have a definite negative impact on such implementation.

Rather than de-funding, and thus ending these discretionary programs, we believe that they, along with the Public VR program need and deserve significant increases in funding for fiscal year 2003. The Consortium for Citizens with Disabilities (CCD) recommendations increases in funding of \$50 million for PWI and \$75 million for supported employment state grants. CCD has recommended a very significant increase for the Title I state grants and feel that there be an increase of a minimum of 10 percent over the amount appropriated in 2002.

We have attached detailed information on the supported employment program, the Projects with Industry program, and the challenges facing the Public VR program, along with a justification for an increase in funding for these three programs. Given that the funding for PWI and supported employment constitutes 92 percent of the total funds that the Administration is seeking to roll into the Section 110 funding, there is really no substantive increase in VR funding beyond the Consumer Price Index (CPI) increase mandated in the Rehabilitation Act.

The co-chairs and other members of the Employment and Training Task Force would be glad to meet with you and your staff to discuss this matter at your convenience.

- Alan Dinsmore, American Foundation for the Blind—202–408–0200; Cheryl Bates-Harris, NAPAS—202–408–9514; Charles Harles, I-NABIR—202–546–2847; Celane McWhorter, APSE—703–683–1166
   American Congress of Community Supports and Employment Services
- —American Congress of Community Supports and Employment Services (ACCSES); American Foundation for the Blind; American Network of Community Options and Resources; Association for the Education and Rehabilitation of the Blind and Visually Impaired; Association for Persons in Supported Employment; Council of State Administrators of Vocational Rehabilitation (CSAVR); Easter Seal; Helen Keller National Center; Inter-National Association of Business, Industry and Rehabilitation (I-NABIR); National Association of Developmental Disabilities Councils; International Association of Psychosocial Rehabilitation Services (IAPSRS); National Association of Protection and Advocacy Systems (NAPAS); National Industries for the Blind; National Mental Health Association; NISH; Paralyzed Veterans of America; The Arc of the United States

#### PROJECTS WITH INDUSTRY

Projects With Industry was created in 1968 as part of the Rehabilitation Act. Its purpose is to develop cooperative arrangements between rehabilitation organizations and private employers in building competitive employment placement programs for persons with disabilities. According to the U.S. Department of Education, approximately 13,000 persons with disabilities obtained jobs through Projects with Industry programs in 2000 at an average cost per placement of \$1,700. The PWI program is currently funded at \$22.1 million. This is the type of program that the Bush Administration should value and increase—not eliminate.

PWI differs from other placement services in several respects. First and foremost, business is recognized as a full partner in the process. Business Advisory Councils (BAC) are key to every aspect of the program from determining labor market needs to designing training that will meet employer needs. There are over 2500 businesses that currently serve on PWI BAC's.

# PWI IS NOT A DUPLICATION OF THE STATE VOCATIONAL REHABILITATION (VR) PROGRAM

PWI's are not a duplication of the State VR program, or of other job training or placement programs. The business partnerships make PWI services fundamentally unique and different from VR services. Most of the projects provide job training as well as placement services. Often the job training is done in conjunction with the members of the BAC. These members also contribute a great deal in goods and services to the services available to job seekers, creating a match for the federal dollars that range from the required 20 percent to 100 percent, with an estimated average match of almost 40 percent.

### PWI NEEDS TO BE A FEDERAL PROGRAM

Many PWI projects are national or multi-state in nature. Job prospecting and client placements don't end at the state lines. The job prospecting moves along industry lines.

try lines. With PWIs operating as Federally-funded projects, a peer review, competitive grant process is used to select the most qualified from a national pool of applicants. This national competitive process helps to assure quality and openness of opportunity.

PWI organizations also work in strong partnership with a broad variety of other programs from School to Work, TANF, One-Stops, Workforce Development Boards, Ticket to Work, Business Leadership Networks, and many locally based programs.

Choice is a major concern among people with disabilities, advocates, and policy makers. Job seekers with disabilities which are barriers to employment need to be able to choose from an array of providers and PWI offers an excellent alternative.

### FEW, IF ANY, PWI'S WOULD SURVIVE UNDER THE ADMINISTRATION'S PLAN

If the Administration's budget proposal is implemented, few, if any, current PWI's will survive. Even if states were to decide to continue funding the existing PWI's (which is doubtful) it would be too late since most PWI's will end their current grant cycle in September 2002. Most states are so strapped financially that they will need any additional funds to address other priorities. If the PWI funds are rolled into the VR funding, states will have to match these additional funds. As a separate funding stream, PWI funds are already being matched with private resources.

### ANY CHANGES TO THE PWI PROGRAM SHOULD BE MADE THROUGH THE REAUTHORIZATION PROCESS

The appropriate means to consider changes to programs under the Rehabilitation Act is through the reauthorization process. The Rehabilitation Act is up for reauthorization in 2003. The reauthorization process is the appropriate time for the Administration to put forth major policy changes related to the Rehabilitation Act.

# Congress Should Increase Funding for PWI to \$50 million for fiscal year 2003

# SUPPORTED EMPLOYMENT STATE GRANT AND EMPLOYMENT FOR INDIVIDUALS WITH HIGH SUPPORT NEEDS

The Supported Employment (SE) State Grant program was created in 1986 when the Rehabilitation Act was amended to authorize the use of Title I funds for SE, opening doors to competitive, integrated employment options through the state VR system for the first time to individuals who require intense and long term supports in order to become employed. The only experience the VR system had traditionally had prior to the inclusion of SE in the Act in providing services to individuals with "the most significant disabilities" was in extended employment services—segregated workshop settings. The State Grant was established to provide incentives and assistance to include such individuals in their traditional employment caseloads. The SE State Grant program has been funded as a separate "line item" by the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee since that time. Advocates in most states report that these designated funds are the primary reason the VR system provides SE services.

The administration suggests that the SE State Grant "overlaps" with the state vocational rehabilitation program funded through Section 110, Title I of the Act and, therefore, can easily be subsumed under the Title I umbrella, given additional Title I funding for fiscal year 2003. The assumption is that extra funding is all that is necessary for the state Title I programs to pick up the services currently provided through the SE State Grant program. This is a very dangerous assumption for individuals with the most significant disabilities. While states can use Title I funds for SE, they rely on the SE State Grant money for a significant number of the individuals they serve in supported employment, and it will be difficult to maintain the current level of commitment to SE under the President's proposal.

The VR accountability system provides significant disincentives both for the system and the individual counselor to provide supported employment services without designated funds. While supported employment can be considered an acceptable outcome, far more time and resources will be spent in securing the coveted "26" code for an individual in SE. In the absence of weighted measures, the counselor/office/ region that spends Title I resources on successful supported employment will likely have fewer numbers of individuals reported in their annual outcomes. This puts individuals who require extensive and/or expensive work place supports at a disadvantage in the more generic Title I program. The presence of the separate SE funding stream has allowed the state VR systems

The presence of the separate SE funding stream has allowed the state VR systems to gradually move s to traditional competitive, integrated options for individuals with significant disabilities. Over all we know that more 150,000 individuals (reported aggregate number in 1996) with significant disabilities have had access to VR funded supported employment since its inception. This number continues to increase, in large part due to the SE State Grant program. National data indicate the growing effectiveness of the program: fiscal year 1991—9,528 total SE placements; fiscal year 1994—13,950 total SE placements; fiscal year 1998—23,056 total SE placements.

Supported Employment creates invaluable partnerships with the business community. It is not just a placement, but an on-going relationship with the employer, providing the VR and other supporting public agencies a new and different forum for interaction with local businesses. Not only have there been over 150,000 placements in supported employment, many more employers have been offered and/or received long term public support for their supported employees.

A final and very important consideration is the ultimate impact on funding for the states. Title VI–C does not require a state match while Title I does. Because of this discrepancy states will have to identify additional funds in order to access funding they now receive with no required match. The State VR systems along with individuals they currently serve in supported employment will lose vital service funds under the Administration's proposal.

### THE PUBLIC VOCATIONAL REHABILITATION (VR) PROGRAM

The Public VR Program is one of the most cost effective programs ever created by Congress. It enables hundreds of thousands of individuals with disabilities to go to work each year and become tax-paying citizens. Each year, the Program assists over 1.2 million individuals with disabilities to go to work by providing services and supports to eliminate barriers to employment. Of those served each year, over 230,000 enter competitive employment. Over the last 10 years, the Public VR Program has faced a number of challenges that have been compounded by minimal increases in Federal funding. Those challenges include:

Special Education.—The federal appropriation for special education increased by approximately 140 percent between 1997 and 2002, with an increase of over \$1 billion in fiscal year 2002. Increased funding for special education has increased the demand for VR services as increasing numbers of special education students leave school and seek VR services to assist them in securing meaningful employment.

The Ticket to Work and Work Incentives Improvement Act of 1999 is intended to address disincentives to work found in the Social Security disability programs (SSDI and SSI) and to increase employment opportunities for individuals enrolled in these programs. As the Ticket to Work Program is implemented nationwide over the next 2 years, many people receiving tickets will go to the Public VR Program for information and services.

Temporary Assistance for Needy Families (TANF).—A recent General Accounting Office (GAO) report found that individuals with disabilities represent approximately 44 percent of the remaining TANF population. State welfare agencies are increasingly turning to State VR agencies for assistance in meeting the needs of individuals with disabilities who are left on the TANF caseloads. Impact of the Workforce Investment Act of 1998 (WIA).—With the passage of WIA, the Public VR Program was faced with yet another priority. As states implement

Impact of the Workforce Investment Act of 1998 (WIA).—With the passage of WIA, the Public VR Program was faced with yet another priority. As states implement WIA's One-Stop approach to employment services, many are expecting financial participation from State VR agencies in the administrative costs of the One-Stop centers.

*Impact of the Olmstead Decision.*—As individuals with disabilities are moved out of institutions, the Public VR Program will be playing a major role in assisting them in obtaining work.

Attracting and Retaining Qualified Counselors.—The 1998 amendments to the Rehabilitation Act mandate that counselors working for State VR agencies meet the highest state standard for persons in that profession (in most cases, requiring a masters degree). One third to one half of the incumbent counselors in many states do not meet the state's standard, and must be provided additional education and training, often at a cost of as high as \$30,000 per counselor. State VR agencies are finding it more and more difficult to attract and retain qualified individuals to serve as VR counselors.

Unfortunately, the Public VR program is severely under-funded to meet the mandates in the Rehabilitation Act and the challenges facing it. Under the current appropriation, VR can meet the needs of only a small percentage of eligible individuals and many State VR agencies have been forced to implement an order of selection (a mandated system where assistance is targeted to serve individuals with the most significant disabilities). The Rehabilitation Act mandates that the annual Federal appropriation for the

The Rehabilitation Act mandates that the annual Federal appropriation for the Public VR Program grow at a rate at least equal to the change in the Consumer Price Index (CPI) over the previous fiscal year. Congress has not seen fit during the last 6 years to provide any more than the CPI increase. This is particularly problematic because the formula used to distribute these funds, which is based on a state's per capita income and population, results in significant variations in the increases in individual state allotments.

### PREPARED STATEMENT OF THE RAILROAD RETIREMENT BOARD

Mr. Chairman and Members of the Committee: We are pleased to present the following information to support the Railroad Retirement Board's (RRB) fiscal year 2003 budget request.

The RRB administers comprehensive retirement/survivor and unemployment/sickness insurance benefit programs for railroad workers and their families under the Railroad Retirement and Railroad Unemployment Insurance Acts. The RRB also has administrative responsibilities under the Social Security Act for certain benefit payments and Medicare coverage for railroad workers. During fiscal year 2001, the RRB paid \$8.4 billion in retirement/survivor benefits to more than 700,000 beneficiaries, and \$119 million in unemployment/sickness insurance benefits to nearly 42,000 claimants.

### PRESIDENT'S PROPOSED FISCAL YEAR 2003 BUDGET

The President's proposed budget for fiscal year 2003 would provide \$97.72 million for RRB administrative operations, which is approximately the same as the amount appropriated in fiscal year 2002. An additional \$6.39 million would be provided under the Administration's proposed legislation to charge Federal agencies the full cost of post-retirement benefits for their employees under the Civil Service Retirement System and the Federal Employees Health Benefits Program.

under the Administration's proposed legislation to charge Federal agencies the full cost of post-retirement benefits for their employees under the Civil Service Retirement System and the Federal Employees Health Benefits Program. We estimate that the proposed funding would be sufficient for a staffing level of 1,064 full-time equivalent staff years (FTE's), which is 37 FTE's less than we plan to use in fiscal year 2002. Consistent with guidance from the Office of Management and Budget, our projections for salary and benefits reflect an estimated increase of 2.6 percent effective in January 2003. The proposed budget reflects the assumption that we could reach the lower staffing level through attrition, provided that we discontinue nearly all outside hiring beginning in mid-fiscal year 2002, which we do not believe is reasonable given our current workloads. A reduction-in-force would be necessary in fiscal year 2003 if sufficient attrition does not materialize.

In order to fund 1,064 FTE's, we would also need to defer obtaining contractual services to assist us with information technology initiatives, suspend subsidizing the transit benefit program for our employees, and impose reductions in other areas, such as training, travel, and supplies. Furthermore, these reductions in staffing and administrative resources would have an adverse impact on customer service. At this level of funding, the accuracy and timeliness of our claims processing operations would decline from the levels we expect to achieve in fiscal year 2002. We would also need to defer a planned comprehensive study to determine the causes of erroneous Railroad Retirement Act payments, and the development of an action plan to eliminate or minimize these causes. In addition, we would need to delay a variety of key information technology investments, including three Internet pilot projects that would make customer information more readily accessible.

The Administration's proposed budget assumes that the RRB, as a trust fund agency, will continue to pay actual costs to the General Services Administration (GSA) for rental of space and services. If GSA were to charge the RRB the commercially equivalent rate for space in fiscal year 2003, our rental costs and total costs would increase by approximately 3.2 million.

In addition to the requests for administrative expenses, the Administration's budget includes \$132 million to fund the continuing phase-out of vested dual benefits, and \$150,000 for interest related to uncashed railroad retirement checks.

### REQUEST FOR ADDITIONAL FUNDING IN FISCAL YEAR 2003

Budget-driven cutbacks would be particularly harmful in fiscal year 2003 because of the increased workload created by enactment of the Railroad Retirement and Survivors' Improvement Act of 2001. The RRB is already operating at maximum capacity in order to implement the provisions of the new law on a timely basis. As shown in our Annual Performance Plan, however, this has made it necessary to reschedule some information systems improvements and other project activities, which will need to be completed in fiscal year 2003 along with the agency's regular production work.

We estimate that the RRB will need an additional \$3.28 million in fiscal year 2003, resulting in a total appropriation of \$101 million for administrative expenses under current law. This funding would provide for a total staffing level of 1,083 FTE's (18 fewer than the fiscal year 2002 funded level), and would allow us to fill critically important vacancies without risking the need for a subsequent reduction-in-force (RIF). RRB staffing has already been reduced by more than 35 percent since 1993 through a combination of attrition, buyouts and RIF's. Further significant reductions in staffing would undermine our succession planning efforts and jeopardize our ability to fulfill our mission.

The additional funding would also allow for restoration of cutbacks in other important areas. An estimated \$806,000 would be used for task orders to provide assistance with strategic information technology initiatives. These include:

-Conversion of the RRB's payroll/personnel system to a new operating system,

-Development of an E-Government initiative to allow railroad employers to report data over the Internet,

-Development of an automated system to support annuity adjustments based on reported earnings, and

-Conversion of existing agency systems to a new database management system. In addition, approximately \$650,000 would be used to restore the subsidized transit benefit program for RRB employees, and \$298,622 would be used to restore reductions in funding for training, travel, and supplies.

### STRATEGIC MANAGEMENT OF INFORMATION TECHNOLOGY

During fiscal year 2001, the RRB completed development of its enterprise architecture with the publication of the Common Information Technology Requirements Vision, Conceptual Architecture Guiding Principles, Technical Reference Model and various architecture domain documents. During fiscal year 2002, we are building upon this effort to develop a gap analysis and migration plan of necessary actions to reach the target architecture.

While developing the gap analysis, we are actively pursuing further automation and modernization of our various claims processing systems. Automation initiatives in recent years have significantly improved operations and allowed the agency to reduce staffing in key areas. Ongoing and planned projects will further increase and enhance the efficiency and effectiveness of our benefit payment operations and program administration. Key initiatives funded at the President's proposed level of the budget can be grouped into two major categories, as described below.

Application Design Services.—Initiatives in this category focus on automation projects that are critical to our long-range strategy to promote better customer service through automation, while lowering the costs and increasing the efficiency of our operations. Specific investments planned for fiscal year 2003 include:

- -Document imaging (\$123,000).-This multi-year initiative is key to accomplishing our objective of paperless processing in our claims operations. These funds will be used for licensing and performance-based contractual support.
- -E-Government (\$425,000).-In order to meet the requirements of the Government Paperwork Elimination Act, we have been developing interactive electronic service capabilities. These funds will be used for performance-based contractual support.
- -System development tools (\$43,000).—The agency will require additional software development tools to remain current with the changing technologies in electronic commerce and to participate in interagency initiatives that seek to better coordinate data sharing among agencies.

Technology Infrastructure Services.—These investments are required to establish a firm foundation for the planned technology advances and to maintain our operational readiness. The specific investments in this category in fiscal year 2003 include:

- -Information Security (\$250,000).—As a result of our review under the Government Information Security Reform Act, several information security weaknesses were identified. These funds will be used for contractual assistance (\$150,000) to improve our overall information security structure and to conduct a vulnerability assessment (\$100,000).
- *Enterprise Architecture (\$100,000).*—In order to close the gaps between the current and target architectures, contractual assistance will be used to ensure the development of an efficient and effective implementation plan over the coming years.
- *Énterprise Storage Lease Payment (\$161,000).*—In order to support the growing use of electronic services, additional data storage was required. After a competitive selection process, an enterprise network storage system has been installed. This investment represents the second year of the capital lease for this equipment.
- -Standard Workstation Infrastructure (\$500,000).—This represents the amount required to continue the agency's policy of annually replacing and upgrading one-fourth of the agency's desktop computers, printers and related equipment and software needed to ensure an adequate work environment. -Network Operations (\$250,000).—This amount represents replacements and up
- -Network Operations (\$250,000).-This amount represents replacements and upgrades to network servers and related equipment needed to support a stable and efficient network throughout the agency.

### FINANCIAL STATUS OF THE TRUST FUNDS

Railroad Retirement Accounts.—At the end of fiscal year 2001, the net position in the railroad retirement accounts was \$19.8 billion, an increase of \$1.2 billion over the previous year. In June 2001, we released the 2001 Section 502 Report, which projected the status of the retirement trust funds under three employment assumptions. The report indicated no cash flow problems for 25 years. These projections were later updated to reflect the provisions of the Railroad Retirement and Survivors' Improvement Act of 2001. The updated projections show cash flow problems only under a pessimistic employment assumption, and then not until calendar year 2022.

Railroad Unemployment Insurance Accounts.—The equity balance of the railroad unemployment insurance accounts at the end of fiscal year 2001 was \$40.1 million, a decrease of \$53.7 million from the previous year. The RRB's latest annual report on the financial status of the railroad unemployment insurance system, issued in June 2001, was generally favorable. The report indicated that even as maximum daily benefit rates rise 52 percent (from \$48 to \$73) from 2000 to 2011, experiencebased contribution rates are expected to keep the unemployment insurance system solvent, except for the need for a short-term loan from the Railroad Retirement Account in fiscal year 2002. However, projections show a quick repayment of the loan even under the RRB's most pessimistic employment assumption. The average employer contribution rate remains well below the maximum throughout the projection period, but a periodic resumption of the surcharge required to maintain a minimum account balance was also predicted. We did not recommend any financing changes based on this report.

In conclusion, we want to stress the RRB's continuing commitment to improving our operations and providing quality service to our beneficiaries. Thank you for your consideration of our budget request. We will be happy to provide further information in response to any questions you may have.

# PREPARED STATEMENT OF THE COUNCIL OF STATE ADMINISTRATORS OF VOCATIONAL REHABILITATION

The testimony submitted is presented on behalf of the Council of State Administrators of Vocational Rehabilitation (CSAVR), comprised of the chief administrative officers of the State Rehabilitation Agencies in the states, the territories, and the District. These agencies provide services to eligible persons with mental and/or physical disabilities in order that they can take their place in competitive employment.

You in Congress created the Public Vocational Rehabilitation Program over 80 years ago. Indeed, this is truly one of your success stories in which we hope all of you take pride.

### CSAVR'S RECOMMENDATIONS

The fiscal year 2002 appropriation for the Public VR Program was \$2.48 billion, an increase of 3.4 percent over the fiscal year 2001 appropriation. The President's request for fiscal year 2003 would combine the funding for four discretionary programs (Projects with Industry, Supported Employment State Grants, Recreation Projects, and Migrant Farm Worker Projects) into the appropriation for the Public VR Program. While this would provide an increase above the mandated CPI increase for VR (i.e., 2.1 percent for fiscal year 2003), the consolidation of these funding streams does not result in any new funding being available to serve individuals with disabilities who are seeking to become gainfully employed. CSAVR does not support the President's proposal to consolidate these funding streams. For fiscal year 2003, CSAVR recommends an increase of \$245 million above the fiscal year 2002 appropriation for the Public VR Program. This represents an increase of 10 percent above the fiscal year 2003.

### JUSTIFICATION

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. While Congress may have thought it was funding each of the States at least at the cost-of-living rate, this was not the case.

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 render persons with disabilities employable 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 arguments that it is better to put people to work and make them taxpayers as opposed to living off the taxpayers on welfare, in Institutions, or worse, have often been made. Common sense tells us these arguments are true.

As you know, the authorizing law provides that each state is to receive an allotment based on whatever Congress appropriates if that State can provide the matching resources. The law also provides that at least a cost of living be added to the total appropriations each year and is to be considered a minimum, not a "cap". Over the last 10 years, the Public VR program has faced a number of challenges

Over the last 10 years, the Public VR program has faced a number of challenges that have been compounded by minimal increases in Federal funding. Welfare-to-Work programs are increasingly turning to State VR agencies for employment and training services because of the high percentage of people with disabilities who remain on the welfare rolls. The work incentives provisions and the Ticket-to-Work Program in the Ticket to Work and Work Incentives Improvement Act of 1999 are intended to encourage millions of Americans who receive Social Security disability benefits to seek assistance in entering or re-entering the workforce. Many of these individuals will turn to State VR agencies for services, potentially placing an enormous burden on the Public VR Program. Implementation of the Workforce Investment Act of 1998 and the Supreme Court's Olmstead decision which calls for the movement of people with disabilities from institutions to community living will increase the demand for VR services leading to employment.

Inovenient of people with distantics from instruction to the second second second for VR services leading to employment. As you also know, over these past few years, Congress has authorized considerable additional resources for Special Education. Now those young men and women who have been in special education are turning to vocational rehabilitation for services as adults. This "transition" is demanding increased resources to serve these individuals. We believe that if we in fact can serve individuals with disabilities leaving school, that will deflect them from having to get on SSI and can help them get into the world of work and toward self-sufficiency.

As you are also aware, Congress placed even greater responsibility upon the State Vocational Rehabilitation Program, with the passage and promises of the Americans with Disabilities Act (ADA). The ADA promises to expand opportunities for all Americans with disabilities. If Congress in its wisdom really meant to do just that, does it not also need to provide the means to accomplish this mission?

It is our belief that it is vital that the State Vocational Rehabilitation Program have the resources available to assist people with disabilities to fully realize the promise of this landmark legislation.

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.

Most states have been able to get sufficient state funding in order to fully match the Federal appropriation. Together, these funds 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" nec-essary to rehabilitate an individual into employment.

Basic State Vocational Rehabilitation provides services designed to lead to gainful employment for over 1.2 million people with disabilities each year. Of this number, each year over 230,000 are placed in competitive employment. Despite this expenditure, there still are not sufficient funds to serve all the eligible, disabled individuals 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 reha-bilitation 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.

Stagnant since 1990. With these statistics in mind, the CSAVR strongly urges that the Congress assist us in facing this challenge by providing Federal appropriations for Basic State Voca-tional Rehabilitation Services with a 10 percent (including the CPI, or approxi-mately \$245 million) increase over the fiscal year 2002 appropriation. The CSAVR estimates that nearly 125,000 more persons will receive services and over 25,000 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 pur-

pose 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; by increasing 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 Voca-tional Rehabilitation Services has helped reduce the Federal Deficit. Indeed, the Congressional Budget Office (CBO) has stated that "a reduction of funds for rehabilitation . . . would generate increases in other parts of the federal and state budg-

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 com-prehensive services for independent living program; (5) a supported employment program; and, among others, (6) special projects and demonstration efforts.

The Courcil strongly supports adequate funding for all Sections of the Act. We appreciate the opportunity to appear before this important Subcommittee today and am available to answer any questions about this Program and our recommendations.

### PREPARED STATEMENT OF THE AMERICAN NETWORK OF COMMUNITY OPTIONS AND RESOURCES

The American Network of Community Options and Resources (ANCOR) appreciates this opportunity to bring attention to a proposal in President Bush's fiscal year 2003 budget that would eliminate funding for the Supported Employment State Grants program. ANCOR calls on Chairman Harkin and the Senate Labor, Health and Human Services, and Education Appropriations Subcommittee to protect funding for this important discretionary program that provides individuals with mental retardation and other significant disabilities with the supports and services necessary to obtain or retain employment in the community.

ANCOR is the national organization representing over 700 private providers of supports and services to more than 150,000 individuals with mental retardation and other disabilities. ANCOR members provide both community-living and vocational and employment services and supports, including supported employment services.

As part of its effort to eliminate funding for ineffective, duplicative, and overlapping job training programs, the Administration's proposed budget would eliminate funding for the Supported Employment (SE) State Grants program, a discretionary program authorized under the Rehabilitation Act of 1973, as amended. The proposal consolidates funding for SE and several other discretionary programs dedicated to individuals with disabilities into the Vocational Rehabilitation (VR) State Grants program.

ANCOR respectfully disagrees with the Administration's statement that there is no longer a need for a separate supplemental source of dedicated funds to ensure that supported employment services are provided. Full and adequate funding for the SE grant program has never been more important than today when the nation is committed to removing barriers for people with disabilities living and working in their communities.

Individuals with the most severe disabilities—including individuals with mental retardation—have traditionally been underserved or unserved by state VR programs.—State VR services are time-limited to 18 months and funding for services has traditionally gone to individuals who most benefit from them and can return to work quickly. Individuals with mental retardation and other significant disabilities, on the other hand, often have high-cost, long-term support needs that may last beyond 18 months. ANCOR members throughout the nation provide on-going, long-term supports and services to assist individuals with mental retardation and other significant disabilities who need on-going, long-term supports and services to individuals with mental retardation and other significant disabilities who need on-going, long-term services and who want to work but whose employment needs beyond what VR has historically provided will remain unmet by many state VR agencies.

Individuals with significant disabilities need more, not less, viable employment options.—The Department of Education's Rehabilitation Services Administration (RSA) recently eliminated extended employment as an acceptable employment outcome for individuals with the most severe disabilities. With the 70 percent unemployment rate of individuals with disabilities, the Administration should not propose—and the Subcommittee should not support—eliminating funding for another viable employment option for individuals with significant disabilities. Eliminating funding for the SE grant program will be a double whammy for these individuals who are already at a disadvantage for receiving services from the state VR agency.

viable employment option for individuals with significant disabilities. Eliminating funding for the SE grant program will be a double whammy for these individuals who are already at a disadvantage for receiving services from the state VR agency. Further, eliminating funding for SE grants goes directly against the Supreme Court's July 1999 *Olmstead* decision, which affirmed the right of individuals to receive services in the community. It is also inconsistent with President Bush's Olmstead Executive Order and his New Freedom Initiative commitment to eliminate barriers—including employment barriers—to people with disabilities.

Eliminating funding will jeopardize the success of the Ticket to Work Program by undercutting one of its goals—the expansion of services by the private sector.—In December 1999, the Senate unanimously passed the Ticket to Work and Work Incentives Improvement Act (Public Law 107–70) (TTWWIIA), which created the Ticket to Work and Self-Sufficiency Program (Ticket Program). Two significant principles of TTWWIIA are to increase the universe of private providers who will assist Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) beneficiaries with disabilities in obtaining employment and increase the employment rate of people with disabilities and reduce their reliance on Social Security benefits.

Eliminating SE grant funding flies in the face of successful implementation of the Ticket Program and will cause more reliance on public assistance programs such as SSI. Private providers—serving as Employment Networks (ENs) under the Ticket Program—will not be able to provide SE supports and services that will allow individuals to retain employment, earn higher wages, and reduce their reliance on SSI.

viduals to retain employment, earn higher wages, and reduce their reliance on SSI. At the same time that the Ticket Program is attempting to increase the base of private providers, eliminating funding for the SE grant program only serves to erode this base. Eliminating funding for the state grant program sends the wrong message to current and future SE providers, individuals in SE, and the employers who hire them—that individuals with the most significant disabilities cannot work in the community and that they are not worthy of any chance to try.

States will be tempted to address their own budget shortfalls.—While the President's budget encourages states to continue funding SE services, ANCOR believes that states will not heed such advice. Most states are in a period of fiscal constraint and are calling for across-the-board budget cuts. State VR funding is already inadequate to meet current responsibilities. Over half of state VR agencies were under an order of selection by the second quarter of fiscal year 2002. Consolidating SE funding into the larger VR program will only allow states to continue their practice of failing to meet the employment needs of individuals with severe disabilities, thereby preventing these individuals from obtaining employment and reducing their reliance on SSI.

It will cost states more dollars to continue to provide SE services without the dedicated grant program. In contrast to the state VR program, the SE grant program does not require state-matched funding. Given states' fiscal environments, many state VR agencies are more likely to use additional funding from consolidation to meet the needs of eligible individuals who can return to work quickly with little cost to the VR program.

Individuals with mental retardation and other significant disabilities only stand to lose from the Administration's proposal. ANCOR urges the Subcommittee to recognize the value of people with disabilities and their employment options. ANCOR respectfully requests the Subcommittee provide full funding for the Supported Employment State Grants program in its fiscal year 2003 Labor, Health and Human Services, and Education appropriations.

# PREPARED STATEMENT OF THE ASSOCIATION FOR PERSONS IN SUPPORTED EMPLOYMENT

# SUPPORTED EMPLOYMENT STATE GRANTS FUNDING ESSENTIAL FOR VOCATIONAL REHABILITATION SERVICES FOR INDIVIDUALS WITH "MOST SEVERE DISABILITIES"

Issue.—The Administration's fiscal year 2003 Budget requests Congress to eliminate the Supported Employment State Grant Program, along with three additional discretionary programs under the Rehabilitation Act, and place the funding instead into the State VR Grant program (Section 110, Title I), with no requirement that the service requirement be transferred with the funds. The separate Supported Employment State Grant is authorized in Title VI–C of the Act, and funds are distributed to each state by formula (with no state match) specifically for supported employment services. Under this program States are required to develop a separate state plan for supported employment, and the SE State Grant funds can only be used to cover supported employment services—services limited by law to competitive, integrated employment (with individualized supports) for individuals with "the most significant disabilities." Supported employment experts across the country report that these funds are crucial to both direct supported employment services and to supported employment infrastructure and capacity building at the state and local levels. Rather than eliminate the program, SE advocates believe it is time for the funds to be increased. The program has been held at the current \$38 million for many years.

Background.—The Supported Employment State Grant program was created in 1986 when the Rehabilitation Act was amended to authorize the use of Title I funds for SE. This opened the doors to competitive, integrated employment options through the state vocational rehabilitation system for the first time to individuals with more challenging disabilities—folks who require intense and often long term supports in order to become employed and were the time identified by labels—such as MR, DD, TBI, MH, Deaf-blind, multiple disabilities, etc. The only experience the VR system had traditionally had in providing services to these individuals prior to that time was in extended employment services, more commonly known as sheltered workshops. The State Grant was established to provide incentives and assistance to the state VR system to include individuals with the most significant disabilities in their traditional employment case loads. The SE State Grant program has been funded as a separate "line item" by the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee since that time. Advocates in most states report that these designated funds are the primary reason the VR system provides SE services.

The Problem with the President's Request.—The administration suggests that the SE State Grant "overlaps" with the state vocational rehabilitation program funded through Section 110, Title I of the Act and, therefore, can easily be subsumed under the Title I umbrella, given additional Title I funding for fiscal year 2003. The assumption is that extra funding is all that is necessary for the state Title I programs to pick up the services currently provided through the SE State Grant program. This is a very dangerous assumption for individuals with the "most significant disabilities."

- -Congress authorized Title VI-C as a separate program as an incentive to ensure access to vocational rehabilitation for these individuals. The need for continuation of this program was carefully re-examined during two subsequent reauthorizations. The Administration is now asking Congress to change this authorization on an appropriation bill, without the thoroughness dedicated to policy changes during a reauthorization process. This is far more than a funding issue and should at a minimum be explored when the Act is reauthorized next year.
- -While states can use Title I funds for SE, most states rely on the SE State Grant money for a significant number of the individuals they serve in supported employment. More and more states are funding SE with their Title I funding, but the SE designated funds are an important incentive to do so. The funds are also spent in some states on expansion of SE services to un- or under-served individuals in the VR system. We believe that it will be difficult for states to maintain the current level of commitment to supported employment when the State has access to this money to serve individuals with less intense support needs.
- -The VR accountability system provides significant disincentives both for the system and individual counselor to provide supported employment services without designated funds. The 26 coded closure, assigned to cases when an individual is considered rehabilitated is the benchmark used to evaluate the outcomes each year of individual counselors, local VR offices and the state systems. While supported employment can be considered an acceptable outcome, far more time and resources will be spent in securing the coveted "26" code in SE. The counselor/ office/region that spends Title I resources on successful supported employment will not have as many closures at the end of the year as those who use the Title I funds for individuals who require less support. This puts individuals in SE at a disadvantage in the Title I program.

# THE IMPORTANCE OF SUPPORTED EMPLOYMENT SERVICES AND THE SUPPORTED EMPLOYMENT STATE GRANT LINE ITEM IN THE APPROPRIATIONS BILL

The presence of SE has allowed the state VR systems to gradually move towards traditional competitive, integrated options. Over-all we know that well over 150,000 individuals (reported aggregate number if 1996) with significant disabilities have had access to VR funded supported employment since its inception and the number continues to grow, in large part due to the SE State Grant program. Supported employment costs an average of only \$1,255 more than sheltered workshop closures. Wages in supported employment are nearly double the wages for individuals in sheltered workshops. The average hourly wage in sheltered work is \$2.42 while the average wage in supported employment is \$5.42. Despite this data, only one in four individuals eligible for SE in the VR system has access to this service. Most remain in segregated settings, either in workshops or day activity centers. SE is the path to independence and integrated employment.

Recent regulatory changes by the Rehabilitative Services Administration limiting acceptable State VR employment outcomes to integrated settings has increased the importance of continuing the SE State Grant program as both a direct service program and to build the badly needed infrastrucure to ensure the integrated mandate works for individuals with the highest support needs. The designated supported employment funding is important in ensuring that this change does not unintentionally screen individuals with the most significant disabilities out of the State VR system.

Supported Employment creates invaluable partnerships with the business community. It is not just a placement, but an on-going relationship with the employer, providing the VR and other supporting public agencies a new and different forum for interaction with local businesses. Not only have there been over 150,000 placements in supported employment, far more businesses that have been offered and/or received assistance to allow them to hire and retain supported employees.

Because of the implementation of the formula, some states will actually lose money in the Administration's scheme of collapsing these funds into Section 110. At a minimum it will cost the state more to receive the additional Section 110 funds, for these funds must be matched with state dollars, while the Supported Employment State Grant does not require a state match. The administration believes that this will result in more funds for SE, given the addition of the required state match. Our concern is that in the face of rapidly declining resources in state budgets, the opposite will occur and the money will be lost to the state instead, with the ultimate losers being individuals with high support needs who will lose their opportunity for employment. APSE urges the Subcommittee to restore the funding, along with an increase as recommended by the Consortium for Citizens with Disabilities, for the SE State Grant program.

For more information, please contact:

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# PREPARED STATEMENT OF KELLY SHUPAL, HOUSTON, TX

I am writing in regard of concern for Projects With Industries Program (PWI). Our local PWI program has helped numerous individuals over the years overcome barriers to employment and return to gainful employment. PWI is important to people with disabilities and businesses in Texas. It has been helpful in placing individuals with disabilities back into suitable gainful employment. I am requesting that as a member of the Senate Appropriations Subcommittee

I am requesting that as a member of the Senate Appropriations Subcommittee that you please consider maintaining federal funding for PWI and the other discretionary programs in the Rehabilitation Act as well as the basic state grant program Funding for PWI should be \$50 million for next year (fiscal year 2003).

Here are some of the last several years statistics showing gainful outcomes.

	10/97-9/98	10/98-9/99	10/99-9/0	10/0-09/01
Number of Customers Served	224	250	245	233
Number of Customers Served /w Significant Disabilities	140	115	137	199
Total Number of Customers Placed	83	105	104	139
Average Hourly Wage	\$8.35	\$8.46	\$8.82	\$8.66

Thank you for your consideration for support of a good program.

### PREPARED STATEMENT OF THE AMERICAN LEGION

The American Legion appreciates the opportunity to submit our views on the fiscal year 2003 budget as it pertains to the Veterans Employment and Training Service (VETS) within the Department of Labor (DoL).

The mission of VETS is to promote the economic security of America's veterans. This stated mission is executed by assisting veterans in finding meaningful employment.

Annually, DOD discharges approximately 250,000 service members. These recently separated service personnel actively seek employment or prepare to continue their formal or vocational education. The veterans' advocates within the VETS program play a significant role in helping these recently separated service personnel to reach their employment goals.

The employment and training benefits offered through the VETS program are invaluable to transitioning servicemembers.

–VETS provides employers with a labor pool of quality applicants with marketable and transferable job skills.

-VETS took the initiative in identifying military occupations that require civilian licenses, certificates or other credentials at the local, state, or national levels.

-VETS helps to eliminate barriers to recently separated service personnel and assists in the transition from military service to the civilian labor market.

VETS has begun an information technology project with the Computing Technologies Industry Association, to recruit veterans recently separated from the military; assess their interest and skill level for a career in information technology; provide occupational skills training and certification; and place these veterans into information technology jobs. VETS continues to expand its PROVET (Providing Reemployment Opportunities for Veterans) program. PROVET is an employer-focused job development and placement program that focuses on screening, matching and placing job ready transitioning service members into career-building jobs. PROVET programs are currently operating in several States. In addition to employment services, VETS also supports the Transition Assistance Program (TAP), the Disabled Transition Assistance Program (DTAP), Veterans Preference in the Federal workplace, and the Uniformed Services Employment and Re-employment Rights Act (USERRA). The American Legion strongly recommends restoring funding for the Assistant Secretary for Veterans Employment and Training Service (ASVET) within DoL's fiscal year 2003 budget at a funding level of \$300 million.

Staffing levels for Disabled Veterans' Outreach Program (DVOP) Specialists and Local Veterans' Employment Representatives (LVERs) should match the Federal mandates or those statutes should be rewritten. The American Legion supports an additional \$54 million and \$38 million respectively for the DVOP and LVER programs for fiscal year 2003 funding. These increases will allow the programs to raise staffing levels to adequately provide comprehensive case management job assistance to disabled and other eligible veterans.

The American Legion strongly opposes any attempt to move VETS to the Department of Veterans Affairs (VA).

DoL is the nation's leading agency in the area of job placement, vocational training, job development, and vocational counseling. Due to the significant barriers to employment experienced by many veterans, VETS was established to provide eligible veterans with the services already being provided to job ready Americans. Working with the local employment service offices, VETS gave eligible veterans the personalized assistance needed to assist in the transition into the civilian workforce. VA has very limited experience in the critical areas of job placement, vocational training, job development, and vocational counseling through its Vocational Rehabilitation Program. A side-by-side comparison of VETS and Vocational Rehabilitation Program success rate in actual job placement would prove to be very revealing.

tion Program success rate in actual job placement would prove to be very revealing. If VETS were to transfer to VA, funding for the agency, which now comes from the Federal Unemployment Trust Account, would have to derive from some other source since moving the agency would place it under VA line item in the Federal budget. This forces the agency to compete with NASA, HUD and other Federal agencies for scarce resources.

In the President's budget request for fiscal year 2003, he proposes to add \$197 million to VA's budget for a new competitive grant program that replaces programs currently administered by the DoL. The American Legion expressed opposition to a similar recommendation proposed by the Congressional Commission on Service members and Veterans Transition Assistance in 1999.

The American Legion recommends an increase in NVTI budget to \$3 million annually.

The National Veterans Training Institute (NVTI) provides standardized training for all veterans' employment advocates in an array of employment and training functions. Some suggest that moving VETS to VA would improve the overall performance of VA's Vocational Rehabilitation Program (Voc Rehab). Others would argue that moving Voc Rehab to VETS in DoL would be a much better approach. Nearly all VETS employees attend NVTI and receive continuing training, whereas few (if any) Voc Rehab employees ever attend NVTI training. The American Legion perceives the relationship between VETS and DoL to be much more germane than VETS and VA.

The American Legion recommends that \$5 million of VETS funding be provided for incarcerated veterans' education and transition assistance programs beginning in fiscal year 2003.

Currently there is minimal to no effort being made in providing meaningful outreach to incarcerated veterans. All too often, the state prison systems are failing to provide adequate vocational and life skills training to inmates that are nearing their release dates. VETS could provide meaningful assistance to veteran inmates. The Federal government, in cooperation with individual states, must provide effective outreach services to incarcerated veterans to assist in a successful transition to a crime free civilian life.

The American Legion recommends \$30 million be provided for veterans training programs similar to the Service Members Occupational Conversion and Training Act (SMOCTA).

SMOCTA was developed as a transitional tool designed to provide job training and employment to eligible veterans discharged after August 1, 1990. Veterans eligible for assistance under SMOCTA were those with a primary or secondary military occupational specialty that the Department of Defense (DOD) has determined is not readily transferable to the civilian workforce; or those veterans with a service connected disability rating of 30 percent or greater.

Those eligible veterans received valuable job training and employment services through civilian employers that built upon the knowledge and job skills the veterans acquired while serving in the military. This program not only improved employment opportunities for transitioning servicemembers, but also enabled the federal dollars invested in education and training for active duty servicemembers to be reinvested in the national job market by facilitating the transfer of skills from military service to the civilian workforce.

The American Legion welcomes the opportunity to work with the Assistant Secretary for Veterans' Employment and Training and his staff to improve and enhance the overall performance of VETS. However, The American Legion believes reinventing the wheel within VA would be counterproductive and ineffective. The American Legion believes that many of VETS problems stem from persistent inadequate Federal funding, failure to be staffed at Federally mandated levels, and inconsistent leadership at the local, state, and national levels.

The VETS program is one of the best-kept secrets in the Federal government. It is comprised of many dedicated individuals who simply cannot maintain a quality program without substantial funding and staffing increases. The American Legion believes the VETS programs is a good investment; one that actually returns money to the United States Treasury. This program cannot continue to be neglected without experiencing a serious diminution in service.

Thank you for allowing The American Legion to express its views on this critical issue.

# DEPARTMENT OF HEALTH AND HUMAN SERVICES

## NATIONAL INSTITUTES OF HEALTH

# PREPARED STATEMENT OF THE NATIONAL MARFAN FOUNDATION

The members of the National Marfan Foundation (NMF) thank you for the opportunity to provide written testimony in support of the budget of the National Institutes of Health (NIH) and the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS). This is the second year that the NMF is submitting written testimony on its own. We have been previously included in the written and spoken testimony of the Coalition for Heritable Disorders of Connective Tissue (CHDCT). We would first like to express our gratitude of the Committee's on-going support of NIH research, and most particularly their support for increased funding for research on rare and genetic disorders—research that might not otherwise have been funded. The NMF believes that the Congress should strive to reach the intended goal of

The NMF believes that the Congress should strive to reach the intended goal of the doubling the NIH budget by fiscal year 2003. The NMF joins the Ad Hoc Group for Medical Research Funding, in asking that Congress support the bipartisan goal of doubling the NIH budget by approving a \$27.3 billion for fiscal year 2003—a sentiment shared by the President, the Congress and the American people. The NMF along with the Coalition of Heritable Disorders of Connective Tissue, the NIAMS Coalition, and the Coalition of Patient Advocates for Skin Disease Research urges Congress to provide \$520.9 million for NIAMS in fiscal year 2003, which is a 15.7 percent increase.

The Marfan syndrome is a potentially fatal, relatively rare genetic disorder of the connective tissue which results in manifestations within in the cardiovascular, skeletal, ophthalmologic and pulmonary systems making it extremely difficult to manage. The NMF represents people affected with the Marfan syndrome. Voluntary health organizations such as ours consistently hear the frustrations, confusion and despair of people who deal with the daily medical issues associated with genetic disorders. In multi-systemic disorders such as Marfan syndrome, numerous physicians in specialties such as cardiology and cardiovascular surgery, orthopedics, ophthalmology, respiratory/pulmonary, neurology, and genetics must be consulted to manage the manifestations of this syndrome. The families are distraught from the overwhelming emotional turmoil of dealing with so many doctors and the fear of losing their life at an early age, not to mention the tremendous monetary burden. These circumstances are multiplied many times over since this genetic disorder can affect more than one family member and more than one generation.

It is estimated that approximately a quarter of a million people in the United States are affected by the Marfan syndrome and relate disorders. The Marfan syndrome is a potentially fatal, genetic disorder of the connective tissue. The Marfan syndrome is a multi-system disorder because the connective tissue is essentially the glue and the scaffolding of the body, and manifests itself in the heart, eyes, skeleton and blood vessels. Individuals with the Marfan syndrome are uncharacteristically tall, with arms, legs, toes and fingers that are disproportionately long and thin. Typically, patients also have poorly developed muscles and abnormally curved spines.

<sup>\*</sup> The life-threatening aspect of this disorder is the weakening of the aorta, the largest artery that supplies blood to the heart. In the Marfan syndrome, the abnormalities in the connective tissue place a great deal of stress on the aortic artery and significantly weaken the walls of this most important blood vessel. Tears form in the walls of the aorta and death can only be prevented by surgical intervention. However, even with the diagnosis and management of the disorder, complications of all sorts do arise and unfortunately is still taking the lives of young people. For example, the Kiefer Family from Iowa has been fighting this uphill battle for years. Here is her story

Our family struggles with Marfan syndrome go back to 1989. Senator Harkin, you know some of the struggles our family has been dealing with trying to increase funding for medical research. In October of 1989, our phone rang at 4 a.m. It was our daughter-in-law informing us our son, Scott was at Mercy Hospital with severe chest pain and could we please come. On the way to Des Moines we discussed what could possibly be wrong with someone who had always been so physical. Scott had been a U.S. Marine, an Iowa National Guardsman, an avid run-ner, a rappeller, a bicyclist and involved with the YMCA. The news at the hospital was not good. An echocardiogram was done and I heard the Dr. say-I believe he has an aortic aneurysm. An angiogram was performed and revealed an aortic RUP-TURE. Blood was pouring into his chest cavity. Surgery had to be performed imme-diately. He was given a 50/50 chance of survival. Miraculously, he did survive and within the next 2 weeks he developed pneumonia and had a pacemaker implanted to help his damaged heart

Scott's life had to charge drastically and he wasn't easy for "a seemingly healthy young man with a family." Medicines every day that had to be monitored carefully,

ould take his live at a young age. Our family lives also changed. Within 2 weeks of Scott's surgery, my husband and our two daughters were diagnosed with Marfan. Everyone in my family was diag-nosed. I was certain they would die and I would be left alone. Thirteen years ago, information on Marfan syndrome was slim. Our family was one of the pioneers in information on Martan syndrome was simil. Our family was one of the protects in genetic testing because we were a three-generation family. It took 3 years for two of our six grandchildren to be diagnosed with Martan. They are our youngest daugh-ters children, now ages 13 and 16 and they both have aortic involvement. Our fam-ily does not exhibit many of the typical Martan characteristics. However, they all have aortic involvement and the aorta is one thing you cannot live without. I became involved with National Marfan Foundation in 1989 and became a board

member in 1990. The foundation is my strength in the struggle with Marfan syndrome.

I have testified before this committee before. It was a great experience for me. I always say, "I hate what Marfan has done to my family, but it did make me an assertive person." Scott also testified before the Senate and the House committee hearings.

My husband and Scott did continue to have problems. My husband has been hospitalized twice with atrial fibrillation and is on medications. Scott had to have surgery in 1995 for an abdominal aortic aneurysm and had a continuing struggle with proper medication.

Unfortunately, Scott had to have a third surgery in June 2001. His artificial graft had grown to the scar tissue of the first surgery and was pulling the artificial graft away from the heart. Scott did not survive the surgery. Let me tell you as a parent, away from the heart. Scott did hot survive the surgery. Let me ten you as a parent, to lose a child (even if he was 44), I believe it is the worst possible tragedy a parent can experience. A loss to big to comprehend. We will never be the same. He was a great husband, a fantastic father, the most loving son, a protective brother, a sup-portive uncle and a true friend to many. He was the Public Information Specialist for the State of Iowa Human Services. He was finding success as a stand-up comedian. It was something he really enjoyed.

My husband is now facing surgery to repair his aorta. He is 66 and we are frightened to have to go through the surgery. Our daughters are 42 and 38, mildly affected with Marfan syndrome, both having aortic aneurysms. They are on betablockers and are doing well at this time. At the NMF conferences, the Marfan specialists strongly suggest children be pre-

scribed beta-blockers as soon as they are diagnosed to reduce the stress on the aorta. We actually had to plead with our local pediatric cardiologist to prescribe them for our grandchildren. Looks like our grandson has more aortic involvement than our granddaughter. The need for expanded research and education is required.

Many lives are lost to Marfan syndrome and other disorders and other diseases. Medical research holds the key to answers, better therapies, and cures for genetic disorders, cancer, diabetes, heart disease and hundreds of others. Medical research goal of the NMF. There is much work to be done. I know first hand Senator Harkin is large supporter of medical research. We have had many conversations on this subject. He knows medical research is vital to all. I am proud Senator Harkin represents the state of Iowa and is the chair of this committee. Senator Harkin and committee members, I am asking you to support expanded research on behalf of my family, the NMF and thousands of others who will benefit from the increase in funding. Increased funding will someday help other families so they never have to lose a very special person in their lives. Thank you for allowing me to relate our personal story of our struggle with Marfan syndrome. It is stories such as these that move us to advocate for this Committee's support

It is stories such as these that move us to advocate for this Committee's support for increased research funding. Research is the only hope for Marfan-affected individuals.

To this day ignorance still exists on how to adequately diagnose the Marfan syndrome. Many people die at a young age in the emergency room with a ruptured aorta because these people were never diagnosed. One of the main problems is that there is no simple diagnostic test for this multi-system disorder. Because most features of the Marfan syndrome progress with age, the diagnosis is often more obvious in older persons however, this can turn out to be deadly. Furthermore, those persons who are considered to be candidates of this syndrome but cannot get a precise diagnosis must also continually monitor themselves since the symptoms manifest over time. Research is desperately needed in this area. Development of a rapid molecular diagnostic test could save thousand of lives.

Research into the basic mechanisms of the Marfan syndrome has borne fruit. In 1991, scientists discovered the cause of the Marfan syndrome, an alteration of the gene that encodes the protein fibrillin-1. Although this important finding did not lead us directly to a cure, it has allowed scientists to focus their research to look for answers to more specific questions. More research is needed to determine how this mutant gene actually produces the change in human biology that leads to this disease and is responsible for variability within the syndrome from mild to extremely severe cases. Additional basic research in molecular studies will also help us to fully investigate the interaction of the fibrillin-1 gene product with other molecules in the extracellular matrix to better understand pathogenesis of this disease. The use of this knowledge to develop a genetic manipulation strategy to eventually cure this disease is becoming technically feasible but is years away. In the meantime, more immediate issues need to be dealt with. Clinical research is needed to identify strategies and therapies for reducing aortic

Clinical research is needed to identify strategies and therapies for reducing aortic enlargement, to determine the optimal time for surgical intervention and to predict risk for aortic dissection. This is extremely important to save lives as noted in a recent letter to the NMF. A young woman writes "My cousin's 17 year-old daughter died with a ruptured aortic aneurysm. She knew she had Marfan syndrome and had echocardiograms every 6 months. Her aorta was not large enough for surgery but she must have not read the book, because she died anyway. She had an echocardiogram just 6 weeks before she died." It is stories such as these that alert us to the fact that much more research is needed in this most crucial area. It is imperative to determine what are the clinical features and presentations of acute aortic dissection in Marfan patients and how is this different from non-Marfan patients.

Clinical research can also offer more solutions to be used immediately to alleviate some of the pain and disabling effects such as curvature of the spine, dislocated lenses in the eye, and abnormalities in the heart valves. Clinical research of treatments for back pain due to scoliosis and more specifically for dural ectasia, the enlargement of the membrane that surrounds the brain and spinal cord, are desperately needed to reduce the amount of pain and suffering endured by Marfan-affected individuals.

Funding biomedical research through the NIH is today's investment in America's future. The technology and the science are available to understand and ultimately cure or eradicate many of these devastating genetic disorders. Support for the NIH is especially crucial to unlocking the mysteries of rare diseases, such as the Marfan syndrome. We need your support.

Mr. Chairman, there is another important topic that the NMF must address in our testimony. Our members expect to benefit in extraordinary ways from the incredible success of the Human Genome Project. In fact, they already have. However, the NMF cannot stress enough the importance of this subcommittee understanding that we are really at the end of the beginning stage. If we as a society fail to take the next steps to fully develop the potential that has been unleashed by sequencing the human genome, it will be a mistake with very real health consequences for very real people.

Thanks to the Human Genome Project, we know the sequence of DNA. Now, we have to identify every gene, learn their functions, learn how they contribute to disease and determine what can be done about it. The President's request for the Na-

tional Human Genome Research Institute is the minimal amount that needs to be done. Obviously, with the enormity of the task ahead, additional funding can only enhance and expedite the advances that we all seek. Your committee's support for this funding is critical and we urge you to do all you can to encourage this vital work.

## PREPARED STATEMENT OF THE NATIONAL MPS SOCIETY

My name is Les Sheaffer, I serve on the Board of Directors of the National MPS Society and as Chairman of the Committee on Federal Legislation. My 9 year old daughter Brittany suffers from MPS III. I am submitting this testimony for the purposes of expressing the views of the National MPS Society with respect to congressional appropriations for the National Institutes of Health and biomedical research priorities and issues.

<sup>1</sup> I wish to offer my thanks to Chairman Harkin and the members of the Subcommittee for their continuing support for enhanced investment in genetic and biomedical research, training and infrastructure at the National Institutes of Health.

There are 11 primary types of Mucopolysaccharidosis (MPS) and Mucolipidoses (ML) are genetic Lysosomal storage disorders caused by the body's inability to produce certain enzymes. Normally, the body uses these enzymes to break down and recycle dead cells. In affected individuals, the missing or insufficient enzyme prevents the normal breakdown and recycling of cells resulting in the storage of these deposits in virtually every cell of the body. As a result of the storage, cells do not perform properly and cause progressive damage throughout the body including the heart, bones, joints, respiratory system and central nervous system. While the disease may not be apparent at birth, signs and symptoms develop with age as more cells are damaged by the accumulation of deposits. The most unfortunate result of these disorders is childhood mortality in many cases.

MPS research has gained momentum in recent years, private sector investment, funding of research by non profit organizations, improved technology, increasing collaboration and the essential federal investment in valuable MPS and ML related research on the part of the National Institutes of Health have all contributed to a better understanding of these disorders.

The average MPS researcher obtains approximately 85 percent of the funding they utilize for MPS and ML research projects from the National Institutes of Health and roughly 60 percent of these investigators have 2 or more grants at any given time. These statistics are based upon the results of a poll of the Scientific Advisory Board of the National MPS Society in 2000. Clearly, strong federal funding of MPS related research is essential to ensure investigators have resources needed to perform critical research pursuing development of effective therapies for MPS and ML disorders.

The primary institutes supporting MPS related research include the National Institute of Diabetes Digestive and Kidney Diseases (NIDDK), National Institute of Neurological Disorders and Stroke (NINDS), National Heart Lung Blood Institute (NHLBI) and National Institute of Child Health and Human Development (NICHD), additionally resources for development and maintenance of animal models is supported by the National Center for Research Resources (NCRR).

The NINDS is sponsoring a scientific conference to be held in September of 2002 bringing key investigators in the current MPS research community together with professionals in relevant fields to explore "Mucopolysaccharidosis—Therapeutic Avenues in the Central Nervous System". This conference is being supported by the NIDDK, the institute that has historically had the largest investment in MPS related and the Office of Rare Diseases.

We look forward with great anticipation to meaningful collaborative research efforts that may result from this event and potential issuance of Requests for Applications and or other mechanisms providing for enhancement of support and stimulation of activity of critical research that contributes to the development of effective treatments to improve the quality of life and ultimately save the lives of many children and individuals suffering from these deadly disorders.

As you know Requests for Applications (RFA) are a valuable funding mechanism for stimulating research in a targeted area. For example we are hopeful the RFA soliciting proposals for Gene Therapy for Neurological Disorders (NS-02-007) may benefit many disorders including Lysosomal Storage Disorders (LSD) the family of disorders to which MPS and ML belong. The progression of neurological damage in MPS disorders is a profound threat to the lives of MPS children and has yet to effectively treated or managed in any MPS disorder. Targeted funding mechanisms with a concentrated focus on proposals addressing MPS Central Nervous System (CNS) issues will in our view will present a meaningful contribution to filling the gaps in important current research and address one of the most critical elements of the progression of MPS disorders, as noted above, the continued damage to the central nervous system and the current inability to deliver effective treatments to the brain.

In light of these facts it is clear that resources and infrastructure to support intramural and extramural research are essential to ensuring current MPS and ML related research is supported and resources are available to take advantage of the promising research proposals we expect to see in the near future. Therefore on behalf of the Board of Directors and the membership of the National

Therefore on behalf of the Board of Directors and the membership of the National MPS Society I wish to express our steadfast support for the proposed NIH budget increase of 15.7 percent over fiscal year 2002 bringing the total fiscal year 2003 budget to \$27.3 billion, completing the Congress and administrations goal of doubling the NIH budget over 5 years.

Continued strong funding of the NIH will remain essential to ensure the continued advancement of basic research science and understanding of thousands of diseases affecting society, diseases that like MPS and ML rob the quality of life, financial stability and ultimately the lives of millions of American children and adults.

In closing I wish to again thank the members of the Labor Health and Human Services Subcommittee for your continued dedication to medical research and the completion of the Congressional commitment to double the budget of the National Institutes of Health. It is our sincere hope that future budget and appropriations decisions continue to reflect the advancement of and investment in medical research as the highest possible priority for years to come. Our children and those of future generations deserve nothing less.

# PREPARED STATEMENT OF THE SJÖGREN'S SYNDROME FOUNDATION

### INTRODUCTION

Sjögren's syndrome (pronounced SHOW-grens) is one of this country's most prevalent autoimmune diseases, striking as many as 4 million Americans, ninety percent of whom are women. This disease devastates the lives of those who suffer from it, yet we still know little about what causes Sjögren's or how to treat it. The Sjögren's Syndrome Foundation (SSF) is doing all it can with its limited re-

The Sjogren's Syndrome Foundation (SSF) is doing all it can with its limited resources to encourage and support studies to increase understanding of this illness, but we need more help from NIH and other federal research agencies. We believe our country's scientific establishments are at a point where significant headway can be made in increasing our understanding of this terribly debilitating disease. Our Foundation and those afflicted by this disease desperately need the help of the NIH to accomplish our goal of increased understanding of the cause and effective treatment of Sjögren's.

At the end of this presentation are specific suggestions of what we think can and should be done. Before making these recommendations, however, we will state what Sjögren's syndrome is, how it has affected the lives of particular individuals, and where current research is leading us.

### WHAT IS SJÖGREN'S SYNDROME?

In Sjögren's syndrome, the immune system turns against one's own body. Moisture-producing glands are primary targets, resulting in hallmark symptoms of dry eyes and dry mouth. These symptoms alone can be devastating. If not treated, dry eyes can lead to corneal ulcers and abrasions and potential blindness. Even with treatment, dry eyes cause pain, frequent eye infections, and blurred vision. The few treatments available—moisture drops and salves and closure of the puncta to decrease tear drainage—are palliative and don't correct the problem; they are also expensive and over-the-counter costs are often not covered by insurance.

Untreated dry mouth can lead to rampant caries, gum disease, and loss of teeth. The lack of saliva to protect the lining of the mouth, throat, tongue, and digestive tract, leads to chronic burning, pain, susceptibility to yeast infections, and intolerance for many foods. Those with dry mouth suffer from difficulty swallowing and talking and problems with digestion and reflux. Many with Sjögren's do not have dental insurance, and even if they do, insurance often does not cover costs resulting from Sjögren's.

Because moisture-producing glands exist throughout the body, the impact of dryness extends to the lining of the lungs and gastrointestinal and urinary tracts, the ears, nose, sinuses, throat, vagina, and skin. Autoimmune inflammation and destruction in Sjögren's can affect any body organ and system, including the pancreas, thyroid, liver, and gastrointestinal, vascular, nervous, and urinary and reproductive systems. Debilitating joint and muscle pain are common. In addition, maternal antibodies associated with Sjögren's can cause fetal heartblock. Sjögren's can also result in lymphoproliferative disorders, leading to development of non-Hodgkins lymphoma at a rate that is 44 times higher than in the general population.

#### PERSONAL IMPACT

Realizing in human terms what it is like to live with a disease that takes no day off best demonstrates why research truly is so important. A few of the stories our Foundation has recently received follow:

Foundation has recently received follow: Billie from North Carolina writes us: "My short story is a painful one, but I think quite common—it is one of the struggle for diagnosis, the friends you lose, the marriage that fails, the health insurance you can't get, treatment costs that make it a hardship to live, the struggle to find meaning in life when you are alone and no one believes you."

Susan Meyer from Connecticut writes: "Before being diagnosed with Sjögren's syndrome, I was once sent home from work because the nurse thought I had contagious mumps due to swollen parotid (salivary) glands. I was told not to return without a doctor's note. I saw several physicians at that time, but no one could diagnose the problem. I was finally diagnosed at 31, and since that time have experienced the following: eyes so dry and sensitive to light that I would sit in a stall in the ladies room at work for 10 minutes just so I could close my eyes; eyes so red and swollen that I was too self-conscious to look directly at people; vasculitis (inflammation of the blood vessels) which would develop into open sores on my legs and feet and eventually prompted treatment with cyclophosphamide, a form of chemotherapy, which then put me into early menopause at the age of 38; I have taken corticosteroids for 8 years putting me at risk for osteoporosis and cataracts; I have fatigue and muscle weakness which sometimes makes even getting dressed too tiring. Sjögren's patients are also at risk for developing non-Hodgkin's lymphoma, which I was diagnosed with at the age of 37." Dr. Teri Rumpf from Boston writes: "I received my PhD, my first job offer, and

Dr. Teri Rumpf from Boston writes: "I received my PhD, my first job offer, and my first incorrect diagnosis all in the same month. I was a 36-year old single mother, with a great deal of enthusiasm and no time to be sick. I needed to work, but it was a struggle to get up, get dressed, and get my son off to school each morning . . . My illness had been sending out signs and signals for years, but no one was really paying attention. It took 9 years to establish the diagnosis of Sjögren's syndrome, and after such a long time, it was a relief to have a disease with a name, even if no one had heard of it. Eventually, my body failed me, and I have had a continual fight to remain on disability. I feel that it is very difficult to be ill with any dignity in this country and that people are punished twice, once by the burden of the illness and once by the lack of support for people with chronic illnesses."

Joan Manny from Maryland writes: "My symptoms of Sjogren's syndrome became a burden for me and my family. The almost constant vasculitic symptoms (leg rashes called petechiae or purpura, swelling, pain and stiffness and occasionally an agonizing itch) made it difficult to plan family activities. By the end of the day my shoes no longer fit because of the swelling of my feet and legs, and without energy to do anything else, I spent evenings sitting with my feet elevated. When I awakened in the morning, my mouth was dry as paper, and the mucus that had accumulated in my lungs was so thick that it took about an hour in the morning to cough it up. I waited until the rest of the family left the house each day, because the sound of my coughing almost made them sick . . . Sleep became difficult. I have had frequent, painful parotid swelling usually accompanied by a low-grade fever and red, irritated eyes due to the constant dryness despite the frequent use of artificial tears. My children are grown now, and my dryness is better because of a drug studied at NIDCR, but I still suffer from difficult symptoms and look forward to a day when, finally, there might be a cure."

### APPROPRIATIONS LANGUAGE

Sjögren's syndrome was first identified over 100 years ago, causes serious medical problems and devastation of quality of life for up to 4 million Americans, and yet little is known about its causes or treatment.

Part of the mission of the Sjögren's Syndrome Foundation is to find ways to increase research in Sjögren's so patients and their caretakers will have practical and successful treatment options to help make their lives better. SSF funds initiatives that will increase the likelihood of more research, provides grants to private researchers, and has partnered and offered partnerships with NIH to increase interest in supporting Sjögren's initiatives.

Through these initiatives by SSF, the first international classification criteria on Sjögren's have been developed. This is critical to future progress in Sjögren's research, especially epidemiological studies; researchers now have a common frame of reference by which to include patients in their studies. A proposed major study on dry eye epidemiology and outcome measures, once considered by NEI, holds even greater promise now because of the Foundation's success in developing this international consensus on criteria, and we are working with NEI to resurrect that study. We are now supporting the development of outcome measures based on these criteria, which will open more avenues for research. Finally, a promising new Sjögren's mouse model for basic scientific studies is available, and the Foundation expects to work with the developer in making the model available. We recognize that our efforts—while significant—cannot bring about the major

We recognize that our efforts—while significant—cannot bring about the major breakthroughs we need without federal help. That is why we are requesting federal attention be directed toward research into the causes, treatments, and a cure for Sjögren's syndrome.

Sjögren's syndrome. We are grateful for the help given by the Senate HHS appropriations subcommittee last year—for the first time, Sjögren's was mentioned in text accompanying an appropriations bill. It is too soon to determine precisely how effective that language will be, but we are heartened by increased discussions with NIH. We need recognition of the magnitude of the problems related to Sjögren's and action based on that recognition; continued reference to the need for Sjögren's research in appropriations text can help bring this about.

Symptoms of and medical problems caused by Sjögren's syndrome cross many specialties and are relevant to the missions of many institutes at NIH. Sjögren's does not have just one natural home within NIH. In addition to research on dry eyes and dry mouth, we need research on musculoskeletal, immunological, gastrointestinal, lung, reproduction, endocrine, and nervous system manifestations and the crossover from an autoimmune process to cancer. Research about diseases disproportionately affecting women, studies related to aging, and complementary therapies are areas of great interest to patients with Sjögren's.

SSF has initiated discussions with pertinent NIH institutes and taken an active role in the compilation of the NIH Autoimmune Diseases Research Plan. The inclusion of Sjögren's syndrome in the 2002 appropriations bill gave extra weight to our requests, and we are grateful for that. We continue to encourage NIAMS and NIAID to find a way to honor our request in the 2002 NIH-Sjogren's language that they recognize Sjögren's to be part of their mission and include it in their portfolio of grants.

### NIDCR AND NEI

NIDCR has taken a leadership role in investigating Sjögren's. This institute houses the Sjögren's Syndrome Clinic, which provides patient treatment, referral to other institutes for additional treatment, and a natural history study and ongoing clinical trials. The intramural program completed studies over the past year on 6 medical aspects of Sjögren's syndrome, is conducting pilot clinical trials on 4 drugs that might help those with Sjögren's, and is collaborating on autoantibody studies in Sjögren's. The Gene Therapy and Therapeutics Branch is conducting studies in Sjögren's animal models and tissue engineering. NIDCR currently supports 9 extramural research projects, including promising studies on muscarinic receptors.

We gratefully acknowledge and thank the Senate subcommittee for supporting the doubling of the NIH budget over a 5-year period. We urge members to recognize that some institutes, such as NIDCR, do not receive the increased budget in proportion to other institutes.

NEI also provides major federal support of Sjögren's, treating patients from NIDCR's Sjögren's Syndrome Clinic and most recently investigating Cyclosporin A for treatment of dry eye. NEI currently funds 19 extramural studies on Sjögren's and dry eye, the largest number of extramural grants at NIH on Sjögren's-related studies.

We request that NIDCR and NEI are supported in current endeavors, and that they are urged to expand their support of investigations in Sjögren's. NIDCR is considering launching an international registry for Sjögren's, and we are discussing a major dry eye epidemiology study with NEI. Both are desperately needed if we are to make greater progress. The opportunities exist, the interest is there, and we need the urging of Congress to enable NIH to include appropriations for these projects.

We have incredible opportunities ranging from immunology to cell biology, from drug development to genetic engineering, which might eventually bring about changes to actually block Sjögren's from developing. Investigations into complementary medicine can be expanded to encompass more studies on Sjögren's. We have unprecedented opportunities for research in the areas of immunomodulation, gene therapy, and creation of artificial glands. We are making new discoveries in the area of antibodies targeting muscarinic receptors and secretegogues, we have an internationally agreed upon definition for our disease, and we have a new mouse model. We must take advantage of these opportunities.

# THE NIH AUTOIMMUNE DISEASES COORDINATING COMMITTEE, NIAID, AND NIAMS

In addition to ensuring the funding exists and future programs are encouraged for current endeavors at NIDCR and NEI, another avenue for support has arisen this one emphasizing the cross-cutting nature of autoimmune diseases, particularly Sjögren's. The NIH Autoimmune Diseases Coordinating Committee, overseen by NIAID, has just completed compilation of an NIH Autoimmune Diseases Research Plan. This plan, requested by Congress in December 2000, covers the more than 80 autoimmune diseases, including Sjögren's syndrome. We gratefully acknowledge NIAID's involvement of scientists from the Sjögren's

We gratefully acknowledge NIAID's involvement of scientists from the Sjögren's Syndrome Foundation in the plan's compilation. We have worked closely with NIH and other national voluntary health agencies to assimilate needs and opportunities for basic science (including genetics), clinical studies, epidemiology, and education and communication dissemination in the NIH Autoimmune Diseases Research Plan. Now that plan must be funded. NIH estimates that \$400-\$450 million a year will be needed.

We request the Senate Appropriations HHS subcommittee include funding of this plan in the 2003 appropriations bill. In addition, we specifically ask the subcommittee for help to make sure that Sjögren's syndrome is included as a priority in the execution of that plan.

We also appreciate the generosity of advice and time provided by NIAMS to discuss ways to increase research. We have not yet made progress on partnerships, but with continued inclusion of language that NIAMS and NIAID recognize that Sjögren's is part of their mission and should be included in their portfolio of grants, we will make that progress.

# WHAT ARE WE ASKING THE SENATE APPROPRIATIONS SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES TO DO?

1. Encourage NIH to recognize the need for Sjögren's research and to support scientific workshops on Sjögren's.

According to researchers at NIH, the best way to increase interest and generate excitement for Sjögren's research within the scientific community is to hold workshops with participants from related areas and on shared concerns. The SSF is committed to this action. We can't do it alone and need appropriations language asking for support of and participation in such workshops on the part of institutes whose responsibilities include the many scientific aspects of Sjögren's. This includes NIAMS, NIAID, NEI, NIDCR, NINDS, NICHD, NCCAM, and NCI.

2. Encourage NEI to pursue an epidemiology study on dry eye and Sjögren's syndrome.

3. Help us ensure that the needs of the 4 million Americans with Sjögren's syndrome are included implementation of the NIH Autoimmune Diseases Research Plan.

We desperately need a registry on Sjögren's and studies in epidemiology before greater progress in research can be made. We request support for these projects in addition to inclusion of Sjögren's in the plan's call for studies on genetics, basic research, clinical studies, and education.

Sjögren's syndrome is one of the most prevalent autoimmune disorders, and within the NIH budget allotted for autoimmune disease, Sjögren's receives very little compared to other autoimmune diseases in relation to its prevalence. Of the total amount for autoimmune disease, the majority has gone to just three autoimmune diseases—rheumatoid arthritis, juvenile diabetes, and multiple sclerosis. That leaves a small percentage for the other approximately 77 autoimmune disorders! We need to ensure that as a national plan for autoimmune disease is executed, Sjögren's syndrome is a priority.

4. Support the NIH Autoimmune Diseases Research Plan by providing the \$400-\$450 million a year needed to execute the plan, as described above.

Autoimmune diseases make up the third largest disease category in the United States and include more than 80 diseases, many of which overlap and share symptoms. Yet, autoimmune disease currently receives only a fraction of the NIH budget. NIH has come up with a plan that cuts across all institutes to cover autoimmune disease; it's time such a plan is funded.

5. Continue to support our request from the previous year that NIAMS and NIAID include Sjogren's as part of their mission and portfolio of grants.

### PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM) fully supports the Administration's fiscal year 2003 budget request of \$27.3 billion, a 15.7 percent increase, for the National Institutes of Health (NIH). The proposed fiscal year 2003 budget for the NIH includes new funding to expand the nation's biodefense research agenda and at the same time strengthens resources for research facilities, scientific personnel, and investigator initiated research on a vast array of diseases that continue to threaten public health. The Administration's budget request fulfills the bipartisan commitment to double the NIH budget by fiscal year 2003, a goal supported by the ASM to take advantage of new scientific opportunities. The ASM is grateful for the bipartisan support that Congress has shown the NIH, and for the generous funding increases provided for biomedical research.

The September 11 tragedy has transformed the nation. We have seen the human toll of lives, illness and fear as the result of the deliberate use of anthrax. The capability to develop effective measures to counter the effects of a potential bioterrorism attack has never been more urgent. At the same time, we must increase research efforts to combat old and new diseases that threaten to undermine health and wellbeing in this country and globally.

Fortunately, investments in basic and clinical research have produced medical advances in the past year which will help the nation respond to both deliberate and naturally occurring infectious diseases, including: the elucidation of the mechanisms by which anthrax toxin destroys cells, hastening the development of new drugs to treat anthrax; clinical research that suggests it is possible to "stretch" available does of licensed smallpox vaccine by dilution; a new anthrax vaccine, based on a bioengineered component of the anthrax bacterium called recombinant protective antigen (rPA) which will soon enter human trials; a number of improved HIV/AIDS treatments; the first vaccine against a blood infection common among hemodialysis patients; a hybrid vaccine that protects mice from West Nile infection; a new DNA-based vaccine that prevents the Ebola virus infection in monkeys and is now ready for human clinical trials; and the complete genome sequencing of several pathogenic bacteria. The progress and success of microbial genomics has been a critical achievement for biomedical research, with the complete genomic sequence of five disease causing bacteria, including *E.coli* 0157:H7, *Salmonella typhimurium, Ureaplasma urealyticum, Streptococcus pneumoniae and Streptococcus pyogenes*.

# BIOTERRORISM-RELATED RESEARCH: SCIENTIFIC OPPORTUNITIES TO PROTECT THE NATION

The ASM strongly supports the Administration's budget request of \$3.99 billion, an increase of \$1.5 billion for the National Institute of Allergy and Infectious Diseases (NIAID), which spearheads the bioterrorism research efforts of the NIH. The NIAID supports unprecedented research opportunities in the scientific disciplines of microbiology, immunology and infectious diseases, key fields which promise better understanding of the mechanisms of infectious diseases, antimicrobial resistance, and the human immune system. As the lead agency at NIH for infectious diseases and immunology, NIAID has developed a Strategic Plan for Counter-Bioterrorism Research and a detailed NIAID Counter Bioterrorism Research Agenda, with short-, intermediate-, and long-term goals for both basic and applied research. Research into the basic biology and disease-causing mechanisms of pathogens underpins all efforts to develop interventions to counter bioterrorism agents. The investment in research on counter bioterrorism and the genetics of microbes should have positive spin offs for other diseases, such as West Nile virus, dengue, influenza and multidrug resistant infections.

The \$1.75 billion proposed in total for NIH bioterrorism related research in fiscal year 2003 (\$441 million for basic research and development; \$592 million for drug and vaccine discovery and development; \$194 million for clinical research; and \$521 million for research facilities) is needed to accelerate discovery and development of knowledge and products that will rapidly increase countermeasures to control bioterrorism agents and to enhance the capability to do research on threat agents. Antimicrobial and vaccine strategies depend on breakthroughs in basic research, genomics and computer sciences. The genome sequencing of the smallpox and chol-

era pathogens recently was completed, that of the anthrax bacterium is nearly completed, and sequencing will be done on a host of other potential bioterrorism agents. The NIAID's ambitious research agenda includes development of new vaccines, therapeutics, and diagnostic tests for potential agents, as well as unraveling the basic biology of microbes and of human host responses to infection. Studies will be expanded on microbial genomes to sequence the genomes of the various species and strains of microbes most likely to be used by terrorists and by performing comparative analysis of these genomes and their protein products to develop new leads for the development of new and improved diagnostic devices, drugs, vaccines and forensic tools. Comparative microbial genomics and proteomics will yield new insights into the genetic basics for why different species of microbes and different strains of the same species differ from one another and their virulence and susceptibility to antibiotics. Such research will help assess preventative and therapeutic strategies using existing products.

The NIH is mounting a multi-layered assault on a long list of threatening microbes that will include expanded research resources for: extramural research project grants; expansion of the research infrastructure, in particular additional high-level biosafety laboratories; creation of ten Centers of Excellence for Bioterrorism and Emerging Infections nationwide, development of a centralized research reagent repository, expansion of research training and challenge grants to industry and academia. A major component of the research program is to enhance the research infrastructure at intramural and extramural sites to enable research efforts on pathogenic microbes and potential terrorism agents and to meet new biosecurity requirements.

Substantial and comprehensive increases in resources will be needed if this effort is to be successful in attracting and synergizing the long-term interest of academic scientists and industry in support of research to develop biomedical tools to detect, diagnose, treat, and investigate diseases caused by deadly pathogens.

### NEW AND EMERGING AND DRUG RESISTANT INFECTIOUS DISEASES—THREATS TO PUBLIC HEALTH AND GLOBAL SECURITY

The ASM remains alarmed by the persistence of infectious diseases in this country and abroad, and by the real possibility of even greater problems in the future. Worldwide more than 13 million deaths result from infectious diseases. In the United States, infections are significant killers and cost more than \$120 billion annually. The multiple threats of emerging, re-emerging and drug resistant infections mandate that we accelerate the pace of biomedical research.

Emerging and re-emerging pathogens appear at a time of increasing microbial resistance to standard therapeutics, two trends that together complicate already complex challenges for the research community. Antimicrobial resistance must be become a priority area of research efforts and new funding should be provided for the interagency Antimicrobial Resistance Action Plan released in 2001. In the United States, most Staphylococcus aureus infections acquired in hospitals are now resistant to the drug of choice. Approximately 14,000 people in this country alone are infected and die each year from a drug resistant microbe acquired in a hospital setting. Antimicrobial resistance is growing and spreading worldwide, affecting the ability to successfully treat respiratory, diarrheal, sexually transmitted, hospital-associated and other infections. Resistance to chloroquine, the main anti-malaria drug, is impairing efforts to control this disease in Africa. More research is needed to advance the field of study and develop new diagnostic, therapeutic and preventive approaches.

In his budget message to Congress, President Bush cautioned that infectious diseases "make no distinctions among people and recognize no borders." Aided by rapid travel and constant cultural exchanges, infectious diseases not only have not disappeared, they have persisted as a global problem. They exact a heavy toll not only in the United States, where infections are the third leading cause of death, but worldwide, with infectious diseases the leading cause of death for those under age 45 and particularly children. These sad statistics, and the entry into the United States of new pathogens such as the West Nile Virus 2 years ago, compel this nation to approach infectious disease as a global issue.

Both developed and developing countries face significant challenges from infectious disease. In 1999 alone, the five leading infectious causes of death took more than 11.5 million lives across the globe. In some countries the HIV infection rate exceeds 30 percent, while worldwide during the past year, 5 million new HIV infections further burdened the political, economic, and health care systems of individual nations. In some of those nations, the gross domestic products will decline from 8 to 20 percent due to the effects of HIV/AIDS. Malaria is an ancient disease that causes great morbidity and mortality. It causes an estimated 300 million to 500 million new infections each year, and from 1 million to 3 million deaths. The World Bank reports that annual global economic losses due to malaria total \$12 billion. Infectious diseases are not just the concern of those in medicine and health care, but also of world leaders.

Aware of these political implications, the Congress consistently has invested in the NIH's long-standing efforts against malaria, HIV/AIDS, and other diseases of global impact. In fiscal year 2001, the NIAID formalized a global health research plan for HIV/AIDS, malaria and tuberculosis, to extend on-going programs related to these diseases. Recently NIH scientists described a mechanism by which malaria parasites enter red blood cells, providing a potential target for vaccine or drug development. In fiscal year 2003, NIAID will support three new international centers of excellence for malaria research and fund the testing of malaria vaccines in early human clinical trials. Likewise, two HIV DNA vaccine candidates underwritten by the NIH are on their way toward phase I human trials. These and other successes validate the President's budget request to extend both the vigorous AIDS research underway and the Global Fund to Fight HIV/AIDS, Malaria, and Tuberculosis. The ASM commends the proposed fiscal year 2003 budget in its continued high-

The ASM commends the proposed fiscal year 2003 budget in its continued highlevel support to these and other public health concerns such as food-borne illnesses, hospital-acquired infections, and chronic disorders with microbial causes.

### BIOMEDICAL RESEARCH FOR THE 21ST CENTURY

Biomedical research is an expansive enterprise that becomes more complex, more costly, and more demanding as technological tools and health policy issues grow in importance. To guide an idea or a solution from the bench to the bedside now involves coordinated teams of people, science disciplines and institutions working within a well-built infrastructure.

Both preparedness and foresight must distinguish present-day biomedical research. Expecting the unexpected and ensuring a strong response from science calls for an improved research infrastructure—training and career development, including adequate stipend levels to attract the best young scientists to pursue careers in research and programs to increase the participation of minorities in research careers; and increased support for state-of-the-art equipment and secure facilities for pioneering research on bioterrorism agents. The ASM commends the proposed NIH budget's provision for a record number of research grants and training positions. Investigator-initiated research is the basis for scientific creativity and productivity. Basic research remains the foundation from which advances and the ideas for future advances in biomedical research evolve.

In the past 20 years, biomedical research has helped extend our life expectancy by 6 years. Such tangible benefits to public well-being come from dedicated innovation and investment in biomedical research. The proposed budget for the NIH will enhance its ability to seize scientific opportunities to advance both national health and national security.

### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR GERIATRIC PSYCHIATRY

The American Association for Geriatric Psychiatry (AAGP) appreciates this opportunity to present its recommendations on issues related to fiscal year 2003 appropriations for mental health research and services. AAGP is a professional membership organization dedicated to promoting the mental health and well being of older Americans and improving the care of those with late-life mental disorders. AAGP's membership consists of approximately 2,000 geriatric psychiatrists as well as other health professionals who focus on the mental health problems faced by senior citizens.

AAGP would like to thank the Subcommittee for its continued strong support for increased funding for the National Institutes of Health (NIH) over the last several years, particularly the additional funding you have provided for the National Institute of Mental Health (NIMH), the National Institute on Aging (NIA), and the Center for Mental Health Services (CMHS) within the Substance Abuse and Mental Health Services Administration (SAMHSA). Although we generally agree with others in the mental health community about the importance of sustained and adequate Federal funding for mental health research and treatment, AAGP brings a unique perspective to these issues because of the elderly patient population served by our members.

There are serious concerns, shared by AAGP and researchers, clinicians, and consumers that there exists a critical disparity between appropriations for research, training, and health services and the projected mental health needs of older Americans. This disparity is evident in the convergence of several key factors:

- -demographic projections inform us that, with the aging of the U.S. population, there will be an unprecedented increase in burden of mental illness among aging persons, especially among the baby boom generation;
- -this growth in the proportion of older adults and the prevalence of mental illness is expected to have a major direct and indirect impact on general health service use and costs;
- -despite the fact that effective treatment exists, the mental health needs of many older adults remain unmet;
- —a lack of quality education programs exists to train sufficient numbers of geriatric mental health providers;
- -a major gap exists between research and service delivery; and
- -despite recent significant increases in appropriations for support of research in mental health, the allocation of NIMH and CMHS funds for research that focuses on mental health and aging is disproportionately low, and woefully inadequate to deal with the impending crisis of mental health in older Americans.

#### DEMOGRAPHIC PROJECTIONS AND THE MENTAL DISORDERS OF AGING

With the baby boom generation nearing retirement, the number of older Americans experiencing mental disorders is certain to increase in the future. By the year 2010, there will be approximately 40 million people in the United States over the age of 65. Over 20 percent of those people will experience mental health problems. A national crisis in geriatric mental health care is emerging and has received recent attention in the medical literature. Action must be taken now to avert serious problems in the near future. While many forms of mental and behavioral disorders can occur late in life, they are not an inevitable part of the aging process, and continued research holds the promise of improving the mental health and quality of life for older Americans.

It is also important to note that the current number of health care practitioners, including physicians, who have training in geriatrics is inadequate. As the population ages, the number of older Americans experiencing mental problems will almost certainly increase. Since geriatric specialists are already in short supply, these demographic trends portend an intensifying shortage in the future. There must be a substantial public and private sector investment in geriatric education and training, with attention given to the importance of geriatric mental health needs. We will never have, nor will we need, a geriatric specialist for every older adult. However, without mainstreaming geriatrics into every aspect of medical school education and residency training, broad-based competence in geriatrics will never be achieved. There must be adequate funding to provide incentives to increase the number of academic geriatricians to train health professionals from a variety of disciplines, including geriatric medicine and geriatric psychiatry.

Current and projected economic costs of mental disorders alone are staggering. For example, the direct medical costs of caring for patients with Alzheimer's disease ranges from \$18,000 to \$36,000 a year per patient, depending on the severity of the disease. In addition, there are other expenses associated with caring for an Alzheimer's disease patient including social support, care giving, and often nursing home care. It is estimated that total costs associated with caring for patients with Alzheimer's disease is over \$100 billion per year in the United States. Psychiatric symptoms (including depression, agitation, and psychotic symptoms) affect 30 to 40 percent of people with Alzheimer's and are associated with increased hospitalization, nursing home placement, and family burden. These psychiatric symptoms, combined with Alzheimer's disease, can increase the cost of treating these patients by more than 20 percent. Although NIA has supported extensive research on the cause and treatment of Alzheimer's, treatment of these behavioral and psychiatric symptoms has been neglected and should be supported through NIMH.

Depression is another example of a common problem among older persons. Of the approximately 32 million Americans who have attained age 65, about five million suffer from depression, resulting in increased disability, general health care utilization, and increased risk of suicide. Approximately 30 percent of older persons in primary care settings have significant symptoms of depression; and depression is associated with greater health care costs, poorer health outcomes, and increased mortality. Older adults have the highest rate of suicide rate compared to any other age group.

The enormous and widely underestimated costs of late-life mental disorders justify major new investments. 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.

### THE BENEFITS OF RESEARCH ON PUBLIC HEALTH

The U.S. Surgeon General's Report on Mental Health (1999) and the Administration on Aging Report on Older Adults and Mental Health (2001) underscore the prevalence of mental disorders in older persons and provide evidence that research supports the development of effective treatments. These reports summarize research findings showing that treatments are being developed and tested that are effective in relieving symptoms, improving functioning, enhancing quality of life, including preliminary findings suggesting that these interventions reduce the need for expensive and intensive acute and long-term services. However, it is also well demonstrated that there is a pronounced gap between research findings on the most effective treatment interventions and implementation by health care providers. This gap can be as long as 15 to 20 years. These reports stress the need for translational and health services research focusing on identifying the most cost-effective interventions, as well as creating effective methods for improving the quality of health care practice in usual care settings. A major priority (neglected to date) is the development of a research agenda focusing on health services research on mental health and aging that examines the effectiveness and costs of proven models of mental health service delivery for older persons.

Special attention also needs to be paid to investigations of inadequately or poorly studied, serious late-life mental disorders since illnesses such as schizophrenia, anxiety disorders, alcohol dependence and personality disorders have been largely ignored by both the research community and the funding agencies, despite the fact that these conditions take a major toll on patients, their care givers, and society at large. Many of AAGP's members are at the forefront of groundbreaking research on Alzheimer's disease, depression, and psychosis among the elderly, and we strongly believe that more research funds must be focused in these areas. Improving the treatment of late-life mental health problems will benefit not only the elderly, but also their children, whose lives are often profoundly affected by those of their parents.

While the funding increases supported by this Subcommittee in recent years have been essential first steps to a better future, a committed and sustained investment in research is necessary to allow continuous progress on the many research advances made to date.

## NATIONAL INSTITUTE OF MENTAL HEALTH

The President's proposed increase of \$3.7 billion (15.7 percent) over fiscal year 2002 represents the final step in the doubling of the NIH budget between fiscal years 1999 and 2003. This increase would bring the NIH budget to a level of \$27.3 billion. While AAGP applauds the President's commitment to double the NIH budget, we are concerned that the proposed budget increase for NIMH lags far behind the nearly 14 percent increase proposed for other NIH institutes. For NIMH, the President is proposing \$1.359 billion for scientific and clinical research, a \$105 million increase over the agency's fiscal year 2002 appropriation of \$1.254 billion, amounting to an increase of 7.8 percent. As Congress moves forward with deliberations on the fiscal year 2003 budget, AAGP believes that NIMH should receive a percentage increase that, at the very minimum, is at least equal to the average percent increase for the NIH institutes.

Commendable as recent funding increases for NIH and NIMH have been, AAGP would like to call the Subcommittee's attention to the fact that these increases have not always translated into comparable increases in funding that specifically address problems of older adults. Data supplied to AAGP by NIMH indicates that while extramural research grants by NIMH increased 59 percent during the 5-year period from fiscal year 1995 through fiscal year 2000 (from \$485,140,000 in fiscal year 1995 to \$771,765,000 in fiscal year 2000), NIMH grants for aging research increased at less than half that rate: only 27.2 percent during the same period (from \$46,989,000 to \$59,771,000).

AAGP is pleased that in recent months NIMH has renewed its emphasis on mental disorders among the elderly, and commends the creation of an intra-NIMH consortium of scientists concerned with mental disorders in the aging population. However, funding for aging mental health research is still not keeping pace with that of other adult mental health research, and is actually decreasing proportionally when considered in the context of anticipated projections in growth of mental disorders in older persons. For example, the proportion of total NIMH newly funded extramural research grant funding devoted to aging research declined from an average of 8 percent from fiscal years 1995 to 1999 to a low of 6 percent in fiscal year 2000. It is likely that one reason for the decline in funding of new grants is due to the lack of grant review committees at NIMH with specific expertise in aging. Grant review committees with specialized expertise in geriatrics are needed to assure fair review of research proposals that take into account knowledge of the unique biological factors associated with the aging brain, the universal presence of co-occurring medical disorders, and different nature of financing and health service delivery for older Americans.

In addition to supporting research activities at the NIMH, AAGP supports increased funding for the other institutes at the NIH that address issues relevant to geriatric mental health, including the NIA and the National Institute of Neurological Disorders and Stroke.

### CENTER FOR MENTAL HEALTH SERVICES

It is also critical that there be adequate funding increases for the mental health initiatives under the jurisdiction of the CMHS within SAMHSA. While research is of critical importance to a better future, the patients of today must also receive appropriate treatment for their mental health problems. SAMHSA provides funding to State and local mental health departments, which in turn provide community-based mental health services to Americans of all ages, without regard to the ability to pay. AAGP was pleased that the Labor-HHS conference agreement for fiscal year 2002 included \$5 million for evidence-based mental health outreach and treatment to the elderly. AAGP worked with members of this Subcommittee and its House counterpart on this initiative, which is a very important first step in addressing the mental health needs of the nation's senior citizens.

Funding for the dissemination and implementation of evidence-based practices in "real world" usual care settings must be a top priority for Congress. Despite significant advances in research on the causes and treatment of mental disorders in older persons, there is a major gap between these research advances and clinical practice in usual care settings. The greatest challenge for the future of mental health care for older Americans is to bridge this gap between established research findings and clinical practice in the community. Adequate funding for this geriatric mental health services initiative is essential to disseminate and implement evidence-based practices in routine clinical settings across the states. Consequently, we would urge that the \$5 million for mental health outreach and treatment for the elderly included in the CMHS budget for fiscal year 2002 be increased to \$20 million for fiscal year 2003.

# AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

One of the most valuable resources in our efforts to improve access to and the quality of geriatric mental health services is the Agency for Healthcare Research and Quality (AHRQ). In recent years the Agency has supported important research on mental health topics including studies on children's mental health issues, the impact of mental health parity on consumers' share of mental health costs, improving care for depression in primary care, and cultural issues in the treatment of mental illness in minority populations. This work represents important contributions to the mental health literature and to the advancement of effective diagnosis and treatment of mental illness. We applaud these efforts and urge the Committee to increase support for the critical work of this Agency. However, we are concerned that the research agenda of the Agency has not given more attention to geriatric mental health issues. The prevalence of undiagnosed and untreated mental illness among the elderly is alarming. Affective disorders, including substance abuse dependence are often

However, we are concerned that the research agenda of the Agency has not given more attention to geriatric mental health issues. The prevalence of undiagnosed and untreated mental illness among the elderly is alarming. Affective disorders, including depression, anxiety, dementia, and substance abuse dependence, are often misdiagnosed or not recognized at all by primary and specialty care physicians in their elderly patients. There is accumulating evidence that depression as a co-occurring condition with a variety of chronic diseases can exacerbate the effects of cardiac disease, cancer, strokes, and diabetes. Research has also shown that treatment of mental illness can improve health outcomes for those with chronic diseases. Effective treatments for mental illnesses in the elderly are available, but without access to physicians and other health professionals with the training to identify and treat these conditions, far too many seniors fail to receive needed care.

AAGP believes there is an urgent need to translate advancements from biomedical and behavioral research in geriatric mental illness to clinical practice. By utilizing the resources of the evidence-based practice centers under contract to AHRQ, results from geriatric mental health research can be assessed and translated into findings that will improve access, foster appropriate practices, and reduce unnecessary and wasteful health care expenditures. We urge the Committee to direct the Agency to

support additional research projects focused on the diagnosis and treatment of mental illnesses in the geriatric population. We also believe a high priority should be given to the dissemination of scientific findings about what works best in the diagnosis and treatment of geriatric mental illness to ensure that physicians and other health professionals have access to significant advancements in care.

# CONCLUSION

Based on AAGP's assessment of the current need and future challenges of late life mental disorders, we submit the following recommendations:

1. The current rate of funding for aging grants at NIMH and CMHS is inad-equate. Funding for NIMH and CMHS aging research grants should be increased to be commensurate with current need (at least three times their current funding levels). In addition, the anticipated projected future increase in mental disorders among our aging population in terms of dollar amount of grants and absolute number of new grants should be built into the budget process;

2. A fair grant review process will be enhanced by committees with specific expertise and dedication to mental health and aging;

3. Infrastructure and reporting mechanisms within NIMH and CMHS are essential to support the development of initiatives in aging research, monitor the quality and number of applicants for aging research grants, and management of those grants. Those individuals in the Office of the Director of NIMH and in the Office of the Director of CMHS who are designated to oversee the aging research agendas and initiatives for these two agencies should provide regular reports to Congress to ensure accountability; and

4. AHRQ should undertake additional research projects focused on the diagnosis

AGP strongly believes that the present research infrastructure, health care fi-nancing, and healthcare personnel with appropriate geriatric training, and the mental health delivery systems are grossly inadequate to meet the challenges posed by the expected increase in the number of elderly with mental disorders. Congress must support funding for research that addresses the diagnosis and treatment of mental illnesses, as well as programs that increase the quality of life for those with late-life mental illness.

AAGP looks forward to working with the members of this Subcommittee and others in Congress to establish geriatric mental health research and services as a pri-ority at NIMH, CMHS and AHRQ.

# PREPARED STATEMENT OF THE LEUKEMIA & LYMPHOMA SOCIETY

# INTRODUCTION

I am pleased to submit this statement on behalf of the Leukemia & Lymphoma Society (LLS). During its 52-year history, the LLS has been dedicated to finding a cure for the blood cancers—leukemia, lymphoma, and myeloma. Our central con-tribution to the search for a cure is funding a significant amount of basic and translational research in the blood cancers. In 2002, we will fund almost \$38 million in research grants. In addition to our role as a funder of research, we provide a wide range of services to individuals with the blood cancers, their caregivers, families, and friends. Finally, we advocate responsible public policies that will advance our mission of finding a cure for the blood cancers.

We are pleased to report that impressive progress has been made in the treatment of many blood cancers. Over the years, there have been steady and impressive strides in the treatment of the most common form of childhood leukemia, and the survival rate for that form of leukemia has dramatically improved. And just last year, a new therapy was approved for chronic myelogenous leukemia, a form of leukemia for which there were previously limited treatment options, all with serious side-effects. This new therapy, a signal transduction inhibitor called Gleevec, is a so-called targeted therapy which corrects the molecular defect that causes the disease, and does so with few side effects.

LLS contributed to the early research on Gleevec, as it has contributed to basic research on a number of new therapies. We are pleased that we played a role in the development of this life-saving therapy, but we realize that our mission is far from complete. Many forms of leukemia and lymphoma present daunting treatment challenges, as does myeloma. There is much work still to be done, and we believe the research partnership between the public and private sectors can be strengthened.

The grant programs of the LLS are in three broad categories: Career Development Grants, Translational Research Grants for early-stage support for clinical research, and Specialized Centers of Research. In our Career Development program, we fund Scholars, Special Fellows, and Fellows who are pursuing careers in basic or clinical research. In our Translational Research Program, we focus on supporting investigators whose objective is to translate basic research discoveries into new therapies.

The work of Dr. Brian Druker, an oncologist at Oregon Health Sciences University and the chief investigator on Gleevec, was supported by a translational research grant from LLS. Dr. Druker is certainly a star among those supported by LLS, but our support in this field is broad and deep. Through the Career Development and Translational Research Programs, we are currently supporting more than 400 investigators in 33 states and ten foreign countries.

Our new Specialized Centers of Research grant program (SCOR) is intended to bring together research teams focused on the discovery of innovative approaches to benefit patients or those at risk of developing leukemia, lymphoma, or myeloma. The awards will go to those groups that can demonstrate that their close interaction will create research synergy and accelerate our search for new therapies, prevention, or cures.

### PLANNING FOR THE FUTURE

Despite enhancements in treating blood cancers, there are still significant research opportunities and challenges. LLS will continue to raise funds in the private sector to support blood cancer research. We offer the following recommendations for the federally funded blood cancer research effort:

-Fund the programs authorized by the Hematological Cancer Research Investment and Education Act.—This bill, authored by Senators Kay Bailey Hutchison and Barbara Mikulski (S. 1094) and Representatives Phil Crane, Marge Roukema, and Vic Snyder (H.R. 2629), has passed the Senate. The bill directs the National Institutes of Health (NIH) to strengthen its blood cancer research program by coordinating those research efforts. The bill also establishes a blood cancer educational program for patients and the public, to be administered by an agency within the Department of Health and Human Services. We anticipate final action on this legislation and urge the Committee to fund the programs authorized by this bill.

LLS is already involved in a wide range of educational initiatives, and we urge HHS to implement the blood cancer education program as a collaborative public-private sector initiative. We believe that approach will best capitalize on the experience and expertise of private sector organizations while allowing an expansion of these programs to serve more individuals in need of information about the blood cancers.

- Encourage NCI to implement research initiatives proposed by the Leukemia, Lymphoma, and Myeloma Progress Review Group (LLM-PRG).—In December 2000, the National Cancer Institute (NCI) convened a blue-ribbon panel of extramural researchers, clinicians, and advocates to provide advice on the NCI's blood cancer research program. This group of experts, called the Leukemia, Lymphoma, and Myeloma Progress Review Group, or LLM-PRG, made a series of recommendations aimed at strengthening the blood cancer research program. One of those recommendations was for a public-private sector translational research consortium with the lofty goal of reducing by half the period of time necessary for development of a new blood cancer therapy. This idea is one that we would like to see developed further, because it reflects our philosophy that collaboration and cooperation are critical to improvements in cancer treatment; it also reinforces the commitment of LLS to increase our investment in translational research in order to speed the movement of basic research findings to the bedside. The implementation of the LLM-PRG report and the specific recommendation for a translational research consortium appears to have slowed in recent months, and we urge Congress to encourage NCI to move forward with an implementation strategy.
- -Continue Progress Toward Doubling the NIH Budget.-LLS is pleased to have this opportunity to express our sincere appreciation to this Subcommittee for its leadership in shepherding through Congress large increases in funding for NIH. You have had the foresight to make an impressive investment in biomedical research, and the benefits have only begun to be reaped. Gleevec is an outstanding example of important research aimed at developing more targeted cancer therapies that do not have the serious side effects of much traditional chemotherapy. We believe the development of additional targeted therapies is pos-

sible, and the long-term investment in basic, translational, and clinical research has made these new therapies a realistic possibility. LLS and its advocates are integrally involved in efforts of the cancer commu-

LLS and its advocates are integrally involved in efforts of the cancer community, the larger biomedical research community, and the voluntary health agency community to create a positive environment for biomedical research and guarantee that support for NIH remains strong even after the budget is doubled.

We appreciate the opportunity to submit this statement, and we look forward to working with the Subcommittee toward our shared goal of a strong biomedical research effort in the United States.

# PREPARED STATEMENT OF THE RESEARCH SOCIETY ON ALCOHOLISM

The Research Society on Alcoholism (RSA) appreciates the opportunity to present its views about the importance of alcohol research within our nation's priorities for health and improving the quality of life. The RSA is a professional society of over 1,400 members who are committed to understanding and intervening in the negative consequences of alcohol through basic research, clinical protocols, psychosocial research and epidemiological studies.

The cost of alcohol abuse and dependence on American society and individual lives is staggering. The cost to the nation is estimated at approximately \$185 billion annually. Not only are the fiscal costs real and powerful, but alcohol misuse is costly in other ways as well.

A recently released report on college drinking, sponsored by the National Institute on Alcohol Abuse and Alcoholism, reveals that 1,400 college students between the ages of 18–24 die each year from unintended alcohol-related injuries. 500,000 students between the ages of 18 and 24 are unintentionally injured under the influence of alcohol.

Equally disturbing is the increasing trend of alcohol consumption among children ages 9 to 15. A report issued last year by the Robert Wood Johnson Foundation, "Substance Abuse: The Nation's Number One Health Problem," states that by the 8th grade, 52 percent of adolescents have consumed alcohol. The Leadership to Keep Children Alcohol Free, a multi-year national initiative founded by the National Institute on Alcohol Abuse and Alcoholism, The Robert Wood Johnson Foundation, and joined by additional federal agencies, reports that almost one-third of eighth graders and half of tenth graders have been drunk at least once. One-fifth of ninth graders report binge drinking (consuming five or more drinks in a row) in the past month.

Alcohol abuse and alcoholism are a major cause of medical morbidity, mental retardation, accidental death and injury, homicide, suicide, lost productivity, and disruption of family. For some subgroups, such as the American Indians, the costs associated with alcohol misuse are disproportionately higher and may be directly linked to some of the major health problems in this group such as hypertension and diabetes. The Indian Health Service estimates that the age-adjusted alcoholism mortality rate for American Indians is 63 percent higher than the rate for all other races in the United States.

Despite, or perhaps because of, the widespread impact and effects of alcohol, it has been impossible to identify a single cause or solution to alcohol's negative consequences. The causes and consequences of alcoholism can be discerned in the interactions of molecules, brain pathways, individuals, families and communities.

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) forges an integrated, multidisciplinary approach in attacking the problems of alcohol abuse and alcoholism. Because of this committee's historic support for the growth of biomedical research, and the investment in NIAAA more specifically, the alcohol research community has made important strides in clarifying many of the factors which we now know contribute to risk to alcoholism and the overall negative consequences of alcohol abuse and dependence. We have seen significant advances in disentangling the roles of genetics and environment genetic influence and role of family history in alcohol dependence, we have begun to identify the critical components of effective treatment, and we have begun to explore effective integrated treatments for those who suffer from the most severe forms of the disease. Given our scientific understanding of alcoholism only a few decades ago, this is truly remarkable progress.

While recognizing these advances, the federal investment in alcohol research has been modest given the magnitude of the consequences from alcohol abuse and dependency on the nation. There must be a strong national commitment to alcohol research and treatment of alcohol-related disorders if we hope to reverse current trends that result in unintended deaths, escalating health costs and lost productivity. The leadership of the Research Society on Alcoholism has framed the following set of priorities which, if adequately supported, will move the field significantly forward and provide translational benefits to additional NIH priorities.

- --İdentification of Molecular Targets of Alcohol in the Brain.--NİAAA-funded research has successfully identified molecular targets of alcohol in the brain. The characterization of these targets may lead to the discovery of compounds that block specific effects of alcohol. These discoveries have already led to the prevention of alcohol-related birth defects in mice. Increased funding will allow the NIAAA to stimulate additional research on the molecular basis for the actions of alcohol.
- -Brain Mapping and Organ Imaging in Alcoholism.—Tremendous progress has been made in mapping the brain pathways that are involved in alcohol addiction and alcohol-related brain damage through advanced imaging technology. Further research in this area is necessary to fully understand the impact of alcohol abuse and addiction on the underlying brain systems. The development of advanced instrumentation is also necessary to enhance the understanding of alcohol dependence as a "brain event," other alcohol-related medical disorders, and our understanding of brain interactions with other substances such as illicit drugs and tobacco.
- Medications Development for Alcoholism Treatment.—NIAAA-sponsored research has resulted in the development of pharmacotherapies that have been proven effective in the treatment of alcoholism and alcohol-related disorders in some patient populations but not in others. Additional funding is needed to aggressively pursue a range of activities from basic to clinical research in an effort to ensure that new products are in the pipeline.
- *—Prevention of Alcohol Abuse in Adolescents.*—The alarming rates of college campus deaths and the increasing use of alcohol among elementary and secondary school-aged children requires further study on the causes of alcohol abuse among this age group and the development of strategies for effective prevention and intervention. The magnitude and severity of this problem will require an interdisciplinary, multi-agency effort.
- Interdisciplinary, multi-agency effort. —Health Disparities.—We know that there appears to be an increased risk for alcoholism and alcohol-related disorders within certain ethnic/racial groups, however, it is unclear why this risk exists and whether or not the risk applies to all members of the group. Initial studies with certain racial groups have identified specific strengths and vulnerabilities which are important to further explore if we are to address the needs of all Americans. The role of gender, ethnicity, socio-economic status, and other variables in determining the effects of alcohol use and abuse requires additional study. Greater understanding of these variables will lead to improved treatments of alcoholism and alcohol-related organ damage in women and in ethnic minorities.
- -Multidisciplinary Research on Fetal Alcohol Syndrome.—Fetal alcohol syndrome is the most common preventable cause of mental retardation. Despite this fact, a recently released study by the Centers for Disease Control and Prevention indicates that the rates of binge drinking during pregnancy—consumption patterns consistently related to damage to the developing fetus—has remained unchanged through the late 1990s. NIAAA-sponsored research has studied the biological mechanisms through which alcohol impacts the fetus. Additional research is needed that will lead to effective interventions for the prevention and treatment of fetal alcohol syndrome. —Longitudinal Studies.—Alcoholism develops over years in response to inter-
- -Longitudinal Studies.—Alcoholism develops over years in response to interactions among genetic, psychological, and social factors that are not fully understood. A longitudinal study that recruits subjects in early adolescence and follows persons as they develop and struggle with alcohol problems will help lead to an understanding of where interventions might best be targeted. A longitudinal study of this nature will require a multi-Institute approach. RSA urges the Committee to provide adequate resources for the NIAAA to plan and spearhead a longitudinal study of this nature.

*Request.*—The Research Society on Alcoholism believes that the continued support of NIAAA and NIH are imperative to the national effort to combat alcohol abuse and alcoholism and improve the quality of life for all Americans. The RSA respectfully submits the following two requests for which we urge the Committee's strong support.

(1) The Research Society on Alcoholism supports the President's proposed \$3.7 billion increase for the National Institutes of Health that will result in a total fiscal year 2003 budget of \$27.3 billion. We urge the Committee to provide the NIH a funding level of at least \$27.3 billion to complete the national campaign to double the NIH budget by 2003. (2) The Research Society on Alcoholism requests a total fiscal year 2003 NIAAA budget of \$475 million. This request represents the professional judgement of the alcohol research community and is justified on the basis of historic under funding of the NIAAA, pursuit of significant advances in recent years and the promise of new opportunities presently at hand.

Thank you for the opportunity to present our views.

### PREPARED STATEMENT OF THE DORIS DAY ANIMAL LEAGUE AND PEOPLE FOR THE ETHICAL TREATMENT OF ANIMALS

Thank you for the opportunity to submit testimony on behalf of the 1 million members and supporters of the Doris Day Animal League (DDAL) and People for the Ethical Treatment of Animals (PETA) requesting appropriations for the National Institute of Environmental Health Sciences' (NIEHS) National Toxicology Program Interagency Center for the Evaluation of Alternative Toxicological Test Methods (NICEATM) for Interagency Coordinating Committee for the Validation of Alternative Methods (ICCVAM) activities for fiscal year 2003. This request is also supported in separate testimony by The Humane Society of the United States. This entity, ICCVAM, was permanently authorized in 2000.

### FUNCTION OF ICCVAM

The ICCVAM performs an invaluable function for regulatory agencies, industry, public health, and animal protection organizations by assessing the validation of new, revised and alternative toxicological test methods that have interagency application. After appropriate independent peer review of the test method, the ICCVAM recommends the test to the federal regulatory agencies that regulate the particular endpoint the test measures. In turn, the federal agencies maintain their authority to incorporate the validated test method as appropriate for the agencies' regulatory mandates. This streamlined approach to assessment of validation of new, revised and alternative test methods has reduced the regulatory burden of individual agencies, provided a "one-stop shop" for industry, animal protection, public health and environmental advocates for consideration of methods and set uniform criteria for what constitutes a validated test method. In addition, from the perspective of animal protection advocates, ICCVAM can serve to appropriately assess test methods that can refine, reduce and replace the use of animals in toxicological testing. This function will provide credibility to the argument that scientifically validated alternative test methods, which refine, reduce or replace animals, should be expeditiously integrated into federal toxicological regulations, requirements and recommendations.

# HISTORY OF ICCVAM

The ICCVAM is currently composed of representatives from the relevant federal regulatory and research agencies. It was created from an initial mandate in the NIH Revitalization Act of 1993 for the NIEHS to "(a) establish criteria for the validation and regulatory acceptance of alternative testing methods, and (b) recommend a process through which scientifically validated alternative methods can be accepted for regulatory use." In 1994, NIEHS established the ad hoc ICCVAM to write a report that would recommend criteria and processes for validation and regulatory acceptance of toxicological testing methods that would be useful to federal agencies and the scientific community. Through a series of public meetings, interested stakeholders and agency representatives from all 14 regulatory and research agencies, developed the NIH Publication No. 97–3981, "Validation and Regulatory Acceptance of Toxicological Test Methods." This report has become the sound science guide for consideration of new, revised and alternative test methods by the federal agencies and interested stakeholders.

After publication of the report, the ad hoc ICCVAM moved to standing status under the NIEHS' NICEATM. Representatives from federal regulatory and research agencies and their programs have continued to meet, with advice from the NICEATM's Advisory Committee and independent peer review committees, to assess the validation of new, revised and alternative toxicological methods. Since then, two methods have undergone rigorous assessment and are deemed scientifically valid and acceptable. The first method, Corrositex, is a replacement for animalbased dermal corrosivity tests for some chemicals. The second, the Local Lymph Node Assay, is a reduction and refinement of an animal test for the skin irritation endpoint. The open public comment process, input by interested stakeholders and the continued commitment by the federal agencies has led to ICCVAM's success. It has resulted in a more coordinated review process for rigorous scientific assessment of the validation of new, revised and alternative test methods.

### REQUEST FOR APPROPRIATIONS

On December 19, 2000, the "ICCVAM Authorization Act" which makes the entity a permanent standing committee, was signed into Public Law No. 106–545. For the past few years, the NIEHS has provided approximately \$1 million per fiscal year to the NICEATM for ICCVAM's activities. In order to ensure that federal regulatory agencies and their stakeholders benefit from the work of the ICCVAM, it is important to fund it at an appropriate level. I respectfully urge the Subcommittee to support an appropriation for the NIEHS's NICEATM for ICCVAM's activities at \$5 million for fiscal year 2003. With the increasing workload assigned to the ICCVAM, the entity has been chronically underfunded. This year alone it is anticipated that several new, revised or alternative test methods will be under scientific review by the ICCVAM, its new advisory committee and independent peer review panels. In addition, several methods that have currently been approved by the European Centre for the Validation of Alternative Methods (ECVAM) will be expeditiously assessed by the ICCVAM for integration into United States federal regulations, requirements and recommendations. The ECVAM receives an annual appropriation of millions of dollars more than our ICCVAM, which demonstrates the European Union's commitment to humane, sound science. ECVAM has provided assessments of a number of test methods which are or will be used by international companies. To ensure that good, humane science is prioritized for new federal testing programs, it is imperative that the ICCVAM receive an increase in its appropriation for this fiscal year. The success of the entity will only be realized by properly funding its increasing workload. This appropriation request includes all FTEs, funding for independent peer review assessment of test methods and meetings of the ICCVAM and other activities as deemed appropriate by the Director of the NIEHS.

### REQUEST FOR COMMITTEE REPORT LANGUAGE

I also respectfully request the Subcommittee consider the following report language for the House Labor, Health and Human Services, Education and Related Agencies Appropriations bill:

"The Committee supports the assessment of scientific validation of new, revised and alternative toxicological test methods by ICCVAM. The Committee supports the use of the ICCVAM to streamline consideration of new, revised and alternative toxicological test methods. The Committee also urges the incorporation of scientifically validated new, revised and alternative test methods into federal regulations, requirements and recommendations in an expeditious manner. To this end, the Committee has provided \$5 million to support ICCVAM's activities."

Thank you for the opportunity to submit this request on behalf of the Doris Day Animal League and People for the Ethical Treatment of Animals.

### PREPARED STATEMENT OF THE AMERICAN GASTROENTEROLOGICAL ASSOCIATION

### SUMMARY OF RECOMMENDATIONS

The American Gastroenterological Association ("AGA") urges Congress to increase funding for medical research on digestive diseases and disorders through budgetary increases to the National Institutes of Health ("NIH"), the Centers for Disease Control and Prevention ("CDC"), and the Agency for Healthcare Research and Quality ("AHRQ").

AGA encourages Congress to provide at least a 16 percent increase over fiscal year 2002 for NIH, raising the funding levels from \$23.6 billion to \$27.3 billion, as recommended by the Ad Hoc Group for Medical Research Funding, thus achieving the bipartisan goal of doubling the NIH budget by fiscal year 2003. Within NIH, AGA recommends at least a commensurate increase for the National Institute of Diabetes and Digestive and Kidney Diseases ("NIDDK"), the National Cancer Institute ("NCI"), and the National Institute of Allergy and Infectious Diseases ("NIAID"), each of which support a considerable portfolio of gastrointestinal research. These increases would allow for further research on the diagnosis, treatment and cure for debilitating and devastating digestive diseases. Despite the real and frightening threats of bioterrorism and the devastation caused by cancer, areas of deep commitment by the AGA, the AGA urges Congress not to favor one illness disproportionately over others by allocating a huge funding increase to select Institutes at the expense of other equally important NIH Institutes and Centers.

AGA also urges Congress to increase funding over fiscal year 2002 by 17.5 percent to \$7.9 billion for the CDC, as recommended by the CDC Coalition, and by 30 percent to \$390 million for AHRQ, as recommended by the Friends of AHRQ.

## MEDICAL RESEARCH RECOMMENDATIONS

AGA is the nation's oldest, not-for-profit specialty medical society, consisting of over 12,500 gastroenterologic physicians and scientists who are involved in research, clinical practice, and education on disorders of the digestive system. As the nation's leading voice on gastrointestinal research, AGA is uniquely qualified to advise Congress on the current status of federally supported digestive disease research programs and the areas in need of further research.

Each year more than 62 million Americans are diagnosed with digestive disorders.—Among the more common digestive disorders are food borne illness, inflammatory bowel disease, obesity, gastrointestinal cancers, and motility disorders. In some of these areas, medical research has brought us close to developing lifesaving treatments and cures. Yet, in others, we still lack even a basic understanding of the cause and transmission of the disease. This testimony focuses on these serious health problems and makes recommendations on how Congress should allocate this country's precious medical research dollars to combat digestive diseases.

# Preventing and Mitigating the Threat of Bioterrorism Involving Our Food and Water Supply

AGA is acutely aware of the threats presented by terrorists to the nation's food and water supplies. As such, it is vital that medical researchers and clinical physicians, and the nation as a whole, enhance their understanding of the symptoms, treatments and cures for such food and water borne illnesses as salmonella, E.coli, campylobacter, botulism, cholera, and typhoid. The AGA is dedicated to offering its expertise in the area of food and water borne illnesses to help prevent the potentially devastating events that would result if such an attack were to occur.

Each year an estimated 76 million cases of food and water borne illness, such as salmonella, E.coli, campylobacter, botulism, cholera, and typhoid, occur in the United States, according to the CDC. Food borne pathogens enter the body through the gastrointestinal tract and often cause nausea, vomiting, abdominal cramps and diarrhea. The resultant loss of electrolytes and fluids leads to dehydration and shock, and, if not treated, death from vascular collapse and renal failure. Those populations at-risk for severe repercussions from food and water borne illness include those with decreased immune systems, pregnant women and fetuses, young children, elderly, those taking antibiotics and antacids, and those with inadequate access to health care such as the homeless, migrant farm workers, and those with low socio-economic status.

The threat presented by food and water borne illnesses is considerably larger now in light of the efforts by terrorist organizations to infiltrate our country. Food borne pathogens have evolved throughout generations to adapt to the human host, making them viable agents for bioterrorist threats. These bacteria first attach to the lining of the gut, with each pathogen possessing a unique set of attachment factors. Once attached, they begin to spread toxins throughout the body. Currently, there are no vaccines available to prevent either the attachment of any of these bacteria to the gut or to inhibit the spread of the toxins through the host.

Scientific opportunities exist for addressing the threats posed by food borne illness. The NIH has undertaken studies in the past several years to identify the pathophysiology and pathogenesis of food and water borne disease. While promising advances have been made, more research is desperately needed to better understand the disease process and to develop appropriate vaccines and other treatments for these diseases.

AGA recommends that Congress encourage the NIH, especially NIDDK and NIAID, and others conducting food and water borne illness research like the United States Department of Agriculture and CDC, to concentrate intensively on research into treatments for food and water borne illness, including vaccines to prevent the attachment of the bacteria to the gut and to prevent the spread of the toxin in the host. The AGA urges Congress to make a modest investment of \$10 million per year, over a 5-year period, to be dedicated to research aimed at eradicating the disabling and potentially deadly effects of food and water borne illness.

### Inflammatory Bowel Disease

It is estimated that 1 million Americans have inflammatory bowel disease ("IBD"), which includes Crohn's Disease and Ulcerative Colitis. Crohn's Disease usually causes intermittent deep inflammation at any site within the gastrointestinal tract but especially the small and large intestine, whereas Ulcerative Colitis causes continuous inflammation and sores in the top layers of the lining of the large intestine.

Fortunately for the 1 million Americans who suffer from the terrible disease, there is new hope. Researchers recently identified the first gene associated with IBD. See Yasunori Ogura et.al., "A framshift mutation NOD2 associated with susceptibility to Crohn's disease." Nature 411 (2001): 603–606. Importantly, recent works suggest that several other genes, yet to be identified, also play an important role in an individual's susceptibility to Crohn's Disease or Ulcerative Colitis. While IBD is believed to be a multigenic disease with as many as seven genes causing susceptibility, even this breakthrough discovery of the first gene will undoubtedly lead to further identification of the complex factors that cause IBD, leading to more effective management, treatment, and ultimately a cure for this devastating illness. We stand at an important crossroads in IBD research. Additional research is needed now to maintain momentum and discover new therapies and cures.

AGA recommends that Congress dedicate \$100 million in fiscal year 2003 and such sums as may be necessary in fiscal year 2004–2006 to NIDDK to expand and intensify IBD research. Particular emphasis should be placed on research that identifies the other genes that are believed to cause susceptibility to IBD, animal model research on IBD, and clinical studies and treatment trials aimed at patients with IBD. Research is also needed to understand the interaction between microbial flora (bacteria) and the mucosal lining of the gut through the study of the barrier function of the gut lining and the subsequent mucosal immune response in subjects with IBD. The final step to fully understanding this disease is correlating the genetic characteristics of patients with IBD with the clinical symptoms they present, enabling physicians to develop targeted treatments for patients based on their genetic makeup. We believe that it is essential that Congress appropriate the \$100 million as a supplemental effort to eradicate IBD, and not in a manner that would detract from other important areas of NIDDK research.

#### Nutrition and Obesity

According to the Body Mass Index (BMI) scale, a widely accepted measurement that takes into account both a person's weight and height, 110 million adults in this country are either overweight (61 million) or obese (49 million); 31.3 percent of men and 34.7 percent of women are considered to be clinically obese; one in five children are clinically obese. The number of obese adults in the United States has doubled in the last 25 years. According to NIH, obesity is a complex multifactorial chronic disease that develops from an interaction of genotype and the environment. This disease is an integration of social, behavioral, cultural, psychological, metabolic and genetic factors.

Despite the fact that obesity is gaining more recent attention, a significant amount of ground must be covered before medical research catches up with the need to address the problem in a comprehensive manner. There are a growing, but inadequate, number of grants being funded to examine this disease. AGA recommends that Congress urge NIDDK, the National Institute of Child Health and Human Development, the Office of Research on Women's Health and the Center for Research on Minority Health to increase RO1 funding for obesity research by 15 percent for fiscal year 2003.

# Gastrointestinal Cancers

Approximately 226,600 new cases of gastrointestinal cancers will be diagnosed this year. Sadly, 129,800 Americans will die from these cancers. The most common cancers involve the colon/rectum, stomach/esophagus, and pancreas.

AGA applauds the NCI for its commitment to improving the understanding of, and seeking cures to, these and other gastrointestinal cancers through mechanisms such as Progress Review Groups on colorectal and pancreatic cancers. However, more research is needed. Congress should urge the NIDDK to augment its efforts in these areas, and to particularly focus resources on the genetic aspects of these cancers, diagnostic tests for genetic abnormalities and prevention of these cancers, the modulation and understanding of epithelial injury and repair, the environmental factors relating to the development of these diseases, and the development and treatment of Barrett's Syndrome in patients with GERD.

### Motility Disorders

It is estimated that up to 30 percent of all Americans may be affected at some time during their lives by motility disorders. Irritable bowel syndrome ("IBS"), the most common motility disorder, is especially troubling because a patient does not present with any pathognomonic symptoms or laboratory findings of the disease, making diagnosis and treatment extremely difficult. Instead, patients present with abdominal pain, bloating, gas, diarrhea, and constipation. IBS is believed to be caused by overly sensitive intestines that have muscle spasms. Further research is needed in this area due to the high prevalence of this disease

Further research is needed in this area due to the high prevalence of this disease as well as the lack of knowledge on how to identify, diagnose, and cure it. A lack of a basic understanding of IBS has made drug manufacturers reluctant to fund research. If more federally funded research was focused on IBS, it would stimulate more private-public partnerships, and lead to advances in medical knowledge. As such, AGA urges Congress to direct the NIDDK to focus additional resources on IBS. Specifically, AGA recommends that NIDDK support research into the devel-

As such, AGA urges Congress to direct the NIDDK to focus additional resources on IBS. Specifically, AGA recommends that NIDDK support research into the development of physiologic tests to characterize the phenotypic subgroups of functional gastrointestinal disorders, including non-ulcer (functional) dyspepsia, functional constipation, and irritable bowel syndrome (motility). Additionally, AGA urges Congress to also encourage the Office of Research on Women's Health to devote more of its attention to these areas of research in light of the high incidence of IBS among women.

#### MEDICAL RESEARCH INFRASTRUCTURE

### Training of Physician-Scientists

While research has expanded our medical knowledge and enabled physicians and other providers to better prevent diseases, diagnose disorders, and treat people, there is growing concern that the number of physician-scientists (e.g., investigators who have medical degrees) is declining. If this trend continues, the shortage of physician-scientists will begin to slow key medical research endeavors and advancements. Research training must be reinvigorated.

A recent study documenting this decline points to the tremendous debt incurred by medical school graduates who have more lucrative options outside of research as a primary cause. See Tamara R. Zemlo et al., The Physician-Scientist: Career Issues and Challenges at the Year 2000, 14 The FASEB Journal 221–230 (2000). A medical school graduate incurs an average debt of \$99,089, as reported in the Medical School Graduation Questionnaire by the Association of American Medical Colleges.

Unfortunately, clinical researchers are oftentimes expected to raise funds to support their research and a substantial proportion of their own salaries. For such support, young clinical researchers often turn to the NIH. However, in 1999, NIH began to phase out the R29 grant mechanism for first-time investigators. Despite substantial increases in NIH spending, the number of young physicians applying for their first NIH grant decreased by 30 percent over the past 5 years. AGA views this problem as an immediate and serious threat to the future of bio-

AGA views this problem as an immediate and serious threat to the future of biomedical research generally, and gastrointestinal research in particular. To alleviate this growing problem, AGA urges Congress to increase funding for the continued expansion of clinical research and clinical research training opportunities. Congress should take the following steps: increase career support for established clinical investigators; enhance the K24 award mechanism to enable established clinical investigators to mentor new investigators; and provide a line-item appropriation for the continued expansion of the Extramural Loan Repayment Program for Clinical Research administered by the NIH Office of Director. Additionally, Congress should applaud NIH for constructing and implementing the loan repayment provisions of the Clinical Research Enhancement Act in an expeditious manner.

### Digestive Disease Research Centers

Digestive Diseases Research Core Centers are key to establishing strong research networks and advancing medical knowledge.—Currently, fifteen fully funded centers exist which conduct basic and clinical research on a variety of digestive disorders. They have been highly successful in expanding medical knowledge on pancreatic disease, genetic diseases (e.g., hemochromatosis) and gene therapy, pediatric gastrointestinal diseases, hepatitis C, IBS, IBD, H.pylori, inflammatory cytokines, and food safety. AGA commends NIDDK for developing and enhancing this program and recommends that Congress urge NIDDK to maintain full funding for these centers.

### Small Equipment Grants

As technology continues to evolve, laboratory research equipment is becoming more expensive to purchase and maintain. Researchers struggle to keep the instrumentation in their laboratories up-to-date. NIH's current Shared Instrumentation Grant Program offers equipment grants for which researchers can apply for equipment with a minimum cost of \$100,000; an appropriate mechanism for use in replacing pieces of large equipment. However, a similar grant program does not exist to assist researchers in replacing less expensive (\$50,000-\$100,000), often highly utilized, pieces of equipment. Researchers' small equipment needs are just as critical as larger pieces of equipment and the cost of replacing such instrumentation can be prohibitively expensive to support on a single grant application. Therefore, AGA urges Congress to suggest that NIH study the need for a small equipment grant program comparable to the existing Shared Instrumentation Grant Program.

## Evaluation Tap

AGA is grateful to Congress for the substantial investment made in biomedical research in the last 4 years. The goal of doubling the NIH budget is within reach and AGA is hopeful that Congress will achieve this goal in fiscal year 2003. However, AGA remains concerned that the obligations to transfer NIH funds to various non-NIH agencies has detracted significantly from NIH research activities and is having a destructive impact on such activities. AGA urges Congress to embrace the funding recommendations made by Friends of AHRQ and the CDC Coalition to fulfill the research needs of these agencies, rather than reprogramming NIH funds to achieve these ends.

## CONCLUSION

The diseases described above continue to take a huge toll on America's health and economy. AGA appreciates Congress' commitment to biomedical research, to the NIH in recent years, and to digestive diseases research in particular. However, more effort is needed. Congress must keep up the momentum it has started, and in some cases, devote even more resources. AGA appreciates the opportunity to present its views on the fiscal year 2003 appropriations. Please call Michael Roberts, Vice President of Public Policy and Government Relations at AGA, at (301) 941–2618 if you have further questions.

## PREPARED STATEMENT OF THE NATIONAL ALLIANCE FOR EYE AND VISION RESEARCH

The National Alliance for Eye and Vision Research (NAEVR) is pleased to have the opportunity to submit its views to the Committee. NAEVR is a nonprofit advocacy coalition of 43 organizations dedicated to expanding our national capacity to address eye and vision research opportunities and to ensure the best eye health for all Americans. The NAEVR organizations represent the spectrum of vision research and eye health interests, including researchers, providers, consumer advocates and industry.

We would like to begin by thanking the Committee for your continuing commitment to biomedical research supported by the National Institutes of Health (NIH) and the National Eye Institute (NEI). Congress has been tremendously supportive of pushing the frontiers of medical research through support of the NIH and the NEI. We know that you have many difficult decisions with regard to funding priorities in your Appropriations Bill and we appreciate the strong support that you have provided NIH. With this funding, NEI supported researchers have developed several promising experimental treatments with the potential to halt vision loss and restore sight for millions of Americans. We are now at a turning point. Clinical trials testing a number of new treatments are within our grasp. To advance these promising treatments to clinical trials requires a strong, sustained financial commitment from the federal government.

#### FISCAL YEAR 2003 FUNDING REQUEST

We commend President Bush for proposing a funding increase for NIH that will complete the 5-year national campaign to double the NIH budget by fiscal year 2003. We urge the Committee to provide at least a \$3.7 billion increase for NIH, resulting in a total NIH budget of \$27.3 billion in fiscal year 2003. Within the context of the NIH budget, the National Alliance for Eye and Vision Research requests your support for an NEI budget of \$692 million in fiscal year 2002. This function for the NIH budget of \$6052 million in fiscal year

Within the context of the NIH budget, the National Alliance for Eye and Vision Research requests your support for an NEI budget of \$692 million in fiscal year 2003. This funding level represents the professional judgement of the vision research community as the level necessary to advance important discoveries resulting from previous investments and to pursue new scientific opportunities. The National Alliance for Eye and Vision Research has framed the following set of priorities which, if adequately supported, will move the field of vision research significantly forward and provide translational benefits to additional NIH priorities.

Neurodegenerative Eye Diseases.—Significant advances have been made in research on neurodegeneration across a range of eye diseases, including retinitis pigmentosa, ocular albinism, macular degeneration, and glaucoma. These investigations offer fresh insights on these diseases and suggest new intervention points for prevention and therapy. In light of these exciting developments, additional resources are needed to increase support for research on neurodegenerative eye diseases. Support for extramural research should be expanded, including support for genomic and proteomic resources and for collaborative multidisciplinary research.

Genetics and Gene Therapy Approaches to Neurodegeneration.—Ongoing genetic studies are revealing the normal function of genes and how those functions are impaired when genes mutate which in turn will provide essential insight into many types of vision dysfunction. Gene therapy holds great potential as a therapeutic strategy to halt the progression of many forms of blinding eye diseases, including macular degeneration, retinitis pigmentosa, and glaucoma. Gene therapy has already proven to be successful in preventing vision loss and restoring sight in canine and rodent models with forms of retinitis pigmentosa, a group of inherited incurable forms of blindness. Increased support for the NEI will expedite additional study of gene therapy applications to establish the safety of these potential cures in order to move to clinical trials.

Diabetic Eye Disease.—Diabetic retinopathy is the leading cause of new cases of blindness in this country. Diabetic macular edema, secondary to diabetic retinopathy, is a major cause of vision loss due to the leakage of fluids and other materials from damaged blood vessels. The NEI is implementing the recommendations of the Diabetes Research Working Group related to diabetic eye disease and has initiated plans to develop and evaluate more rapidly new treatments for macular edema through a new multicenter clinical trials network.

Bioengineering and Advanced Instrumentation.—NEI is pursuing the development of advanced assistive devices for the visually impaired, adaptive optics and other imaging techniques to improve non-invasive examination of ocular tissues for both research and disease diagnosis, instruments to analyze the biomechanics of the eye, and instruments to analyze visual performance. Additional study is needed in tissue bioengineering related to artificial cornea and adult stem cell research to replace or regenerate corneal tissue damaged by injury or disease, as well as into other applications of innovative technologies that will enhance or restore vision. *Health Disparities.*—Research in this area will enhance our understanding of

Health Disparities.—Research in this area will enhance our understanding of glaucoma, diabetic retinopathy, and myopia incorporating studies of comorbidity, natural history, and genetics with special emphasis on populations at increased risk. For example, rates of blindness from glaucoma are six times higher in African-Americans than in Caucasians, however age-related macular degeneration is rare for African-Americans as compared to Caucasians. Mexican-Americans have a high rate of diabetes that can lead to the development of the major complications of diabetes, including diabetic retinopathy. NEI-supported researchers have found that 20 percent of a population-based sample of Mexican-Americans living in Tucson and Nogales, Arizona had diabetes. Many of the participants did not realize they had diabetes and almost a quarter of these already had moderate diabetic retinopathy.

Low Vision.—A related area of concern is low vision, or vision impairment which is not correctable by glasses or contact lenses. Currently, there are more than 1 million Americans today in the United States who are legally blind and 2.3 million are visually impaired. More than 50,000 Americans lose their sight each year and nearly half of these individuals go blind needlessly. Approximately 30 million Americans suffer from age-related threats to sight, namely macular degeneration, glaucoma, cataracts and diabetic retinopathy. These conditions are expected to nearly double by the year 2030 as the baby-boomers retire. By the year 2030, more than 66 million Americans will be at risk of developing a common eye disease. 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.

Cation, vocational training, and social services throughout their lives. National Eye Health Education Program.—The National Eye Health Education Program (NEHEP) is coordinated by the NEI in partnership with over 60 national organizations that conduct eye health education programs. NEI has developed and is initiating a program directed at low vision in order to increase public awareness about visual impairment and the impact it has on everyday life. The Low Vision Traveling Exhibit, launched early last year, is being displayed in shopping malls around the country during the next 5 years. The program provides information about low vision services and the devices which are currently available to assist those with visual impairments. This effort is directed at those suffering from visual impairments and also to medical professionals, eye care specialists, managed care organizations, and family members. The NAEVR supports this public education partnership and urges the Committee to provide adequate resources for the continuation of this program and other important eye health public education initiatives.

If we do not make significant investments in vision research, we will have both a health care and economic crisis in this country, given our nation's demographics. With increased support for the NEI, we can make treatments for many vision diseases and disorders happen within our lifetime.

## CONCLUSION

Mr. Chairman, the National Alliance for Eye and Vision Research supports an increased research focus on eye and vision disorders. The benefits of this research will improve the quality of life for all Americans by allowing individuals to remain independent and lead productive, fulfilling lives. We urge the Committee to provide a total NEI budget of \$692 million in fiscal year 2003. We also strongly support a total appropriation of \$27.3 billion for the NIH in fiscal year 2003. In this time of great medical discovery, we must do our best to find ways to prevent and treat eye and vision disorders and provide quality eye care services and devices for those who are already suffering from visual impairment.

Thank you for allowing the National Alliance for Eye and Vision Research to present its views.

# PREPARED STATEMENT OF THE FRIENDS OF NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES

Over the last several years the nation has shown a strong commitment to health research sponsored by the National Institutes of Health (NIH). This financial commitment has allowed the nation to dedicate resources to emerging scientific opportunities that will lead to beneficial health outcomes for the American public. As we near the end of the 5-year national commitment to double the NIH overall budget, we continue to see promise in emerging research; however we are concerned about how we will fund these opportunities.

This dilemma is particularly true for the National Institute of Environmental Health Sciences (NIEHS). This institute plays a critical role in what we know about the relationship between our environmental exposures and disease onset. Through the research sponsored by this Institute, we know that Parkinson's disease, breast cancer, birth defects, miscarriage, delayed or diminished cognitive function, infertility, asthma and many other diseases and ailments have confirmed environmental triggers. Our expanded knowledge, as a result, allows both policy makers and the general public to make important decisions about how to reduce toxin exposure and reduce the risk of disease and other negative health outcomes.

In an effort to continue the expansion of this knowledge base, the Friends of NIEHS supports a tripling of the NIEHS budget by 2006. The Friends of NIEHS is a coalition committed to expanding NIH's environmental health research portfolio through increased appropriations for NIEHS. Made up of over fifty patient, healthcare provider, children's health, and industry groups, the Friends of NIEHS represents an enormously broad constituency dedicated to improving the nation's knowledge about our health and our environment.

The effort to triple NIEHS' budget by 2006 requires an initial increase in appropriations of \$293 million over fiscal year 2002 funding. This additional funding will allow the Institute to continue current projects and pursue promising research in the areas of individual susceptibilities (due to gender, age, racial/ethnic backgrounds, etc.), environmental disease triggers and technologies (such as toxicogenomics and mouse genomics). The Friends of NIEHS respectfully requests Congress to appropriate a total of \$865 million for fiscal year 2003.

## GENERAL HEALTH

Most diseases are suspected of having an environmental trigger that initiates disease development. Examples include: cancer, Parkinson's Disease, Alzheimer's Disease, asthma, infertility, diabetes, and autoimmune disease. The NIEHS has a number of initiatives aimed at determining the environmental causes of these diseases and disorders; however the current funding available to the Institute, despite the recent doubling effort, limits the Institute's research capacity to actively pursue emerging opportunities for prevention, screening, care and treatment.

Individual susceptibility differs based on genetic structure, the time of life at which exposures occur, gender and even socio-economic status. This is particularly relevant when exploring issues of health disparities among low income and ethic/ racial communities. Individuals in these categories are exposed to multiple toxins from countless sources. We must define how we, as individuals, differ in our response to environmental agents. Increased funding will allow the Institute to study genetic interactions to toxin exposure and intensify efforts to develop new methods of screening for environmental health risk factors. Additionally, we believe increased funding would allow the Institute the opportunity to go past studying only known carcinogens and explore for potentially new Cancer causing agents, or those combinations of chemicals/environmental conditions that become carcinogens.

## CHILDREN'S HEALTH

Advocates for children are keenly aware that children are at increased risk for being adversely affected by environmental agents. By virtue of their inherently small stature and rapidly developing bodies, children simply come into contact with more air pollution, more contaminated soil, and more lead paint. Consequently, children are more susceptible to negative health outcomes of toxin exposure. Environmental exposure both during the perinatal period and during the first 5 years of life increase the risk of developing learning and other developmental disabilities, asthma, leukemia, and autism.

Of all the Institutes, NIEHS has done the most to research and expose recognition of harm to child development through environmental pollution. Increased Institute funding will sustain the 12 Centers for Children's Environmental Health and Disease Prevention as well as the 10 Pediatric Environmental Health Specialty Units. The collective ability of these programs to advance the science as well as deliver clinical support is critical to making meaningful progress in children's health promotion in this country.

The contributions of the NIEHS' Centers on Children's Environmental Health have been very significant to both scientific advances and public awareness through demanding partnership between researchers and community resources. NIEHS' focus on early child development and sciences has revealed preventive interventions that can be utilized by parents during the perinatal and postpartum periods to reduce the level of toxin exposure. Further, the Institute's research plays an important role in the development of policy impacting children's environmental health. Environmental health research serves as the basis for programs such as lead paint remediation, clean water and air programs and smoking cessation programs.

## ENDOCRINE DISRUPTION

There is growing evidence that hormone disruption (endocrine disruption) by chemicals is one of the mechanisms through which chemicals in the environment contribute to increases in human diseases. NIEHS has a critically important role to play in building and understanding of these hazards by answering questions that have been raised by other agencies' measurements of chemicals found in both the environment and in humans.

Two recent studies clearly indicate that additional funding is needed to significantly increase NIEHS' research on endocrine-disrupting chemicals. For example, in March 2002, the U.S. Geological Survey (USGS) reported on its first-ever nationwide reconnaissance of the occurrence of pharmaceuticals, hormones and other organic wastewater contaminants in the nation's waters. Thirty-three (33) of the 95 substances analyzed are known or are suspected to be endocrine disruptors. Detection of multiple contaminants was common, including many compounds for which no health guidelines have been established. USGS indicated that little is known about the health effects of the mixtures detected.

Just over 1 year ago, in March 2001, the Centers for Disease Control and Prevention issued its first "National Report on Human Exposure to Environmental Chemicals." The report presents levels of 27 environmental chemicals in human blood and urine (e.g., lead, mercury, and metabolites of organophosphate pesticides). One of the reports purposes is to set priorities for research on the human health effects of environmental chemicals, including those known or suspected to be endocrine disruptors. Of particular interest was CDC's finding of higher-than-expected levels of certain phthalates in women of reproductive age. Certain phthalates are suspected of having endocrine-related toxicity. NIEHS should play a leadership role in identifying the effects of these and the other hormone disruptors detected.

## CONCLUSION

It is better to prevent disease than to have to treat disease. Of all the elements involved in disease development—our genes, our age, and our environment—only the environment is readily within our control. Environmental health science research is our most powerful disease prevention tool.

Search is our most powerful disease prevention tool. The Friends of NIEHS appreciates the support that this Subcommittee has provided for NIH and specifically NIEHS. We realize that there are many competing priorities for the Subcommittee members, and we appreciate your consistent support.

Thank you for the opportunity to submit testimony on these critical areas of funding.

## PREPARED STATEMENT OF THE CYSTIC FIBROSIS FOUNDATION

## INTRODUCTION

On behalf of the Cystic Fibrosis Foundation, I am pleased to submit this state-ment to the Appropriations Subcommittee for Labor, Health and Human Services, and Education. I appreciate the opportunity to describe what cystic fibrosis (CF) is, how it affects patients and their families, and why we urgently seek your help to achieve new treatments or a cure. The CF Foundation is committed to finding a cure for CF as quickly as possible. We believe our efforts will be accelerated through a stronger partnership with National Institutes of Health (NIH).

We are grateful for the leadership role of this Subcommittee in boosting the ap-propriations for the NIH for the past several years. We commend you for your stead-fast commitment to doubling the NIH budget over 5 years, a process that we hope will be successfully completed this year. You have had great foresight in acknowl-edging the importance of this strong biomedical proceeds of fore the our action. edging the importance of this strong biomedical research effort to our nation. We look forward to working with the Subcommittee to ensure that NIH continues to flourish in the future and that our country reaps the benefits of such an impressive investment in biomedical research.

We would like to share with you some of the exciting progress in CF research and explore the opportunity to form a public-private partnership to identify new treat-ments or a cure for CF. We urge you and your colleagues to encourage the NIH to support the mission of the CF Foundation in this tremendous undertaking to translate basic research advances into new treatments through its model clinical trials network. As CF is an "orphan" disease, the role of the NIH in translating basic research into treatments is critical. By encouraging the NIH's support, this partner-ship offers Congress the opportunity to champion promising, mission-driven research.

## CYSTIC FIBROSIS: THE DISEASE

To give you a better idea of the progress we have made in treating CF and the substantial challenges we still face, I would like to share a few statistics. When a child was diagnosed with CF in 1960, that child had a life expectancy of less than 10 years. Today, children who are diagnosed with CF have a life expectancy of more than 20 works. Although this is implemented to the state of the state of the state of the state of the state of the state. than 30 years. Although this is significant progress, it is obviously not the cure we seek

CF is a genetic disease that affects approximately 30,000 children and adults in the United States. An individual must inherit a defective copy of the CF gene from each parent to have the disease. CF causes the body to produce abnormally thick, sticky mucus, due to the faulty transport of sodium and chloride to the outer sursticky mucus, due to the faulty transport of sodium and chloride to the outer sur-faces of the cells that line organs, such as the lungs and pancreas. Individuals with CF experience persistent coughing and wheezing and are particularly susceptible to chronic lung infections, including pneumonia. A bacterial or viral infection that is of little concern or consequence to a person without CF could be devastating and potentially life-threatening to someone with the disease. Individuals with CF also have excessive appetite but poor weight gain because the pancreas is obstructed and digestive enzymes cannot reach the intestines. The treatment of CF depends upon the stage of the disease and the organs in-volved. Patients with CF are often treated by chest physical therapy, which requires vigorous percussion on the back and chest or the use of mechanical devices to dis-lodge the thick mucus from the airways. Powerful antibiotics also may be used to treat lung infections and may be administered intravenously, orally, and by aerosol. Because of the effects of CF on the digestive system, patients cannot absorb enough

Because of the effects of CF on the digestive system, patients cannot absorb enough nutrients and may need to eat an enriched diet and take both replacement vitamins and pancreatic enzymes. Eventually, organ transplantation may be necessary, which offers the few patients who successfully receive donated organs a new chance for a healthy future.

## IMPROVEMENTS IN CF TREATMENTS

In the past few years, there have been several important breakthroughs in new CF therapies, including: (1) the development and approval in 1993 of Pulmozyme®, a mucus-thinning drug that reduces the number of respiratory infections and improves lung function; (2) the use of high-dose ibuprofen therapy to reduce lung inflammation; and (3) the development and approval in 1997 of tobramycin solution

for inhalation, or TOBI®, a reformulated version of a well-known antibiotic that can The gene that causes CF was discovered in 1989 by scientists supported by the

CF Foundation. In the decade since that discovery, researchers have been working to translate the knowledge of the gene into therapies for CF. CF Foundation-supported scientists at several medical institutions are involved in gene therapy research; most are concentrating on the development of safe and effective gene delivery systems. The ultimate success of gene therapy will depend on identifying the optimal means of delivering sufficient quantities of healthy genes to the airways of individuals with CF. We continue to make a significant commitment to gene therapy research because we believe its promise is great.

Although gene therapy appears to be a particularly promising area of research for CF, we also are pursuing a wide range of other research approaches that will help us treat the complex symptoms of CF. Researchers are looking for new types of anti-biotics that will assist in treatment of chronic CF lung infections as well as treatments that will stimulate cells to secrete chloride, resulting in mucus that is less thick and sticky.

- Some promising compounds that are now in clinical trials include the following: —INS 37217 is a compound that is being tested to increase the transport of chlo-
- ride across the cell membrane to form thinner mucus to help clear the airways
- of bacteria and other harmful pathogens, rather than the thick, sticky mucus that now creates a breeding ground for infection. -Phenylbutyrate is another compound that shows promise. It appears to move the abnormal protein formed by the defective CF gene to the proper spot on the cell surface to form a channel for chloride to escape the cell and to inhibit the absorption of excess levels of sodium.

## THE ROLE OF THE CF FOUNDATION

# Tailoring Care for Individuals With CF

How can individuals with CF be sure they have high quality care that reflects these recent research advances, and how are these diverse research projects being

The CF Foundation is the driving force behind both CF treatment and CF re-search. It supports and accredits more than 115 CF care centers at teaching hos-pitals and community hospitals across the country. These care centers offer comprehensive diagnosis and treatment services to individuals with CF. The lives of patients with CF have been greatly improved by the specialized care at these centers, and the CF Foundation considers our role in maintaining this system of care centers, to be one of our core responsibilities. The CF Foundation also maintains a registry including data on patients with CF and their health status, a database that remains vitally important to ongoing efforts to improve the quality of health care for individuals with CF.

## Supporting Research to Advance Care

- The CF Foundation supports a broad array of CF research initiatives, including: —Sponsoring a Therapeutics Development Program that pursues the full spec-trum of CF drug development, from the discovery of promising compounds through clinical evaluation of those compounds. The Therapeutics Development Program applies cutting-edge technologies to CF research through the screening of potential drug candidates, their evaluation in the laboratory, and their test-terior and the screening of potential drug candidates, their evaluation in the laboratory and their test-studies and clinical trials including large scale studies involve ing in pre-clinical studies and clinical trials, including large-scale studies involv-ing patients with CF. In essence, a virtual pipeline for the development of drugs to treat CF has been built.
- Funding a variety of grants to scientists to conduct CF research. The CF Foundation's awards include new investigator research grants, clinical research grants, research fellowships, clinical fellowships, and student traineeships.
- Supporting 10 Research Development Program centers for basic research projects at leading universities and medical schools.
- Maintaining a centralized laboratory dedicated to identification of Burkholderia cepacia complex, a species of bacteria found in agricultural and consumer products that can be lethal to individuals with CF.

## The Therapeutics Development Network: Translating Basic Science Into New Treatments

This myriad of activities is critical to our mission of improving and lengthening the lives of individuals with CF. In 1997, the CF Foundation built an outstanding clinical trials network, the Therapeutics Development Network, to conduct clinical trials to translate basic research findings into new therapies. Our ability to conduct clinical research in a timely fashion through the Therapeutics Development Network is essential to our ultimate success. The Therapeutics Development Network provides access to top researchers to conduct trials, and to numerous patients who can enroll in trials. It conducts Phase I and II clinical trials, and taps into the CF Foundation's nationwide care center network for large-scale Phase III testing. It plays a pivotal role in accelerating the development of new CF treatments to improve and save the lives of individuals with CF.

The clinical research conducted through the Therapeutics Development Network is focused on four types of treatment strategies: gene therapy, protein-assist and chloride channel therapies, anti-inflammatory therapy, and anti-infection therapy. This comprehensive approach of the Therapeutics Development Network is dictated by the fact that a cure for CF will probably be a combination of gene therapy, protein repair therapy, and drug or other therapies. Through the network, eight trials have been completed, and 10 more have been selected for pursuit in the next 18 months.

## The Need for Expansion

To undertake clinical trials on all promising CF therapies, the CF Foundation must increase the number of medical institutions in the Therapeutics Development Network from eight centers to as many as 20 centers around the country. This expansion will help to secure the expertise of a greater number of researchers and work with more patients. The translation of basic science findings into new therapies is not a simple, nor inconsequential, endeavor. The most significant challenge facing the CF Foundation is to ensure that we have the financial resources necessary for the expansion of the clinical trials network as we must pursue all the promising translational and clinical research opportunities before us.

Because CF is an orphan disease, patients are not able to rely on industry to pitch in to the extent necessary to get the job done. The lives of thousands of individuals hang in the balance. The CF Foundation has taken it upon itself to leave no stone unturned and to aggressively pursue promising leads in rapid fashion. Many generous individual and corporate donors and successful special fund-raising events have financed our research and care programs. A few years ago, we received a \$20 million gift from the Bill and Melinda Gates Foundation for a drug discovery program. Just last year, we received a pledge for \$25 million over 5 years from Tom and Cydney Marsico, as a testament to our no-nonsense strategic approach to a cure. However, we remain concerned about the lingering effects of September 11th on our fund-raising successes, but the urgency to cure this disease remains. In order to take the Therapeutics Development Network to the next level, we need a stronger partnership with NIH.

## An Opportunity for a Promising Partnership

NIH has a laudable history of supporting translational and clinical research to ensure that basic research findings move quickly to the patient's bedside. It is obviously of keen interest to Congress to make certain that basic research findings are rapidly translated into treatments. Perhaps the best-known clinical trials system at NIH is that supported by the National Cancer Institute to test potential cancer therapies. Other NIH institutes have clinical trials networks or collaborate with the private sector, including private non-profit organizations, in undertaking clinical trials. All of these initiatives provide crucial support through public-private partnerships to translate basic science into improved treatments for millions of Americans.

ships to translate basic science into improved treatments for millions of Americans. We urge NIH to partner with the CF Foundation to strengthen and expand the Therapeutics Development Network. This multi-institutional network with a centralized data management system and strong patient protections has been acknowledged, by NIH staff and others, as a model for conducting clinical trials, especially for orphan diseases. We believe a collaboration between NIH and the CF Foundation's Therapeutics Development Network would have two clear benefits: (1) it would accelerate the pace of research on new CF treatments; and (2) it would provide valuable information to the NIH regarding the structure of clinical trials networks for other rare genetic or metabolic diseases.

We request that the Subcommittee encourage NIH to enter into a renewed partnership with the CF Foundation to advance CF clinical trials. The Subcommittee has placed great faith in the biomedical research enterprise by providing significant boosts in funding. We hope that the Subcommittee will now urge a robust publicprivate partnership in CF clinical trials to bring about the goal of all basic research findings—helping patients to overcome disease and live longer, healthier lives. By working together, we can continue adding tomorrows every day.

Thank you again for the opportunity to submit this statement. The CF Foundation looks forward to working with Congress in continuing to support this biomedical research enterprise.

## PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL SOCIETY

On behalf of our members, I want to thank the Committee for your leadership in the bipartisan effort to double the NIH budget. As a member of the Ad Hoc Group for Medical Research Funding, the American Psychological Society recommends \$27.3 billion for NIH in fiscal year 2003 as the 5th and final installment of the 5year doubling plan. The rationale for these aggressive increases remains as compelling today as it was in fiscal year 1999, the year that you and your colleagues in the Senate embarked on this path. NIH has experienced a period of unparalleled growth in the past 5 years, and the progress achieved as a result of research funded by NIH will lead us into a new era of discovery and innovation. Within the NIH budget, my testimony today focuses on the behavioral and social

science research activities of NIH.

## OVERVIEW: BASIC AND APPLIED PSYCHOLOGICAL RESEARCH RELATED TO HEALTH

The effects of behavior on health are indisputable. Many leading health condi-tions-heart disease, lung disease, diabetes, developmental disabilities, brain injury, AIDS, and so many more-are behavioral in origin. Consider, for example, the devastating health consequences of smoking, drinking, taking drugs, engaging in risky sexual behaviors. Even conditions which may be biological in origin often are behav-ioral in their manifestation. I'm speaking, for example, of such things as cognitive impairment due to brain injury, mental illness, or dementia. None of these conditions can be fully understood without an awareness of the behavioral and psychological factors involved in causing, treating and preventing them. Understanding be-

havior is as important as mapping a gene or diagnosing a biological disorder. APS members include thousands of scientists who, with NIH support, conduct basic research related to physical and mental health at our Nation's leading universities and colleges. Virtually every institute at NIH supports some amount of psychological science. Examples include: The connections between the brain and behavior; research into how children grow and develop; management of debilitating chronic conditions such as diabetes and arthritis as well as mental disorders; and the be-havioral aspects of smoking and drug and alcohol abuse, so that science may find ways for people to escape addiction. These are some of the most promising research frontiers today, and our field is poised to make significant strides in a number of Scientific areas that a few years ago did not even exist. The basic psychological research conducted by APS members and others in the

field has implications for a wide range of applications at NIH, including developing more effective interventions to prevent such diseases as diabetes, cancer, heart disease, and addiction, even developing more effective hearing aids and speech recognition machines. All of these areas of research are bound together by a simple concept: tion machines. All of these areas of research are bound together by a simple concept: that understanding the human mind, brain, and behavior is central to maximizing human potential. That places these pursuits squarely at the forefront of the most pressing health issues facing this Congress, this Administration, and this Nation. We ask that you continue to help make behavioral research more of a priority at NIH, both by providing maximum funding for those institutes where behavioral science is a core activity, and by encouraging NIH to advance a model of health that includes behavior in deciding its scientific priorities.

#### BEHAVIORAL SCIENCE RESEARCH TRAINING: A GUARANTEED INVESTMENT

The outcomes of science are unpredictable. Yet there is one aspect of science where the time and money invested is guaranteed to pay off: the training of our future scientists. We know that if we provide support now for a young investigator, we will have a well-trained, highly-qualified scientist as a result. We also know that without training, we will not have an adequate pool of researchers to pick up where preceding generations leave off. This is a serious issue in behavioral science at NIH, where the demand for behavioral science investigators at NCI, NIMH, and other institutes outpaces the current supply of behavioral science researchers. In order to meet the future needs of research in health and behavior, NIH must have a comprehensive training strategy in place today, one that focuses on training young in-vestigators in the core disciplines of behavioral and social science research as well as in multidisciplinary perspectives. We ask the Committee to support the develop-ment, in consultation with the relevant scientific community, of a comprehensive training strategy for behavioral and social science research at NIH. This strategy should include all training mechanisms, and should be balanced between interdisciplinary research and traditional core disciplines in the behavioral sciences.

I would now like to turn my attention to the behavioral science research that is taking place at the individual institutes.

## NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH)

Strengthening Clinical Science.—Under the leadership of Acting Director Richard Nakamura, NIMH is working with the Academy of Psychological Clinical Science to explore the development of training models for clinical science in psychology. The goal is to establish training for clinical scientists who will go on to create new ways to diagnose, measure and treat mental disorders, and new ways to evaluate how those treatments translate from the lab to the real world. We ask the Committee to support the efforts of NIMH as the institutes takes this very complex first step in the on-going fight against mental illness. Translational Research in Behavioral Science.—NIMH has demonstrated enor-

Translational Research in Behavioral Science.—NIMH has demonstrated enormous leadership in promoting translational research in behavioral science, aimed at bringing knowledge from the laboratory into clinical research and application. The goal is to develop more effective, theory-based interventions and service-delivery models for mental disorders through increased applications of the garnered data. In simplest terms, this is the result Congress was looking for when it chose to double the NIH budget: the results of research being used to treat patients with complex disorders in an effective and efficient manner. This initiative will develop research centers that support the transition of basic behavioral science research to patientoriented studies regarding new interventions and delivery of services for patients with mental disorders.

Basic Behavioral Research at NIMH.—NIMH is to be commended for promoting the transfer of knowledge into application. At the same time, basic behavioral research at NIMH must continue to receive the same strong support it traditionally receives there. This is crucial, as NIMH is a de facto source of basic behavioral knowledge that is tapped by many other institutes. Until other institutes begin to support larger amounts of basic behavioral science research connected to their respective missions, it is essential that NIMH's programs of research into behavioral phenomena such as cognition, emotion, psychopathology, perception, development, and others continues to flourish. We ask the Committee to encourage NIMH's continued efforts to strengthen the ties between basic and clinical behavioral research, and to encourage NIMH's basic behavioral science portfolio in order to ensure continued progress in our understanding of the causes, treatment, and prevention of mental illness and the promotion of mental health.

## NATIONAL INSTITUTE ON DRUG ABUSE (NIDA)

Behavioral research plays an important role in NIDA's search for solutions to the complex social and public health problems posed by drug abuse and addiction. NIDA supports basic research on such topics as craving, motivation, and decision-making to determine how behavioral and cognitive factors underlie and can lead to drug addiction. Recognizing that for some individuals the initial voluntary behavior to use a drug is more likely to lead to the disease state of addiction, NIDA has a comprehensive behavioral research portfolio that serves as the foundation for all of its prevention and treatment efforts.

NIDA's National Prevention Research Initiative.—NIDA's new Prevention Research Initiative integrates basic science with prevention research. NIDA-supported investigators will draw on basic behavioral, cognitive, developmental, social and neurobiological research to inform the development of innovative and novel prevention interventions. NIDA will focus on preventing the initiation of drug abuse by better understanding basic cognitive processes, such as the decision to use a drug. This basic research component is just one of three components (along with establishment of transdisciplinary prevention centers and community multi-site prevention trials) that NIDA will use to enhance national prevention efforts. Understanding behavior will not only aid in the development of prevention strategies, it will also aid in the development of new therapies for those addicted to drugs. We ask this Committee to increase NIDA's budget in proportion to the overall increase at NIH in order to reduce the health, social and economic burden resulting from drug abuse and addiction in this Nation.

#### NATIONAL INSTITUTE ON ALCOHOL ABUSE AND ALCOHOLISM (NIAAA)

NIAAA has broadened its behavioral science portfolio in order to understand the underlying psychological and cognitive processes that lead people to drink, and the impact of chronic alcohol abuse on those processes. As one example, NIAAA convened a workshop of national experts on social identification and alcohol research to examine ways that group peer pressure and group norms concerning drinking influence drinking. The Institute also convened a group of experts in cognitive research to explore the effects of alcohol abuse on memory, decision-making, cognitive development to begin looking at issues of cognitive rehabilitation.

Combining Behavioral Science with Pharmacology.—With research suggesting a genetic component to alcoholism and alcohol abuse and physiological dependency as a key factor in alcohol intake, the lines are becoming less and less clear between what is considered behavioral and what is considered biological research. An excellent example of how behavioral science research can mesh with pharmacological research is NIAAA's project, Combining Medications and Behavioral Interventions (COMBINE). Over the next 2 years, at eleven treatment research centers across the United States, alcohol-dependent research participants will receive one of two medications (naltrexone and acamprosate), and one of two behavioral therapies (moderate-intensity behavioral therapy. The goal is to develop the most effective therapies that combine both pharmacology and behavior.

College Drinking.—In early April, 2002, NIAAA launched its College Drinking Initiative, highlighted by its just-released flagship report, "A Call to Action: Changing the Culture of Drinking at U.S. Colleges." The report is the result of several years of collaborative work by distinguished alcohol researchers, senior higher education officials, and students as members of NIAAA's Task Force on College Drinking. The release of this study on April 9, 2002 received significant nation-wide media attention on 3 major networks. Led by APS member Dr. Mark Goldman of the University of South Florida, and Reverend Edward Malloy of the University of Notre Dame, the task force's goals are to advise NIAAA and other policy makers on future research that can improve campus prevention and treatment programs, and to provide college presidents, policy makers, and researchers with information on the effectiveness of current interventions. The research strongly supports the use of comprehensive, integrated programs with multiple complementary components that target individuals, including at-risk or alcohol-dependent drinkers, the student population as a whole, and the college and the surrounding community. This is an excellent example of how behavioral science can be a pillar of public health. We ask this Committee to increase NIAAA's budget in fiscal year 2003 in proportion to the overall increase at NIH in order to reduce the Nation's alcohol-related health problems.

## NATIONAL INSTITUTE OF GENERAL MEDICAL SCIENCES (NIGMS)

NIGMS is the only National Institute specifically mandated to support research not targeted to specific diseases or disorders. That legislative mandate also extends to behavioral science research:

"The general purpose of the National Institute of General Medical Sciences is the conduct and support of research, training, and, as appropriate, health information dissemination, and other programs with respect to general or basic medical sciences and related natural or behavioral sciences [emphasis added] which have significance for two or more other national research institutes or are outside the general area of responsibility of any other national research institute."—(TITLE 42, CHAPTER 6A, SUBCHAPTER III, Part C, subpart 11, Sec. 285k)

Despite this legislative mandate, NIGMS does not now support behavioral science research or training. This is an enormous oversight, given the wide range of fundamental behavioral topics with relevance to a variety of diseases and health conditions.

Congress addressed this issue for the past 3 years in the reports on the fiscal year 2000, fiscal year 2001, and fiscal year 2002 appropriations for NIH. Specifically, the Senate said: "The Committee is concerned that NIGMS does not support behavioral science research training. As the only Institute mandated to support research not targeted to specific diseases or disorders, there is a range of basic behavioral research and training that NIGMS could be supporting. The Committee urges NIGMS, in consultation with the Office of Behavioral and Social Sciences, to develop a plan for pursuing the most promising research topics in this area." NIGMS has not responded to your requests. Once again, we ask the Committee to direct NIGMS to develop a plan for establishing a basic behavioral science research program at NIGMS.

## NATIONAL CANCER INSTITUTE (NCI)

Having already established itself as a leader among NIH Institutes in many fields of research, NCI has made enormous advances in the behavioral sciences. *NCI's Behavioral Research Program.*—NCI's comprehensive behavioral science re-search program ranges from basic behavioral science to research on the development, testing and dissemination of disease prevention and health promotion interment, testing and dissemination of disease prevention and health promotion inter-ventions in areas such as tobacco use, diet, and even sun protection. NCI's Behav-ioral Research Program applies conceptual and methodological innovations from psychological science to cancer-related issues. Focusing on transdisciplinary and col-laborative research, NCI's Behavioral Program has expanded to five branches, in-cluding a basic biobehavioral research branch, a health communication and informatics research branch, and the tobacco control research branch. The transdisciplinary research conducted by NCI is an example of the new path for science as disciplines are only made stronger when complimented by others. With transdisciplinary research conducted by NCI is an example of the new path for science, as disciplines are only made stronger when complimented by others. With every new discovery that arises, we see more and more that no branch of science is complete if it stands alone. The great Chinese philosopher Sun Tzu once said, "The musical notes are just five in number, but their combination gives rise to so numerous melodies that one cannot hear them all." The same philosophy must be applied to scientific research; psychology, biology, physics, genetics, technology all are intertwined, and when used together they form a foundation for advancement that is endless. We ask Congress to support NCI's behavioral science research and training initiatives and to encourse other institutes to use these programs as mod training initiatives and to encourage other institutes to use these programs as models.

Health Communications.—Recognizing the central role of effective communication in addressing issues of health and behavior, NCI has also undertaken a major effort to develop science-based communications strategies for disseminating information and persuasive messages about cancer prevention and treatment to the public. Researchers are exploring innovative strategies for communicating cancer information to diverse populations, looking at various communication approaches such as message tailoring and framing with application in multiple communication channels. These messages draw from a foundation of basic behavioral and social science research into such issues as how people learn and remember health information, how they perceive health risks, and how they are persuaded to adopt healthy behaviors.

they perceive health risks, and how they are persuaded to adopt healthy behaviors. It's not possible to highlight all of the worthy behavioral science research pro-grams at NIH. In addition to those I've discussed here, many other institutes play a key role in the NIH behavioral science research enterprise. These include the Na-tional Institute on Aging, the National Heart Lung and Blood Institute, the Na-tional Institute of Child Health and Human Development, the National Institute of Neurological Disorders and Stroke, and within the NIH Director's office, the Office of Behavioral and Social Sciences Research. Behavioral science is a central part of the mission of each of these, and each deserves the Committee's support.

This concludes my testimony. Again, thank you for the opportunity to discuss the NIH and specifically, the importance of behavioral science research in addressing the Nation's public health concerns. I would be pleased to answer any questions or provide additional information.

## PREPARED STATEMENT OF THE AMERICAN CANCER SOCIETY

With more than 28 million volunteers and supporters, the American Cancer Society (the Society) appreciates the opportunity to submit written comments regarding increased funding for cancer research and application programs in fiscal year 2003. The American Cancer Society is the nationwide, community-based, voluntary health organization dedicated to eliminating cancer as a major health problem by pre-venting cancer, saving lives, and diminishing suffering from cancer through research, education, advocacy, and service. As the nation's largest cancer-fighting organization, we too are making hard choices and setting priorities for our community cancer control activities based on an evaluation of the success of current programs and interventions. The Society has set ambitious goals for the year 2015 to reduce the number of people dying from and being diagnosed with cancer and to significantly improve the quality of life for all cancer patients, survivors, and their fami-lies. To that end, the Society appreciates and encourages this Committee's leader-ship and help in providing significant increases in funding for the development and continuation of effective strategies to prevent cancer, promote healthier lifestyles and provide access to early detection tools and follow-up care.

Our nation has benefited immensely from our past federal investment in cancer. But our work is by no means finished. This year about 1,284,900 new cancer cases will be diagnosed, and 555,500 Americans will die of cancer—more than 1,500 peo-

ple a day. Cancer is the second leading cause of death in the United States. But we have seen dramatic progress and promise in new cancer research, and our past research investments have shown that many cancer deaths can now be prevented through early detection and quality treatment, and by making changes in lifestyle and behavior. To further our progress in decreasing cancer incidence and mortality rates in the face of changing population demographics, we must invest substantial new resources in cancer research and control now to thwart a new cancer and public health crisis and address current and future health care needs of medically underserved populations—older Americans, minorities and the poor—that are hit hardest by cancer.

A variety of proven activities and programs at the National Institutes of Health (NIH), National Cancer Institute (NCI) and Centers for Disease Control and Prevention (CDC) can be enhanced and expanded today to accelerate our progress against cancer through research, prevention, early detection, and improving access to quality care. These programs are critical to our nation's ability to address the anticipated dramatic increases in cancer cases and death and the associated growing health care expenditures resulting from our booming elderly population. To that end the Society would like to thank appropriators for maintaining a focus on crucial health programs while at the same time funding our nation's priorities relating to the war on terrorism. We understand the difficult decisions you face.

The Society applauds President Bush's personal and professional commitment to the fight against cancer as demonstrated in his fiscal year 2003 budget. Recognizing the difficult choices necessary in the current budget climate, the Society is committed to continued increases for cancer prevention and control programs and is grateful for the President's proposed increase for cancer research at the NIH and the CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP). We owe our citizens our continued best effort on the cancer front, and the Society encourages Members of Congress to continue the commitment to initiatives that will help eliminate cancer and advance biomedical research as a whole.

Not only is research important, but the application of NIH research to the general population through chronic disease programs at the CDC is also vital. This is the fifth and final year of the effort to double the budget of the NIH. The Society is fully supportive of this effort and therefore requests \$27.3 billion for the NIH for fiscal year 2003. We are grateful for the bipartisan support the committee has shown over the years and we look forward to the completion of the doubling this year.

We have consistently advocated for funding of the National Cancer Institute (NCI) Director's By-Pass Budget, for which full funding this year would be \$5.69 billion. As you know, more than 30 years ago, the Congress and President Nixon established the NCI and gave it special budget authority to present its budget directly to policymakers at the highest level. The Society urges Congress to carefully consider the extraordinary opportunities outlined in the By-Pass budget. This year, the President's budget comes close to achieving the fiscal year 2003 By-Pass goal, by including \$5.5 billion for cancer research across the NIH. Currently, NCI is able to fund fewer than 30 percent of all the peer-reviewed and approved grants it receives. Additional funding as outlined by the President will enable the NCI to move forward with additional peer-reviewed and approved research grants, foster the development of new drugs to treat cancer successfully, enhance and expand methods of cancer prevention and early detection, optimize quality of life for people living with cancer, and better understand health disparities. Demographic changes that are anticipated over the next decade elevate the importance of addressing the structure in the structure of th

Demographic changes that are anticipated over the next decade elevate the importance of addressing health disparities. Medically underserved groups—particularly racial and ethnic minorities and the poor—are among the fastest growing segments of our population and are currently experiencing poorer health status and outcomes. The Society strongly believes it is vital to the nation's overall well-being to eliminate health disparities in cancer research, access, delivery, and incidence rates. Key to this effort is increasing our understanding of cultural differences and finding effective methods of communication for our nation's diverse communities.

The Society was pleased to work with a bipartisan majority in Congress to establish the National Center for Minority Health and Health Disparities (NCMHD) at the NIH. With the large mandate Congress has given it, the new Center needs an infusion of resources to succeed at its important mission. The Society therefore requests funding for the Center of \$199.6 million in fiscal year 2003. Specifically, working independently and alongside our partners in One Voice Against Cancer (OVAC), the Society is urging Congress to double the financial commitment to NCMHD over the course of the next three fiscal years to enable the Center to promote minority health and to lead, coordinate, support, and assess the NIH effort to reduce and ultimately eliminate health disparities. In this effort NCMHD will conduct and support basic, clinical, social, and behavioral research, promote research infrastructure and training, foster emerging programs, disseminate information, and reach out to minority and other health disparity communities.

To truly capitalize on the enormous investment our nation makes in biomedical research, the knowledge we gain and advances we make as a result of that investment must be applied to the population as a whole. The Society strongly believes that investments in CDC have a positive impact on the nation's public health, and we appreciate your ongoing leadership on this issue. The Society recommends a significant expansion of the application of research, including cancer education, outreach, prevention and screening efforts through the CDC. Many CDC program areas have proven effective in saving lives, educating the public on cancer prevention, and providing wider access to early detection. Because we know that we must ensure that discoveries through research actually reach all Americans, we ask Congress to provide \$348 million for cancer prevention and control programs at the CDC's Chronic Disease Center. These programs combine the national reach of the federal government with the "on the ground" activity of our state and local health departments.

The mission of CDC's Comprehensive Cancer Control Initiative (CCC) is to develop an integrated and coordinated approach to reduce the incidence and mortality associated with cancer through prevention, early detection, treatment, rehabilitation, and palliation. With 2002 funding, CDC provides support and technical assistance to plan and implement comprehensive cancer control activities and programs in 19 states and one tribal organization. Health agencies use this funding to establish broad-based cancer coalitions, provide epidemiological support, and develop and implement a comprehensive cancer control plan targeted towards the needs of their state. Additionally, CDC and its partners have developed a framework for establishing priorities, addressing cancer issues, and prioritizing the use of limited state and federal resources for comprehensive cancer control. The Society recommends that Congress invest \$10 million in fiscal year 2003 to further the impact of these programs for all Americans.

The CDC's National Program of Cancer Registries provides support for cancer registration activities in 45 states, the District of Colombia and three territories, work that has benefited from increases thanks to the bipartisan support of the Congress in the past 2 years. The program provides states with resources essential for directing cancer prevention and control efforts. The Society recommends \$55 million for the National Program of Cancer Registries in fiscal year 2003 to continue the efforts of state registries to build the foundation of a comprehensive prevention strategy. CDC would use increased resources to help state cancer registries aggressively use their registry data to develop effective strategies to prevent and control cancer, especially in medically underserved areas and those in greatest need. By using a registry effectively, a state can more comprehensively deal with its cancer burden by: understanding specific cancer patterns; monitoring trends over time; determining whether cancer control methods are effective; setting priorities for scarce health care resources; advancing public health research; and providing information that can be used on a national basis to determine cancer incidence.

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The CDC continues to work with partners to address the issues relating to prostate cancer early detection. The Society requests \$20 million to continue CDC research activities and fund education, data collection, and awareness activities surrounding this disease. Through prostate cancer control initiatives, CDC is working to provide the public, physicians, and policymakers with the information they need to make informed decisions about the potential risks and benefits of prostate cancer screening and follow-up. CDC is also conducting a large, population-based study to assess whether prostate-specific antigen screening tests and digital rectal examinations reduce deaths from prostate cancer. Between 1990 and 2000, an estimated one-half million American women died from breast and cervical cancers, despite the fact that almost all deaths from cervical cancer and 30 percent of deaths from breast cancer could have been prevented through widespread use of Papanicolaou (Pap) tests and screening mammography. While breast cancer cannot yet be prevented, mammography is the best way to detect breast cancer in its earliest, most treatable stage. The CDC has established the NBCCEDP to create, expand and improve community based screening services for women at risk. Obviously, identifying women who should be screened and encouraging them to take advantage of early detection are the biggest challenges for this program, for which increased resources are necessary. The program currently reaches only a fraction of those women eligible for its benefits. We are grateful that the President singled out this program in his budget for an increase. The Society recommends \$220 million for the NBCCEDP to help increase cancer screening and early detection of breast and cervical cancer. In 1999 Congress established the first Ovarian Cancer Control Initiative at the

In 1999 Congress established the first Ovarian Cancer Control Initiative at the CDC to improve survival from ovarian cancer, the deadliest of gynecological cancers. For the past 2 years, the CDC has laid the foundation for an evidenced-based initiative to improve survival from ovarian cancer. The CDC convened agenda-setting meetings in 2000 to form the basis of the initiative and funded studies that will lead to earlier detection of ovarian cancer. Recent reports of new studies suggest that ovarian cancer produces protein patterns, which could result in a screening tool. This new research adds to the urgency of the CDC's involvement in ovarian cancer. Significant additional CDC resources are needed, however, to develop a risk model to define the most appropriate population for screening and to design and implement education strategies that reach women and health care providers about early detection. The Society requests \$8 million for fiscal year 2003 to ensure that these needs are met.

Skin cancer is the most common form of cancer in the United States and is largely preventable when sun protection measures are used consistently. The goal of the CDC's Skin Cancer Prevention Program is to increase awareness of skin cancer and influence attitudes and behaviors related to sun exposure habits among young adults and teens. To help further increase awareness of this common form of cancer the Society asks for \$10 million for the Skin Cancer Prevention Program in fiscal year 2003.

For most Americans who do not use tobacco, dietary choices and physical activity are the most important modifiable determinants of cancer risk. While tobacco accounts for one-third of all U.S. cancer deaths, research suggests that about another one-third of cancer deaths occurring in the United States each year are due to inadequate nutrition, sedentary lifestyles, and obesity. The Society urges Congress to provide \$130 million in fiscal year 2003 to support CDC's National Tobacco Control Plan (NTCP). The Society further recommends an appropriation of \$60 million for CDC's state-based campaigns aimed at yielding improvements in healthy eating, physical activity and obesity control. Steps can be taken early in life to teach healthy behaviors and prevent chronic disease. CDC's Coordinated School Health Program provides effective guidance and essential funds for schools to implement such programs. The Society requests \$35 million for the chronic disease functions of the School Health Program.

The CDC's efforts to prevent and reduce chronic disease in our nation also include surveillance and research. The Behavior Risk Factor Surveillance System (BRFSS) provides critical information to state and local governments, enabling them to target messages more effectively toward diverse populations to modify behaviors that cause or lead to chronic disease. The Society requests \$10 million in fiscal year 2003 for BRFSS. Similarly, CDC's Prevention Research Centers (PRC) are an important link between biomedical research and translation to healthier lifestyles and healthier people. PRCs are academic health centers that focus on reducing behavioral and environmental risk factors while promoting disease prevention within the communities they serve, concentrating on elderly and medically underserved populations. These centers improve quality of life and save scarce health care dollars in costly treatments and the Society requests \$50 million to help in this important mission. Finally, CDC's Racial and Ethnic Approaches to Community Health (REACH) program supports community-driven coalitions to eliminate disparities in health care. REACH 2010 is an effort to eliminate disparities in health status experienced by racial and ethnic minority populations. With increased funding of \$50 million, REACH can create more demonstration projects that will lead us closer to ending health disparities.

Research holds the key to improved prevention, early detection, diagnosis, and treatment of cancer. The Society is firmly convinced that the knowledge gained through research at NIH and NCI will lead to better methods for early detection, treatments and eventual cures for many types of cancer. We also know that effective interventions for many cancers are available today that, if applied across the entire population, could significantly reduce our nation's cancer burden. CDC plays a key role in translating and delivering our research achievements at the community level, and increased funding will expand the reach of these successful cancer prevention, awareness, and early detection programs to ensure that they reach all Americans.

We are thankful for the broad bipartisan support cancer programs and research have traditionally enjoyed and we look forward to your continued assistance. The challenge for Members of Congress and for the Society is to reduce the gap between what is known and what is practiced. We must build support for cancer prevention, detection, and treatment that will eradicate the disease and we must find ways to achieve a balance between research and application. If we apply what we have learned through NIH, NCI, and CDC programs and capitalize on new promises, including life-saving cancer clinical trials, we will make a real difference in the lives of patients and families touched by cancer.

## PREPARED STATEMENT OF THE COALITION FOR HEALTH FUNDING

"We are a Nation at risk. We face a world of new threats and ancient foes." Centers for Disease Control and Prevention, *Public Health's Infrastructure: Every health department fully prepared; every community better protected.*—Report to Congress, March, 2001

The Coalition for Health Funding is pleased to provide the Subcommittee with testimony recommending fiscal year 2003 funding levels for the agencies and programs of the U.S. Public Health Service. Since 1970, the Coalition's member organizations, representing 40 million health care professionals, researchers, lay volunteers, patients and families, have been advocating for sufficient resources for PHS agencies and programs to meet the changing health challenges confronting the American people. The Coalition for Health Funding is the nation's oldest, most broadly based alliance focused on the breadth of discretionary health spending. One of the important principles that unites the Coalition's members is that the health needs of the nation's population must be addressed by strong, sustained support for a continuum of activities that includes biomedical, behavioral and health services research; disease prevention and health promotion; health care services for vulnerable and medically underserved populations; ensuring a safe and effective food and drug supply; and education of a health professions workforce in adequate numbers to address the breadth of need.

Since the terrorist attacks of 9/11, and the subsequent anthrax attacks, the public is acutely aware of the role of public health in protecting them from the consequences of terrorism involving biological, chemical, or nuclear agents. The events also have dramatically demonstrated the extent to which the nation's public health infrastructure has been allowed to deteriorate. The Coalition for Health Funding applauds the extraordinary Congressional response to this serious deficit and supports the President's fiscal year 2003 request for continued public health infrastructure enhancement.

But while government agencies at the local, state and federal levels have a leading role in preparing for and responding to the terrorist challenge, all aspects of our health and public health system are critical to the success of this effort. It is rel-atively easy to understand the importance of strengthening the ability of local, state and federal public health agencies' ability to detect and respond rapidly to a delib-erately released infectious agent, such as anthrax or smallpox. The importance of addressing racial and ethnic health disparities and access to essential medical care services in the context of the threat of bioterrorism may seem less clear—but populations at higher risk for both chronic diseases and naturally occurring infectious diseases and with less access to health care services are both more vulnerable to deliberately introduced diseases and less visible to the health care system when hours count. Similarly, it may be easy to understand the need to train more public health professionals, such as epidemiologists and public health lab technicians, to prepare and respond to terrorism. But who will take care of those who fall ill, or who need emergency vaccinations, or preventive medicines when we are facing serious shortages in the number of nurses, pharmacists, and allied health professionals? These and many other activities supported by the PHS agencies and programs, such as vaccine research conducted at the National Institutes of Health, medical errors research conducted at the Agency for Healthcare Research and Quality, and food and drug safety review conducted by the Food and Drug Administration, are clearly related to bioterrorism preparedness and response and need strong support. At the

same time, even those activities that cannot be linked to bioterrorism, such as preventing birth defects, heart disease, or HIV/AIDS, are essential in our preparedness efforts because a healthy America is a strong America.

The whole continuum of public health activity must be strongly supported to achieve both optimal terrorism preparedness and optimal health outcomes for the American people.

Each year, the Coalition for Health Funding works with other health alliances to determine an appropriate level of federal support for health discretionary programs. For fiscal year 2003, the Coalition is recommending \$51.7 billion be provided for the major programs and agencies of the U.S. Public Health Service. The Coalition's recommendation also includes funding for the Indian Health Service and the Food and Drug Administration, which are not within the jurisdiction of this Subcommittee, but are important federal public health agencies. The Coalition (9.5 percent) over the President's request, may appear excessive, but they reflect both the professional judgment within the various agencies as well as our own members' assessment of community and national needs. The Coalition presents these recommendations to the Subcommittee in the hope that it will view them as important targets in our efforts to achieve our mutual goal of improving the health and quality of life for all Americans.

The following is a partial list of the Coalition's findings and recommendations; the attached table provides the Coalition's recommendations for all the public health agencies:

## NATIONAL INSTITUTES OF HEALTH (NIH)

The Coalition supports the President's request for \$27.3 billion in fiscal year 2003 for the National Institutes of Health and applauds the Members of the Subcommittee for leading the national effort to double our investment in the promising research supported and conducted by the NIH. The Coalition recognizes that the doubling goal has been, and continues to be, difficult to achieve in the context of many unmet health care needs, and that improved health outcomes are only achieved with the translation of NIH research discoveries into practice. This is effectively achieved, for all Americans, through a strong investment in other federal public health agencies and, in turn, state and local health agencies and community-based programs. Therefore, the Coalition cautions that the increase for NIH in fiscal year 2003 must not come at the expense of other public health programs.

The primary reasons for a continued major investment in the NIH include the many health challenges that still confront us, the burgeoning scientific opportunities that are now available, particularly as a result of the scientific achievement of sequencing the human genome, and the large economic benefits that accrue as we make progress against diseases. Recent NIH investments have helped create new diagnostic methods, new treatments, new vaccines, and new cures. Just a few of these examples include Hepatitis B, Haemophilus influenzae Type B, pneumococcus and pertusis vaccines with the potential to save millions; the development and FDA approval of Gleevac for use in treating chronic myelogenous leukemia; and newly developed medications for schizophrenia that have reduced hospitalizations by 30 percent and saved \$1.7 billion in annual hospital costs.

The Coalition also appreciates that medical research is a vision not a precise blueprint. It must be flexible enough to respond to society's changing health care needs and dynamic enough to open the way to ever more promising frontiers of fundamental research. Scientific discoveries are the result of a series of incremental steps that pave the way for future breakthroughs. This process needs sustained support. With it, and support for other public health partners, we will be ready to meet the challenges of the future.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The Coalition for Health Funding recommends an overall funding level of \$7.9 billion for CDC in fiscal year 2003. This amount is \$1.1 billion more than the fiscal year 2002 funding level. The Coalition believes this is the amount needed to enable CDC to carry out its vital mission of disease prevention and health promotion. The Coalition is extremely pleased that Congress provided \$2.3 billion in fiscal

The Coalition is extremely pleased that Congress provided \$2.3 billion in fiscal year 2002 to the CDC to continue, and greatly enhance, the process of re-building the nation's seriously eroded public health infrastructure in order to prepare for bioterrorism and other terrorism threats. The Coalition supports the President's fiscal year 2003 request to provide \$1.636 billion for public health infrastructure and bioterrorism preparedness, including \$940 million for state and local health departments. The Coalition further recognizes that this level of funding will need to continue for the foreseeable future to truly re-build our public health system at the local, state and federal level.

There are many other aspects of the President's budget request for the CDC, however, that are troubling. While nearly 60 new FTE's are requested for bioterrorism activities, approximately 150 other FTE's are proposed for elimination. CDC is a critical agency for many program areas and it is difficult to see how it can carry out its other responsibilities in the areas of infectious disease, immunizations, HIV/ AIDS prevention, chronic disease prevention and health promotion, birth defects and developmental disabilities activities, and many other programs, without adequate staff. In addition, apart from bioterrorism activities, the President has proposed an overall cut of 4.1 percent for CDC that affects many of these same program areas. We cannot afford, as a nation, to diminish our investment in the programs that do so much to achieve improved health outcomes by translating knowledge gained through our investment in the NIH. By cutting CDC programs, we harm our overall progress toward building a healthy, strong America.

## HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

The Coalition for Health Funding recommends an overall funding level of \$7.5 billion for HRSA in fiscal year 2003. This amount is \$1 billion more than the fiscal year 2002 funding level and is the amount that the Coalition believes is needed to provide adequate resources for the important programs that HRSA administers that address access to needed medical and health care services for medically underserved populations.

<sup>^</sup> The Coalition is pleased that the President has requested a significant 8.5 percent increase for community health centers, although this is short of the amount needed to achieve the President's expressed goal of doubling the number of health centers over 5 years. The Coalition is also pleased to see increased, and new, funding for hospital planning and infrastructure preparedness for bioterrorism threats, as well as support for health professions school curriculum development for bioterrorism training.

However, there are many areas in the HRSA budget that the President proposes to cut deeply that the Coalition opposes. Chief among these is the elimination of the Title VII Health Professions Education programs. These programs are beginning to document formally what its supporters have long known: that it has a solid track record in recruiting and training the kind of health professionals that practice in, and stay in, medically underserved areas; and it has a solid track record in training needed health professionals in short supply. These now include pharmacists, allied health professionals, dentists, a range of public health practitioners, psychologists, physician assistants, as well as nurses.

The Coalition also opposes a proposed 40 percent cut, or \$85 million, to the Children's Hospitals Graduate Medical Education program that trains physicians providing direct care for children in free-standing children's hospitals. Similarly, the Coalition opposes the proposed elimination (\$120 million) of the Community Access Program designed to help communities address the still massive numbers, over 40 million, of uninsured Americans. When bioterrorism increases are set aside, the President proposes to cut existing HRSA programs by \$740 million, or 12 percent.

President proposes to cut existing HRSA programs by \$740 million, or 12 percent. Also disturbing is the proposed level funding for many other programs. This includes the Ryan White CARE Act programs at time when the United States is experiencing an increase in the number of new HIV/AIDS cases. Flat funding is proposed for the Maternal and Child Health Block Grant at a time when many states are facing budget deficits, and an upsurge in the number of families needing TANF assistance. Family Planning services, which support 4,600 clinics across the United States that provide comprehensive services including screening for cancer, HIV, and other diseases as well as contraception and teen pregnancy prevention, are another critical safety net service that needs increased resources.

#### SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

The Coalition for Health Funding recommends an overall funding level of \$3.6 billion for SAMHSA in fiscal year 2003. This amount is \$500 million more than the fiscal year 2002 funding level and is the amount that the Coalition believes is needed to provide adequate resources for the agency charged with leading national systems addressing mental illness and substance abuse. Within this amount, the Coalition recommends \$952 million for the Center for Mental Health Services (CMHS); \$2 billion for the Substance Abuse Block Grant; \$360 million for the Center for Substance Abuse Treatment (CSAT) and \$360 million for the Center for Substance Abuse Prevention (CSAP). While the Coalition appreciates the President's request for an additional \$66 million for CSAT, as only 20 percent of the 13–16 million people needing treatment services are currently receiving care, this comes at the expense of substance abuse prevention programs which receive a \$45 million cut in the request. Although treatment saves taxpayers \$7 for every \$1 invested, prevention can reduce the need for any treatment for many people. Both efforts need increased and sustained resources.

ČMHS is level funded in the President's request. This is most unfortunate when over 50 million adults in the United States are affected by mental illness in any given year and more than 5 million adults and children are diagnosed each year with a severe mental illness, such as schizophrenia. People can and do recover, but recovery depends on getting services when and where they are needed—preferably early in the course of the illness and close to home. CMHS, working with its state, local and private sector partners, is instituting state-of-the-art systems of care for those who suffer from mental illness.

Finally, mental health and substance abuse problems are just beginning to surface in the wake of the 9/11 terrorist attacks and will intensify as we approach the anniversary of the tragedy. This is not the time to essentially flat-fund the federal agency that provides essential resources to a system of mental health and substance abuse services that the overwhelming majority of those suffering from these illnesses depend on.

## AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

The Coalition for Health Funding recommends an overall funding level of \$390 million for AHRQ in fiscal year 2003. This amount is \$90 million more than the fiscal year 2002 funding level.

The Coalition is very disappointed in the President's request for a \$48 million (16 percent) cut in this agency which is charged with providing critical information on healthcare quality, ways to reduce medical errors, ways to improve access to healthcare services, and ways to more efficiently utilize healthcare resources. A cut of this magnitude will dramatically curtail AHRQ's ability to carry out its mission. It will, for instance, be unable to fund any new research or training grants and funding for current grants for non-patient safety research will be reduced by 50 percent, reducing our knowledge and understanding of how to provide cost-effective, quality healthcare. As we move, again, into double-digit medical inflation and face the tremendous challenge of an aging baby-boomer population, the research conducted by AHRQ is more relevant and more needed than ever.

The Coalition sincerely appreciates this opportunity to provide its fiscal year 2003 funding recommendations to the Subcommittee for the agencies and programs of the U.S. Public Health Service. The Coalition's recommendations for all of the public health agencies are provided in the accompanying table. The Coalition, and its member organizations, look forward to working with the Subcommittee in the weeks ahead to improve the health of all Americans.

## COALITION FOR HEALTH FUNDING BUDGET COMPARISON

[Dollars in millions]

Agency	Fiscal year 2002	President's request fiscal year 2003	Dollar change President's fiscal year 2003–2002	Percent change President's fiscal year 2003–2002	CHF recom fiscal year 2003	Dollar change CHF fiscal year 2003–2002	Percent change CHF fiscal year 2003–2002
HRSA <sup>1</sup>	\$6,405	\$6,007	- \$398	- 6.2	\$7,500	+ \$1,095	+ 17.0
CDC 1	6,721	5,760	- 961	- 14.2	7,900	+ 1,179	+17.5
NIH <sup>2</sup>	23,623	27,335	+ 3,712	+ 15.7	27,335	+ 3,712	+ 15.7
SAMHSA <sup>1</sup>	3,151	3,208	+ 57	+1.8	3,652	+ 501	+15.8
AHRQ <sup>2</sup>	300	251	- 46	- 15.3	390	+ 90	+ 30.0
IHS <sup>2</sup>	2,824	2,884	+61	+ 2.1	3,019	+195	+6.9
FDA <sup>2</sup>	1,413	1,432	+ 19	+ 1.3	1,625	+ 212	+15.0
OPHS <sup>2</sup>	219	259	+ 40	+ 18.3	262	+ 43	+19.6
Secretary <sup>3</sup>	46	43	- 3	- 6.5	43	- 3	- 6.5
Totals	44,702	47,179	+ 2,481	+ 5.5	51,726	7,024	+ 15.7

<sup>1</sup>Reflects Program Level minus user fees and mandatory spending, but does include Bioterrorism funding from PHSSEF.

<sup>2</sup> Reflects Total Budget Authority.

<sup>3</sup> Reflects Office of Public Health Preparedness and Cyber security only.

## PREPARED STATEMENT OF THE AMERICAN COLLEGE OF RHEUMATOLOGY

The American College of Rheumatology (ACR) appreciates the opportunity to provide testimony to the Senate Labor, Health and Human Services and Education Subcommittee regarding fiscal year 2003 appropriations to key programs within the Department of Health and Human Services.

The 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, rheumatic and musculoskeletal diseases. Arthritis means swelling, pain and loss of motion in the joints of the body. There are more than 100 rheumatic diseases that cause this condition, which can sometimes be fatal, in both children and adults of all ages. These chronic diseases cause life long pain and disability. Arthritis is the leading cause of disability in the United States, affecting approxi-

Arthritis is the leading cause of disability in the United States, affecting approximately 43 million Americans. Arthritis has been found to rank first among the 10 leading health problems of individuals age 50 and older. By the year 2020, the prevalence of arthritis will increase to an estimated 60 million Americans. The provision of care to people who are disabled contributes significantly to the financial costs paid by the government, private insurers, and to society as a whole. More than \$65 billion are spent yearly due to medical costs and lost productivity associated with arthritis and related diseases each year.

This burden will surely increase, possibly uncontrollably, as the baby boomer group continues to age. Although some forms of arthritis are predominant in older individuals, arthritis also affects children and adults of all ages. The number of individuals affected, as well as associated costs, will increase as the size of our elderly population continues its upswing. As such, the ACR strongly believes that Congress should support the funding levels recommended below so that necessary research and treatments to combat these prevalent diseases can continue.

## THE NATIONAL INSTITUTES OF HEALTH

The goal of the National Institutes of Health (NIH) is to acquire new knowledge to help prevent, detect, diagnose, and treat disease and disability, from the most rare genetic disorder to the common cold. Money allocated to the NIH is dispersed to the different institutes within the NIH, such as the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and the National Institute of Allergy and Infectious Diseases (NIAID), whose agendas include a substantial focus on arthritis and related research areas.

Along with the Administration, the ACR supports an appropriation of \$27.3 billion for the NIH in fiscal year 2003. This \$3.7 billion, 15.7 percent, increase represents the final step toward the bipartisan goal of doubling the NIH by 2003, and the largest 1-year increase ever for the NIH. The ACR is pleased that the Senate Budget Committee's budget blueprint included the doubling of the NIH, as does the Housepassed budget resolution. The ACR commends Congress and the Administration for their bipartisan, 5-year effort to double the NIH budget.

## THE NATIONAL INSTITUTE OF ARTHRITIS AND MUSCULOSKELETAL AND SKIN DISEASES

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), a branch of the NIH, leads the federal medical research effort in arthritis and rheumatic diseases. Specifically, the NIAMS conducts research related to the causes, treatments and prevention of diseases of the bone, joints, muscle, skin and other connective tissues. The NIAMS sponsors research and research training at universities and medical centers throughout the United States. Research sponsored by the NIAMS leads to the development of more effective treatments, which leads to decreased costs and improved quality of life for patients suffering from rheumatic diseases.

One example of the important work of NIAMS is the Osteoarthritis Initiative (OAI) launched last year. Osteoarthritis is the most common form of arthritis, and occurs when cartilage wears away. If affects approximately twenty one million people. The OAI is a public-private partnership to collect information and define disease standards on 5,000 people at high risk of having OA and at high risk of progressing to severe OA. Funds will be provided for as many as six clinical research centers to establish and maintain a natural history database for osteoarthritis that will include clinical evaluation data and radiological images, and a biospecime repository. All data and images collected will be available to researchers worldwide to help quicken the pace of scientific studies and biomarker identification.

The ACR strongly supports an appropriation of \$520.9 million for the NIAMS in fiscal year 2003. This would represent a \$72.1 million or 16 percent increase from

the NIAMS funding level of \$448.8 million in 2002. Under President Bush's proposal, the NIAMS would receive a budget of \$488 million, an increase of \$38 million or 8 percent. Funding for the NIAMS has received steady increases in recent years. The ACR, however, is concerned that funding for the NIAMS has not kept pace with the allocations to the other NIH institutes, especially considering that musculoskeletal conditions are among the most common chronic conditions affecting Americans. The ACR, therefore, urges Congress to provide the NIAMS with a 16 percent increase in fiscal year 2003.

## THE NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES

The National Institute of Allergy and Infectious Diseases (NIAID), also a branch of the National Institutes of Health, conducts research that strives to understand, treat, and ultimately prevent the myriad of infectious, immunologic, and allergic diseases. The NIAID's research focuses on the basic biology of the immune system and mechanisms of immunologic diseases including autoimmune disorders. To accomplish its goals, the NIAID carries out a wide range of basic, applied, and clinical investigations within its own laboratories, and provides research grant, contract, and cooperative agreement support to scientists at universities and other research institutions throughout the country and the world.

The ACR recommends a fiscal year 2003 appropriation of \$2.8 billion for the NIAID. This would represent a 15.7 percent increase from the NIAID 2002 funding level of \$2.4 billion. The ACR urges Congress to provide this funding level increase for research on arthritis, rheumatic and musculoskeletal diseases in addition to the NIAID's important bioterrorism research.

## THE AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

The Agency for Healthcare Research and Quality (AHRQ) is one of the primary health care research bodies within the Department of Health and Human Services. AHRQ's mission is to support, conduct, and disseminate research that improves access to and outcomes and quality of health care services. AHRQ often collaborates with other Department of Health and Human Services (HHS) agencies, particularly the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). AHRQ's health services research complements the biomedical research of the NIH by helping physicians, hospitals, purchasers and other stakeholders in health care delivery make informed decisions about what treatments work best, for whom, when, and at what costs.

A collaborative research study between AHRQ and the Centers for Medicare and Medicaid Services (CMS) found that chronic conditions such as arthritis, often suboptimally managed in clinical practice, contribute significantly to poor physical function among women age 65 and older enrolled in Medicare + Choice. Components of this work has been published in many journals and presented and many meetings, and may lead to the development of a new quality indicator aimed at improving arthritis care for Medicare + Choice plans.

The ACR recommends an appropriation of \$390 million for AHRQ for fiscal year 2003. This represents a \$91 million increase over AHRQ's 2002 budget of \$299 million.

The ACR is concerned with the President's proposed budget of \$252 million for AHRQ, a decrease of \$48 million or 16 percent. Under this budget, AHRQ would be unable to fund any new research or training grants. Funding for current grants (except for protected areas such as patient safety research) would be reduced by 50 percent, requiring grant and contract renegotiations that will significantly reduce our knowledge and understanding of how to cost-effectively provide quality health care. Reductions in the AHRQ funding stream will result in lost opportunities for research projects currently in the middle of a 2- or 3-year grant cycle. Mid-course interruptions will halt some projects just as these initiatives are about to bear fruit in the form of improved patient health outcomes and reductions in healthcare expenditures.

## THE NATIONAL ARTHRITIS ACTION PLAN

The National Arthritis Action Plan (NAAP) is an innovative program developed jointly between the Centers for Disease Control (CDC) and the Arthritis Foundation to improve the quality of life of those suffering from arthritis. The NAAP, housed within the CDC National Center for Chronic Disease Prevention and Health Promotion, helps deliver the advances made in the biomedical research system to millions of Americans who have arthritis. The NAAP is designed to increase recognition among the general public, people with arthritis and their families, medical care providers, and policy makers, of the impact of arthritis, what can be done to prevent or delay its onset, and what effective interventions and are available to reduce disability and improve the quality of life of people with arthritis. It has made a tremendous impact in how state public health departments address

It has made a tremendous impact in how state public health departments address this national health problem. The program currently enables 36 state health departments to develop or enhance programs to improve the quality of life for the millions of Americans affected by arthritis. Increased funding would establish programs in more states, as well as expand existing programs.

The ACR strongly recommends a fiscal year 2003 appropriation of \$24.5 million for the NAAP. This represents a \$10.6 million increase from the NAAP 2002 budget of \$13.9 million. The Administration's 2003 budget plan, however, would cut NAAP funding by 6 percent, for a total of \$13.07 billion. The ACR commends the Senate Budget Committee for restoring funding to the CDC Center for Chronic Disease Prevention and Health Promotion, under which the NAAP is funded, in its budget blueprint.

## PEDIATRIC RHEUMATOLOGY WORKFORCE

The Children's Health Act of 2000, signed into law in October of 2000, recognized juvenile arthritis as a national health care priority. It authorized funding for a federal pediatric rheumatology workforce study to determine whether the number of pediatric rheumatologists is sufficient to address the health care needs of children with arthritis and related conditions. It also states that should the study find that the number of pediatric rheumatologists is not sufficient, strategies to help address the shortfall are to be developed. The ACR urges Congress to appropriate \$1 million in fiscal year 2003 for the Health Resources and Services Administration (HRSA) to conduct such a study. This study will help ensure that the nearly 300,000 children with arthritis have access to the specialty care that plays a critical role in preventing and properly managing the pain and disability associated with the disease.

## SUMMARY

As physicians involved in both research and specialized patient care, ACR members are acutely aware of the magnitude of the challenges that disease and disability place on the health care delivery system. The ACR would like to thank the subcommittee for its support of these programs in recent years, and encourages the subcommittee to provide a strong investment in these programs for fiscal year 2003. Current basic science research is providing breakthrough advances that have the potential to revolutionize our understanding of arthritis and the care of rheumatic patients. This important research leads to the development of more effective treatments, decreasing costs and improving the quality of life for patients suffering from rheumatic diseases.

## 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 Willebrand disease, and other bleeding disorders.

## BACKGROUND

Bleeding disorders are caused by genetic defects in the body's blood coagulation system, usually a missing protein, that prevents or slows down blood clotting. There are several types of bleeding disorders. The most recognized bleeding disorder is hemophilia, a predominantly male disorder affecting approximately 20,000 individuals in the United States. The most common bleeding disorder is von Willebrand disease, which affects between one to 2 percent of the U.S. population. Throughout their lives, people with hemophilia and other bleeding disorders are

Throughout their lives, people with hemophilia and other bleeding disorders are dependent on blood clotting factor products to supply the missing protein needed for their blood to clot normally. Today, most people with hemophilia in the United States prefer clotting factors manufactured using recombinant-DNA technologies. These products contain only a small amount of blood plasma. Until the mid-1990s, only clotting factors fully derived from concentrated blood plasma were available, with as many as 60,000 donors contributing to a single vial of product. As a result of their dependence on blood-based products, the hemophilia and

As a result of their dependence on blood-based products, the hemophilia and bleeding disorders community has been severely affected by HIV and hepatitis. More than 80 percent of people with hemophilia born before 1992 have hepatitis C. During the 1980's, half of all persons with hemophilia became infected with HIV. More than 5,000 members of the hemophilia community have died of HIV/AIDS.

## RICKY RAY HEMOPHILIA RELIEF TRUST FUND

NHF and the hemophilia community continues to be deeply indebted to the Committee for its leadership in providing full funding of the Ricky Ray Hemophilia Relief Fund Act. NHF worked for nearly a decade to achieve compassionate relief for those persons in our community and their families who were affected by HIV/AIDS. Full funding of the Ricky Ray Relief Fund enabled the Ricky Ray Program Office to move quickly in reviewing petitions and making compassionate payments to eligible individuals and their families. In little more than 1 year, the Program Office reviewed the nearly 6,200 petitions to the Trust Fund and made payments of \$543 million on approximately 5,700 of those petitions. The remaining petitions have either been denied or continue to be processed by the Program Office. The Health Resources and Services Administration (HRSA) has performed in an

The Health Resources and Services Administration (HRSA) has performed in an exemplary manner in implementing and administering the Ricky Ray Relief Trust Fund. The high level of service provided by the Ricky Ray Program Office has not gone without recognition. The Department of Health and Human Services bestowed upon the program its prestigious Secretary's Distinguished Service Award for innovative use of technology in accomplishing program objectives and efficient management of administrative costs. HRSA awarded the program its Group Performance Award for effectively partnering with the hemophilia community, and the Public Employees Roundtable presented the Program Office its Public Service Award for Excellence by a Federal program.

NHF is grateful for the compassion that has been demonstrated by the Program Office and expressed its appreciation earlier this year with the awarding of the Dr. L. Michael Kuhn Award to Ricky Ray Program Office Director Paul Clark for his service to the hemophilia community.

## PREVENTION AND TREATMENT

The national network of hemophilia treatment centers (HTCs) created by Congress in 1974 remains essential to ensuring that comprehensive and specialized care is available for persons with bleeding disorders. The HTC role has expanded dramatically over the last three decades, evolving with the needs of the hemophilia and bleeding and clotting disorders community to provide coordinated HIV/AIDS and hepatitis care, blood safety surveillance, prevention, and improved disease management. These programs, carried out in conjunction with the Centers for Disease Control and Prevention (CDC), have demonstrated significant reductions in mortality and morbidity associated with HTC care. More than 70 percent of the hemophilia community participate in one of the 150 centers that comprise the HTC network. NHF urges the Committee's strong support for strengthening these programs within CDC.

HTCs also provide needed services to the hemophilia community through the special projects of regional and national significance set-aside within the Maternal and Child Health Bureau (MCHB) Block Grant. MCHB funds are utilized by HTCs to cover the non-reimbursable costs of providing on-going nursing, prevention, dental, and rehabilitative services and support. MCHB funding for HTCs has remained steady for the past nearly 20 years, resulting in eroded resources over time. Additional MCHB funds are needed to enable HTCs to continue meeting the needs of the hemophilia and bleeding disorders community and to expand outreach, services and support staff. NHF requests the Committee's support for increased funding for the MCHB Block Grant to enable \$3 million to be made available for HTCs.

## HEMOPHILIA RESEARCH

## Gene Therapy and Genotyping

NHF is appreciative of the Committee's continued commitment to research. The strengthened research funding provided by the Committee to the National Institutes of Health has brought about rapid advances in science, particularly in hemophilia gene therapy. It is widely believed that hemophilia, as a single gene defeat, will be among the first diseases treated and cured by gene therapy. We are particularly appreciative of the significant funding commitments to this promising research that have been made by the National Heart, Lung, and Blood Institute (NHLBI) and encourage the Committee's continued support for NHLBI's blood programs.

Genotyping of the hemophilia community is essential to the successful introduction of gene therapy into hemophilia treatment and prevention efforts. Genotyping is necessary to select optimal gene therapy treatments for each individual, conduct

pre-treatment risk assessments for potential inhibitor-induced complications, and perform testing to improve pre- and post-natal care and delivery management. It is estimated that there are between 7,000 and 8,000 families with hemophilia in the a "gene" history. The Centers for Disease Control (CDC) currently conducts gene variation studies

within the hemophilia community related to inhibitors to clotting factors. Through its hematologic branch laboratory, the CDC has a unique ability to genotype populations, like the hemophilia community, that are too small to attract commercial interests. NHF urges the Committee to provide CDC additional funding resources to genotype the hemophilia community and establish a national databank for the genetic information needed to assist in the appropriate management of gene therapy care for persons with bleeding disorders.

## HIV and Hepatitis C

HIV and hepatitis C HIV and hepatitis C continue to severely impact the hemophilia community. More than 2,500 people with hemophilia are living with HIV/AIDS. Nearly all of these individuals also are co-infected with hepatitis C (HCV), and more than 80 percent of all persons with hemophilia born before 1992 have the disease. NHF has been grateful for the support of the Committee in encouraging continued partnerships be-tween NHF and the National Institute of Allergy and Infectious Disease (NIAID) to address the hemophilia community's HIV and hepatitis needs. NIAID hosted a workshop in 1999 to develop strategies for treatment of HIV and associated complications in the hemophilia population. Becommendations from this

associated complications in the hemophilia population. Recommendations from this workshop have served as a blueprint for research initiatives on HCV, HIV-infected persons in the hemophilia community with no history of progression to AIDS (long-term non-progressors), and the effects of HIV therapies on hemostasis. The findings from these studies could yield information substantially benefiting NIH's broader HCV treatment improvement efforts. NHF is appreciative of NIAID's leadership in supporting research related to liver disease progression and response to HCV treat-ment among HIV/HCV co-infected persons with hemophilia and encourages the Committee's continued strong support of this effort.

## WOMEN WITH BLEEDING DISORDERS

Bleeding disorders in women often are left undiagnosed and untreated, leading to anemia, unnecessary procedures including hysterectomy, complications of menstrua-tion and pregnancy, and significant quality of life issues. Severe bleeding is a lead-ing cause for hysterectomy among U.S. women of childbearing age. Of these dis-orders, von Willebrand disease (vWD) is the most prominent, affecting an estimated 1 to 2 percent of the U.S. population.

In 1998, CDC, working with NHF, launched a public awareness and education campaign to inform the public and providers about the symptoms, diagnosis, complications and treatment of women's bleeding disorders. Since its inception, this campaign has resulted in strategic links with key provider organizations, government, women's center of excellence health centers, and lay and medical journalists. Informational materials have been made available to millions of women through women's magazines, partnerships with local health organizations, presentations and exhibits at health and provider organization meetings, NHF's own information net-work and website, and links with other websites. NHF urges the Committee's continued strong support of this effort by CDC.

NHLBI also has played a key role in this campaign by continuing to support re-search to improve diagnosis and treatment of vWD and to identify needed elements for the future development of gene-based treatments and therapies. NHF thanks the Committee for its leadership in addressing this pressing health need and calls for the Committee's support of a NIH consensus conference on women with bleeding disorders to determine next steps for research to improve and diagnosis of these disorders.

## RECOMMENDATIONS

Once again, NHF and the hemophilia community are truly indebted to the Committee for its leadership in providing full funding of the Ricky Ray Hemophilia Re-lief Trust Fund. This Trust Fund has provided needed relief and brought closure to the terrible tragedy of HIV/AIDS within our community. We also are grateful for the Committee's support of hemophilia research, prevention, treatment, and out-reach initiatives. For fiscal year 2003, we urge the Committee to:

Strengthen its funding support for the hemophilia and bleeding and clotting dis-orders prevention and treatment programs within CDC.

- -Correct the current funding shortfall for HTC services by providing \$3 million for the treatment center network. -Expand available funding within CDC to enable genotyping of persons with he-
- mophilia and establish a databank for this genetic information.
- Continue to support additional resources for hemophilia gene therapy research within the increases provided for NHLBI.
- -Provide support for continued collaboration between NIAID and NHF to improve HCV treatment options for HCV and HCV/HIV co-infected persons in the hemophilia community
- -Support continued efforts to expand awareness of women's bleeding disorders and call for a NIH consensus conference to determine next research steps for improving treatment and diagnosis of these disorders. Thank you for the opportunity to provide this statement to the Committee.

## PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR DENTAL RESEARCH

## INTRODUCTION

Mr. Chairman and members of the committee: I am Dr. Steven Offenbacher, Di-rector of the University of North Carolina School of Dentistry Center for Oral and Systemic Diseases and President of the American Association for Dental Research (AADR). I am presenting testimony on behalf of AADR. I would like to discuss our 2003 budget recommendations for the National Institute of Dental and Craniofacial Research (NIDCR). In addition, I will discuss the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Disease Control and Prevention (CDC)

The American Association for Dental Research (a Division of the International Association for Dental Research) is a non-profit organization with over 5,000 individual members and 100 institutional members within the United States.

Its mission statement rests on three pillars:

Advance research and increase knowledge for the improvement of oral health Strengthen the oral health research community Facilitate the communication and application of research findings

Mr. Chairman and members of the Committee, I want to thank you for this opportunity to testify about the ongoing work of NIDCR.

#### WHY DENTAL RESEARCH IS IMPORTANT

Dental research is concerned with the prevention, causes, diagnosis, and treat-ment of diseases and disorders that affect the teeth, mouth, jaws, face, and related systemic diseases. Dental researchers are leaders in studies of disfiguring birth defects, chronic pain conditions, oral cancer, infectious diseases, including oral infections and immunity, bone and joint diseases, the development of new diagnostics and biomaterials, and the interaction with systemic diseases that can compromise oral and craniofacial health.

Throughout the lifespan, the oral cavity is continuously challenged by both infections that may have systemic as well as local implications for health. Through their research, dental scientists continue to demonstrate that the "the mouth is a window to the body.

Research into the causes of oral diseases and new ways to treat and prevent these diseases is estimated to save Americans \$4 billion annually. Oral health is an essential and integral component of health throughout life. Of

the 28 focus areas for Healthy People 2010, oral health is integrated into 20 of them. No one can be truly healthy unless he or she is free from the burden of oral and craniofacial diseases and conditions.

- Mr. Chairman, I would like to offer some statistics on the extent of the problem: -Dental caries, or tooth decay, is one of the most common diseases among 5-17 vear olds
- 80 percent of tooth decay in permanent teeth is now found in only 25 percent of school-aged children.
- -Minority children ages 2-4 in the United States have more dental decay than white children.
- 18 percent of children aged 2-4, 52 percent of those aged 6-8, and 61 percent of 15-year-olds have experienced tooth decay.
- -16 percent of children aged 2-4, 29 percent of those aged 6-8, and 20 percent of 15-year-olds have untreated tooth decay.
- -Only 23 percent of children and 15 percent of adolescents have received dental sealants—a simple and noninvasive service to prevent tooth decay.
- -Oral lesions are common in teenagers who use spit tobacco.

—According to the Centers for Medicare and Medicaid Services, approximately 500 million dental visits occur annually in the United States, with an estimated \$60 billion currently being spent on dental services. Yet, many children and adults needlessly suffer from oral diseases that could be prevented. In fact, 30,000 Americans will be diagnosed with oral and pharyngeal cancers this year, resulting in more than 8,000 deaths—many of which could have been prevented.

#### THE IMPORTANCE OF SALIVA RESEARCH

NIDCR scientists are using gene therapy methods to repair damaged salivary glands and are developing artificial salivary glands which also have great potential in the treatment of conditions such as Sjögren's Syndrome, in which the salivary glands cease to function.

Saliva, like blood and urine, can be used to detect and measure many compounds in the body. It is easy to collect in a non-invasive manner and to store. In 1993, a conference supported by the NIDCR was held to discuss utilizing saliva as a diagnostic medium. To this day, remarkable technological advances are promising to revolutionize the field of diagnostics as we know it. Experimental salivary assays have already been developed for detecting antibodies for measles, mumps, and rubella. Saliva is also reliable in diagnosing viral hepatitis A, B, and C in laboratory tests and is being used increasingly to monitor Alzheimer's disease, Sjögren's Syndrome, cystic fibrosis, diabetes, breast cancer, and diseases of the adrenal cortex. Saliva has the potential to serve as a source for assessment and monitoring of systemic health and disease states and exposure to environmental, occupational, or abusive substances as well as to agents dispersed by bioterrorists. In fact, dental researchers continue to pursue a saliva-based diagnostic test for anthrax exposure.

## NEW SCIENTIFIC FIELDS

Biomimetics and tissue engineering are two relatively new scientific fields. Biomimetics studies the process of how nature designs and produces its various tissues such as skin, bone, and tendon. Based on the principles of biomimetics, tissue engineers fabricate unique molecules and materials that promote the growth of new tissues that are lost due to disease, trauma, or congenital defects.

One area of great interest within both disciplines is stem cell research. This interest results from the fact that stem cells are capable of generating many specialized cell types. There are now opportunities to develop unique strategies for the repair and regeneration of oral facial structures adversely affected by congenital disorders, disease, or injury.

Research is currently underway that will lead to the development of safe and effective stem cell-based treatments. The goal is to foster research on human and mouse embryonic and adult stem cell biology that could help clarify the complications that come about during oral, dental, and craniofacial development and disease.

## ORAL FACIAL STRUCTURES

Jaw growth is a slow and gradual process, taking place as we grow into adulthood. Sometimes the upper and lower jaws may grow at different rates, resulting in a mismatch between these jaws. Patients may have difficulty chewing and speaking properly, develop jaw joint problems, and have teeth, which are not properly aligned. These patients tend to be very self-conscious and insecure about how they look and may suffer from significant chronic pain. Corrective jaw surgery improves function and provides an improved facial balance and appearance.

## TEMPOROMANDIBULAR JOINT DISORDERS

The temporomandibular joint and its associated muscles are frequently the source of chronic pain. Every time a person chews, smiles, yawns or talks, this joint is at work. When the joint is not functioning properly, a variety of symptoms may occur, including headaches, sore jaw muscles, locking of the jaw, clicking and grating sounds of the joint, or pain when opening or closing the mouth. Some doctors now subscribe to a conservative medical management of these symptoms whenever possible. Those who do not respond to medical management, may need surgical treatment to treat their problems. It is now possible to get surgery to preserve the joint without causing scarring in the joint itself.

## CLINICAL RESEARCH

A study published by the Institute of Medicine of the National Academy of Sciences, pointed to the need for focused high-quality clinical dental research. The recommendations included increased funding, educating scientists to explore existing resources, improving peer review for clinical research, exploring new career development programs for young and seasoned researchers, and addressing structural barriers within dental schools that limit the conduct of clinical research. NIDCR has implemented a number of steps, including training in clinical trial design, and also will explore options proposed by the NIH Director's Advisory Committee on Clinical Research which include expanded use of the General Clinical Research Centers, collaboration with industry and incentive awards for clinical researchers.

## RECOMMENDATIONS

1. National Institute of Dental and Craniofacial Research.—The AADR supports an increase of 22 percent for the fiscal year 2003 NIDCR budget, representing a total appropriation of \$420,000,000. This recommendation will result in a doubling of the NIDCR budget over the period 1999–2003, consistent with the congressional commitment to double the NIH budget in 5 years. The additional funds will support the following initiatives:

—New saliva based diagnostic tools

-Restoring health to orofacial tissues and organs using biomimetic tissue engineering and stem cell approaches

-Temporomandibular joint disorders.

2. Centers for Disease Čontrol and Prevention, Division of Oral Health.—The CDC seeks to improve the nation's oral health status, including trends in oral diseases, access to oral health services, and health disparities by evaluating prevention and control interventions. It also assists states in collecting and utilizing this information to improve the oral health of their citizens. Currently, the Division of Oral Health is funded at \$10,839,000.

The AADR is recommending \$17 million for fiscal year 2003 to enhance the CDC's grant program to states and to address oral health issues through prevention research.

3. The Agency for Healthcare Research and Quality (AHRQ).—The lead agency for supporting research to improve the quality of health care, reduce its costs, and broaden access to essential services. Its programs bring practical, science-based information to health practitioners, consumers, and health care purchasers.

The AADR supports an increase in funding to \$390,000,000 for AHRQ, an amount that would allow the agency to expand its portfolio of projects to include those related to bringing the advances of biomedical research into cost-effective dental practice. The AHRQ is encouraged to continue its dental scholar-in-residence program and to promote and conduct oral health services research.

This concludes my testimony. Thank you for this opportunity to testify.

## PREPARED STATEMENT OF THE COALITION FOR HEALTH SERVICES RESEARCH

The Coalition for Health Services Research (Coalition) is pleased to offer this testimony for the record regarding the role of health services research in improving our nation's health. The Coalition is the advocacy arm of the Academy for Health Services Research and Health Policy (Academy). Through the Academy, the Coalition represents more than 3,400 individual researchers, scientists and policy experts as well as 115 organizations that produce and use health services research information including universities, providers, employers, and health plans. We are grateful for the funding support the Subcommittee has provided for health

We are grateful for the funding support the Subcommittee has provided for health services research over the past several years. Funding increases at the Agency for Healthcare Research and Quality, the Centers for Medicare and Medicaid Services, the Centers for Disease Control and Prevention, and the National Institutes of Health have allowed researchers to:

- -Find that uninsured children often have at least one working parent. The findings, which countered the assumption that parents of uninsured children are not employed, helped pave the way for the development of the State Children's Health Insurance Program (SCHIP), which extended health insurance to many low-income children and their parents. According to the U.S. Department of Health and Human Services, total SCHIP enrollment for fiscal year 2001 was approximately 4.6 million persons.
- —Develop a new technology to help emergency room doctors improve their decision-making about whether to hospitalize or discharge patients with chest pain. It is estimated that 200,000 people per year could be spared an unnecessary hospital stay and that more than 100,000 unnecessary critical care unit admissions could be avoided, resulting in an estimated annual savings of \$700 million.

-Find that newer antidepressant drugs are equally effective as older antidepressants in treating depression. This research led the American Psychiatric Association and American Pharmaceutical Association to develop practice guidelines on the use of antidepressant drugs.

Yet more questions need to be answered. Increased funding for those agencies that support health services research is needed in order to:

-develop practical approaches to keeping medical inflation in check;

-promote improvements in clinical practice and patient outcomes;

-speed clinical discoveries into practice;

-develop processes to increase patient safety;

-determine how to increase access to care;

--find cost effective methods for improving quality especially for those with chronic illnesses; and

-better prepare the health care system to respond effectively to natural catastrophes and terrorist attacks.

The demand for health services research information and the need to improve our health care system cannot and will not be effectively met without the continued leadership of the Subcommittee and the Congress. Your support for the health services research being funded by a variety of federal agencies will allow millions of Americans to live longer, lead improved lives and save health care purchasers, including the federal government, hundreds of millions of dollars each year.

### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

AHRQ's mission is to promote improvements in clinical practice and patient outcomes, in the financing, organization, and delivery of health care services, and in access to quality care. AHRQ's health services research compliments the biomedical research of the NIH by helping clinicians, patients, and health care institutions make choices about what treatments work best, for whom, when, and at what costs.

For fiscal year 2003 the Coalition is requesting that Congress fund ARHQ at \$390 million. This is \$90 million above its fiscal year 2002 level of \$300 million and \$139 million above the President's request. The President's fiscal year 2003 proposed budget would decrease current funding for AHRQ by \$48 million, a 16 percent cut that will dramatically curtail AHRQ's ability to carry out its mission. The proposed cuts are targeted such that research on quality, quality measurement, disease management, outcomes, access and financing of health care will be most crippled. At the proposed \$251 million level, AHRQ will be unable to fund any new research or training grants. Funding for current, non-patient safety grants will be reduced by 50 percent, requiring mid-grant renegotiations that will significantly reduce our knowledge and understanding of how to cost-effectively provide quality health care. This will also mean that AHRQ will be unable to fund many of the grants nearing their completion date, thereby losing the investment and the benefit which would have been derived from prior Congressional appropriations.

An increase in funding is needed to allow AHRQ to continue its work on providing the evidence-based information needed to reduce medical errors, improve access to health care services, and more efficiently utilize health care resources. An increase in funding is also needed to further research in eliminating racial and ethnic disparities, compile the first national report on quality and assist in improving emergency responsiveness.

It is important to note, that AHRQ is the only federal health research agency that examines the entire health care system with an eye towards improving quality and efficiency. AHRQ conducts research that cuts across the jurisdictional lines of the other agencies and it frequently collaborates with the NIH, CDC, VA and other agencies in developing programs and answering critical questions. If AHRQ is forced to cut back on the research it conducts, Congress should not assume that NIH or any other agency will immediately begin to fund this type of research. Foundations are unable to make up the difference and, while private firms may choose to conduct some of this research, these firms often do not make the results available to the public for proprietary reasons. As the largest purchaser of health care services, the Federal government has an important role and responsibility in ensuring quality services are provided for those citizens relying on Federal programs while reducing costs to the American taxpayers.

The Coalition's fiscal year 2003 budget request of \$390 million will ensure AHRQ can not only continue its critical health mission, but also further fulfill its role in improving the quality of health care and the quality of life for all Americans.

## CENTERS FOR MEDICARE AND MEDICAID SYSTEMS

## Office of Strategic Planning (OSP)

OSP guides the development and implementation of new health care financing policies and evaluates their impact on Medicare and Medicaid beneficiaries, participating providers and the States. Congress has greatly increased CMS's administrative responsibilities over the past several years without providing commensurate funding for research. In addition, there have been significant changes in the Medicare and Medicaid programs that need to be continually monitored to determine if any refinements are necessary. CMS has also been given the responsibility of overseeing the SCHIP program. While OSP has received funding increases over the past 2 years, these increases have largely been for projects directed by Congress.

Under the Administration's proposal, CMS will see its research budget cut almost in half from \$55.3 million to \$28.4 million. After subtracting \$12.4 million for the Medicare Beneficiary Survey, and \$6 million for CMS to meet other statutory requirements, CMS will have only \$10 million in discretionary research funding. However, their fiscal year 2003 commitments for funding projects already underway is \$17 million. This means CMS would have to cut existing research by \$7 million. The Coalition supports a funding level of \$60 million to ensure that CMS can meet its current obligations and expand research into areas such as quality care for those with chronic illnesses; plan and beneficiary participation in managed care; approaches to educating beneficiaries through use of the Internet (e-health); and the impact of technological changes on the Medicare and Medicaid programs and beneficiaries.

## CENTERS FOR DISEASE CONTROL AND PREVENTION

A continuing concern is the issue of inadequate research focusing on the infrastructure of public health, public health services research. While much attention has focused on research on the sickness care system, and on improving the public health system's ability to respond to a terrorist attack, insufficient resources have been allocated for a comparable focus on research to improve the delivery of public health services. Of specific concern are:

- -How can the public health infrastructure be improved and made more effective? -How do we target critical public health activities to reach individuals and com-
- munities that typically encounter barriers in accessing the health system?
- -How cost-effective are public health and prevention programs?
- -How will new advances in understanding disease be applied in public health?

# National Center for Health Statistics (NCHS)

NCHS is the Federal government's principal vital health statistics agency. NCHS represents an investment in broad-based, fundamental public health and health policy statistics. The data maintained by NCHS is critical to the research performed by our members. For example, NCHS provides the data for: —Quarterly tracking of health insurance and access to care, important to under-

- -Quarterly tracking of health insurance and access to care, important to understanding the impact of public policy and the economy on children and families; -Measuring the health status of Americans and how it changes, a critical ele-
- ment in evaluating the value we get as a nation from our investment in health; —Understanding trends in the use of health care services, including the extent to which new medical technology is adopted, the burden placed on the health care system by different diseases and illnesses, and the ways in which prescription drugs are prescribed and used;
- -Monitoring the capacity and performance of our health care system by, for example, tracking waiting times in emergency departments and measuring unmet health care needs;
- -Focusing policy and health programs on issues of greatest importance by providing a credible, scientific basis for understanding the magnitude of problems, and by helping generate hypotheses for health services and biomedical research; and
- —Measuring and understanding differentials between different groups in the population, including racial and ethnic differences in health, in order to help identify strategies for narrowing these gaps.

Last year, Congress increased funding for NCHS by \$5 million. For fiscal year 2003, the President proposes to decrease the budget of the NCHS by \$1 million. The Coalition believes that NCHS requires at least \$180 million, an increase of \$50 million over current spending levels, in order for the agency to be brought up to date technologically, and to provide the data needed by both public and private sector researchers and policy makers.

## Extramural Prevention

Under the President's budget proposal, CDC's \$17 million extramural prevention research budget—the only extramural health services research program at the CDC—would be eliminated. CDC developed this program to move knowledge about effective strategies for preventing disease and disability from research to implementation in diverse community practices and programs. The program uses a model of community-based participatory prevention research, and has supported over 50 projects based in states and localities throughout the country. Cutting this program will eliminate the second round of projects designed and initiated by communitybased research collaborations. The Coalition urges restoration of the \$17 million so that CDC can conduct the second round of projects and collaborate with others to accelerate the dissemination of research results to professionals and communities who can put the results into practice.

## NATIONAL INSTITUTES OF HEALTH

As part of its ongoing research agenda, most of the Institutes of the NIH fund health services research. The proportion of NIH funding for health services research needs to be maintained and expanded to assure that the investments in biomedical research result in improved health services for the American people. The Coalition fully supports the commitment to double the NIH budget by the end of fiscal year 2003 with the understanding that appropriate proportions of this investment must be targeted to fund health services research.

## NEED FOR FEDERAL FUNDING

The Coalition for Health Services Research is grateful for the leadership of this Subcommittee in recognizing the important role of health services research. We urge the Subcommittee to continue the progress made during the last several years by providing a substantial investment in Federal health services research programs in the fiscal year 2003 appropriations bill.

Thank you.

## PREPARED STATEMENT OF THE NORTH AMERICAN BRAIN TUMOR COALITION

## THE HISTORY OF THE NORTH AMERICAN BRAIN TUMOR COALITION

My name is Pam Del Maestro, and I am the Chair of the North American Brain Tumor Coalition, or the NABTC. The NABTC is a network of charitable organizations that support brain tumor research and provide support services and educational materials and services to individuals with brain tumors, their families, and their friends. We have formed this coalition to raise public awareness and to advocate public policies that will enhance and accelerate the development of new brain tumor therapies and that will ensure that brain tumor patients have access to quality health care.

I am very pleased to be speaking for the NABTC. I am an oncology nurse, and in my professional life I have fought to provide brain tumor patients with outstanding health care. The advances in brain tumor treatment are coming much too slowly, and the prognosis is dire for many who receive a diagnosis of a brain tumor. Our coalition, which includes patients, family members, friends, brain tumor researchers, and others, is dedicated to improving that prognosis. The NABTC is comprised of 12 organizations, 11 of which are located in the United States and represent all regions of the country.

As a Canadian, it is an honor to chair the NABTC and speak for its members. I wish to mention our history as a North American coalition because we believe that brain tumor research and treatment will improve only if there is cooperation and collaboration among all in our community—cooperation among researchers from different countries, collaboration among those at different research institutions, and cooperation among research and advocacy groups.

## A BRIEF DESCRIPTION OF BRAIN TUMORS AND THE UNIQUE CHALLENGES THEY POSE

Brain tumors have been described as diseases that affect the "organ that is the essence of the self." Because brain tumors can have such devastating effects, we often avoid talking about them. It is very important, however, that we all have a better understanding of diseases that affect neurological function; only with awareness and understanding can we wisely and effectively facilitate the advancement of research and treatment.

Brain tumors are not a single disease; there are at least 126 types of central nervous system tumors. Treatment of brain tumors is difficult not only because of their diversity, but also because of their location. The treatments that are generally effective with cancers are significantly less effective with brain tumors. For example, the surgical removal of the entire organ or the tumor—a treatment option for many cancers—is simply not an option for many brain tumors. When surgery is an option, the patient often has neurological damage from removal of the tumor, and "remission" does not have the same meaning as with other cancers. Moreover, radiation and chemotherapy—essential weapons for many cancers—pose real challenges as brain tumor therapies. A "curative" dose of radiation may cause serious, if not devastating side effects, and the potential benefits of chemotherapy may be blocked by the blood-brain barrier.

An individual may suffer mental impairment, seizures, and paralysis as a result of a brain tumor, and the treatment of an individual's brain tumor may have serious and long-term side effects. Children and adults who are treated for brain tumors may have permanent neurological damage from their treatment, and for both this damage may require life-long care.

## HOPE FOR THE FUTURE

The hope for brain tumor patients today and tomorrow is research, and brain tumor research strategies must be innovative, creative, and interdisciplinary. Several years ago, the NABTC urged the National Cancer Institute (NCI) and the National Institute of Neurological Disorders and Stroke (NINDS) to convene a planning meeting to set the course for brain tumor research. We believed the time was right for such a Brain Tumor Progress Review Group (BT–PRG) meeting; we thought that advances in basic science might be translated into improved treatments, with the proper investment of funds, the right research strategy, and talented researchers dedicated to the task.

The July 2000 brain tumor research planning meeting, jointly sponsored by NCI and NINDS, was a positive experience for the researchers, clinicians, and advocates who participated. More importantly, however, it produced an outstanding brain tumor research plan. The BT–PRG report established scientific priorities in basic biology, epidemiology, detection and diagnosis, treatment, and outcomes. In order to accomplish the identified research priorities, the BT–PRG recommended that the following resources be made available: models for use in therapeutic screening, in preclinical trials, or to study the basic biology of brain tumors; tissue banks and databases; genomics and high-throughput screening; improved communication and collaboration among scientists of different disciplines; and improved training of brain tumor researchers.

Unfortunately, the plan to implement the specific recommendations of the BT– PRG appears to be stalled. Brain tumor patients are understandably impatient when research initiatives are delayed or when any bureaucracy negatively influences the research endeavor. The brain tumor community wishes to see substantial and meaningful progress toward some of the core research proposals in the BT– PRG.

## IMPLEMENTATION OF BT-PRG RECOMMENDATIONS

The NABTC is pleased that NCI has taken critical steps to strengthen the NCI– NINDS Neuro-Oncology Branch. This joint venture of the two Institutes that are most involved in brain tumor research is already providing leadership in brain tumor research and care. However, there is much more to be done by this Branch to advance brain tumor research, and it cannot be done without the resources to develop a long-term plan for the Branch and without the funds to implement such a plan.

a plan. The NABTC strongly endorses the Neuro-Oncology Branch because we believe it is a model for an interdisciplinary approach to brain tumor research and that it can provide leadership to researchers and clinicians in institutions across the country. We propose below some initiatives to strengthen brain tumor research; these proposals relate to the Neuro-Oncology Branch and to the recommendations of the BT-PRG.

## NABTC PROPOSALS TO ENHANCE BRAIN TUMOR RESEARCH

The BT–PRG had as one of its core goals increased communication, cooperation, and collaboration among scientists from different disciplines who are involved in brain tumor research. Scientists who are involved in cancer biology and genetics, neurobiology, immunology, and radiation biology are among those who contribute to brain tumor research, and it is imperative that they work collaboratively. To advance brain tumor research and realize the potential of the BT-PRG, the NABTC recommends a number of actions. Our recommendations are quite similar to those we made to the Subcommittee last year. Our impatience is matched only by our determination, and we will persist in advancing these proposals, which we think are important to the brain tumor research effort:

- -NCI should develop a strategic plan and budget for the Neuro-Oncology Branch to ensure the smooth functioning of the Branch and to ensure that it is a leader in training brain tumor researchers.—The Neuro-Oncology Branch has already assumed a leadership role in brain tumor research and care. The NABTC believes that the Neuro-Oncology Branch may play an especially important role in the training of brain tumor researchers. Unless brain tumor researchers receive training in translational research and understand the benefits of interdisciplinary approaches to brain tumor research, the development of new therapies will certainly not accelerate and may be threatened. Fulfilling this important training role is a daunting challenge for the Neuro-Oncology Branch, but we believe the NIH should embrace this opportunity.
- -NCI and NINDS should consider a number of initiatives to encourage collaboration and coordination among extramural researchers.—Two such approaches are:
- -NCI and NINDS should organize and fund a series of interdisciplinary meetings of researchers that would focus on the subjects of brain tumor biology and etiology.—The BT-PRG stressed that brain tumor research will advance by utilizing interdisciplinary approaches. Experts agree that meetings of researchers from different disciplines can foster new insights on brain tumor research, and they also agree that brain tumor biology and etiology are prime topics for such meetings. We urge NIH to take a leadership role in sponsoring such meetings.
- —The Center for Scientific Review (CSR) should coordinate review of brain tumor research proposals.—Brain tumor researchers believe that brain tumor research proposals will receive a fair and thorough review only if the review panels enjoy the expertise of brain tumor biologists. CSR should guarantee that brain tumor research proposals are reviewed by review panels whose members have brain tumor research experience.
- members have brain tumor research experience. -NCI and advocacy organizations should cooperate in the education of brain tumor patients and physicians regarding brain tumor treatment options.—The organizations that comprise the NABTC have significant knowledge and experience in providing materials and support to newly-diagnosed brain tumor patients when they are making treatment decisions and throughout their treatment and recovery experience. Nevertheless, the relatively limited enrollment of adult brain tumor patients in clinical trials suggests that these educational initiatives, which focus on all treatment options, including clinical trials enrollment, are not sufficient. NCI has invested significantly in educational materials on clinical trials, and these materials are being utilized by brain tumor organizations and patients. The NABTC believes its own efforts and those of NCI would be strengthened through coordination of public and private sector initiatives. The NABTC recommends that NCI work with patient and advocacy organizations representing those with rare cancers to ensure that its clinical trials education materials and programs meet the needs of those with rare cancers, including brain tumors.

### APPRECIATION FOR THE LEADERSHIP OF THE SUBCOMMITTEE ON NIH ISSUES

The NABTC would like to express its sincere appreciation for the leadership of this Subcommittee in ensuring substantial funding increases for NIH over the last 4 years and for your commitment to completing the 5-year NIH doubling process in fiscal year 2003. These large boosts in funding have allowed NIH to flourish and researchers around the country to continue their promising and life-saving work. Our recommendations are made in the spirit of seeking to enhance and improve the NIH research program and to ensure that the brain tumor research program at NIH is as strong as possible. These goals are only realistic because of your hard work in building the research infrastructure and funding it adequately.

Thank you again for your leadership. We look forward to working with you in the future, and we will do everything we can to create a positive environment for NIH funding increases.

The NABTC appreciates the opportunity to submit this statement. We are gratified by the efforts of the federal government in brain tumor research. However, the challenges of brain tumors are so great that we come to you with a steadfast commitment to achieving a cure through research and a sense of impatience about accomplishing that goal.

## PREPARED STATEMENT OF THE ALZHEIMER'S ASSOCIATION

Thank you for inviting me back to testify before your Subcommittee. As you know, I am a National Board member of the Alzheimer's Association. You have heard my personal story before. Both my grandfather and my father died of Alzheimer's disease.

With each year that passes, my fear grows—my fear that the disease process that destroyed their memories, and ultimately their lives, has begun developing in my own brain. My fear grows not just for myself, but also for my generation—the 14 million baby boomers who will get Alzheimer's disease if we don't find a way to beat this dreadful disease.

At the same time, my hope grows. Today I testify with more enthusiasm, more confidence that scientists are on the verge of a breakthrough. My hope is joined with a sense of urgency. In the quest to find a breakthrough for Alzheimer's disease, this nation is in a race against time.

nation is in a race against time. In the midst of the enormous challenges you face, I urge you to maintain your commitment to medical research funding for Alzheimer's disease, and increase funding to \$1 billion a year as soon as possible. In this race against time, we can't afford to slip. Today, the Alzheimer's Association is releasing a national survey by Peter D. Hart Research Associates regarding Americans' concerns about Alzheimer's disease. I ask that the survey enalyzis he submitted for the receard This survey confirms what I

Today, the Alzheimer's Association is releasing a national survey by Peter D. Hart Research Associates regarding Americans' concerns about Alzheimer's disease. I ask that the survey analysis be submitted for the record. This survey confirms what I see every day—that Americans of every age are terrified by the threat of Alzheimer's disease, and that they overwhelmingly support the shared efforts of this Subcommittee and the Alzheimer's Association to increase funding for Alzheimer research to \$1 billion annually. I would like to share just a few of the findings from the survey.

the survey. Ninety-five percent of Americans believe that Alzheimer's disease is a serious problem facing our nation. Perhaps they know as well as we in this room do—our window of time is very short. Perhaps they know that this disease can strike anyone, even a President of the United States.

Senator Harkin and Senator Specter, you have led this Congress in the effort to double funding for NIH. Our survey shows that Americans support your work. In fact, in this election year, voters say medical research is one of the most important areas for federal spending, ranking second only to education spending, and placing ahead of spending on the military.

More importantly, however, to those of us who sit before you today—three fourths of Americans agree with the proposal that Congress should increase funding for Alzheimer research to \$1 billion per year. There is a broad coalition of voters who unite behind this proposal, with large majorities of both young (75 percent of 18–34 year olds) and old (77 percent 65 years old and older) agreeing that funding for Alzheimer research should be increased.

Half of us in the room already have the time bomb of Alzheimer's disease ticking away in our brains, each and every day. Congress must find a way to defuse this bomb, before it destroys our brains and ultimately our entire selves.

The American people have every right to be afraid of this horrible disease. By the middle of the century, 14 million of today's baby boomers will have Alzheimer's disease. For most of them, the process that will destroy their memories, their lives, and their savings has already begun.

Mr. Chairman. We know there are many competing priorities before this Subcommittee, and we understand the fiscal constraints you face as you balance those priorities. But as we look to the future of the 14 million baby boomers and indeed, the future of each and every American, the case for \$1 billion investment in Alzheimer research is overwhelming. This hearing demonstrates your own concern about the looming crisis and your commitment to averting it. On behalf of everyone in the Alzheimer's Association, for every family dealing with Alzheimer's disease, and for all of us sitting here before you, thank you.

# PREPARED STATEMENT OF THE NATIONAL COALITION FOR OSTEOPOROSIS AND RELATED BONE DISEASES

The National Coalition for Osteoporosis and Related Bone Diseases (the Coalition) appreciates this opportunity to present our position on the need for continued and

expanded funding for osteoporosis and related bone diseases research at the National Institutes of Health.

The Coalition is committed to reducing the impact of bone diseases through expanded biomedical, clinical, epidemiological, and behavioral research. The participants of the Coalition are the National Osteoporosis Foundation, the American Society for Bone and Mineral Research, the Osteogenesis Imperfecta Foundation, and the Paget Foundation for Paget's Disease of Bone and Related Disorders. The bone diseases represented by our Coalition affect people of all ages, races and ethnic groups and lead to permanent deformity and lifelong disability.

## WHY ARE WE CONCERNED ABOUT AMERICA'S BONE HEALTH?

Bone is living, growing tissue that gives us the framework upon which all the other systems of our body depend. Bones have a tremendous impact on how we live, function, and perform. But, we sometimes forget that bones are composed of active cells and are subject to metabolic and genetic processes, trauma, and the gradual wear and tear caused by aging.

wear and tear caused by aging. Bones begin to develop long before birth. When the skeleton first forms, it is made of flexible cartilage, but within a few weeks it begins the process of ossification, where the cartilage is replaced by hard calcium phosphate and stretchy collagen, the two main components of bone. This combination of collagen and calcium makes bone strong and flexible to withstand stress.

Bone building continues throughout life. The body constantly renews the bone through a process called remodeling. This process consists of two stages—resorption and formation. During resorption, old bone tissue is broken down and removed by cells called osteoclasts. Once this has been done, bone formation begins and new bone tissue is added to the skeleton to replace the old bone tissue. Cells called osteoblasts perform this task. During childhood and teenage years, new bone is added faster than old bone is removed. As we age, the process may slow down. If resorption exceeds formation you will begin to loose bone mass, which can leave you vulnerable to osteoporosis and related fractures. An understanding of bone diseases is critical if there is to be hope of preventing people from suffering the numerous diseases associated with changes in bone structure and function.

#### WHAT ARE THE MAJOR DISEASES OF BONE AND MINERAL METABOLISM?

Osteoporosis is the most prevalent bone disease in this country. It is characterized by low bone mass and structural deterioration of bone tissue, leading to bone fragility and an increased susceptibility to fractures of the hip, spine, and wrist. Men as well as women suffer from the disease. Older people, especially women, can develop osteoporosis as a result of insufficient exercise and calcium intake, in combination with hormonal changes and genetic factors. Building up adequate stores of calcium in the bones as a child, teenager, and young adult is a key factor in preventing or delaying the development of osteoporosis at a later age.

The National Osteoporosis Foundation's recently published report "America's Bone Health: The State of Osteoporosis and Low Bone Mass in our Nation" states that osteoporosis and low bone mass are currently estimated to be a major public health threat for almost 44 million U.S. women and men aged 50 and over. This represents 55 percent of the population aged 50 and older in the United States in 2002. By the year 2020, it is estimated that over 61 million Americans will be affected if additional steps are not taken now to prevent, diagnose, and treat this disease.

tional steps are not taken now to prevent, diagnose, and treat this disease. Each year approximately 1.5 million fractures are associated with osteoporosis. Beginning at age 50, white women have a 40 percent chance of fracturing the spine, hip, or distal forearm in their lifetime. This figure rises to 50 percent if all fracture sites in the body are considered. A woman's risk of a hip fracture is equivalent to her combined risk of developing breast, uterine and ovarian cancer.

The cost to the health care system associated with osteoporotic fractures is approximately \$17 billion annually. In addition to the economic cost of the disease, the human cost of the disease is immense but difficult to measure. Depression and anxiety are common following a fracture. One-fourth of those who were ambulatory before the hip fracture require long term care afterwards. Quality of life is affected following a fracture due to fears about additional fractures, limited mobility and coping with deformity.

- Scientists have made great strides in the following areas:
- —In recent years, there have been significant advancements in the treatment of osteoporosis as new medications have been developed, including a drug that has promise in building bone.
- Scientists have made a major breakthrough in understanding the genetics of this complex disease. While many genes may be involved, a single gene has

been identified as being responsible for high bone mineral density. Additional genetic research will give insight into the development of new therapeutic agents to increase bone density.

- Researchers are now beginning to develop an understanding of the risk factors and treatments for osteoporosis in men, which has been under-diagnosed, under-reported, and inadequately researched in the past. This is critically important because there are an estimated 14 million men with osteoporosis in 2002 and the prevalence of this disease is expected to increase by approximately 40 percent to well over 20 million in 2020.
- Research supported by the NIAMS has resulted in the design of a 7-month, high intensity jumping regimen that will increase peak bone mass at two clinically critical sites, the hip and the spine. Investigators discovered that children who participated in the jumping program had a significantly greater change in bone mineral content in both the hip and spine compared with a control group, as well as showing positive differences in bone mineral density and bone areas. This regimen, which can easily be incorporated into the regular elementary school curriculum, has potentially important public health implications with re-spect to optimizing peak bone mass attainment in young people. Scientists have found that minor variations in a gene for the bone protein, col-
- lagen, can lead to lower bone density in young girls. These variations, while not causing apparent disease, may define a high susceptibility group for osteoporosis later in life. Identifying and understanding genetic susceptibility to osteoporosis early in life may facilitate the targeting of interventions to those who will most benefit from them.

Paget's Disease of bone is the second most common bone disease in the world. Prevalence in the population over 60 ranges from 1.5 percent to 8 percent. Paget's disease is a serious, chronic skeletal disorder that may result in large, malformed, and fragile bones in one or more regions of the skeleton. In Paget's disease there is excessive bone resorption followed by excessive bone formation, resulting in bone that is architecturally unsound. Complications may include arthritis, fractures, bow-ing of limbs and hearing loss if Paget's disease affects the skull. Pain is the most common symptom.

- Scientists have found that:
- A virus such as measles virus may in part be responsible for the development of Paget's disease.
- -There is a strong genetic component involved in Paget's disease and several possible sites on three different chromosomes have been identified that may be involved.
- -Paget's is linked to chromosome 18q, and through grant awards from the NIAMS, investigators are exploring the possible involvement of multiple genes in the predisposition to the disease.

Osteogenesis Imperfecta (OI) is a genetic disorder of the skeleton that is typically diagnosed in infancy. It affects between 20,000 to 50,000 adults, children and in-fants in the United States. It results in brittle bones, causing as many as several hundred broken bones in a lifetime, hearing loss, brittle teeth, short stature, skel-etal deformities and respiratory difficulties. For example, a cough or sneeze can break a rib, rolling over can break a leg. The most serious form of OI is frequently lethal to newborns

- Recent research findings include: —In a New England Journal of Medicine article published October 1, 1998, the results of a 5-year observational study suggested that regular intravenous doses of pamidronate (a bisphosphanate) helped increase bone mineral content, reduce fractures, increase mobility, and decrease bone pain in children with OI. Continued research to determine the long term effects and improve understanding of how the drug is working are needed. Two other drug therapies have proven successful in the test tube and are ready for study in animal models.
- -OI is caused by weakened collagen, or not enough collagen. Recently, researchers have developed a technique to suppress the gene that causes the weakened collagen. This was successful in the test tube and is now being tested in animal models. This technique would effectively make all cases of OI into mild cases.
- Bone marrow transplantation is being tested in the laboratory. Some researchers are devising techniques to genetically engineer bone precursor cells, which reside in the bone marrow, to correct for the faulty OI gene and still maintain their ability to form bone when transplanted back into the marrow. Other researchers are testing the potential for normal bone marrow stromal cells injected into OI bone marrow to take over synthesis of bone matrix components. If either technique is successful, they would lay the groundwork for trans-

planting corrected cells into a person's bone marrow so that the cells could repopulate the bone, making it stronger.

Scientists are on the brink of discoveries that can revolutionize health care and the treatment of bone diseases. While remarkable advances in research have been made, the cause of many bone diseases remains unknown or is poorly understood.

The National Institute of Arthritis and Musculoskeletal and Škin Diseases (NIAMS) leads the Federal research effort on bone diseases. However, the need for trans-NIH research is very vital. Bone-related diseases cut across many NIH institutes.<sup>1</sup> Given the breadth and depth of these diseases and the enormous cost associated with providing medical care, we urge the Committee to instruct NIH to make this one of its top trans-NIH priorities.

Opportunities for further research include these critical areas that need illumination:

- -Large-scale multi-center trials are needed to determine the most effective and least costly way to combine the new treatments for osteoporosis, which can both prevent bone breakdown and build new bone.
- -Large-scale long-term clinical trials are also needed to determine whether agents that prevent bone loss reduce fracture risk in women with low bone mass.
- -Research is needed to apply the remarkable new developments in genomics and proteomics to osteoporosis and related bone diseases. This approach will lead to a better understanding of skeletal aging, and the effects of hormones and local factors; and will result in new approaches for diagnosis and treatment.
- -Research is needed to determine the bioavailability of various calcium supplements, including a comparison of those with the same calcium salt.
- -Research is needed to determine how children, adolescents, and young adults maximize peak bone mass.
- -Determining why bone is a sanctuary for tumors. Once tumors go to bone they are incurable.
- -Determining how the bone microenvironment enhances the growth of tumor cells.
- —Determining the factors involved in normal bone remodeling and how manipulating these factors affect the propensity of tumor to go and grow in bone.
- —Some people with OI may have the same type of weakened collagen, yet exhibit different levels of symptom severity. By studying mice with these variations, researchers may discover modifying genes that are responsible for the variation. These genes, or their products, could then be used to modify the severity of OI in humans.
- —Respiratory failure is the leading cause of death for young adults with OI. Research into respiratory and cardiovascular complications could save lives.
- —Addressing the effects of aging on OI.
- -Research into dentinogenesis imperfecta and orthodontic manipulation in people with OI.

Mr. Chairman, the Coalition offers our sincere thanks for the efforts of this Subcommittee in securing appropriations to double the budget for the National Institutes of Health. We are grateful for your commitment to this important effort. Without adequate funding of the NIH, research progress will be immeasurably slowed.

We join the Ad Hoc Group for Medical Research Funding in urging the Committee to provide an appropriation of \$27.3 billion in fiscal year 2003 for the National Institutes of Health to achieve the bipartisan goal of doubling NIH by fiscal year 2003. We also support the NIAMS Coalition recommendation of a 15.7 percent increase for the National Institute of Arthritis and Musculoskeletal and Skin Diseases, the lead bone research institute. In addition, we ask your support for increased funding for NIA, NIDCR, NIDDK, NCI, and NICHD, which also fund bone-related research.

for NIA, NIDCR, NIDDK, NCI, and NICHD, which also fund bone-related research. Mr. Chairman, on behalf of the Coalition, we thank you for the opportunity to testify before this Committee.

<sup>&</sup>lt;sup>1</sup>Institutes and Centers such as the National Cancer Institute (NCI), the National Institute of Child Health and Human Development (NICHD), the National Institute on Aging (NIA), the National Heart, Lung and Blood Institute (NHLBI), the National Institute of Dental and Craniofacial Research (NIDCR), the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), and the National Center on Minority Research and Health Disparities (NCMHD) and the Office of Research on Women's Health.

## PREPARED STATEMENT OF THE AMERICAN ACADEMY OF OTOLARYNGOLOGY—HEAD AND NECK SURGERY, INC.

I am K.J. Lee, President of the American Academy of Otolaryngology—Head and Neck Surgery representing more than 11,000 specialists who treat patients with disorders of the ears, nose, throat and related structures. Among these disorders are head and neck cancer, middle ear infections, deafness and hearing loss, dizziness, sinusitis, taste and smell problems, sleep disorders, and voice problems—disorders which affect millions of Americans and cost our health care system billions of dollars each year. I am here today to ask you and your Committee to persist in your efforts to double funding for the National Institutes of Health, and specifically to identify additional funding for the National Institute on Deafness and other Communication Disorders (NIDCD).

Over the last fourteen years, NIDCD has made great progress toward realizing its unique mission of understanding the normal and disordered processes of hearing, balance, taste, smell, voice, speech, and language. The NIDCD has supported researchers who are devoting their careers to finding the causes, cure and prevention of such disorders, which collectively affect more Americans than cancer, heart disease, orthopaedic disorders, or visual problems.

Mr. Chairman and members of the committee I would like to highlight a few areas of research requiring attention and focus from the National Institutes of Health:

## OTITIS MEDIA

Otitis media is one of the most common bacterial infections in children, affecting more than 60 percent of American children during the first year of life and up to 95 percent of all children by age 6. Parents know that otitis media is the most common pediatric diagnosis and the most common reason why children undergo surgery, accounting for more than 20 million office visits in this country and costing the U.S. health care system up to \$5 billion annually. Otitis media can lead to lifethreatening diseases such as meningitis, and is also associated with chronic or fluctuating hearing loss capable of producing speech, language, and educational delays in vulnerable children. About 60 percent of all acute otitis media infections are caused by bacteria.

Thus, there has been growing interest over the past 10 years in developing vaccines. A seven-valent pneumococcal conjugate vaccine known as Prevnar has been proven effective in reducing episodes of otitis media. A growing body of research has suggested that persistent or chronic otitis media with effusion refractory to treatment is related to the presence of biofilms in the middle ear. Other diseases in which biofilms play a role include cystic fibrosis and Legionnaire's disease.

The vaccines currently being used to control otitis media are not targeted at the bacteria that exist as biofilms in the middle ear and associated structures. Research is needed to further define the role of biofilms in common diseases of the ear and upper aerodigestive tract and to determine whether the biofilm forms of bacteria are equally susceptible to antibiotics.

#### BALANCE DISORDERS

In the United States, falls are the leading cause of both fatal and non-fatal injuries for persons age 65 and over. Falls and the resulting injuries have become one of the most serious health issues for elderly individuals today. Over 2 million people in the United States fall and sustain serious injury annually and over \$20 billion is spent each year for the treatment of injuries in the elderly after falls. Falls are the number one reason for nursing home admissions, thereby affecting the loss of an independent lifestyle for many senior citizens.

More research is needed on identifying elderly individuals at risk for falling and to develop protocols for improving balance and gait factors in those individuals, which would account for individual differences in the complex multiple sensory and motor systems responsible for maintaining balance. While there have been some attempts to address this problem through the establishment of community-based "falls clinics", their results have not been very promising.

We appreciate the support of this committee over the years and I can assure you that the investment in research has given many of our patients new hope. The following are a few examples of the accomplishments in the field of otolaryngology research:

Over 280,000 Americans suffer partial or complete loss of voice and speech as a result of cancer of the head and neck, and 12,000 of these individuals die each year. Intramural scientists from NIDCD and the National Cancer Institute (NCI) have collaborated to develop new therapy alternatives to surgery for patients with head and neck cancer which result in remission and preservation of the organs involved in voice and speech.

As part of the collaboration, NIDCD scientists completed a phase one clinical trial to determine the tolerance and response of people with advanced head and neck cancer to combined treatment with the chemotherapy agent Paclitaxel (Taxol) and radiation. It resulted in 70 percent of the patients with advanced cancers getting a complete remission and preserving their voice and speech. Fifty-one percent remain in complete remission and 56 percent are alive 3 years after treatment. Treatment as an outpatient was well tolerated due to low incidence of acute toxicity from chemotherapy, but side effects of the combined therapy included a several month delay of recovery of swallowing, which was relieved by nutritional supplements. Follow-up studies are likely to include the addition of a drug to reduce the side effects experienced in this trial.

There are also studies underway on new drugs that target the specific molecular abnormalities that cause cancers involving the vocal tract. NIDCD and NCI are collaborating to conduct a 2-year Phase I trial of a new drug to be given along with radiation for treatment of patients with cancers with the vocal tract. Studies to identify the genes activated by a signal known as Nuclear factor kappaB which cause these cancers are also being conducted.

#### HEARING PARENTS OF DEAF CHILDREN FAVOR GENETIC TESTING FOR DEAFNESS

Genetic testing is now an option for deaf people and their families. However, little attention has been given to the public's perception on the value and impact of the testing. Parents with normal hearing who have one or more deaf children were recently surveyed about their attitudes toward diagnostic and prenatal testing for deafness. Ninety-six percent of the respondents were shown to favor genetic testing for deafness, including prenatal testing.

for deafness, including prenatal testing. The study shows that genetic testing should be combined with genetic counseling to help parents of deaf children make informed decisions concerning medical management and necessary intervention strategies.

# LANGUAGE DEVELOPMENT IN PROFOUNDLY DEAF CHILDREN WITH COCHLEAR IMPLANTS

A cochlear implant is an electronic device designed to provide sound detection as well as improved speech understanding and speech production. The cochlear implant is surgically implanted in the ear. It bypasses the damaged parts of the ear and sends electrical "sound" directly to the hearing nerve or the auditory nerve.

Cochlear implants have proven to be a useful communication tool in deaf adults. Many can read lips and some can talk on the phone which is difficult without visual cues. Cochlear implantation in children may result in the acquisition of spoken language.

After receiving the implants, deaf children start developing their English language skills at a similar rate to that of children who have normal hearing. These findings suggest that earlier implantation in deaf children would result in shorter delays in language development.

#### RECOMMENDATIONS

In order to expand support for pursuing these and other initiatives and the conduct of clinical research, the American Academy of Otolaryngology—Head and Neck Surgery recommends a funding level of \$393,382,000 for NIDCD. This level of funding will double NIDCD's budget over 5 years. I speak on behalf of all otolaryngologists—head and neck surgeons and their col-

I speak on behalf of all otolaryngologists—head and neck surgeons and their colleagues in related scientific disciplines in thanking this Subcommittee and the Congress for making progress in biomedical research possible through generous appropriations to the NIH and other funding agencies. I will gladly answer any questions you might have.

# PREPARED STATEMENT OF THE EPILEPSY FOUNDATION

The Epilepsy Foundation is the national voluntary organization that works for people affected by seizures through research, education, advocacy and service.

Founded in 1968, its national office is based in Landover, Maryland. The national office and its network of 58 affiliates across the country provide many direct services to individuals and families, including: community education; employment assistance; recreation; professional education conferences; assisted living; and case management and counseling.

The Epilepsy Foundation supports medical research to find better treatment and an eventual cure for epilepsy, and works with federal government agencies and Con-

gress to advance the interests of people with epilepsy. Epilepsy is a neurological condition characterized by recurrent, unprovoked sei-Epilepsy is a neurological condition characterized by recurrent, unprovoked sei-zures. At least 2.3 million people currently have epilepsy; the number of people af-fected by epilepsy, family members, teachers, care givers, employers is an exponen-tially far larger number. A recent CDC study in Texas found 1.8 percent of adults had been diagnosed with epilepsy or seizures. Approximately 181,000 new cases of epilepsy occur each year; 10 percent of all Americans will experience seizures in their lifetimes.

#### MEDICAL RESEARCH ADVANCEMENT

The Epilepsy Foundation actively supports the efforts of Congress to double fund-ing for the National Institutes of Health. We are pleased that NIH maintains strong bi-partisan support and has enjoyed significant increases in funding. These investments in our nation's health are paying dividends. In the last decade considerable progress has been made in identifying genes associated with epilepsy and in devel-oping medications, devices and surgical treatments.

Two years ago, participants in a historic scientific conference predicted that prevention and a cure for epilepsy are only a generation away. Now the scientific community is working on next steps and ways to measure progress toward those goals. The conference, "Curing Epilepsy: Focus on the Future", was sponsored by the Na-tional Institute for Neurological Disorders and Stroke (NINDS), which is the pri-mary federal sponsor of epilepsy medical research. The Epilepsy Foundation was one of the co-sponsors. NINDS, together with scientific experts have developed a set of henchmarks and arisiding the prime strength of the second strength of t

of benchmarks and priorities to guide future research. Specifically, the conference and the benchmarks look at how epilepsy begins, ways of identifying people at risk and how to develop treatments that will prevent epi-lepsy in those people as well as continuing the search for new therapies, free of side effects, to prevent seizures. Clearly there are significant opportunities for advancements in epilepsy research.

# THE IMPACT OF SEIZURES

Despite this progress and hope for the future, epilepsy remains a chronic condition that usually requires a lifetime of medical treatment. As many as 44 percent of people with epilepsy continue to have seizures despite treatment; 56 percent have early or delayed seizure control with treatment. Currently, there is no cure for epilepsy.

A recent cost study estimates that the cost of epilepsy, focussed on its most narrow measures, the direct medical costs, and the indirect costs as identified by the impact on earning and home production, is \$12.5 billion annually.<sup>1</sup>

The consequences of seizures continue to be severe and life altering, even among people with well-controlled seizures. Their impact spans employability, income lev-els, education, marriage, fertility, life expectancy and life style. The Texas study showed high levels of pain, anxiety, poor health, depression, and fatigue among adults living in the community, to the degree that their quality of life was negatively affected about 40 percent of the time.<sup>2</sup> Twenty-five percent of all people with epilepsy are unemployed; among those who

are partially or poorly controlled, unemployment approaches 50 percent. Marriage and fertility rates are reduced in people with epilepsy,<sup>3</sup> there is an increased risk of brain damage and increased mortality<sup>4</sup> and stigma remains a fact of life for too many people<sup>5</sup> fueling discrimination and isolation from the mainstream of life.

<sup>&</sup>lt;sup>1</sup>Begley C, Famulari M, Annegers J, et al. The cost of epilepsy in the United States: an esti-mate from population-based clinical and survey data. Epilepsia. 2000; 41: 342–351. <sup>2</sup>Centers for Disease Control. Health-related quality of life among adults with epilepsy—Be-havioral Risk Factor Surveillance System, Texas, 1998. MMWR Morb Mortal Wkly Rep. 2001; 50, 2: 24–35. <sup>3</sup> Morrell MJ. Reproductive function in women with epilepsy. Presented at the American Acad-

<sup>&</sup>lt;sup>•</sup> Morren Mo. Reproductive function in women with epilepsy. Presented at the American Acad-emy of Neurology 49th Annual Meeting; April 12–19, 1997; Boston, MA. <sup>4</sup>Tomson T. Mortality in epilepsy. J Neurol. 2000; 247: 15–21. <sup>5</sup>Fisher RS, Vickery BBG, Gibson P, et al. The impact of epilepsy from the patient's perspec-tive I. Epilepsy Research. 2000; 41: 39–51.

Children with epilepsy are at special risk of learning difficulties. Studies have documented deficits in language, visual-spatial function, problem solving, and adaptive behaviors, even in the absence of co-morbidity.<sup>6</sup> Children with epilepsy have unique difficulties when compared to those with other chronic illnesses such as asthma and diabetes; achievement scores are lower, there are problems with self-concept, depression, and behavior.<sup>7</sup> These studies demonstrate the critical importance of early recognition and treatment, as well as the often unanticipated consequences that a diagnosis of epilepsy can have.

# RESEARCH AND PUBLIC HEALTH RECOMMENDATIONS

The Epilepsy Foundation supports the doubling of the NIH budget. We expect that the NINDS will update Congress and the epilepsy community on the progress being made to implement the recommendations from the conference entitled "Curing Epilepsy: Focus on the Future." Continuing to invest in basic and clinical research is crucial to meeting our goal of preventing and curing epilepsy. However much more needs to be done to address the impact of epilepsy and to improve the quality of life of those living with the disorder. Experts agree that timely recognition of seizures and effective treatment can reduce the risk of subsequent brain damage, as well as disability and mortality from injuries incurred during a seizure and from recurring seizures.

In 1993 Congress recognized this need and directed the Centers for Disease Control and Prevention (CDC) to develop an epilepsy program within the National Center for Chronic Disease Prevention and Health Promotion. As a result, the CDC initiated a number of activities including a public health campaign geared toward teen awareness and education, a project with the Agency for Healthcare Research and Quality to develop provider education materials and surveillance and prevention research activities to better analyze trends in access to care, levels of care and other demographic variables.

This agenda is much larger than current resources for the program. In fiscal year 2001, Congress appropriated \$4 million for the CDC epilepsy program. In fiscal year 2002 Congress appropriated \$6.5 million. However, additional resources will be needed in order to expand the reach of the program into local communities and to fulfill the legislative intent.

In 2000, Congress expanded the program by passing the Children's Health Act of 2000. The goals for this program include progress in research, epidemeology and surveillance, early detection, improved treatment, public education and expansion of interventions to support people with epidepsy and their families in their communities. The Children's Health Act of 2000 also authorized a new program within the Health Resources and Services Administration. HRSA is directed to create grants to improve access to health and other services regarding seizures; and to gear projects toward encouraging early detection and treatment for those living in medically underserved areas.

#### FISCAL YEAR 2003 FUNDING RECOMMENDATIONS

Epilepsy research funded by the National Institute of Neurological Disorders and Stroke is vital to continuing the fight against epilepsy. The promise of future breakthroughs in epilepsy research can only be achieved by increased funding for epilepsy research and prevention programs. The Foundation urges Congress to increase the federal commitment to epilepsy research by allocating sufficient funding for the NINDS, the Centers for Disease Control and the Health Resources Services Administration.

- -Epilepsy Program at the Centers for Disease Control and Prevention.—The Epilepsy Foundation supports \$11 million for the CDC epilepsy program, a \$4.5 million increase.
- -Health Resources and Services Administration.—The Epilepsy Foundation supports an initial investment of \$3 million in order to create demonstration projects to improve access to health care for people with epilepsy.
- *Doubling the National Institutes of Health Budget.*—The Epilepsy Foundation supports the efforts to double the funding for the NIH, particularly the National Institute of Neurological Disorders and Stroke (NINDS). In keeping with this effort, we support a \$1.5 billion funding level for NINDS in fiscal year 2003.

<sup>&</sup>lt;sup>6</sup>Herman BP, Austin J. Psychosocial status of children with epilepsy and the effects of epilepsy surgery. In: The Treatment of Epilepsy: Principles and Practices. Philadelphia, Penn: Lea & Febiger; 1993: 1141–1148.

<sup>&</sup>lt;sup>7</sup> Austin JK, Huberty TJ, Huster, GA, et al. Academic achievement in children with epilepsy or asthma. Devl Med Child Neurol. 1998; 40: 248–255.

Thank you for the opportunity to submit testimony to the Subcommittee. We look forward to working with you in the 107th Congress.

# PREPARED STATEMENT OF THE ACADEMIC HEALTH CENTERS CLINICAL RESEARCH FORUM

My name is William F. Crowley and I am the Director of Clinical Research at Massachusetts General Hospital. I am presenting testimony on behalf of the Academic Health Centers Clinical Research Forum, an organization comprised of over 20 academic institutions concerned with the status of clinical research in this country.

try. Mr. Chairman, research supported by the National Institutes of Health has produced a wealth of knowledge about the fundamentals of human health and disease. Irreversibly diseased organs can now be replaced by grafts and transplants; and infections once thought to be hopeless can now be treated with antimicrobial medications. In 1900, life expectancy was 50 years; today it is 77. Over the past three decades, the death rate from heart attacks has dropped 30 percent in the past three decades. And for the first time, we have begun to see modest declines in cancer death rates.

While the ultimate goal of medical research is to save lives and reduce suffering, we cannot overlook one of its most important by-products: The investment in NIH yields dividends to the economy of as much as 40 percent annually. According to a May 2000 report, entitled The Benefits of Medical Research and the Role of NIH, bottom-line returns to the economy are enhanced by greater productivity resulting from longer lives and better overall health. Research also stimulates jobs and other economic benefits that flow from new industries in biotechnology, pharmaceuticals and medical technology.

Indeed, the impact of medical research has proved to be among our country's greatest achievements, saving countless lives and improving the quality of life. But the full value of research has been realized only when it is viewed as a continuum, one that encompasses basic research on the fundamental processes underlying biological and behavioral as well as clinical research, where knowledge gained in the laboratory is translated into cures and effective treatments, or more specifically, where it is put in the hands of physicians and health care professionals. To emphasize one facet of that continuum over another undermines the central tenet of medical research—namely, to safeguard and improve the lives of all Americans.

To achieve that objective, Mr. Chairman, requires a balanced investment in research—one that encompasses basic and clinical research as well as epidemiological and health services research. And to ensure that the research investment is always in balance requires constant monitoring, both by NIH and by Congress. Common sense tells us that the accumulation of fundamental knowledge for its own sake is of little value unless it finds its way to physicians' offices and hospitals, where it can be put to use in promoting good health or diagnosing, preventing and treating disease. In that regard, clinical research can be described as the neck of the scientific bottle, through which all scientific developments must flow before they can be of any benefit to the public. Advances in genetics, neuroscience and molecular biology, for example, will count for little unless clinical researchers are able to translate them into new and effective medical practices. Nor will the practices be of full benefit to the public without the analysis of health services and epidemiological researchers.

This Subcommittee's leadership has set the stage for unprecedented investments in NIH. And for that we are all most grateful. Those investments have allowed us to decipher the human genome sooner than anticipated, heralding a new era for discoveries about how the body works and how to make it work better. Those same investments have also led to breakthroughs in basic science that allow us to sharpen our focus on the molecular nature of disease.

What does all that mean? For most Americans, research is research. They make no distinction between basic research and clinical research. But as Donald E. Stokes wrote in his book, Pasteur's Quadrant, the public deeply values science "not for what it is, but for what it's for."

And what it's for is the patient. Whether the dividends from scientific breakthroughs are ever fully realized hinges upon the clinical research enterprise. In a very real sense, it is the very linchpin of research. In fact, it is the only way that you and your colleagues can truly know that the enormous investment of taxpayer dollars has produced results.

I use the term "enterprise" to underscore that clinical research embraces a wide spectrum of studies involving interactions with patients, diagnostic materials and data, and studies involving disease origins and epidemiology, translational research, clinical trials, prevention and health promotion, and behavioral and health services research.

That may sound like a laundry list of scientific jargon. But simply put, the clinical research enterprise is the mechanism for ensuring that new knowledge finds its way into doctor's offices and hospitals, where it can be put to use in preventing, diagnosing and treating illness and disease. In basic research, the starting point for scientists is a desire to understand how organisms behave at their most fundamental levels. Clinical researcher are more likely to begin from the opposite direction—the patient—and try to determine the cause of their misery. Mr. Chairman, all sources of research depend on one another. As Pasteur himself

Mr. Chairman, all sources of research depend on one another. As Pasteur himself noted, clinical and basic research are no more separable than the tree from its fruit. Because the two are so interdependent, a decline in either basic or clinical research can hold back progress. And when that happens, all Americans pay in terms of health and economic productivity. In order to prevent that from occurring, the Academic Health Centers Clinical Research Forum recommends the following: Accelerate ongoing clinical research training activities.—Moving basic research

Accelerate ongoing clinical research training activities.—Moving basic research into clinical practice is a complex and time-consuming process requiring teams of highly qualified experts. For every grant application for clinical research NIH receives, it receives two applications for basic research grants. This is due in large part to the paucity of physician-scientists equipped to conduct clinical studies. In order to keep pace with new scientific discoveries in basic science, NIH should redouble its research training efforts, including mentored training for new and junior investigators (K23 awards) and career support for established clinical investigators (K24 awards).

Strengthen loan repayment efforts.—The heavy educational loan burden for medical students is a significant obstacle for those students who might otherwise wish to pursue a career in clinical research. A new extramural loan repayment program for clinical researchers was launched last year. We recommend that support for that program be expanded to stimulate greater interest on the part of young investigators.

Create an Office of Clinical Research.—A Director's Panel on Clinical Research was established in 1995, but has not convened since December 1997. Although individual institutes and centers may develop research priorities that take into account clinical research opportunities, there is no single oversight body within the NIH Director's office to nurture this important facet of study. We recommend that a permanent office be established as soon as possible.

Establish an NIH advisory panel on clinical research.—Advisory committees can play a valuable role in helping to guide public policy. We recommend that an advisory panel be established that represents the interests of the scientific, physician and patient advocacy communities.

Mr. Chairman, thank you for the opportunity to appear before the Subcommittee. I would be happy to answer any questions you may have.

# PREPARED STATEMENT OF THE NATIONAL BREAST CANCER COALITION

# INTRODUCTION

Thank you, Mr. Chairman and members of the Subcommittee for your dedication and leadership in working with the National Breast Cancer Coalition (NBCC) to help in our fight to eradicate breast cancer.

As you know, the National Breast Cancer Coalition is a grassroots organization dedicated to ending breast cancer through the power of action and advocacy. The Coalition's main goals are to increase federal funding for breast cancer research and collaborate with the scientific community to design and implement new models of research; improve access to high quality health care and breast cancer clinical trials for all women, and; expand the influence of breast cancer advocates in all aspects of the breast cancer decision making process. Nearly 600 NBCC advocates will be on Capitol Hill on Tuesday, April 30th, to lobby their Senators and Representatives on a legislative agenda that reflects these goals. NBCC truly believes that with our extraordinary determination and unbelievable spirit, combined with your continued support for high quality breast cancer research, this deadly disease will someday be eradicated.

#### CONTINUED FUNDING FOR BREAST CANCER RESEARCH IS CRITICAL

The Coalition would like to emphasize the advancements in breast cancer research that have come about as a result of your longstanding support for this issue. Developments in the past few years have begun to offer breast cancer researchers fascinating insights into the biology of breast cancer and have brought into sharp focus the areas of research that hold promise and will build on the knowledge we have gained. We are at a point where we are now able to target genes and begin to know how to address one woman's breast cancer in a different way from another woman's. This knowledge is leading us forward in finding the answers to prevention of breast cancer, as well as how to detect it earlier, and treat it more effectively. Now is precisely the time to continue your support for this important research.

# THE BREAST CANCER AND ENVIRONMENTAL RESEARCH ACT

NBCC asks for your support for increased appropriations for breast cancer research at the National Institute of Environmental Health Sciences (NIEHS). Last year, Senators Chafee, Reid, Hatch and Leahy introduced S. 830, the Breast Cancer and Environmental Research Act. (Representatives Lowey and Myrick introduced the House companion bill, H.R. 1723.) This legislation would establish Breast Cancer and Environmental Research Centers at the National Institute of Environmental Health Sciences to support research on environmental factors that may be related to the etiology of breast cancer.

It is generally believed that the environment plays some role in the development of this disease, but the extent of that role is not yet understood. NBCC believes that a strategy must be developed and more research done to determine the impact of the environment on breast cancer. It is only when we understand what causes this disease that we will have a better idea of how to prevent it, how to treat it more effectively, and how to cure it.

Women want to do all they can to reduce their risk of breast cancer or a recurrence. However, little is known about how the millions of environmental exposures we encounter each day impact the incidence of breast cancer. While there have been isolated studies looking at the suspected environmental links to breast cancer, overall, the issue of what causes breast cancer and the association between the environment and breast cancer has been chronically underfunded and understudied.

The Coalition believes the Breast Cancer and Environmental Research Act is the appropriate strategy to examine this question. Many Members of Congress from across the political spectrum agree with this approach as well. NBCC specifically appreciates this Subcommittee's recommendation in CR 107–84 regarding the need for additional research in the realm of breast cancer and the environment. We thank the Subcommittee for taking these important first steps in endorsing the goals set forth in this legislation. The time is right for the Committee to move forward in the fight to eradicate this disease by providing \$30 million to fund up to eight breast cancer and environmental research centers, which would make grants using a peer review and programmatic review process that involves consumers. NBCC urges the Committee to use the tremendously successful Department of Defense (DOD) Peer-Reviewed Breast Cancer Research Program (BCRP) as a model for the structure of this research program.

# ACCOUNTABILITY AT NIH

Finally, NBCC believes the issue of accountability at NIH is an especially timely one with respect to the completion of doubling the NIH budget. We would like to see collaboration among consumer advocates, NIH and Congress, to create mechanisms to ensure a higher level of accountability for federally funded breast cancer research. The National Breast Cancer Coalition understands that the level of funding is meaningless unless the funds are allocated appropriately. The Coalition believes that the call for increased accountability should be a col-

The Coalition believes that the call for increased accountability should be a collaborative effort, and wants to work with the Committee and with NIH and NCI. The Programmatic Review Group (PRG), which Dr. Klausner convened in 1998 to provide an account of NCI's plan to eradicate breast cancer, was a good beginning; however, a more comprehensive strategy is necessary.

however, a more comprehensive strategy is necessary. We know that NIH and NCI are as committed as we are to finding prevention and cures for this disease. However, there needs to be outside oversight of NIH to monitor this process. NBCC believes that it is inappropriate for a government agency to design its own oversight; rather, the public must design and participate in a process that can review decisions without bias. The time is right for Congress to request an independent audit of research funding at NIH—using breast cancer research funding as a model. The question of whether changes may be needed in the grant mechanism and research structure at these Institutes should be explored. This outside evaluation is necessary to update processes or to uproot outmoded or duplicative efforts that no longer make sense. The Coalition also seeks answers to the questions that remain. For instance, how is breast cancer research funding currently being spent? Who sets priorities and what criteria are applied? And, how can we, as consumer advocates, seek to influence how the money is being spent?

NBCC believes that some of the answers to these questions lie in the model of accountability in the Department of Defense (DOD) Army Peer-Reviewed Breast Cancer Research Program (BCRP). While the DOD BCRP is significantly smaller and more focused than NCI and NIH, it has an effective infrastructure of accountability that serves as a good model for other research programs to follow.

The DOD Integration Panel has outside members that include advocates on both levels of peer and programmatic review. Also, the DOD Breast Cancer Research Program has reported the progress of the program to the American people during two public meetings called the "Era of Hope." These meetings have been the only times a federally funded program reported back to the public in detail not only on the funds used, but also with regards to the research undertaken, the knowledge gained from that research and future directions to pursue. These meetings allowed scientists, consumers and the American public to see the exceptional progress made in breast cancer research through the DOD Peer-Reviewed Breast Cancer Research Program.

As we are all aware, these are taxpayer dollars. We owe it to all of our constituencies to assure them that this investment is spent wisely. The National Breast Cancer Coalition supports increased appropriations for breast cancer research so that we can eradicate this disease as soon as possible, however, it is vital that the public understand how the funds are being spent. NBCC would like to work with Members of this Subcommittee on this issue.

# CONCLUSION

Chairman Harkin, Senator Specter, and members of the Subcommittee, thank you again for the incredible investment you have made in helping us work to eradicate breast cancer. NBCC looks forward to continuing to work with you to end this disease.

# PREPARED STATEMENT OF THE AMERICAN SOCIETY OF TROPICAL MEDICINE AND HYGIENE

The American Society of Tropical Medicine and Hygiene (ASTMH) greatly appreciates the opportunity to present its views to the Subcommittee. The ASTMH is a professional society of 3,500 researchers and practitioners dedicated to the prevention and treatment of infectious and tropical diseases. The collective expertise of our members is in the areas of basic science, medicine, vector control, epidemiology, and public health.

The staggering burden of tropical and infectious diseases confronts us on a daily basis. Poor health and the spread of infectious disease across borders have profound effects on the social and economic development and stability of nations around the globe. With the enormous volume of travel and trade today, and with the expanded deployment of American troops, infectious diseases can affect populations around the globe within 24 hours. The globalization of infectious disease has brought an increased realization that infectious diseases represent not only a humanitarian concern but also a bona fide threat to the health and national security of the United States.

The tragic events of September 11th have brought new challenges and threats that we are forced to confront as a nation and has underscored the need to strengthen our efforts and conduct countermeasures to global infectious disease with a sharp focus on bioterrorism prevention and treatment.

Now more than ever, we must be vigilant in our efforts to control and eradicate infectious diseases. In this new era, we must marshal the efforts of government, industry, international organizations and private foundations if we are to protect our national security against biological and chemical attacks and protect Americans against infectious diseases and antimicrobial resistance. Tuberculosis (TB) and malaria are renewed threats because they are becoming increasingly drug resistant. Monitoring, preventing, and controlling antimicrobial resistance requires sustained effort, commitment, and collaboration among public and private sectors, with support and leadership from the federal government.

# NATIONAL INSTITUTES OF HEALTH (NIH)

Mr. Chairman, the Society thanks you and members of the Subcommittee for your strong leadership in the area of biomedical research. Investments in NIH have led to an explosion of knowledge that promises to advance our understanding of the biological basis of disease and unlock new strategies for disease prevention, diagnosis, treatment, and cures. For example, new rapid methods for detecting tuberculosis can detect small amounts of the bacteria in 9 days, cutting 2–3 weeks off the current diagnostic standard. New drugs have been developed to treat anthrax, which has been hastened following the identification of how the anthrax toxin enters and turn off a cell's internal switches, giving researchers the ability to construct new anti-toxin compounds based on known features of the protein rather than by randomly screening large numbers of compounds.

domly screening large numbers of compounds. The ASTMH commends President Bush for proposing a fiscal year 2003 budget of \$27.3 billion for the NIH, the funding level necessary to complete the bipartisan national campaign to double the NIH budget by 2003. We urge you to support an NIH funding level of at least \$27.3 billion in fiscal year 2003. This investment will permit an aggressive pursuit of bioterrorism research on prevention and treatment as well as the pursuit of promising research avenues, including the development of new vaccines and drug therapies for diseases such as malaria, TB, dengue fever, cholera and other diarrheal diseases, HIV/AIDS, and a myriad of other viral bacterial, fungal, and parasitic disease agents.

As a result of the increased funding of the NIH, new scientific and research opportunities are being pursued that hold the potential to prevent and control tropical and infectious diseases around the world. Infectious diseases are the second leading cause of death worldwide, accounting for over 13 million deaths (25 percent of all deaths worldwide in 1999). Twenty well-known diseases—including TB, malaria, and cholera—have reemerged or spread geographically since 1973, often in more virulent and drug-resistant forms. At least 30 previously unknown disease agents have been identified in this period—including HIV, Ebola, and hepatitis C—for which no cures are available.

Additional support for clinical research is needed to take advantage of existing opportunities and develop new approaches to accelerate efforts to develop vaccines and drug therapies for HIV/AIDS, malaria, TB, and hepatitis C. Emerging scientific opportunities and recent developments in infectious disease research include sequencing the human genome and recombinant DNA technologies for developing new vaccines, such as the very successful vaccines against hepatitis B that are now given to all children in the United States. Although it will be a great challenge, we are optimistic that similar such vaccines can be developed against the big three global killers: AIDS, TB, and malaria.

# NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES (NIAID)

The ASTMH supports the fiscal year 2003 budget recommendation of \$3.9 billion for the National Institute of Allergy and Infectious Diseases (NIAID).—During the past 15 years three factors have prompted NIAID to grow significantly: the emergence of HIV/AIDS in the early 1980s; results from basic research that are now driving new approaches to solving clinical and public health problems; and the realization that infectious diseases will continue to emerge unpredictably and at times explosively. These factors, coupled with the urgent need to undertake an aggressive bioterrorism research agenda, justify a significant investment in NIAID activities as proposed by the President. There are several important on-going issues relating to NIAID's research efforts in tropical and infectious diseases that we would like to highlight.

Malaria.—Malaria has been undergoing a global resurgence in recent years, partially related to drug resistance, with 275 million cases occurring annually, and a death toll estimated at 1 to 2 million, primarily children. It is a disease of staggering importance, especially in sub-Saharan Africa, where 90 percent of the cases and deaths occur. More than 10 million U.S. citizens travel to areas of the world where malaria is transmitted annually, and must take drugs with side effects and ever-decreasing efficacy. In every military campaign of the past 100 years executed in areas where malaria was transmitted U.S. forces have had more casualties from malaria than from hostile fire. The malaria parasites rapidly develop resistance to the drugs we use, and there is no vaccine on the horizon. NIAID-supported basic research has led to the sequencing of the genome of the malaria parasite responsible for 99 percent of all deaths, and the Anopheles mosquito that transmits the parasite; both of which sequences will be published this year. These remarkable accomplishments lay the foundation for entirely new generations of drugs to prevent and treat infections, anti-mosquito interventions to prevent infection, and most importantly the development of malaria vaccines.

*Emerging Infections.*—There are numerous emerging infectious agents among the viruses, bacteria, protozoa, and fungi that make up the microbial world. Because the frequency of world travel makes the United States part of a global community, diseases that emerge in foreign countries are also health threats in the United States.

Acquired Immunodeficiency Syndrome (AIDS).—In the United States, an estimated 271,000 people are living with HIV, and the rate of the new HIV infections, approximately 40,000 per year, continues at an unacceptably high level. NIAID-supported basic research identified the HIV protease enzyme as a target for antiviral drugs, which led to the development of very potent protease inhibitors, that have prolonged and improved the quality of life for many HIV-infected people. However, effective, low-cost tools for HIV prevention, such as a vaccine and affordable drug therapies, are needed urgently to bring the HIV epidemic under control. *HIV Vaccine Research Program.*—The ASTMH notes with concern that the Administration has proposed the transfer of the Department of Defense HIV/AIDS vaccine program to the NIAID. For more than a decade the Defense Department HIV Vaccine program has complemented the NIAID vaccine programs in a number of ways, largely because it is organized, managed, and funded differently. The program's ability to effectively and efficiently develop and test preventive HIV vaccines, primarily on clades of the virus not found in the United States, plays a significant

HIV Vaccine Research Program.—The ASTMH notes with concern that the Administration has proposed the transfer of the Department of Defense HIV/AIDS vaccine program to the NIAID. For more than a decade the Defense Department HIV Vaccine program has complemented the NIAID vaccine programs in a number of ways, largely because it is organized, managed, and funded differently. The program's ability to effectively and efficiently develop and test preventive HIV vaccines, primarily on clades of the virus not found in the United States, plays a significant role in our national research effort. The DOD, in large part due to its longstanding, well-respected overseas laboratories has collaborations and agreements that facilitate execution of of current and planned clinical trials to test the efficacy of new vaccine products. The ASTMH urges that the important research initiatives undertaken by both the Defense Department program and the NIAID continue under the Institute's administration because of the unique but complementary role of the two programs. We urge that the Defense Department HIV vaccine research program leadership and infrastructure administered from the Walter Reed Army Institute of Research be retained.

*Tuberculosis (TB).*—TB is the eighth leading cause of death worldwide. One-third of the world's population has latent TB, constituting a huge reservoir from which active TB can surface. Moreover, multidrug-resistant TB is an increasing problem.

Hepatitis.—Hepatitis (liver inflammation) can be caused by several viruses. The most common are hepatitis A, a food- and water-borne infection that is a particular risk for travelers, and hepatitis B and hepatitis C, both of which are blood-borne. We now have excellent vaccines for hepatitis A and B, but none for hepatitis C, which kills about 9,000 Americans annually.

The Society commends the NIH and NIAID for their continued leadership and focus on tropical and infectious diseases. We urge the Subcommittee to strongly support efforts of the NIAID to develop new and improved methods for treating illness, controlling outbreaks, and preventing epidemics that continue to challenge global health.

Tropical Medicine Research Centers.—The NIH's tropical disease research program is funded primarily by the NIAID. The International Centers for Tropical Disease Research network was established by NIAID to build new and strengthen established partnerships between U.S. scientists and investigators from tropical disease endemic areas and bring together NIAID and other government agencies with interests in tropical disease research, and academic scientists and private industry, to encourage translational and collaborative research. The Society strongly urges that the Committee express its continued support for these unique research opportunities.

#### FOGARTY INTERNATIONAL CENTER (FIC)

The Fogarty International Center (FIC) is a unique component of NIH with a mandate to support training in biomedical research on behalf of the developing nations of the world. The ASTMH wishes to acknowledge the significant contributions of the FIC in overall support of tropical disease research, and their efforts to train scientists in molecular biology and molecular epidemiology techniques of relevance to developing countries in which research collaborations will be conducted. The training program in clinical investigation is a necessary component of new NIH initiatives such as the HIV Prevention and Vaccine Trials Networks and other expanding human research programs in the developing world. The Society supports training local investigators as an investment in the research itself.

The Fogarty International Center recently launched the International Clinical, Operational, and Health Services Research and Training Awards (ICOHRTA) initiative that supports training to facilitate collaborative, multidisciplinary, international clinical, operational, health services and prevention science research between U.S. institutions and those in developing countries, as well as emerging democracies of Eastern Europe, Russia, and the Newly Independent States. The FIC is partnering with five other NIH Institute (NIMH, NIDA, NIA, NCCAM, and NIDCR) in support of this initiative.

It is just this sort of synergy between research and training, between intramural and extramural NIH, among different NIH institutes and other government agencies with different mandates, and between United States and developing country investigators, that offers the best hope of successfully reducing the grim toll taken by diseases like malaria not only on African children but on our own citizens. Addressing the health disparities of developing nations through training and technical assistance will facilitate essential communication and cooperation necessary to addressing global infectious disease and engendering goodwill. Poor health and poor quality of life in developing countries lead to the desperation that causes unrest and instability.

The NIAID and the Fogarty International Center have taken the lead with initiatives for training students and young scientists and clinicians in tropical medicine and international health. However, compared to the need, there remains a shortage of training opportunities and especially support for junior researchers at the point in their training when they must choose between more mainstream careers in clinical medicine or other areas or research, or the sometimes more challenging path of tropical medicine and infectious disease research.

The ASTMH urges the Subcommittee to provide the Fogarty International Center with the adequate resources to continue ongoing activities and program expansion, such as the FIC's ICOHRTA program and new initiatives that provide training and career development opportunities. The Society requests your support for a fiscal year 2003 budget of \$100 million for the Fogarty International Center.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The ASTMH is disappointed that the President has proposed a \$10 million cut in the CDC Infectious Disease program budget and flat funding for the CDC programs addressing HIV/AIDS, sexually transmitted diseases and tuberculosis for fiscal year 2003. These recommendations appear extremely short-sighted given the growing burden the country faces as the result of these new and re-emerging infectious disease threats. The Society believes the CDC must receive adequate resources to launch a comprehensive, coordinated attack against these killers. A strong federal commitment to domestic and international research, prevention and treatment activities targeted towards infectious and tropical infectious disease, whether naturally occurring or resulting from a deliberate terrorist act, is absolutely critical to protecting our nation's health and national security interests. The ASTMH appreciates the Subcommittee's past support for these critically important CDC public health initiatives and hope you will continue to provide sufficient resources for these programs in fiscal year 2003. We also urge you to continue to fund the CDC's efforts to control global malaria.

#### CONCLUSION

As we enter this new era of immense challenges and opportunities, we must aggressively pursue the battle against tropical and infectious diseases, which undoubtedly will intensify in the years ahead. 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 tropical infectious diseases as well as from biological and chemical warfare. We stand at the threshold of an exciting new era of medical progress, exemplified by the completion of the sequencing of the human genome. Opportunities for new treatments, diagnostics, cures, and preventive measures have never been greater. We must also be prepared to confront the new challenges and threats that we face. The path of progress will be different in the coming era, as the demand increases for a broader science base, more interdisciplinary research, and improved technology.

#### REQUEST

The Society greatly appreciates your support for our nation's investment in infectious disease research, control, and prevention activities. We urge you to continue your tremendous support for the NIH by providing an appropriation of at least \$23.7 billion for the NIH in fiscal year 2003. We hope you will support the President's request to provide \$3.9 billion to the NIAID. The Society also urges the Subcommittee to take an important step in facilitating greater international collabora-

tion and cooperation among public health researchers and clinicians by providing the training and career develop opportunities we have discussed. In that regard, the Society requests a budget of \$100 million for the Fogarty International Center. We recognize that there are many worthy programs competing for limited funds in your appropriations bill, however, we also request that the Committee support increased funding for the CDC's infectious disease activities. The Society of Tropical Medicine and Hygiene appreciates the opportunity to ex-

press our views and for your consideration of these requests.

# PREPARED STATEMENT OF THE AMERICAN DIABETES ASSOCIATION

Thank you for the opportunity to submit testimony on the important issue of funding diabetes research at the National Institutes of Health (NIH) and diabetes programs at the Centers for Disease Control and Prevention (CDC). Our government needs to significantly increase diabetes research funding at NH not only for the millions who currently have diabetes, but also for the millions who are developing diabetes now and in the future. I am R. Stewart Perry, Chair of the American Diabetes Association (ADA) Govern-

ment Relations Committee and member of the National Board of Directors. I am a long-time ADA volunteer who is committed-as is the Association-to helping all people affected by this serious disease. Along with approximately 16 million other Americans, I have Type 2 diabetes.

Americans, I have Type 2 diabetes. Diabetes is a serious disease, and is a contributing and underlying cause of many of the diseases on which the federal government spends the most health care dol-lars. Diabetes is a significant cause of heart disease (which costs our nation \$183.1 billion each year), a significant cause of stroke (\$43.3 billion each year), the leading cause of kidney disease (\$40.3 billion). Diabetes is also the leading cause of adult-onset blindness and lower limb amputations. Additionally, aside from all of these related conditions, diabetes alone costs our nation \$98.2 billion a year.

Approximately 40,000 people suffering from diabetes live in each congressional district. The following illustrates how diabetes affects your district in realistic terms:

-177 of your constituents will develop heart disease this year because of diabetes. -154 of your constituents will develop end stage renal disease this year because of diabetes.

-129 of your constituents will lose a foot or leg this year because of diabetes.

-55 of your constituents will go blind this year because of diabetes. Given the systemic damage diabetes imposes throughout the body, it is no surprise that the life expectancy of a person with the disease averages 10-15 years less than that of the general population.

Unfortunately, the spread of diabetes will only get worse in the coming years unless we see a significantly larger funding commitment by the federal government. Indeed, a CDC report issued in September of last year finds that the prevalence of diabetes nationwide increased by 50 percent between 1990 and 2000. If diabetes keeps increasing at this rate, its prevalence will double in just over 15 years.

# RECENT FUNDING INCREASES

The American Diabetes Association appreciates that Congress has begun to give greater attention to diabetes research at NIH in recent years and that the current Administration has proposed an overall increase in the NIH budget. However, dur-Administration has proposed an overall increase in the rate suggest resolution, increase in the rate of the past decade, diabetes funding has stagnated even while the burden has grown significantly. During one year in the 1990s, diabetes research funding grew as little as one-half of 1 percent. Indeed, from 1987–2001, appropriated diabe-tes funding as a share of the overall NIH budget has dropped by more than 20 per-cent (from 3.9 percent to 2.9 percent) while the death rate due to diabetes has in-creased by more than 40 percent. Thankfully, the past 4 year have brought larger increases in diabetes funding than we had seen over the majority of the decade. Only over these years did the growth in diabetes research funding finally keep pace with the growth of the overall NIH budget. At a time when diabetes is exploding across our nation, it is essential that we dramatically increase the research funding levels for diabetes.

# CONQUERING DIABETES: A WELL-THOUGHT-OUT PLAN

There is, in our opinion, no way around the fact that diabetes research funding at NIH and diabetes control program funding at CDC have for many years fallen far short relative to the impact of the disease on our nation. When we—and the larger diabetes community—ask for increased appropriations for diabetes funding at NIH and CDC, we approach with the backing of a well thought-out plan. This plan was requested by Congress and designed by leading experts in the field of diabetes research. As you are aware, in 1997 Congress directed NIH to establish a team of national diabetes experts to develop a comprehensive plan that could lead to the elimination of diabetes. In the spring of 1999, Conquering Diabetes, the final report of the Diabetes Research Working Group (DRWG), was presented to Congress.

The DRWG's Strategic Research Plan is a document that has been widely reviewed and supported by the diabetes research community that sets forth a com-prehensive plan of attack against diabetes. Indeed, in questioning before the committee in 2000, NIDDK Director Dr. Allen Spiegel expressed his strong support for the DRWG plan and the recommendations it puts forward.

Conquering Diabetes identifies the challenges associated with diabetes and provides compelling evidence attesting to the magnitude of the problem. It also analyzes the federal government's current commitment to diabetes research. Most importantly, Conquering Diabetes identifies hundreds of scientific opportunities, which it lays out in a realistic 5-year plan, that we believe could lead to better treatments, and hopefully, a cure. But in order to implement the plan, funding has to be increased in order to capture these otherwise lost research opportunities.

# NIH ALLOCATION CRITERIA

Since 1997, the issue of how NIH allocates its multi-billion dollar annual budget has been explored internally by NIH, and externally by the National Academy of Science's Institute of Medicine and by a subcommittee of the Senate Labor and Human Resources Committee.

During this time, NIH has stated that it uses seven criteria in setting research priorities:

-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:

time; —The economic and social costs of a disease; —The need to act rapidly to control the spread of a disease; and —The existence of scientific opportunities related to a disease. Each year, according to NIH, "deciding how and where to distribute [its] money . . . requires a fresh assessment of the nation's health needs and renewed evaluation of scientific opportunity."<sup>1</sup> Based upon the findings of the DRWG, diabe-tica means then fulfills the association of these criteria. Yeat despite meating them tes more than fulfills the requirements of these criteria. Yet despite meeting them, diabetes research has been, and continues to remain, significantly underfunded at NIH in light of the many existing scientific opportunities as well as the burden diabetes poses on our nation.

# WHY ACROSS-THE-BOARD INCREASES ARE NOT EQUITABLE

Conquering Diabetes outlined a feasible 5-year plan that, as requested by Congress, contained a realistic budget to guide its implementation. As you may remember, the DRWG's fiscal year 2002 budget recommendation called for \$1.3 billion across all NIH institutes, more than \$500 million above the current funding level.

Mr. Chairman, we appreciate the increases of the last few years. Congress should be proud of the bi-partisan support for the effort to double the NIH budget. But this should not equate to an automatic institute-by-institute doubling.

Some institute budgets are larger not only due to scientific opportunities, but due to special consideration in years past. Unfortunately, across-the-board percentage increases make it difficult, if not impossible, to address funding shortfalls for dis-eases that now have promising scientific opportunities. Diseases like diabetes that have not received funding commensurate with their national burden, as well as with existing scientific opportunities, continue to fall behind as a result of this funding strategy.

Across-the-board increases for all institutes simply do not allow the Congress, or the nation, to deal with the serious problem of diabetes anytime soon. While on the surface across-the-board increases appear equitable to everyone, it actually perpet-uates inequity in absolute dollar terms. In reality, a 15 percent increase means

<sup>&</sup>lt;sup>1</sup> "Setting Research Priorities at the National Institutes of Health." Working Group on Priority Setting, NIH. 1997.

much more for diseases and institutes with large budgets, and far less for diseases and institutes with small budgets.

Continuing with an across-the-board approach in this final year of the NIH doubling effort means that these discrepancies in funding will continue to grow. This is not inherently bad so long as the difference accurately reflects the scientific opportunities and health impact of disease on the nation. But in the case of diabetes at least, it does not.

The net effect of an across-the-board approach is that past funding legacies still affect the funding priorities at NIH to this day. The end result is that some diseases do end up "pitted" against others because of the failure to rigorously apply the criteria supposedly embraced by NIH. By not constantly making an honest assessment of the health challenges faced by our nation and by not looking harder at the scientific opportunities facing the research community, NIH has perpetuated an inequality in funding based on decisions made many years before.

# INCREASED DIABETES FUNDING HAS STRONG BI-PARTISAN, BI-CAMERAL SUPPORT

Implementing the recommendations of the DRWG has widespread, bi-partisan support in Congress. Every year for the past several years, over 140 Members of Congress have signed a letter arguing for the importance of significantly increased diabetes funding—to levels approaching those recommended by the DRWG—at NIH.

Unfortunately, Mr. Chairman, even with such strong Congressional support and oversight, implementation of the DRWG recommendations at NIH remains a distant reality. As I have stated, we feel that an honest application of NIH's own stated criteria of assessing the health burden of the nation and the scientific opportunities that are available would bring us much closer to realizing the DRWG plan. Perhaps it is time that this committee take a more active role in ensuring that NIH's allocation criteria are properly used and followed.

# CENTERS FOR DISEASE CONTROL AND PREVENTION

In addition to the importance of diabetes research, the ADA also believes strongly in programs that benefit people currently with diabetes in directly tangible ways. Indeed, the benefits of basic research cannot be fully realized unless the results are translated into public health interventions. To this end, we believe strongly in the work funded by the Division of Diabetes Translation and the Centers for Disease Control and Prevention (CDC). With its fiscal year 2002 budget of \$62 million, the Division of Diabetes Translation provided support for state- and territorial-based diabetes control programs to reduce the complications associated with diabetes. In fiscal year 2002, the Division provided limited support to 34 states, 8 territories, and D.C. for core diabetes programs, and more substantive support to 16 states for comprehensive programs. Although every state and territory has at least a core program, unfortunately the core programs do not even come close to addressing the needs statewide. Instead, they simply serve as a rudimentary framework upon which a comprehensive program can be built.

CDC also conducts other activities to help people currently living with diabetes. For example, CDC works with NIH to jointly sponsor the National Diabetes Education Program (NDEP), which seeks to improve the treatment and outcomes of people with diabetes, promote early detection, and prevent the onset of diabetes. In addition, CDC funds work at the National Diabetes Laboratory to support scientific studies that will improve the lives of people with diabetes.

Even while the Division of Diabetes Translation conducts a number of activities to help people with diabetes, it suffers a similar problem as its NIH counterpart, NIDDK. Compared to other diseases, diabetes remains significantly underfunded at CDC. If adequately funded, the Division would be able to expand its comprehensive programs to every state as well as conduct and fund additional projects to assist people with diabetes. Without CDC's diabetes programs and projects in all parts of the country, it will be exceedingly difficult—if not impossible—to control the escalating costs associated with diabetic complications and to stem the epidemic rise in diabetes rates.

Chronic diseases, including diabetes, account for nearly 70 percent of all health care costs as well as 70 percent of all deaths annually. However, less than \$1.25 per person is directed toward public health interventions focused on preventing the debilitating effects associated with chronic diseases, demonstrating that federal investment in chronic disease prevention remains grossly inadequate. We cannot ignore those Americans who are currently living with diabetes and other diseases.

#### CONCLUSION

I firmly believe that we could rapidly move toward curing this disease and eliminating the \$45 billion federal outlay going to diabetes treatment and care if the DRWG plan can be fully funded and CDC funding be increased. Widespread support exists in Congress to fund these scientific research opportunities in diabetes that will result in better treatment, care and a cure for the disease. Your leadership can help accomplish this goal.

The American Diabetes Association strongly urges the committee and Congress to fully fund trans-NIH diabetes research at the \$1.5 billion level recommended by the DRWG for fiscal year 2002. Since there are several institutes at NIH with a diabetes portfolio, we urge that these funds be distributed to such institutes according to the level outlined in the DRWG plan. Furthermore, we ask that the committee provide each such NIH institute with clear direction from Congress to implement the DRWG plan. In 2000, the committee report included language urging the Director of NIH to

In 2000, the committee report included language urging the Director of NIH to take a "lead role in overseeing implementation of the recommendations" of the DRWG. We would also ask the committee to consider making a mid-year request of NIH as to the steps it has taken to fulfill the DRWG's recommendations.

We also ask that the Division of Diabetes Translation at CDC receive an fiscal year 2002 appropriation of \$100 million. This budgetary increase would allow the Division to implement a Comprehensive Diabetes Control Program in every state and territory, thus moving the government in the direction of truly helping all Americans with diabetes.

Mr. Chairman, as you work through the allocation process with the NIH leadership, we strongly urge you to take a new look at across-the-board increases since they will not meet our nation's need to address many diseases, including the epidemic of diabetes.

Speaking on behalf of the 17 million Americans with diabetes, a disease that crosses gender, race, ethnicity and political party; a disease that is among the most costly, debilitating, deadly and prevalent in our nation; and a disease that is exploding throughout our nation; I appreciate the opportunity to submit this testimony. The American Diabetes Association is prepared to answer any questions you might have on these important issues.

# PREPARED STATEMENT OF THE LYMPHOMA RESEARCH FOUNDATION

# INTRODUCTION

It is my pleasure to submit this statement on behalf of the Lymphoma Research Foundation (LRF). This is an exciting year for those of us who are dedicated to finding a cure for lymphoma and providing educational and other services to individuals with this disease, their families, and their friends. Our organization is the result of a merger last fall between the Cure For Lymphoma Foundation and the Lymphoma Research Foundation of America where we determined that we could best serve the community by joining forces. We come to you as a united organization, still dedicated to finding a cure for lymphoma. We believe our participance on important complement to the work of the Ne

We believe our activities are an important complement to the work of the National Cancer Institute (NCI). LRF has limited funds for research, but we give serious and creative thought to how we might use our resources to advance the field and encourage promising researchers. We look forward to opportunities to discuss with NCI our research funding philosophy and the ways in which our research portfolio might supplement that of NCI.

In our public policy efforts, we take a very broad view of the research process. We believe that federal funding for basic, translational, and clinical research must be adequate to support promising avenues for basic research and the efficient translation of basic findings into new treatments. We also seek to ensure that new products are reviewed promptly by the Food and Drug Administration (FDA); new therapies are reimbursed promptly and fairly by Medicare, Medicaid, and private payers; and individuals with lymphoma are guaranteed access to high quality care.

# THE BURDEN OF LYMPHOMA

We are gratified that the incidence of most cancers is declining. This improvement is the product of earlier detection of cancer and better therapies for many cancers. However, these encouraging numbers do not reveal the contrary experience with lymphoma. Since the 1970s, incidence rates for non-Hodgkin's lymphoma (NHL) have increased dramatically, making it one of the fastest rising cancers in the United States. The number of individuals diagnosed with NHL each year has doubled since the 1970s, and NHL is the second fastest rising cancer in incidence and death rates in the United States.

In 2002, there will be a total of more than 60,000 cases of lymphoma diagnosed in the United States—53,900 cases of non-Hodgkin's lymphoma and 7,000 cases of Hodgkin's disease. More than 24,000 individuals will die from non-Hodgkin's lymphoma in 2002. The 5-year survival rate for non-Hodgkin's lymphoma is only 53 percent. These are numbers that concern all of us, and our mission is to change them.

We are pleased that NCI is investing in research that will help us understand the increase in incidence of NHL, as well as the increase in the death rate. This is an important avenue of research inquiry, and we appreciate the active involvement of NCI in this research field.

#### LYMPHOMA RESEARCH ADVANCES AND OPPORTUNITIES

Over the last several years, there have been a number of important advances in lymphoma research. Some have led to new therapies for lymphoma, and others have advanced our basic understanding of lymphoma and may result in new treatments. These advances include:

- -The development of a monoclonal antibody for the treatment of indolent B-cell NHL, a therapy that is only the first that uses the body's own immune system to fight cancer.
- —A new therapy that combines a monoclonal antibody and a radioisotope and represents an important new treatment option for individuals who may have failed other treatments.
- -Cancer vaccines that employ immunotherapy to rally the body's defenses against disease. These products are being tested in several trials across the country.
- —Use of genetic analysis techniques to identify subpopulations of lymphoma patients who respond more favorably to chemotherapy. The commercialization of this technology may allow physicians to offer a more specific diagnosis, as well as make predictions regarding an individual's response to chemotherapy. This advance may be an important part of a trend toward the more precise targeting of therapies for individual patients.

# PROGRESS REVIEW GROUP ON LEUKEMIA, LYMPHOMA, AND MYELOMA

In December 2000, NCI convened a meeting of extramural scientists, physicians, and advocates in a research planning meeting called the Leukemia, Lymphoma, and Myeloma Progress Review Group (LLM–PRG). This blue-ribbon group evaluated the NCI blood cancer research portfolio, new research opportunities, and obstacles to research progress. Many of those who are affiliated with LRF participated in the deliberative process of that blue-ribbon panel, and we found the site-specific planning process to be one of high quality. NCI has engaged in a series of cancer site-specific planning groups, a process that has been hailed by most as thoughtful and informed by experts in the field.

by experts in the field. The LLM-PRG report was finalized in June 2001, and NCI has been working to develop a plan for implementing the recommendations of that plan. Unfortunately, there has been limited progress in this effort. The contributions of the leaders in the field of leukemia, lymphoma, and myeloma in this strategic planning process should not be ignored. Our recommendations for action by Congress relate to ensuring that NCI does not ignore the findings of its own cancer research planning process.

#### FISCAL YEAR 2003 RECOMMENDATIONS FROM CFL

LRF recommends the following actions, to capitalize on important basic research advances and accelerate the development of new lymphoma therapies:

- -NCI should be encouraged to move forward with implementation of the recommendations that are included in the LLM-PRG report.—In convening the group of experts in the LLM-PRG, the NCI sought and received solid advice regarding the future direction of research on lymphoma and the other blood cancers. LRF recommends that the advice of this panel be heeded. We request that the Subcommittee include in its report specific language directing NCI to respond to the Subcommittee regarding its plan for implementation of the LLM-PRG proposals.
- -NCI should proceed with a development plan for a private-public sector consortium for lymphoma translational research.-During its deliberations, the LLM-PRG developed the concept of a public-private, interdisciplinary research con-

sortium that would focus especially on the translation of basic research findings into new blood cancer treatments. The ambitious goal of this collaborative was to reduce the time for development of new therapies. Many who participated in the LLM-PRG found this concept the single most exciting recommendation of the report and urged that it be a top priority for implementation by NCI. To date, no further plans for action on this proposal have been developed. We request that the Subcommittee include in its report language requiring NCI to present an update regarding its plan for implementation of the translational research consortium during hearings on the fiscal year 2004 spending bill.

- -Congress should fund the programs that are included in the Hematological Cancer Research Investment and Education Act.—This legislation was introduced by Senator Kay Bailey Hutchison and Senator Barbara Mikulski (S. 1094) and has passed the Senate; its companion (H.R. 2629) was introduced by Representatives Phil Crane, Marge Roukema, and Vic Snyder and is pending action in the House of Representatives. This legislation is intended to coordinate and strengthen the blood cancer research program, as well as to establish a blood cancers educational initiative for patients and the public. We anticipate passage of this bill and urge the Subcommittee to act on key provisions, including research coordination efforts and a new educational initiative at HHS.
- -Congress should sustain progress toward doubling the NIH budget in the 5-year period from fiscal year 1999 to fiscal year 2003.—We would like to take this opportunity to express our sincere appreciation to this Subcommittee for its leadership in doubling the NIH budget over 5 years. We realize that the aggressive research recommendations we have offered are only a realistic possibility because of the work of this Subcommittee and others in the Congress to boost NIH funding substantially over the last 5 years. We salute your work and pledge our assistance in accomplishing the goal of doubling the NIH appropriation. We are gratified that this Subcommittee has already begun a consideration of funding for NIH after the 5-year doubling effort is completed.

LRF would like to thank the Subcommittee for this opportunity to submit comments regarding the fiscal year 2003 funding bill for NIH. NIH is a jewel among federal research agencies, and we appreciate this opportunity to express our strong support and to make recommendations for strengthening the programs at NIH.

# PREPARED STATEMENT OF THE AMERICAN HEART ASSOCIATION

It is highly likely that heart disease or stroke will cause your death or disability or that of a loved one. Heart disease, stroke and other cardiovascular diseases remain America's leading cause of death and a major cause of disability. Cardiovascular diseases account for more than 40 percent of American deaths.

The American Heart Association works to reduce disability and death from heart attack, stroke and other cardiovascular diseases. We commend this Committee for making fiscal year 2002 funding for the National Institutes of Health and for the Centers for Disease Control and Prevention a priority. But, we are concerned that our government is still not devoting sufficient resources for research and prevention to America's No. 1 killer—heart disease—and to our country's No. 3 killer—stroke.

# STILL NO. 1

Heart disease, stroke and other cardiovascular diseases have been America's No. 1 killer since 1919. Nearly 62 million Americans—1 in 5—suffer from one or more of these diseases, including both men and women and Americans of all ages. Hundreds of millions of Americans have major risk factors for these diseases—an estimated 50 million have high blood pressure, more than 41 million adults have elevated blood cholesterol (240 mg/dL or above), 48 million adults smoke, more than 108 million adults are overweight or obese and nearly 11 million have physician-diagnosed diabetes. As the baby boomers age, the number of Americans afflicted by these often lethal and disabling diseases will increase substantially. Cardiovascular disease costs Americans more than any other disease—an estimated \$330 billion in medical expenses and lost productivity in 2002. These diseases constitute 3 of the top 5 Medicare hospital costs. Heart disease is the major cause of premature, permanent disability of American workers, accounting for nearly 20 percent of Social Security disability payments.

# HOW YOU CAN MAKE A DIFFERENCE

Now is the time to capitalize on a century of progress in understanding heart disease, stroke and other cardiovascular diseases. According to a 1999 expert panel supported by this Committee, America's progress in reducing the death rate from cardiovascular disease has slowed, suggesting that new strategies against these kill-ers are needed. The panel also reported that there are striking differences in cardio-vascular disease death rates by race/ethnicity, socioeconomic status and geography. But promising, cost-effective breakthroughs in treatment and prevention are on the horizon. If you complete the 5-year bipartisan goal of doubling the NIH budget by fiscal year 2003 and appropriate the funds necessary to ensure that the NIH heart disease and stroke budget also doubles over the 5-year period, the translation of that research into effective clinical and community initiatives will cut health care costs and improve the quality of life. For fiscal year 2003, we urge you to do the following:

Appropriate \$27.3 billion (a 16 percent increase over fiscal year 2002 funding) for the NIH—the fifth and final step toward the bipartisan goal of doubling NIH's budget by fiscal year 2003.

NIII research provides new treatment and prevention strategies, cuts health care costs, creates jobs and maintains America's status as the world leader in the bio-Lechnology and pharmaceutical industries.
 —Provide \$2.3 billion for NIH heart research and \$316 million for NIH stroke re-

search.

Researchers are on the brink of advances to greatly enhance prevention and to provide new treatments so you and your loved ones can be spared the pain and suf-fering of heart disease and stroke.

Allot \$55 million for the CDC's Cardiovascular Health State Program to expand this activity to 42 states and to initiate research to examine causes of regional disparity of cardiovascular diseases.

Science must be made applicable through community programs that encourage Americans to make healthful lifestyle choices to prevent and control heart disease and stroke.

Support \$12.5 million to continue to help rural communities buy automated external defibrillators (AEDs) and to train rural emergency responders, including police and fire personnel, to use them.

Rural Access to Emergency Devices Act is part of Public Law 106-505, Public Health Improvement Act.

# 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 disease and stroke research and prevention breakthroughs are saving and improving lives. Several examples follow.

- Stents.—Each year more than 1 million angioplasty procedures are performed to widen narrowed arteries to the heart. But, within 6 months, 35 percent of angioplasty procedures must be repeated because the artery narrows again. In a major change in patient care, stents (wire mesh tubes used to prop open an artery) are now used in nearly 80 percent of angioplasty procedures. The use of stents along with angioplasty has significantly reduced the incidence of arstrong and the second s
- moving plaque buildup when one of the main arteries to the brain is severely narrowed. Research has better defined patients for whom this surgery is most
- helpful. More than 130,000 such procedures are performed each year. *State-of-the-Art Life-Extending Drugs.*—Research has produced amazing new drugs to help prevent and treat heart disease and stroke. Cutting-edge drugs to control blood pressure and cholesterol are more effective than ever in saving lives and enhancing quality of life for millions of Americans. Some of these drugs can prevent both heart attack and stroke. When prevention fails, revolu-tionary "clotbuster" drugs, such as tPA, can reduce disability from heart attack by dissolving blood clots causing the attack. In stroke, the use of tPA, within 3 hours of the onset of symptoms, can restore blood flow and reduce chances of permanent disability by 33 percent, saving health care costs. The drug tPA offers hope for the estimated 1.1 million Americans who will suffer a heart attack and the 450,000 who will have a clot-based stroke this year.

Congress should complete the 5-year bipartisan effort to double the NIH budget by fiscal year 2003 to encourage continued investigation into new therapies. We join the Administration and other members of the research community in advocating a fiscal year 2003 appropriation of \$27.3 billion for the NIH, the fifth step in the doubling goal. But, the NIH budget for heart disease and stroke has not kept pace with the doubling initiative. NIH heart disease and stroke research remains disproportionately under funded compared to the enormous burden these diseases place on the nation and the numerous promising scientific opportunities that could advance the fight against heart disease and stroke. The budget for these diseases still receives less than 10 percent of the NIH budget.

We have a particular interest in individual NIH components that relate directly to our mission of reducing disability and death from heart disease, stroke and other cardiovascular diseases. Our funding recommendations for these institutes follow.

#### HEART RESEARCH CHALLENGES AND OPPORTUNITIES FOR NHLBI

Significant advances have been made possible by more than 50 years of American Heart Association-sponsored research and more than a half-century of investment by Congress in the National Heart, Lung, and Blood Institute. However, while more Americans are surviving heart disease and stroke, these diseases can cause permanent disability, requiring costly medical care and loss of productivity and quality of life. Clearly more work is needed if we are to win the fight against heart disease and stroke.

The NHLBI budget has not kept pace with the doubling initiative. We urge this Committee to complete the doubling of the NHLBI budget by fiscal year 2003 and appropriate the funds to ensure that the budget for heart and stroke research and related programs also doubles over the 5-year period. As the fifth step toward reaching this goal, we advocate a fiscal year 2003 appropriation of \$3.2 billion for the NHLBI, including \$1.9 billion for heart and stroke-research and related-activities. A funding level of this amount will allow NHLBI to expand existing programs and invest in promising new initiatives. Several challenges and opportunities to advance the battle against heart disease are highlighted below.

- -Partnership Programs of Excellence in Minority Cardiovascular Health Programs.—Heart disease, stroke and other cardiovascular diseases disproportionately affect minorities. Increased resources are needed to support new partnerships between research-intensive medical centers and health care systems that serve minorities. Such partnerships would facilitate study of complex biological, behavioral and societal factors that contribute to cardiovascular disease health disparities, promote research within the health care systems to improve minority health and reduce health disparities and provide training of investigators to study cardiovascular diseases in minorities. Emphasis would be placed on community involvement in research and outreach strategies for patient recruitment and retention and prompt and effective communication of research findings to health care practitioners.
- *Obesity—Associated Cardiovascular Diseases.*—Obesity has reached epidemic proportions, with an estimated 61 percent of American adults being obese or overweight. Also, obesity is becoming increasingly common in children and adolescents. Obesity is a major risk factor for cardiovascular diseases. Its effects on the young, still-developing cardiovascular systems remain unclear. To forestall the cardiovascular complications of obesity, it is necessary to understand the relationship between body weight and cardiovascular health and disease. Increased funding would allow the NHLBI to support studies to explain how excessive body weight contributes to the development of cardiovascular diseases such as atherosclerosis, enlarged hearts, heart failure and irregular heartbeats. Areas needing further research include role of fatty tissue in inflammation, effects of obesity on the growth of the cardiovascular, respiratory and endocrine systems and complex interactions between overweight and conditions such as chronic sleep loss, high blood pressure and diabetes.
- chronic sleep loss, high blood pressure and diabetes. —Heart Attack, Stroke and Other Cardiovascular Diseases in Women.—Cardiovascular diseases are a major cause of permanent disability and the No. 1 killer of American women, killing more women than the next 9 causes of death combined. About 1 in 5 females live with effects of cardiovascular diseases. The clinical course of cardiovascular disease is different in women than in men and diagnostic capabilities are less accurate in women than in men. After a woman develops cardiovascular disease, she is more likely than a man to have continuing health problems and is more likely to die. But, these diseases are largely unrecognized by both women and their doctors. Extra funding is needed to allow the NHLBI to expand cardiovascular disease research in women and to create more educational programs for patients and health care providers on cardiovascular disease risk factors, as authorized under Public Law 105–340, Women's Health Research and Prevention Amendments.

# STROKE RESEARCH CHALLENGES AND OPPORTUNITIES FOR NINDS

A major cause of permanent disability and a key contributor to late-life dementia, stroke is America's No. 3 killer. Many of America's 4.6 million stroke survivors face debilitating physical and mental impairment, emotional distress and huge medical costs. About 1 of 4 stroke survivors is permanently disabled. An estimated 600,000 Americans will suffer a stroke this year and nearly 170,000 will die. Considered a disease of the elderly, stroke also strikes newborns, children and young adults.

disease of the elderly, stroke also strikes newborns, children and young adults. The NINDS stroke budget has not kept pace with the doubling initiative. We urge a completion of the doubling of the NINDS stroke budget by fiscal year 2003. A fiscal year 2003 appropriation of \$1.6 billion for the NINDS, including \$174 million for stroke, would be the final step toward the goal. This would allow the NINDS to expand research and start new initiatives to prevent stroke, protect the brain during stroke and enhance rehabilitation. Some challenges and opportunities follow.

- -Strategic Stroke Research Plan.—As a result of report language provided by this Committee during the fiscal year 2001 appropriations process, the NINDS convened a Stroke Progress Review Group. This Group crafted a report that will serve as a blueprint for a long-range strategic plan on stroke research. They identified five research priorities and seven resource priorities that, once implemented, will stimulate stroke research. Increased resources are needed to implement the first year of this plan.
- -Emerging Stroke Risk Factors.—More Americans are controlling major stroke risk factors, such as high blood pressure and smoking, yet the number of people falling victim to stroke continues to rise. Scientists are defining new stroke risk factors, re-examining existing ones and reconsidering the long-held belief that no difference exists in risk between young and older patients with similar risk factors. Researchers are studying heart valve disease, irregular heartbeats, the role of inflammation in clogging of arteries, and the long-term effects of previous high blood pressure. Increased funding to study these areas may lead to new ways to prevent stroke.
- *—Therapeutic Strategies for Stroke.*—Several major clinical trials have identified new methods for preventing and treating stroke in high-risk populations. However, with the increased number of strokes, and with the disparities evident in the treatment of stroke, new ways to prevent strokes, to raise awareness and to better treat strokes need to be developed and evaluated. Funding for new clinical studies is crucial for developing cutting-edge stroke treatment and prevention.
- —Stroke Education.—Less than 5 percent of patients eligible for tPA—the only FDA approved emergency treatment for clot-based stroke—receive it. As a member of the Brain Attack Coalition, comprised of organizations committed to fighting stroke, we work with the NINDS to increase public awareness of stroke symptoms and to call 9–1–1. Together, we launched a public education campaign, Know Stroke, Know the Signs. Act in Time, and strive to develop systems to make tPA readily available to appropriate patients. When these measures are implemented, stroke treatment will change from supportive care to early brain-saving intervention. More funding is needed to educate the public and health professionals about stroke.

# RESEARCH IN OTHER NIH INSTITUTES BENEFIT HEART DISEASE & STROKE

Critical research seeking to prevent and find better treatments for heart disease and stroke is supported in other NIH institutes and centers such as the National Institute on Aging, the National Institute of Diabetes and Digestive and Kidney Diseases, the National Institute of Nursing Research and the National Center for Research Resources. It is important to provide sufficient additional resources for these entities to continue and expand their critical work.

# AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

The lead health care quality agency, the AHRQ acts as a "science partner" with public and private health care sectors in improving health care quality, reducing health care costs and broadening access to essential services. The AHRQ is an active participant in developing evidence-based information needed by consumers, providers, health plans and policymakers to improve health care decision making. We join with the Friends of AHRQ in advocating an appropriation of \$390 million for the AHRQ to improve health care quality, reduce medical errors and expand the availability of health outcomes information.

# CENTERS FOR DISEASE CONTROL AND PREVENTION

Prevention is the best way to protect Americans' heath and ease the huge financial burden of disease. Commitment cannot stop at the laboratory door. Resources must be made available to bring research to places where heart disease and stroke live—the towns and neighborhoods of America.

The CDC sets the pace on prevention. It builds a bridge between what we learn in the lab and how we live in communities. We advocate a fiscal year 2003 appropriation of \$7.9 billion for the CDC, with a \$350 million increase for chronic disease prevention and health promotion.

As a result of this Committee's support since fiscal year 1998, the CDC's Cardiovascular Health State Program covers 28 states. However only 6 states receive "comprehensive" funding. This vital program allows states to design and/or implement programs to meet specific state needs to prevent and control heart disease and stroke. The CDC's 1997 report Unrealized Prevention Opportunities: Reducing the Health and Economic Burden of Chronic Disease states, "strong chronic disease prevention programs should be in place in every state to target the leading causes of death and disability . . . and their risk factors." Since cardiovascular diseases remain the No. 1 killer in every state, each state needs a Cardiovascular Health State Program. With fiscal year 2002 funding, the CDC plans to add 3 to 4 states to the program and may elevate up to 2 more states to a "comprehensive" funding level. A fiscal year 2003 appropriation of \$55 million for the Cardiovascular Health State Program would allow the CDC to expand this activity to a total of 42 states and to initiate research to examine the underlying causes of regional disparity of cardiovascular diseases.

The Paul Coverdell National Acute Stroke Registry is designed to track and improve delivery of care to stroke patients. The CDC is developing and testing prototypes for this registry in facilities in Georgia, Massachusetts, Michigan and Ohio. In fiscal year 2002, the CDC will support activities to develop and test prototypes for this registry in 8 sites. An appropriation of \$5 million would allow the CDC to continue this initiative and to design state intervention networks that will develop health care infrastructure for education to further improve stroke response time and acute care.

Also, we recommend the following fiscal year 2003 funding levels for the following CDC programs:

-\$210 million for the Preventive Health and Health Services Block Grant;

- -\$60 million for the Nutrition, Physical Activity and Obesity program;
- -\$83 million for the School Health Education Program; and
- -\$130 million for the Office of Smoking and Health to build a national program to prevent tobacco use, including a public education campaign to reduce youth access to tobacco products.

Coupled with a nationwide comprehensive Cardiovascular Health State Program, these initiatives will help the fight against heart disease and stroke. We urge you to make heart disease and stroke prevention a national priority.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION

About 250,000 Americans die each year from sudden cardiac death—when a heart's electrical rhythms malfunction, causing the heart to suddenly stop beating. Less than 5 percent of the victims live. Small, easy-to-use devices, AEDs can shock a heart back into normal rhythm and restore life. For each minute the heart beat is not restored to its normal rhythm, the victim's chance of survival drops as much as 10 percent. The first responder to a cardiac arrest may not be a medical responder, so the Rural Access to Emergency Devices Act, part of Public Law 106–505, Public Health Improvement Act, authorizes up to \$25 million to help rural communities buy AEDs and train emergency responders. An appropriation of \$12.5 million is needed to complete the authorization of the rural AED component.

#### DEPARTMENT OF EDUCATION

Physical inactivity is a major risk factor for heart disease and stroke. It is especially troubling that our nation's youth has fewer opportunities for physical education. Congress has appropriated funds for the Physical Education for Progress Act. Under PEP, the Education Secretary can award grants to community-based organizations and local education agencies to initiate, expand and improve PE programs for kindergarten through grade 12 students. We advocate a fiscal year 2003 appropriation of \$70 million for PEP.

#### ACTION NEEDED

Significantly increasing funding for medical research and prevention programs will allow us to continue making strides in the battle against heart disease and stroke. Our government's response to this challenge will help define the health and well being of Americans in this new millennium.

# PREPARED STATEMENT OF THE SOCIETY FOR ANIMAL PROTECTIVE LEGISLATION

On behalf of the Society for Animal Protective Legislation (SAPL) I would like to discuss several important issues within the jurisdiction of this committee. The first is the National Institutes of Health's (NIH) continued failure to address this Subcommittee's concern on illegally acquired dogs and cats used in research. Second, providing appropriations of \$5 million for the operation of the National Chimpanzee Sanctuary System as called for in the CHIMP Act. Third, is the NIH's improper oversight of The Coulston Foundation, a grossly negligent biomedical research facility that has been under the constant scrutiny of the U.S. Congress and the American public for years. Finally, SAPL endorses the funding request by the Doris Day Animal League for \$5 million for fiscal year 2003 to implement the National Institute of Environmental Health Sciences' (NIEHS) National Toxicology Program Interagency Center for the Evaluation of Alternative Toxicological Test Methods (NICEATM) for Interagency Coordinating Committee for the Validation of Alternative Methods (ICCVAM) activities for fiscal year 2003.

#### NIH FAILS TO ADDRESS THIS SUBCOMMITTEES CONCERN ON ILLEGALLY ACQUIRED DOGS AND CATS

Approximately 90,000 dogs and cats are used for experimentation in the United States each year. The vast majority of these animals are obtained from breeders who raise the animals under controlled conditions and have extensive information on their genetic background and health and vaccination status. In addition, some dogs and cats are being bred for experimentation at research facilities like the University of Texas.

Despite extensive documentation strongly discouraging the practice, some research facilities are foot-dragging by continuing to buy dogs and cats from random source dealers. These dealers, with a Class B license designation by the U.S. Department of Agriculture (USDA), are notorious for selling animals to laboratories that have been acquired through theft or fraud and for their widespread failure to comply with the minimum requirements under the Animal Welfare Act. Our companion organization, the Animal Welfare Institute, published a book, The Animal Dealers, which provides detailed data on this subject including a confession from a former employee of a Class B dealer and quotes directly from USDA inspection report forms.

Recognizing the severity of the problem, USDA targeted these dealers and increased enforcement efforts at their premises. Stronger enforcement has driven many dealers out of business, but it has not solved the problem. Today, fewer than 25 Class B dealers remain.

A review of USDA inspection reports for Class B dealers reveals a continuing failure to maintain complete and accurate records identifying where they are getting the dogs and cats they sell to laboratories for hundreds of dollars each. Other apparent violations include a failure to provide adequate veterinary care such that animals are suffering from injuries and diseases that have been left untreated, a failure to euthanize animals as needed and with an approved method, and a failure to have a responsible person present to permit USDA inspection of the facilities and the records.

NIH has told this Subcommittee that it is "committed to ensuring the appropriate care and use of animals in research." However, NIH has left the decision of whether or not to buy dogs and cats from random source dealers "to the local level on the basis of scientific need." NIH defends the use of Class B dealers arguing that these dealers are needed to obtain "animals that may not be available from other sources, such as genetically diverse, older, or larger animals." In fact, in the rare circumstance that a researcher asserts the need for such animals, they can be obtained directly from pounds as noted previously.

directly from pounds as noted previously. The distinction between non-purpose-bred animals from pounds versus Class B dealers must be made. By using Class B dealers (middlemen) instead of pounds, researchers are contributing to the problem. In their search to fill researchers' demands for "genetically diverse, older or larger animals," random source dealers and their suppliers may be stealing pets from backyards and farms or they are acquiring animals through fraud by collecting animals offered "free to a good home."

# All animals used in research should be obtained from legitimate sources

Taxpayer dollars, in the form of NIH extramural grants, must not continue to fund purchase of dogs and cats from dealers whose modus operandi are pet theft, acquisition of pets by fraud, payments made under the table and other illegal activities. Three years ago this Subcommittee raised this serious matter. NIH has refused to address it.

Proper oversight of NIH's dispersal of extramural grants is urgently needed. We respectfully request that this Subcommittee include the following language in the HHS appropriations bill: "None of these funds shall be used for research which utilizes dogs and/or cats obtained from random source dealers."

# NATIONAL INSTITUTES OF HEALTH NEGLECTED TO CLOSE THE COULSTON FOUNDATION

Possibly the most tragic case of government-sanctioned animal abuse in the United States has taking place at The Coulston Foundation, a private biomedical research facility located in Alamogordo, New Mexico. The Coulston Foundation currently owns over 250 chimpanzees most of whom have at one time been financially supported by the National Institutes of Health.

I say government-sanctioned animal abuse because The Coulston Foundation is the only research facility to be charged formally four times by the U.S. Department of Agriculture (USDA) for violations of the Animal Welfare Act (AWA) in the Act's 37-year history. In addition, the USDA has officially investigated The Coulston Foundation for violations of the AWA eight times in the last 8 years. In August 1999, to settle pending formal charges, The Coulston Foundation and the USDA reached a settlement agreement in which The Coulston Foundation was required to divest itself of approximately 300 chimpanzees by 2002, allow external financial monitors to inspect the facility, and to "cease and desist" from further violations of the AWA. In 2000, the NIH finally took title of 288 chimpanzees from The Coulston Foundation as part of the USDA divestiture agreement and with complete disregard for the intent of the divestiture agreement, NIH left the 288 chimpanzees in the hands of the very facility (The Coulston Foundation) that was required to divest them for a year.

One of the most grotesque stories of a death reported at The Coulston Foundation was that of Donna, a 36-year old chimpanzee from U.S. Air Force Space Program, who was said to be an "excellent mother" and "enjoy[ed] grooming both humans and chimps." Donna died on November 11, 1999 from a massive infection after carrying a large, dead fetus inside her for up to 2 months. Donna had so suffered that The Coulston Foundation vets removed one liter of pus from her abdomen during a belated C-section and could see her partially decomposed fetus's skull through the ruptured wall of her necrotic uterus. Donna's death prompted the seventh USDA investigation into The Coulston Foundation.

# NIH Refused to Act

The Coulston Foundation is symptomatic of a larger problem: what to do with the hundreds of "surplus" chimpanzees currently being warehoused in laboratories at great annual taxpayer expense. During the 1980's NIH aggressively bred chimpanzees in an attempt to deal with the AIDS crisis. However, it has since been determined that chimpanzees do not serve as a universally acceptable model for human diseases. Therefore, the government is now faced with caring for the chimpanzees that are no longer needed for research.

For years, NIH has fought this Congress, scientists, primate experts, the animal protection community and the American taxpayers' attempts to create a national sanctuary for the retirement of chimpanzees no longer used in biomedical research. NIH claims that science will stop on important research projects if chimpanzees are allowed to be retired when the research institution along with the Secretary of the Department of Health and Human Services decide that the chimpanzee is no longer needed. However, this has consistently been proven to be false and reactionary. That is why the idea of providing for these sentient beings has been so widely supported by a wide collection of diverse interests.

An important victory for chimpanzees, taxpayers and the U.S. Congress was passage of the Chimpanzee Health Improvement, Maintenance and Protection (CHIMP) Act (Public Law 106–551) which was signed into law 2 years. The CHIMP Act will create a public/private sanctuary system to retire chimpanzees formerly used in research permanently. NIH, FDA, CDC and other PHS components have, SAPL estimates, spent hundreds of millions of taxpayer dollars to breed chimpanzees and infect them with HIV, hepatitis, RSV, malaria, etc. Now, due to the declining demand for chimps in research, the surplus of chimpanzees is growing to crisis proportions.

We feel strongly that NIH should not be responsible for maintaining any "surplus" chimpanzees. NIH over breeding and mismanagement are primarily responsible for creating this monumental problem the government faces today. It is therefore not unreasonable for NIH to help pay for the solution from their own increasing taxpayer-funded budget. Federal funding for chimpanzee retirement would represent a tiny fraction of the federal funds used to breed and experiment on chimpanzees over the past few decades.

# The Chimpanzee Health Improvement, Maintenance and Protection Act

The CHIMP Act was signed into law on December 20, 2000, but the NIH has acted slowly upon the intent of the law as laid out specifically in Public Law 106–551. We urge the Congress to ensure NIH lives up to the intent of Congress to create this sanctuary system for the permanent retirement of hundreds of chimpanzees as soon as possible.

We believe it is time to live up to our obligations, first by permanently retiring ALL of the chimpanzees at The Coulston Foundation into the sanctuary system created by CHIMP Act and to provide the same long-term care and permanent, private retirement to the hundreds of chimpanzees currently being warehoused in laboratories. The CHIMP Act authorizes \$30 million for the establishment and operation of the sanctuary system. Because there are hundreds of chimpanzees languishing in various facilities we therefore respectfully request that Congress call on HHS to quickly develop the sanctuary and appropriate \$5 million for the sanctuary system.

The CHIMP Act provides a means by which we can finally give a little peace and compassion to these amazing creatures that have given so much to humanity. Dr. Jane Goodall summed it up perfectly during her testimony before Congress on the CHIMP Act when she said, "These chimps can never return to the wild, but free from cages they can live in a way that will allow them to socialize, feel the breeze in their faces, climb trees, and groom with their friends. That is, surely, the least we can do for them, in return for their sacrifice."

Thank you for your consideration of this testimony. Please feel free to contact us should you require additional information.

# PREPARED STATEMENT OF THE AMERICAN UROGYNECOLOGIC SOCIETY

On behalf of the American Urogynecologic Society (AUGS), I submit written testimony for the Senate Appropriations Subcommittee on Labor, Health and Human Services (HHS), and Education, outlining AUGS' top priorities for fiscal year 2003 for the National Institutes of Health (NIH).

The American Urogynecologic Society is a 22 year-old non-profit organization whose more than 1,000 members have a special interest and/or expertise in the field of urogynecology and reconstructive pelvic surgery. Our membership includes gynecologists, urologists, and allied health professionals in academic and clinical practices. The mission of the Society is to promote research and education in the specialty and improve the quality and delivery of health care to women with pelvic floor disorders.

First and foremost, AUGS would like to thank the Committee for it commitment to biomedical research at the NIH. Past funding increases to the NIH budget have enabled critically important research projects to be funded. Without this financial support for research innovation, projects such as the Urogynecology Program at the National Institute of Children's Health and Human Development (NICHD) and the Urinary Incontinence Treatment Network Initiative at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), would never have been possible. Through the establishment of new research into the challenging and little discussed diseases treated by urogynecologists, researchers have had the opportunity to greatly improve the quality of life for millions of women.

Currently, nearly half of the female population of the United States are diagnosed with urinary incontinence or pelvic floor disorders. Urinary incontinence alone afflicts approximately 13 million adults in the United States, 85 percent of whom are women. As shocking as these numbers seem, they does not accurately reflect all those who suffer from these diseases. Due to the stigma attached to such diagnoses, many Americans will never seek treatment, and will suffer from these debilitating diseases silently their whole lives.

#### Urinary Incontinence (UI)

UI is defined as the involuntary leakage of urine. A broad range of conditions and disorders can cause incontinence, including smoking, genetic connective tissue abnormalities, pelvic surgery, medical conditions (diabetes), chronic constipation, neurological diseases such as multiple sclerosis, stroke or neurologic injury, and degenerative changes associated with aging. It most often occurs as a result of vaginal childbirth. One in four women, ages 30–59, have experienced an episode of urinary incontinence and 50 percent or more of the elderly persons living at home or in long-term facilities are incontinent. Urinary incontinence is the 2nd leading cause for institutionalization.

# Prolapse

This refers to the extrusion the pelvic organs or vaginal walls through the vaginal opening. This creates discomfort or pressure in the vagina as well as urinary and defecatory dysfunction. Prolapse is often associated with stretching and/or tearing of the pelvic ligaments and muscles from vaginal childbirth. Around the time of menopause, estrogen production by the body is reduced and aging changes lead to further weakening of the pelvic support tissues thus producing pelvic prolapse.

#### CURRENT UROGYNECOLOGIC RESEARCH THROUGH NIH

# NICHD

Research done through the NIH has helped to expand the knowledge of the etiology, and the diagnosis and treatment of both urinary incontinence and pelvic floor disorders. The NICHD has led recent efforts to research pelvic floor disorders with its three-pronged research portfolio, and a terminology workshop to uniformly define aspects of research, diagnosis, and treatment. Specifically, the Institute has funded grants that look at the basic science aspects of pelvic floor disorders. The second component of NICHD's research portfolio on pelvic floor disorders focusing on epidemiological research was released in May 2000.

In order to make real progress in preventing and treating prolapse, it is necessary to first understand how and why pelvic floor disorders develop. Increased funding will enable the Institute to research the pathophysiology of pelvic floor disorders. This research is essential to improving the quality of life of women who are faced with the embarrassing conditions for two-thirds of their lives (i.e. post-childbearing). Now that initial research has been established at NICHD, there needs to be additional funding funneled through the clinical trials intervention programs to maintain and expand upon that research.

#### NIDDK

The NIDDK has also played an instrumental role in researching urinary incontinence. The Institute has collaborated with the NICHD in releasing its Urinary Incontinence Treatment Network Initiative. Originally released in July 1999, 9 clinical sites were funded and one data-coordinating center. Through increased Federal funding, NIDDK may be able to add additional clinical sites to this important endeavor. An increased commitment of federal funds is needed to keep the networks functioning at full capacity and to allow more clinical sites to be recruited as the networks become established. This financial investment is the only way that researchers and physicians will be able to collaborative work together to answer the clinically important questions that affect the management of women with pelvic floor disorders and urinary incontinence. Modeled after the highly successful progress review concept of the NCI, NIDDK

Modeled after the highly successful progress review concept of the NCI, NIDDK convened experts to evaluate current research portfolios, identify areas where research is lacking, and recommend research priorities in the urogynecology/urology area. A report by the Bladder Progress Review Group will soon be finalized and released thanks to the coordinated efforts of AUGS and the NIDDK. It is AUGS' hope that the NIDDK will now be able determine how follow up on research recommendations made by the experts, develop a plan to implement new initiatives and communicate and appropriately track progress.

# FISCAL YEAR 2003 BUDGETARY NEEDS

The NICHD has intimated that there will be urogynecologic research within the highly anticipated "Longitudinal," otherwise known as "National Children's Study." This program will be a billion-dollar undertaking by the NICHD and other Federal agencies to begin funding which begins funding in fiscal year 2003, and will study early child care and youth development. The plans are for the study to specifically

look into the correlation between childbirth and the likelihood for mothers to experience urogynecologic problems. This would be in an attempt to provide better care during pregnancy to avoid such problems for women later in life.

The AUGS believes that heightened awareness and acceptance of urogynecologic diseases can best be achieved through increased congressional support, specifically in the form of appropriate funding. Here are some specific ways that Congress can help:

- The AUGS recommends that Congress stay on schedule and double the NIH budget by fiscal year 2003, with \$27.3 billion designated for NIH in fiscal year 2003.
- The AUGS recommends that the committee supports \$1.284 billion for the NICHD in fiscal year 2003, to capitalize on emerging discoveries in women's urogynecologic health care and to address urgent public health needs.
- -The AUGS recommends that the Committee support \$1.7 billion for NIDDK in fiscal year 2003, so that they will be able to respond proactively to the research needs of our organization and others.
- —The AUGS recommends that the Committee encourage the NICHD to fulfill its commitment of \$2 million per year for 5 years to fund new grants for epidemiological research, and \$3 million per year for 5 years to fund new clinical sites and a data coordinating center for the urogynecology program.
- -The AUGS recommends that the Committee support the \$6 million within the NICHD budget dedicated to the planning stages of the "National Children's Study." -The AUGS recommends that the committee support \$1 billion for the National
- -The AUGS recommends that the committee support \$1 billion for the National Institute on Aging (NIA) in fiscal year 2003, to further develop research into the cause and treatment of urogynecologic disorders related to aging.

The NIH has shown tremendous progress in expanding scientific information needed to address the public health challenges caused by urinary incontinence and pelvic floor disorders. The historical accomplishments of the NIH show a clear record of building upon previous knowledge to improve diagnosis and treatment of the disorders that tackle every day. Further understanding of the basic science, epidemiology, and technological advances lead to better treatments and potential cures and, most importantly, possible strategies for prevention of these diseases. Challenges remain both in our scientific and our need to expand research and understanding, therefore, it is crucial that Congress keeps its commitment to doubling the NIH budget over 5 year. Thank you for your consideration, and the opportunity to share the American Urogynecologic Society's views on research priorities for fiscal year 2003.

# PREPARED STATEMENT OF THE SOCIETY OF GYNECOLOGIC ONCOLOGISTS

On behalf of the Society of Gynecologic Oncologists (SGO), I submit written testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services and Education, which outlines SGO's top priorities for fiscal year 2003 appropriations for gynecologic cancer programs.

SGO is a non-profit, international organization made up of almost 1000 gynecologists specializing in gynecologic oncology. SGO is committed to improving the care of women with gynecologic cancer, to raise standards of practice in gynecologic oncology and to encourage on-going research. In 2002, cervical, ovarian, and endometrial cancer will be diagnosed in approximately 75,600 women, accounting for nearly 25,000 deaths in the United States. Gynecologic cancer deaths are some of the leading causes of cancer deaths in women.

After receiving certification in general obstetrics and gynecology by the American Board of Obstetrics and Gynecology, SGO members must train for an additional 3 to 4 years in gynecologic oncology in order to qualify for special gynecologic oncology competence. Although the majority of the nearly 1,000 SGO members are gynecologic oncologists, its membership also includes other related medical specialists, including medical oncologists, radiation therapists and pathologists. In addition, the Society includes individuals who head academic divisions of Gynecologic Oncology in U.S. medical schools, all of the directors of fellowship training programs in Gynecologic Oncology and all of the participants in the National Cancer Institute (NCI) funded collaborative clinical research group—Gynecologic Oncology Group. Approximately 23,400 new ovarian cancers will be diagnosed in the United States

Approximately 23,400 new ovarian cancers will be diagnosed in the United States in the year 2002 and about 14,000 women will die from this disease. Cancer of the Endometrium (uterus) is currently the most common form of cancer of the female reproductive organs. It is estimated that 39,300 new cases of endometrial cancer will be diagnosed, and 6,600 women will die from this disease in 2002. It is also

estimated that cervical cancer will be diagnosed in about 13,000 women, and 4,100 are expected to die from this disease. Recent National Cancer Institute (NCI) discoveries have proved promising in the

development of effective early detection screening tools for ovarian cancer, the silent gynecologic cancer killer. In order to produce successful gynecologic cancer research, funding for Specialized Programs of Research Excellence (SPORES) needs to be ex-panded to create specific SPOREs for cervical and endometrial cancers. It is also imperative that the Cancer Care Outcomes Research and Surveillance (CanCORS) looks at gynecologic cancer. This project could help explain why some groups of cancer patients may not be receiving optimal treatment, and identify strategies for improving their quality of care. SGO also recognizes the effectiveness of the Centers for Disease Control (CDC) Chronic Disease Prevention and Health Promotion, in making American women more aware of preventative measures and treatments for gynecologic cancers, and hopes that it can expand its reach to Americans in the future.

# OVERALL NIH FUNDING

The SGO commends the President, Congress and this Committee for their continued support and commitment to doubling the budget of the National Institutes of Health (NIH) by fiscal year 2003. Research holds the key to improved prevention, diagnosis, and treatment of cancer. Unless NIH funding is increased, progress will slow and promising research endeavors may be abandoned. We remain steadfast in our commitment to advancing the final stage of doubling of the NIH budget by fiscal year 2003, and encourage Congress to make this a reality. —Therefore, as we enter the fourth year of this effort, SGO recommends the \$27.3

billion necessary for the NIH to meet this goal.

#### NATIONAL CANCER INSTITUTE (NCI) FUNDING

We are equally appreciative of the support Congress has provided to the National Cancer Institute (NCI). This Institute is leading efforts to develop better screening tools and treatments for gynecologic cancers, particularly for endometrial and ovar-ian cancer. In addition, the NCI is funding ground-breaking research to develop a vaccine to prevent cervical cancer. This important research may enable us to eradicate cervical cancer in our lifetime. However to do so, we must continue to make investments in medical research.

-To ensure that these critically important research endeavors are fully funded, the SGO recommends that Congress provide the NCI with \$5.1 billion in fiscal year 2003—the amount requested in the NCI Director's bypass budget.

# Cancer Care Outcomes Research and Surveillance Consortium (CanCORS)

NCI's research programs are providing much of the evidence base for the national agenda to improve health care quality. The CanCORS, launched in 1999, is a major initiative to study the impact of cutting-edge interventions on patient-centered outcomes, investigate the dissemination of state-of-the-science therapies into community practice, and analyze disparities in the delivery of quality cancer care. CanCORS multi-center teams will collaborate on large observational cohort studies of newly diagnosed cancer patients. Initial projects are focusing on lung and colorectal cancer, although expansion to other high-prevalence cancer sites is antici-pated. These analyses will support development of an expanded set of core quality and outcome measures that may be collected routinely by tumor registries in support of a national data system to monitor cancer care quality. CanCORS teams also are examining major methodological issues in outcome research conducted in com-munity settings. Expansion of CanCORS to gynecologic cancer would explain why some groups of cancer patients may not be receiving optimal treatment, and help to identify strategies for improving the quality of their care.

to identify strategies for improving the quality of their care. Some specific data in recent American Cancer Society (ACS) studies on cancer in-cidence and mortality in minority populations of the U.S. highlights overwhelming disparities. For example, a 2001 ACS study found that Hispanic women in the United States have twice the incidence of cervical cancer compared with non-Hispanics, and the death rate from cervical cancer is 40 percent higher in Hispanic women than in non-Hispanic women. Inadequate use of Pap screening contributes to later diagnosis in these women and poorer survival of cervical cancer with Hispanic women. According to a source at NCI, African American women have worse survival rates from cervical cancer even though their screening rate is higher than that of Caucasian women. These disparities are proof that more needs to be studied about cancer in minority populations and beyond, if we intend to combat these deadly diseases.

—SGO is concerned about the patterns of care for gynecological cancers and asks Congress to expand CanCORS to gynecologic cancers.

# NCI Specialized Program of Research Excellence (SPORE)

The Ovarian Cancer SPORE program was initiated in 1999 with the funding of four sites. Thanks to fiscal year 2002 funding, a general gynecologic cancer SPORE is also being created at NCI. These SPOREs promote interdisciplinary research and enable the exchange of basic and clinical science to move research findings from the laboratory to applied settings involving patients and populations. The goal of the SPORE program is to bring to clinical care settings novel ideas that have the potential to reduce cancer incidence and mortality, to improve survival and to improve the quality of life. The concept of the program has encouraged a number of Inter-SPORE collaborations aimed at developing much needed prognostic, screening, prevention, and therapeutic tools for ovarian cancer.

The SPOREs also work to identify those women who are at increased risk for developing ovarian cancer, and to develop new tests unique to the ovaries, to help detect ovarian cancer at an early and treatable stage. Trials currently underway show promise, but not optimal survival rates. Presently it is not possible to detect all women with early stage disease. Markers and methods being developed could provide the next generation of clinical trials for early detection of ovarian cancer. Survival rates of gynecologic cancers are far too low, and disparities in care need to be reduced or eliminated.

Additional SPOREs for both endometrial and cervical cancer will enable scientific breakthroughs and help reduce mortality rates. Recently, the ovarian SPOREs have made measurable breakthroughs that may lead to improved detection of this cancer. Researchers now stand ready to develop SPOREs specifically for cervical and endometrial cancers, in order to improve detection methods and created more successful treatments. Research focused on clarifying symptom presentation patterns among ovarian cancer cases may increase the proportion of women who are diagnosed at an earlier stage, when treatment appears to be more effective.

-SGO recommends that Congress create separate SPORES specifically for cervical and endometrial cancers.

# NCI Gynecologic Cancer Progress Review Group

SGO is pleased that the NCI recently released a Gynecologic Cancers Progress Review Group (PRG) report, and established a research agenda. The information compiled in the PRG has great promise for future developments.

-SGO recommends that additional funding be provided to the NCI, ensuring that the important recommendations made by the Gynecologic Cancer PRG are enacted.

# CENTERS FOR DISEASE CONTROL (CDC)—CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION

While cancer research is critical to find a cure, develop better treatments and uncover additional ways to prevent cancer, we also know that the Centers for Disease Control and Prevention (CDC) have a critical role to play. CDC programs to prevent cancer, detect cancer at its earliest stages, and educate the public about cancer risks and necessary behavioral changes have a direct impact on greatly reducing illness and treatment costs. Significant steps have been taken to fund several important CDC cancer related programs and the SGO appreciate the commitment to advancing the National Program of Cancer Registries. However, the Society remains concerned that inadequate funding is provided for the several important CDC initiatives.

# CDC National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

The NBCCEDP provides screening, outreach and case management services to assist high risk, low-income women in all 50 states. To date, one million women have been screened, thousands of breast and cervical cancers have been diagnosed, and thousands of women have been able to receive treatment for cancer. This unfortunately is not nearly enough. Specifically, the NBCCDEP can effectively utilize increased funding to ensure that many more of this nation's low-income and medically under-served women are screened for breast and cervical cancer through programs that have been identified as needing additional support and resources.

-SGO recommends that Congress support \$220 million for the CDC National Breast and Cervical Cancer Early Detection Program.

# CDC Ovarian Cancer Awareness Program

This program is relatively new at the CDC, but it is critically important to raise awareness of this silent and often deadly disease. The CDC intends to develop resources that will ensure patients at-risk or diagnosed with ovarian cancer know about appropriate treatment and referrals. Additional funding will enable the CDC to continue to put the infrastructure behind this much-needed program.

The SGO also participates in One Voice Against Cancer (OVAC), a coalition of over 40 public health organizations representing more than 15 million Americans impacted by cancer and supports OVAC's priorities for fiscal year 2003 appropriations as outlined in its written testimony submitted to the Subcommittee. SGO is working with One Voice Against Cancer (OVAC) and the Ovarian Cancer National Alliance (OCNA) to pursue \$8.0 million for ovarian and \$220 million for breast and cervical cancer.

---SGO recommends that Congress support \$8 million for the CDC Ovarian Cancer Awareness Program.

The SGO greatly appreciates your consideration of these recommendations to improve prevention, diagnosis and treatment for the thousands of American women threatened by gynecologic cancers each year.

# PREPARED STATEMENT OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION

The American Psychological Association (APA) represents 155,000 members and affiliates, and works to advance psychology as a science, a profession, and a means of promoting health and human welfare. APA members are involved in a broad spectrum of programs within the jurisdiction of this Committee—for example, as behavioral scientists whose research is funded by the National Institutes of Health, as university professors whose students depend on federal education aid, or as health service psychologists who provide services in schools or in underserved areas. Within each of these programs and others besides, psychologists are working to make a difference in the lives of health care consumers and within the educational system of this country.

# U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health (NIH).—One of the most important things this Committee can do to improve the long-term health of our nation is to complete the effort to double the NIH budget. To this end, the APA strongly recommends an appropriation of \$27.3 billion for fiscal year 2003.

Six of the ten leading causes of death in the United States are behaviorally based, including HIV/AIDS, smoking, violence, accidents, poor diet, and substance abuse. Other behavioral factors are known to increase individuals' risk for disease, disability and early death: obesity, physical inactivity, inadequate social support, exposure to environmental contaminants, anxiety, and traits of anger, hostility or depression. As important as individual behavior is to health, NIH must also continue to examine social factors—racial/ethnic status, gender, age, income, education, cultural orientation, and community—that have important effects on health. Behavioral and social science research at NIH is making important contributions to health in our nation. Examples are:

- -The National Institute on Drug Abuse (NIDA) is making state-of-the-art substance abuse treatment regimens available to broader community populations through its expanding Clinical Trials Network. This network makes it possible to test new treatments quickly and thoroughly to see whether they are effective outside laboratory settings. Similarly, NIDA is planning a new National Prevention Research Initiative. By establishing Transdisciplinary Prevention Research Centers, NIDA will bring together psychological scientists and other science professionals to work side by side to provide the necessary linkage between basic research and the development of effective new prevention interventions.
- -The National Institute of Child Health and Human Development (NICHD) is investigating the broad influence of environmental factors on childhood development. Working collaboratively with the Environmental Protection Agency and the Centers for Disease Control and Prevention, it is developing the Longitudinal Cohort Study on Environmental Effects on Child Health and Development that aims to quantify the effects of environmental exposures and biological and social factors on child health and development. Importantly, the research will also measure traditional cognitive, social and emotional developmental outcomes within the framework of this study.
- —The National Heart Lung and Blood Institute (NHLBI) has sponsored important research demonstrating the power of social connectedness in helping speed recovery after heart attacks. Such research helps reveal the pathways through which positive experiences and emotions may enhance health or protect against illness. With adequate resources NHLBI can continue its work in this area and

expand initiatives to increase basic behavioral research on the etiology of disease resistance, and examine interventions that may be ready for field testing in community populations. *The National Institute on Alcohol Abuse and Alcoholism (NIAAA)* has developed

- -The National Institute on Alcohol Abuse and Alcoholism (NIAAA) has developed important partnerships with college administrators and student organizations to strengthen its research on college drinking. As a result, NIAAA has recently released A Call to Action: Changing the Culture of Drinking at U.S. Colleges, which identifies both successful intervention strategies, as well as gaps in our understanding of the problem. With sufficient resources, NIAAA would spend additional funds on research to prevent and intervene with alcohol abuse in college settings, and to disrupt drinking patterns that might lead to alcohol dependence after college.
- The National Institute of Mental Health (NIMH) has taken leadership to develop strategies for translating basic research into clinical care practices. Its report, Translating Behavioral Science Into Action, focuses on three areas: understanding basic behavioral processes in mental illness; understanding how mental illnesses and their treatments affect the ability of individuals to function in diverse settings and roles; and understanding how social or other environmental contexts influence the development and prevention of mental illness, and the treatment and care of those suffering from mental illness.
- -National Institute on Aging (NIA) has demonstrated a commitment to furthering research on aging and cognitive function and the many difficult questions involved in long-term maintenance of positive behavior change. But as the aged population expands, so too does the need for these critical areas of research. The Behavioral and Social Research branch conducts multidisciplinary and interdisciplinary behavioral economics research that may address questions of savings and resource allocation in the pre- and post-retirement populations.
- of savings and resource allocation in the pre- and post-retirement populations. *—National Cancer Institute (NCI)* has placed recent emphasis on the interactions of genetic, environmental and lifestyle factors that affect cancer risk and the prevention, detection and treatment of cancer. NCI continues to expand its support of work on both risk determination and risk communication. NCI has also supported long term comprehensive research efforts to define the biological, behavioral and social bases of tobacco use and addiction, and continues to refine treatment options for specific groups (e.g., pregnant women or young smokers). *—National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK)* has sup-
- Particular Institute of Diabetes, Digestive and Ridney Diseases (NDDR) has supported compelling research on the links between depression and diabetes. Diabetics who have co-occurring depressive symptoms have less success managing their illness. Depression has been linked to poorer adherence to medical and behavioral regimens and lower rates of exercise. NIDDK has demonstrated robust results in the Diabetes Prevention Program by demonstrating that diet and exercise can be more successful than medication in preventing the development of diabetes in groups who faced a high risk of diabetes.
- -The Office of Behavioral and Social Sciences Research (OBSSR) exists to help coordinate the behavioral and social science research at NIH, and to enable collaborations on cross-cutting issues that serve the missions of multiple institutes. OBSSR's budget for fiscal year 2002 is \$23.4 million. APA supports an appropriation of at least \$25.8 million for OBSSR in fiscal year 2003. Such an increase would allow the Office to implement the recommendations in the National Research Council's (NRC) recent report, New Horizons in Health: An Integrative Approach. The report identifies research priorities that cut across Institute domains, underscoring the broad significance of social and behavioral science research for multiple disease outcomes as well as health promotion. The NRC report recommends ten priority areas for research investment: predisease pathways, positive health, gene expression, personal ties, health communities, inequality, population health, interventions, methodology, and infrastructure.

# DEPARTMENT OF HEALTH AND HUMAN SERVICES

# Substance Abuse and Mental Health Services Administration (SAMHSA)

# Center for Mental Health Services (CMHS)

- -Mental Health Performance Partnership Grant.—APA urges the Committee to provide \$495 million for this block grant, which is the principal federal discretionary program supporting community-based mental health services for adults with serious mental illness and children with serious emotional disturbance.
- -Post Traumatic Stress in Children.-In 2001, Congress authorized an initiative to help children and adolescents who have witnessed or experienced violence. Because of Congress' foresight, about 20 projects have now been funded that

will help children heal as our nation responds to the tragedies of September 11. APA recommends that this valuable program receive \$23 million.

- -Youth Violence Prevention Initiatives.—APA applauds the Committee for creating this coordinated effort among the Departments of Health and Human Services, Justice, Education, and Labor to develop research-based programs to prevent youth violence and to intervene with families, schools, and communities where violence has already occurred. APA recommends that the Committee provide \$108 million for youth violence prevention initiatives at CMHS, the majority of which will be devoted to funding the Safe Schools/Healthy Students Initiative. APA also recommends that the Committee provide \$110 million for the Comprehensive Community Mental Health Services for Children and their Families Program.
- -Minority Fellowship Program.—The Surgeon General's Report, Mental Health: Culture, Race, and Ethnicity (2001), clearly identifies the existence of racial and ethnic disparities in the mental health system and the related need to increase funding for training minority mental health professionals. Although minorities currently represent 30 percent of our nation's population and are projected to account for 40 percent in 2025, only 7 percent of doctorates awarded in psychology since 1978 have been to people of color. The Committee recognizes the urgency of training additional minority mental health professionals and provides \$8 million for the Minority Fellowship Program.
- vides \$8 million for the Minority Fellowship Program. —*HIV/AIDS*.—The Committee commends SAMHSA on the various HIV/AIDS programs it has initiated in the past 10 years. In fiscal year 2001, Congress appropriated \$7 million to CMHS for grants to community-based providers in traditional and non-traditional settings who provide direct mental health services to racial and ethnic minorities with HIV/AIDS and associated mental health and related problems (e.g., dementia, depression, and chronic, progressive neurological disabilities). Recent reports indicate that 36 percent of new AIDS cases are directly related to injection drug use. The Committee recognizes that individuals suffering from HIV/AIDS and co-occurring mental health and substance abuse disorders present unique and unmet treatment needs necessitating specialized provider training. Therefore, the Committee provides \$3 million for training mental health professionals to provide integrated mental health and substance abuse services for persons suffering from HIV/AIDS and co-occurring disorders.
- -HIV/AIDS Adolescent Demonstration Project.—In the 1980s, the number of babies born with HIV increased at a soaring rate. However by the early 90s, HIV births began to drop nationwide, and by the mid-90s, the numbers decreased sharply because of new antiviral medications that prevented transmission of the virus from mother to child. The Committee is concerned with the health of the children who survived this crisis. A recent American Public Health Association Journal article points to a high percentage of children who were born with HIV, and now as adolescents are suffering from severe behavioral and mental health problems and oftentimes rejection by their adopted parents due to these problems. Therefore, the Committee provides \$3 million to establish a demonstration program to address the needs of these at-risk adolescents.

#### Health Resources and Services Administration (HRSA)

APA recommends that \$6 million in the fiscal year 2003 Labor, HHS and Education Appropriations bill be allocated for the Graduate Psychology Education (GPE) Program in the Bureau of Health Professions within the Allied Health and Other Disciplines budget activity of the Health Resources and Services Administration (HRSA). This unique program was recently established to meet demonstrated mental and behavioral health care needs through integrated, interdisciplinary health care services for America's underserved populations (i.e., rural residents, children, and the chronically ill) and in areas of emerging need. Of the \$6 million, APA recommends that \$3 million be used to fund training in geropsychology to meet the mental and behavioral health needs of older Americans.

Psychological services are an essential component of a "seamless system" of health care for the underserved, one that is comprehensive, preventive and cost-effective. There are over 900 Mental Health Professional Shortage Areas throughout the nation that need services. This shortage of qualified mental and behavioral health professionals needs to be addressed. Approximately 20 percent of children and older adults experience a mental disorder (e.g., anxiety or depression), of which about 60 percent do not receive services. Most of these elderly have one or more behavioral problems (e.g., medication compliance or incontinence) that can be effectively addressed through psychological intervention. There are only 700 identified geropsychologists in the nation and significantly larger numbers are needed to meet

the increasing demands of our growing geriatric population. Maternal and Child Health Block Grant.—APA recommends that the Committee appropriate the full authorization level of \$850 million. The only federal program focused solely on improving the health of all mothers and children, this block grant supports a wide range of activities aimed at reducing infant mortality, preventing injury and violence, addressing racial and ethnic health disparities, and providing comprehensive care for children and adolescents with special health care needs.

# Centers for Disease Control and Prevention (CDC)

National Center for Injury Prevention and Control.—APA recommends \$5 million for the National Violent Death Reporting System to build state capacity to collect and analyze data about violent deaths. This system will help provide critical information to shape violence prevention strategies at the state and national levels. APA also urges the Committee to provide \$20 million for child maltreatment initiatives to further prevention efforts, state-based surveillance, data gathering, program evaluation, and dissemination of effective interventions.

National Institute for Occupational Safety and Health (NIOSH).---NIOSH is the sole agency responsible for conducting research and making recommendations for the prevention of work-related disease and injury. In 1996, NIOSH created the Na-tional Occupational Research Agenda (NORA), the largest stakeholder-based re-search agenda in the United States targeting 21 research priorities. Representatives from over 220 organizations from both the private and public sectors are working together to implement the program's objectives. Every day, about 9,000 U.S. workers sustain disabling work-related injuries: 16 die from an injury and 137 others die from work-related diseases. The annual burden for these occupational illnesses and injuries is \$171 billion, the same as the burden for cancer, yet the total federal in-vestment in occupational safety and health research is just five percent of the NIH cancer research investment. Therefore, APA recommends that the Committee pro-vide a \$60 million increase over fiscal year 2002 funding to \$336.5 million.

National Center for Chronic Disease Prevention and Health Promotion Division of Adolescent and School Health. School-based HIV Education.—At least half of all new HIV infections in the United States are among people under 25, with the ma-jority being infected through unprotected sex. In addition, there are excessively high rates of HIV infection and other serious public health problems among gay, lesbian, bisexual and transgendered, youth, especially youth of color. School health programs are one of the most efficient means of preventing HIV infections among young people because of the size and accessibility of this population. Scientific evaluations of school-based HIV prevention programs have shown that these programs are cost-ef-fective and decrease sexual risk behaviors without increasing sexual activity among high school students. APA commends the CDC for its recently completed 5-year HIV Prevention Strategic Plan, which establishes school-based strategies as a priority for HIV prevention. APA strongly recommends that the Committee provide \$100 million to strengthen and implement educational strategies to prevent HIV, and to inte-grate teen pregnancy and STD prevention initiatives in at least 25 of the nation's largest school districts. Currently, such programs are being funded in 19 of the larg-est school districts most affected by HIV to implement HIV prevention strategies alone

#### Administration on Children and Families

Members of the Committee are already aware that most children who are victims of violence are victimized in their own homes. For this reason, APA urges the Committee to fund the Child Abuse Prevention and Treatment Act at its authorized levels, while restoring the \$34 million provided in fiscal year 2001 for the Child Abuse Discretionary Grants. These funds are critical in helping the Office of Child Abuse and Neglect sponsor activities aimed at developing research-based models for child abuse prevention.

# Indian Health Service

The health disparities that exist for American Indians/Alaska Natives (AI/NA) are particularly acute. Inadequate mental health and substance abuves services con-tribute to a suicide rate for this population that is 72 percent higher than the rate for all races in the United States. The death rate attributed to alcohol for AI/AN is 45.5 per 100,000, as compared to 6.7 per 100,000 for all races. Studies have shown that 70 percent of all suicidal acts (completions and attempts) in AI/AN country involved alcohol. The 2000 National Household Survey on Drug Abuse found that Al/AN had the highest rate of illicit drug use (13 percent) of any major racial and ethnic group, an increase from 1999 of 11 percent. The Committee is alarmed

over these trends and provides an additional \$10 million each for mental health and substance abuse services.

# DEPARTMENT OF EDUCATION

APA supports strengthening our federal investment in the Elementary and Secondary School Counseling Program. In providing funds for this program, Congress has recognized its importance to our nation's children. APA urges the Committee to maintain a separate funding stream for this program at \$60 million.

Individuals with Disabilities Education Act—National Activities (IDEA Part D).— Members of the Committee have demonstrated their commitment to funding services for children with disabilities. Under IDEA Part D, Research and Innovation funds can be used to develop and evaluate research-based practices designed to address the needs of children in special education and enhance our knowledge and implementation of best practices. APA recommends funding IDEA Part D at \$100 million.

Personnel Preparation.—These funds are used to train teachers and related service providers. APA recommends that the Committee fund Personnel Preparation at \$100 million, and that the Department be directed to increase the emphasis on training of related service providers, who extend critical assistance to furthering children's educational progress and are in short supply in many schools.

Thank you for the opportunity to present this statement for the record.

# PREPARED STATEMENT OF THE HIV MEDICINE ASSOCIATION OF IDSA

The HIV Medicine Association (HIVMA) of IDSA represents 2,300 physicians who practice on the frontline of the HIV/AIDS pandemic. Our members treat people with HIV/AIDS in our communities, develop and implement effective prevention interventions and conduct research to develop less complex and less toxic treatment regimens both in the United States and abroad. HIVMA is comprised of physicians from 49 states, the District of Columbia, Puerto Rico and more than 130 countries outside the United States.

HIVMA is a member of the National Organizations Responding to AIDS (NORA) coalition, which is comprised of national organizations representing medicine, public health, community-based service organizations, and civil rights organizations that have joined together to support a comprehensive response to the AIDS pandemic domestically and globally. The funding requests reflected in our testimony represent the consensus of the coalition regarding the funding levels necessary to adequately respond to the pandemic.

respond to the pandemic. Finally, we would like to take this opportunity to thank the subcommittee for their strong support of AIDS programs over the years, which has led to rapid advances in the treatment of HIV disease and has provided access to this treatment from which many have benefited. We are optimistic that if this commitment is sustained that HIV/AIDS disease will one day be eradicated.

#### NATIONAL INSTITUTES OF HEALTH

We are very supportive of the 5-year commitment made to double funding for biomedical research at the National Institutes of Health (NIH), which has contributed to, and will continue to contribute to, improved understanding and treatment for a number of diseases including HIV/AIDS. From this perspective, we recommend a \$384 million increase in HIV/AIDS research funding through the Office of AIDS Research. This funding level will ensure that NIH can adequately implement its fiscal year 2003 AIDS research plan. This plan identifies a number of key priorities, including prevention research, to reduce HIV transmission in the United States and around the world; therapeutic research to respond to those already infected; international research priorities; and research targeting the disproportionate impact of HIV/AIDS on minority populations in the United States. Clearly, it is vital to continue our research efforts to identify a safe and effective vaccine. We would also like to highlight the value of the research and training through NIH that responds to the profound needs in under-resourced countries with significant HIV/AIDS epidemics. In particular, the Fogarty International Center has made invaluable contributions in training clinicians from countries in Africa and Asia where the need for clinical care is great and the resources are minimal.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

Until an HIV vaccine becomes available, the key to reducing the spread of HIV disease is investing resources in HIV prevention programs and epidemiological stud-

ies. To reduce the 40,000 new HIV infections occurring annually in the United States and the 14,000 new infections occurring daily worldwide, we strongly support increasing funding for the Centers for Disease Control and Prevention's (CDC) HIV programs by \$616.2 million. Each of the HIV programs within the CDC's National Center for HIV/AIDS, STDs and TB Prevention (NCHSTP) is critical to curtailing the spread of HIV disease. Surveillance systems play a critical role in identifying trends in new infections in terms of geographic location, mode of transmission and other population demographics—all factors important to informing the development of effective prevention interventions and to accurately targeting resources for clinical care and other supportive services. Community-based prevention programs that target populations at highest risk for HIV infection remain a high priority in light of evidence that there continue to be 40,000 new HIV infections in the United States each year. In addition, it is important that the resources CDC has available to fight HIV/AIDS outside of the United States keep pace with resources devoted through other avenues such as the Global AIDS Fund. CDC's global AIDS program is a vital component of our international response to the AIDS pandemic across the world. We support an increase of \$143.8 million for CDC's global AIDS programs.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION

The Health Resources and Services Administration (HRSA) administers programs that serve a critical role in the healthcare safety nets of our communities. HRSA's HIV/AIDS Bureau funds programs to support a broad spectrum of services from training for health care providers to funding for community health centers. We are particularly concerned with funding for the Ryan White CARE Act, which determines whether many people with HIV/AIDS receive life-saving prescription drugs and health care services. Adequate funding for this program is particularly crucial at this time because of severe cutbacks in the services that state Medicaid programs are able to provide and the increases in HIV infections in low-income communities

where many individuals are uninsured or underinsured. Since 1990, the Ryan White CARE Act has positively affected the lives of many people with HIV/AIDS in the United States through annual grants to more than 600 community-based programs. These programs provide essential funding for primary medical care, dental services, prescription drugs, diagnostic tests, mental health and substance abuse treatment, as well as enabling social services like case management services that help patients attend medical appointments regularly and take their medications appropriately. The Ryan White CARE Act also funds provider training-a program component that remains essential as the standard of care for HIV disease continues to evolve and change.

Many of our physician members rely on CARE Act funds to provide life-saving services to a patient population that is increasingly dominated by individuals who are poor, uninsured and unable to benefit from treatment advances without publicsupported programs. Without Ryan White funds, the outpatient clinics where our members treat patients with HIV/AIDS are vulnerable to closure, leaving patients with little or no access to experienced providers able to offer the complex and costly care necessary to keep people with HIV/AIDS healthy and functioning. Failure to increase funding for Ryan White programs essentially represents a reduction in resources as the number of individuals depending on the program grows each year. With this in mind, we feel an increase in Ryan White funding is essential to maintaining the current level of access to treatment services. Specifically, we support an increase in total Ryan White CARE Act funds of \$303.7 million by:

-increasing Title I funding available to metropolitan areas disproportionately hit by the epidemic by \$43 million

- -increasing the CARE component of Title II by \$50 million
- increasing funding to the AIDS Drug Assistance Programs by \$162 million (An increase in ADAP is becoming increasingly important as state Medicaid programs continue to cut back on their prescription drug benefits.)

-increasing Title III primary care funding by \$14 million -increasing Title IV funding by \$19 million -increasing Part F funding for the AIDS Education and Training Center by \$9.7 million and funding for dental reimbursement by \$6 million We have come a long way since the advent of AIDS 21 years ago. We have learned

a great deal about the virus through research, identified effective prevention interventions, and have dramatically increased life expectancy associated with this disease. We also finally have begun to develop and implement a strategy to address the HIV/AIDS epidemic in under-resourced countries around the world. With the continuing strong support of the Congress for a comprehensive response to the AIDS pandemic, we hold the promise of a brighter future for those who are infected and those who are at risk of infection in the United States and across the world.

# PREPARED STATEMENT OF ILLINOIS NF INC.

Thank you for the opportunity to present testimony to the Subcommittee on the importance of continued funding for Neurofibromatosis (NF), a terrible genetic disorder closely linked to cancer, learning disabilities, heart disease, brain tumors, and other disorders affecting up to 150 million Americans in this generation alone. Thanks in large measure to this Subcommittee's support, scientists have made enormous progress since the discovery of the NF1 gene in 1990. Major advances in just the past year have ushered in an exciting era of clinical and translational research in NF with broad implications for the general population. I am Kim Bischoff, Executive Director of Illinois NF Inc., member of a national

I am Kim Bischoff, Executive Director of Illinois NF Inc., member of a national coalition of NF foundation directors and advocates, and mother of an 18-year-old young woman with NF. I have been actively involved in creating awareness of NF and promoting scientific research in this area since 1986. I appear before you today as an advocate not only for my daughter, but also on behalf of the 100,000 Americans who suffer from NF and the tens of millions of Americans who have diseases related to NF. I also appear before you full of hope and excitement, because every day the scientific community is moving us closer to treatments and a cure for this terrible disease and its related disorders.

# WHAT IS NF?

NF is a genetic disorder involving the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer, and/or death. NF can also cause other abnormalities such as unsightly benign tumors across the entire body and bone deformities. In addition, approximately one-half of children with NF suffer from learning disabilities. It is the most common neurological disorder caused by a single gene. While not all NF patients suffer from the most severe symptoms, all NF patients and their families live their lives with the uncertainty of not knowing whether they will be seriously affected one day because NF is a highly variable and progressive disease.

Approximately 100,000 Americans have NF, and it appears in approximately one in every 3,500 births. It strikes worldwide, without regard to gender, race or ethnicity. Approximately 50 percent of new NF cases result from a spontaneous mutation in an individual's genes, and 50 percent are inherited. There are two types of NF—NF1, which is the more common of the two, and NF2, which primarily involves acoustic neuromas causing deafness and balance problems as well as other types of tumors such as schwannomas and meningiomas.

#### LINK TO OTHER ILLNESSES

Researchers have determined that NF is closely linked to cancer, heart disease, learning disabilities, brain tumors, and other disorders. Research on NF therefore stands to benefit 150 million Americans:

*Cancer.*—Studies have investigated the connection between the ras oncogene, which is critical to control growth and development in healthy cells (and when mutated contributes to the formation of tumors), and the NF1 gene, which produces a protein called neurofibromin which acts as a tumor suppressor. Studies have shown that ras activity can be inhibited by neurofibromin. Since elevated ras activity is involved in 30 percent of all cancer, the inhibition of ras by neurofibromin may result in a cure, not only for NF, but for many of the most common forms of human cancer.

*Heart disease.*—Researchers have demonstrated that mice completely lacking in NF1 have congenital heart disease that involves the endocardial cushions which form in the valves of the heart. This is because the same ras involved in cancer also causes heart valves to close. Neurofibromin, the protein produced by a normal NF1 gene, suppresses ras, thus opening up the heart valve. Promising new research has also connected NF1 to cells lining the blood vessels of the heart, with implications for other vascular disorders including hypertension, which affects 45 million Americans. Researchers believe that further understanding how an NF1 deficiency leads to heart disease may help to unravel molecular pathways affected in genetic and environmental causes of heart disease.

Learning disabilities.—Learning disabilities are the most common neurological complication in children with NF1. Research aimed at rescuing learning deficits in children with NF could open the door to treatments affecting 35 million Americans

and 5 percent of the world's population. Indeed, leading researchers have already rescued learning deficits in both mice and fruit flies with NF1, which will benefit all people with learning disabilities whether or not they have NF.

*Deafness.*—NF2 accounts for approximately 5 percent of genetic forms of deafness. It is also related to other types of tumors, including schwannomas and meningiomas, as well as being a major cause of balance problems.

#### SCIENTIFIC ADVANCES

The progress that has been made in NF research has been nothing short of phenomenal. In only a dozen years since the discovery of the NF1 gene, researchers are now on the threshold of developing a treatment and cure for this terrible disease. Scientists who previously had been pessimistic are now genuinely excited about engaging in therapeutic experimentation and the phase II clinical trials already being conducted by NIH. Because of NF's implication with so many other diseases, many NF researchers believe that NF should serve as a model to study all diseases. Indeed, one leading researcher has stated that more is known about NF genetically than any other disease.

In just the past year alone, scientists have made major breakthroughs bringing NF fully into the translational era, with treatments close at hand. These recent advances have included:

-Developing advanced mouse models showing human symptoms;

Testing of drug therapies on advanced mouse models;

—Rescuing learning deficits in mice;

-Linking NF to hypertension, which affects 45 million Americans, as well as congenital heart disease; and

-Continuing Phase II clinical trials

Other advances since 1990 include:

- The discovery of the NF1 and NF2 genes and gene products.—The NF1 gene was discovered in 1990 and the NF2 gene was discovered in 1993. —Determination and understanding of the functions of the NF1 and NF2 genes
- -Determination and understanding of the functions of the NF1 and NF2 genes and gene products, including the discovery of new pathways impacted by the NF genes and gene products.—Most strikingly, researchers have discovered that NF regulates both the c-AMP pathway affecting learning and memory as well as the ras pathway affecting cancer. This discovery, which brought together cancer and neurology through NF's controlling both of these related pathways, holds monumental implications for finding the treatments and cures for many diseases which affect a vast segment of the population.
- Development of advanced animal models.—Researchers have developed advanced mouse models which exhibit human symptoms, such as malignant tumors, leukemia, and learning disabilities. Such animal models provide a unique method for addressing the fundamental aspects of disease development and for testing therapeutic strategies. NF researchers have also developed the fruit fly as a model animal organism to study not only NF but many other diseases.
   —Commencement of clinical trials at NCI.—As a result of the enormous progress
- -Commencement of clinical trials at NCI.—As a result of the enormous progress made in NF research, NCI has already commenced two clinical trials with NF1 patients, including a phase II trial involving the use of farnesyl transferase inhibitors in pediatric patients.
- —Development of drug and gene therapies.—Leading NF researchers have been actively engaged in developing both drug and gene therapeutic experimentation in mice and fruit flies. In the case of NF1, these experiments have been directly related to tumor suppression and learning deficits. Researchers also believe that a gene therapy for NF2 can be developed; unlike other genetic forms of deafness, in which a mutation leads to a development or structural abnormality in the ear for which it would be difficult to envisage a treatment in the adult, NF2-associated deafness is potentially preventable or curable if tumor growth is halted before damage has been done to the adjacent nerve.
- *Rescuing learning deficits in animal models.*—A paper published in the January 30, 2002 edition of *Nature* demonstrated how researchers were able to rescue learning deficits in mice with the same mutation that causes NF1 in humans disabilities once thought to be irreversible. This discovery has enormous implications for the 35 million Americans suffering from learning disabilities. Studies on fruit flies have also demonstrated that the neurofibromin protein regulates the c-AMP pathway which is known to control learning and memory.
- -Development of Infrastructure.—Researchers, with the help of the government, have been building expanded national and international NF centers, consortia, and other infrastructure for clinical and translational research and treatment.

#### FUTURE DIRECTIONS

NF has fully entered the era of clinical and translational research which hold in-NF has fully entered the era of chinical and translational research which note in credible promise for NF patients, as well as for patients who suffer from many of the diseases linked to NF. This research is costly and will require an increased com-mitment on the federal level. Specifically, future investment in the following areas would continue to advance research on NF:

-Clinical trials;

- -Development of drug and genetic therapies; -Further development of advanced animal models;
- Expansion of biochemical research on the functions of the NF gene and dis-
- covery of new targets for drug therapy; Natural history studies and identification of modifier genes studies are already underway to provide a baseline for testing potential therapies and differentiate among different phenotypes of NF; and
- -Development of NF Centers, tissue banks, and patient registries.

# CONGRESSIONAL SUPPORT FOR NF RESEARCH

The enormous promise of NF research and its potential to benefit tens of millions of Americans in this generation alone has gained increased recognition from Congress and the NIH. This is evidenced by the fact that seven Institutes at NIH are currently supporting NF research (NINDS, NCI, NICHD, NCRR, NEI, NIDCD, and NHLBI), and NIH's total research portfolio has increased from \$3 million in 1990 to \$14 million this year. In May 2000, NINDS sponsored a workshop with NF researchers from across the country to define specific priorities in NF research. This Subcommittee's report language on NF included in past appropriations bills provided an impetus for this workshop which has intensified the NF research effort to move us closer to treatments and a cure.

The enormous advances in NF research would not have been possible without Congress's continued support of the NIH, and I would like to personally thank the Congress's continued support of the NIR, and I would like to personally thank the members of this Subcommittee for their leadership in working towards the goal of doubling the budget of the NIH over 5 years. We are entering the final year of this effort, and Illinois NF Inc. supports the appropriation of \$27.3 billion for the NIH in fiscal year 2003 to achieve this important goal.

At the same time, we are concerned that the NF research portfolio at NIH has declined in recent years, despite appropriations report language recommending a a range of diseases, we are hopeful that completing the doubling of the NIH budget will allow NF research funding to resume its upward trend. We appreciate the Sub-committee's strong support for NF research dating back to 1990, and will continue to work with you to ensure that opportunities for major advances in NF research are aggressively pursued.

This Subcommittee has long recognized that our goal should be to translate the promise of scientific discovery into an improved quality of life for all Americans. The example of the progress realized in NF research demonstrates the success of this vision and commitment.

Thank you again for the opportunity to tell you of the progress and potential of NF research.

# PREPARED STATEMENT OF THE NATIONAL CENTER FOR LEARNING DISABILITIES

My name is John Gantz and I am the volunteer chairman of the Board of Directors of the National Center for Learning Disabilities (NCLD). NCLD is a not-forprofit organization founded in 1977 that seeks to increase opportunities and improve outcomes for children and adults with learning disabilities (LD). As a parent of a child with learning disabilities, I am keenly aware of the need for greater access to services and increased awareness among parents, early child care providers, teachers and other professionals about how early screening and educational intervention can lead to greater success for all children in school and beyond.

I am pleased to submit testimony to encourage the committee's endorsement of Get Ready to Read!, a national screening program for parents of young children and early childhood health, education, and child care professionals to promote reading and school success. The initiative seeks to ensure that all parents, child care providers, teachers, and others have a research-based, easy-to-use screening tool to determine whether children aged 4-5 have the skills necessary to begin to learn to read and write; provide information, training, and support for parents and early childhood professionals to implement screening nationwide and engage in effective learning activities; and increase public awareness of the early literacy needs of all young children.

### BACKGROUND

Effective and developmentally appropriate early literacy instruction depends on all adults who care for a young child understanding where that child is in making progress toward being ready to read and write. Parents of young children and early childhood professionals need a better understanding of the prerequisite skills for reading and other aspects of literacy. They must be able to assess children's skills against standard research-based criteria. They also need to be able to recognize behaviors that place children at risk for reading and other forms of literacy difficulties. In addition, they need information and resources to take effective steps to ensure early success in learning to read, write, listen, and otherwise communicate effectively.

A variety of assessments are used to measure the reading proficiency of America's children by fourth grade. The data show that somewhere between 30 and 40 percent of U.S. fourth graders do not know how to read at grade level. This is an issue that goes well beyond the field of learning disabilities. Early literacy skills, reading proficiency, and school success are concerns of all parents and early childhood professionals.

Due in large part to longitudinal studies supported by the National Institute of Child Health and Human Development (NICHD) of the National Institutes of Health, there is compelling evidence suggesting that specific aspects of a young child's physical, cognitive, and social behaviors are most predictive of later learning difficulty, particularly in the area of early reading and related literacy skills (National Reading Panel, 2000). Studies have shown that learning to read is a relatively lengthy process that begins very early in children's development, well before they start formal schooling (Whitehurst & Lonigan, 1998). There is a high correlation between the number and quality of early language and literacy interactions and the acquisition of linguistic skills necessary for reading (Lyon, 1999).

start formar schooling (winterfutst & boingai, 1996). Inter as a high correlation of tween the number and quality of early language and literacy interactions and the acquisition of linguistic skills necessary for reading (Lyon, 1999). Recent research, including a Roper Starch survey released in 2000, also indicates that while the recognition of learning problems has increased substantially in the last few years, parents continue to wait to seek help for their children. Unfortunately, 40 percent of parents who suspect their children have learning problems wait a whole year or longer before seeking information and help from a teacher, physician or other professionals. Most children with learning disabilities and related problems are identified in third or fourth grades after they have experienced years of frustration and failure. Seventy-five percent of children with reading difficulties not identified by age nine will still have poor reading skills at the end of high school. Early identification and research-based educational intervention dramatically increases success in reading and other school subjects.

#### NEED FOR RESEARCH-BASED SCREENING AND ASSESSMENT

A number of complementary efforts are underway to help the United States become a nation of strong readers. In January, the President signed the No Child Left Behind Act and in early April the President conducted a roundtable with early childhood education experts to discuss how to design early childhood development research and to integrate scientific research with Head Start and other programs focused on preschoolers. Congress has also supported community-based literacy programs to improve the ability of children, as well as adults, to learn to read throughout our country. While the national education goal of having all preschool-age children ready to enter school is shared by parents, early childhood professionals and policymakers, the use of a research-based screening tool for all children in their prekindergarten year to determine early literacy skill development is not yet the first step in assuring this goal. To be effective, such a tool must be based on the results of scientific studies that identify and measure the skills young children need to become ready to read and write. To date, there has also been no coordinated national effort to encourage parents, teachers, child care providers, and others to systematically identify preschool-age children who show signs of early reading and other literacy difficulties using screening tools, and to provide them with related appropriate learning and other informational resources. NCLD's *Get Ready to Read!* initiative seeks to address this urgent problem.

### THE INITIATIVE

In 2000, through the leadership of Senator Thad Cochran and Representative Anne Northup, and in consultation with NICHD, NCLD recruited a team of national early literacy experts to develop the screening tool for *Get Ready to Read!*. The team, under the leadership of Grover Whitehurst, Ph.D., who now serves as the Assistant Secretary for the Office of Education Research Institute at the U.S. Department of Education, and Christopher Lonigan, Ph.D., worked closely with the NCLD staff and advisors to develop a 20-item screening tool. This was accomplished by identifying potential items for the tool from previous longitudinal research. The team assessed these items' predictability of later reading achievement in the second grade through secondary validation using existing data sets with samples of 4- and 5-year-old children from racially diverse, low- and middle-class families. A tool was created that is accessible, easy to use, and reliable. A full technical report on the tool's development is available.

The team, with NCLD's staff and other consultants, also has identified existing resources and developed new materials for parents and early childhood professionals to extend the usefulness of the screening program through specific educational activities. The initial product is a "tool kit" to support screening with orientation, instruction, scoring information, and practical follow-up activities.

## THE SCREENING TOOL

The 20-item screening tool focuses on the building blocks of literacy: linguistic awareness, print knowledge, and emergent writing. The tool is derived from the most current research- and practice-based knowledge about reliable early predictors of reading and other literacy skill success, and early identification of literacy problems in the preschool and early elementary grades. It is designed for both print and Web dissemination and is prepared in English. A Spanish version will be available in 2003. The tool allows for the collection of process and outcome evaluative data. It is easily usable by a wide audience of parents, child care providers, teachers, and related professionals including those who work with children of various cultural and socioeconomic backgrounds. Additionally, *Get Ready to Read!* is being widely disseminated through a network of national and state organizations, as well as through NCLD and a commercial publisher.

One of the most engaging aspects of this tool is that it is very easy to use. Parents, teachers and others can easily determine whether children are acquiring the skills they need to be ready to read and communicate effectively. The tool leads those most interested in the child's future to information and resources that maximize the child's development and minimizes his or her frustration and failure.

### DISSEMINATING THE TOOL AND RESOURCES THROUGH NATIONAL PARTNERSHIPS

Through a national network of 18 national nonprofit partner organizations, NCLD is extensively disseminating *Get Ready to Read!* to assure the widespread continuous use of the tool and other resources. The target audience includes parents, teachers, child care providers, and other professionals. NCLD's intention is to imbed the tool in the systematic operations of early childhood service organizations. In concert, the partners are assisting NCLD in promoting appropriate use of the screening tool for 4–5 year olds, informing the target audience about the skills necessary for early literacy, the potential to screen for these skills, and the consequences of children not acquiring these skills. Through the network of partners, NCLD will distribute up to 300,000 free print copies of the tool utilizing large membership organizations providing direct service to children aged 4–5, and the media focused on this audience. NCLD is also conducting a nationwide public awareness and marketing campaign.

### PRIVATE SECTOR PARTNERSHIPS

NCLD has a formal relationship with a major multimedia educational publisher to disseminate and support *Get Ready to Read!*. The company has assisted NCLD with the design, publishing, and printing of the tool and resource materials. NCLD has also established agreements with a leading educational Web portal to assure widespread electronic dissemination. Through these alliances, NCLD is reaching over 90 million page viewers per month including 300,000 teachers.

### FEDERAL SUPPORT

With federal appropriation dollars and private support, NCLD seeks to launch state and local demonstrations to distribute the tool and resources extensively in specific geographic areas, and assess their effects on parents, early childhood professionals, and communities. At the demonstration sites, NCLD will coordinate dissemination of the tool to the fullest extent possible through its partner organizations and its other contacts. The key emphases of the state and demonstrations is showing that parents and professionals use the screening tool appropriately and accurately interpret information based on the screen; that they have positive reactions in terms of increased knowledge and confidence in taking needed actions; and that they actually take the necessary next steps, including engaging in more literacy-rich activities, obtaining more information, and seeking professional services when appropriate. Mr. Chairman, by supporting NCLD's *Get Ready to Read!* program, you have the

Mr. Chairman, by supporting NCLD's *Get Ready to Read!* program, you have the chance to bring our collective investment in research, early education, and literacy to the next level, to meet the desired goal of school readiness and success. It's an exciting challenge and a tremendous opportunity. Together, we can help parents, child care providers, teachers, and others vested in our young children's well-being to have direct access to an easy-to-use screening tool that can determine whether a child is acquiring the skills needed to be ready to learn to read and write and thus succeed in school. By spending a limited amount of time and money early in a child's life, we can help prevent spending many times that amount later, as well as extensive problems in children's self-esteem and frustration. Let's take action with the reliable science available to us and give young children an early chance at success in school and in their lives. Thank you for your consideration and support.

## PREPARED STATEMENT OF THE PANCREATIC CANCER ACTION NETWORK

My name is Paula Kim and I am one of three founding members of the Pancreatic Cancer Action Network—fondly known as "PanCAN." I helped start this international patient advocacy organization in my home state of California after my father died from pancreatic cancer in 1998. It took nine active months for him to be diagnosed, and once diagnosed, he died within 75 days. This experience left me with many questions, great sadness and disappointment, as well as an opportunity to turn this experience into action aimed at how this disease can be prevented, accurately diagnosed and better treated.

### PanCAN's Mission

My co-founders and I started PanCAN 4 years ago along with a handful of enthusiastic volunteers who shared our commitment to challenging this disease. PanCAN seeks to focus national attention on the need to find the cure for pancreatic cancer. We provide public and professional education that embraces the urgent need for more research, effective treatments, prevention programs, and early detection methods. PanCAN is the first national patient based advocacy organization specifically focused on pancreatic cancer. We now have a full time staff of seven and thousands of volunteers who comprise our 27 TEAM HOPE affiliates all across the country. We even have members from as far away as Japan and Australia who have traveled to the United States to attend our workshops and learn more about what is being done to combat this disease.

### Background on Pancreatic Cancer

Let me begin by telling you a little bit about pancreatic cancer. Approximately 30,200 people in the United States will be diagnosed with pancreatic cancer this year. Pancreatic cancer's 99 percent mortality rate is the highest of any cancer, and the average life expectancy after diagnosis with metastatic disease is just three to 6 months. Pancreatic cancer is the 4th leading cause of cancer death in the U.S. for men and women, and only 4 percent of patients survive beyond 5 years. Because there is no cure or early detection methods, effective treatment options are extremely limited.

If the outlook were not already bleak, you should also know that the Federal government invests less money per fatality in pancreatic cancer research than in any other leading cancer. Thus, pancreatic cancer—in the words of the National Cancer Institute—is "disproportionately underrepresented in both clinical and basic research compared with other cancer sites." Despite a budget of over \$4 billion in fiscal year 2002, the NCI—by their estimates—will spend only \$24.6 million on pancreatic cancer.

Mr. Chairman, in my work with the pancreatic cancer community and talking with loved ones of patients who have died from this disease, I have heard countless dreadful stories of patients who pursued their symptoms for months or years to finally be diagnosed only to die within days, or were told to take over-the-counter medications for indigestion that wasn't indigestion—it was pancreatic cancer, or patients who were opened up for curative surgery only to be closed up and told to go home and get their affairs in order. I have heard from researchers who are stilled due to a lack of opportunities, resources, access to critical tissue specimens, and increasingly burdensome bureaucratic requirements. Unfortunately for all of us, this sad state of affairs leaves us with more questions than answers, and more hope than progress. I can attest to a few glimmers of hope shared from patients who were fortunate to team with highly trained pancreatic cancer specialists with proactive attitudes and approaches to dealing with the disease. There was the 37-year-old mother of two young boys who successfully battled her insurance company to cover her treatments in clinical trials only to lose the real battle to the disease at age 40, or the 63-year-old man who 6 years ago went to three different oncologists who all told him to get his affairs in order, before he found a fourth one willing and able to help him in his quest to live. These few glimmers are the exception and certainly not the rule as they should be.

Clearly, many steps must be taken to make up for lost time in investigating and treating this disease. Pancreatic cancer—the deadliest of all cancers—requires stable support, scientific depth and diversity to even scratch the surface of need. We must begin with a comprehensive plan of action, a critical mass of researchers, maximize the valuable resources of the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), other key agencies and stake-holders to team up and properly diagnose and treat this dreadful disease. PanCAN represents an entire community of survivors and loved ones who are counting on you and the scientific world to step up to the plate and give this disease and its victims the attention and resources that it deserves.

Here are several areas of urgent concern to the pancreatic cancer community:

# Pancreatic Cancer Progress Review Group (PRG)

A few years ago the National Cancer Institute (NCI) established the Pancreatic Cancer Progress Review Group or "PRG." As you know, PRGs are disease specific groups comprised of leading researchers, advocates, experts in cancer charged with identifying and prioritizing scientific needs and opportunities to assist the NCI in developing a national agenda and strategy for implementation that will expedite progress against a specific disease. I was privileged to serve as a member of the Pancreatic Cancer PRG and as Co-Chair on the PRG Health Services Research Committee. Our Pancreatic Cancer PRG Committee issued a report of our recommendations in February 2001. The report notes that the NCI is clearly aware that substantial increases in pancreatic research must be made to understand, prevent and control this deadly disease. The PRG report states "pancreatic cancer care is complicated, requiring a multidisciplinary approach," and further notes that despite investigators best efforts, "outcomes are nearly always disappointing." The Pancreatic Cancer PRG report identified key steps to be taken to increase support for this disease. PanCAN wholeheartedly endorses the steps outlined by the PRG report, and now it is essential that the NCI complete its planned implementation strategy phase of the PRG and provide adequate funding and leadership to implement the strategy derived from the PRG's recommendations. I would like to bring to your attention several specific initiatives that should be immediately implemented or expanded in order to expedite research on pancreatic cancer.

### INCREASE THE NUMBER OF INVESTIGATORS AND SPECIALIZED RESEARCH PORGRAM FOCUSED ON PANCREATIC CANCER

The PRG data suggests that there are less than 10 principal investigators who have multiple grants or a primary focus on pancreatic cancer. The pool of investigators with expertise in pancreatic cancer is very small. We must assemble a critical mass of both new and established researchers that is deep and diverse in talent and expertise. This is the cornerstone and hallmark of significant research progress and has been favorably demonstrated in all areas of disease. Several factors may contribute to this unnecessary situation. For starters, very few researchers are dedicated to pancreatic cancer research at any level because beginning and established investigators generally focus their careers in cancers that have a plentiful and established funding history as well as institutional commitment. In addition, low levels of NCI funding have historically resulted in low levels of pancreatic cancer research enthusiasm among scientists. To rectify this situation, ParCAN = Parcenter and develop meremone that the parties the progress that the progress the progress that the progress that the progress that the progress that the progress the progress the progress the progress that progress that the progress that the progress the progress that the progress the progress that the progress that the progress that the progress the progress the progress that progress that the progress the progress the progress that progress the progress the progress the progress the progress the progress the progress the progress the progress the progress the progress the progress the progress the progress the progress the progress the progress that progress the prog

In addition, low levels of NCI funding have historically resulted in low levels of pancreatic cancer research enthusiasm among scientists. To rectify this situation, PanCAN urges the NCI to take specific steps and develop programs that will provide incentives for doctors and Ph.Ds to pursue careers in pancreatic cancer research. Pancreatic cancer is a deadly cancer that poses tremendous scientific challenges. With more investigators and access to more pancreatic cancer patients, the next logical step to combat pancreatic cancer is to develop institutional commitment and specialized programs for this specific disease. Some immediate suggestions include:

# Fund A Minimum of Five Pancreatic Cancer SPORE Grants by Fiscal Year 2004

The NCI has announced that it will fund at least three inaugural pancreatic cancer-specific Specialized Program Of Research Excellence (SPORE) grants next year, assuming that the applications received meritorious scores following peer review. SPORE's were created by the NCI in 1992 to bring to clinical care settings novel ideas that have the potential to reduce cancer incidence and mortality, improve survival, and to improve the quality of life. Laboratory and clinical scientists work collaboratively to plan, design and implement research programs that impact on cancer prevention, detection, diagnosis, treatment and control. Mr. Chairman, since pancreatic cancer patients are in such dire need of all of treatments that work, and all these programs and services, PanCAN urges the NCI to fund no less than five SPORE grant programs by fiscal year 2004, with additional grants in the successive funding periods. By immediately establishing five SPORE's the NCI will foster and create the institutional commitment and individual research focused on pancreatic cancer that helps create the critical mass required for research progress.

### Continue to Fund Pancreatic Cancer Grants Above the Current Payline

For fiscal year 2002, the NCI increased the payline for 100 percent relevant pancreatic cancer research by 50 percent above the overall payline for NCI research grants. (This means that 100 percent relevant pancreatic cancer grants will be funded at a payline level that is 50 percent higher than grants with less than 100 percent or no relevance to pancreatic cancer.) This bold initiative implemented by the NCI was a clear statement that more research must be undertaken in the area of pancreatic cancer. Because pancreatic cancer basic and clinical research progress lags significantly, PanCAN urges the NCI to continue to fund 100 percent relevant pancreatic cancer grants at a level 50 percent above the payline for all grant mechanisms in fiscal year 2003.

DEVELOP KEY RESOURCES AND INFRASTRUCTURE TO BETTER UNDERSTAND AND DETER-MINE HOW THE MOLECULAR BIOLOGY OF PANCREATIC CANCER CAN BE HARNESSED FOR THERAPEUTIC GAIN

Pancreatic cancer is a unique disease that is difficult to study. Molecular aspects of normal cell differentiation and development of the pancreas are poorly understood. Molecular processes involved in the development of benign and malignant pancreatic diseases are known in part, although the nature and origin of the precursor cells for pancreatic cancer have not been delineated. Developmental biology techniques should prove useful for investigating cell lineage relationships in various animal models of pancreatic cancer and ultimately, in human disease. For example, novel cell labeling techniques have been developed for tracing cell lineage (i.e., mapping precursor-progeny relationships) in vivo during embryonic development. Understanding precursor/progenitor cell biology has greatly aided the development of diagnostic and therapeutic tools in leukemias and in cancer immunology. It is reasonable to anticipate that this knowledge will likewise be valuable for improving pancreatic cancer prevention, diagnosis, and treatment.

Therefore, a high priority of research should be to isolate, characterize, and propagate cells that initially differentiate into the gland itself.—These cells, or their immediate descendants, are likely targets for the various agents that cause pancreatic cancer and may be potential targets for chemoprevention. A number of inherited and acquired tumor-associated gene alterations present in pancreatic cancer have been identified, but significant gaps exist in our understanding of how these alterations occur in pancreatic cancer development, affect the interaction of signaling proteins in the course of the cancer, and influence molecular interactions between tumor and host. It remains a challenge to better understand and determine how the molecular biology of pancreatic cancer can be harnessed for therapeutic gain.

# DEVELOP BETTER METHODS TO CONTACT AND TRACK PANCREATIC CANCER PATIENTS TO DEVELOP OPTIMAL

As I have already noted, most pancreatic cancer patients usually die quickly within 3 to 6 months of being diagnosed and some very quickly. I recently learned that traditional National Cancer Institute research protocols compile a database of patients over several years for large studies. This is a problem with pancreatic cancer patients, as 99 percent of the patients are no longer alive to provide information to the researchers attempting to identify environmental and genetic factors, and gene-environment interactions that may have contributed to the development of the disease. For this reason, PanCAN urges that new "ultra-rapid methods" for case ascertainment must be developed, tested and implemented so that pancreatic cancer patients can be contacted very quickly after their diagnosis. Such methods may include immediate electronic reporting from pathology, radiology, and laboratory medicine departments, which would provide information on new patients in a timely manner.

### INCREASE AWARENESS AND EDUCATIONAL PROGRAMS ON PANCREATIC CANCER

There is a great lack of information on pancreatic cancer and its symptoms among both medical professionals and the public. Until actual screening tests are developed for this disease, awareness programs must be developed to educate people about risk factors, symptoms and symptom management for pancreatic cancer. PanCAN urges the CDC and the NCI to identify and coordinate the public health role in combating pancreatic cancer, so that the agencies can provide the public with adequate information on understanding the known risk factors, talking to one's doctor about this disease, selecting appropriate symptom and pain management for pancreatic cancer, and obtaining quality end of life care for those with advanced stage terminal disease.

disease. Mr. Chairman, the Federal research enterprise in the United States has made significant advances in combating many devastating diseases over the years. Unfortunately, pancreatic cancer has not been one of these victories. With your support, we can increase the Federal resources dedicated to improving diagnosis and treatment of this disease. Our goal is to make inroads against this disease so that in the near future the diagnosis of pancreatic cancer will no longer be a virtual death sentence for the 30,200 individuals who will be afflicted with this disease this year. The rate of incidence is increasing and is an alarming fact. Let's replace helplessness with hope.

Our motto at PanCAN is "Together, we can make a difference." Mr. Chairman, working with you and your colleagues, along with the NIH, CDC and the scientific community, I know that WE CAN and WILL make a difference in the lives of pancreatic patients and their loved ones.

Thank you for this opportunity to submit testimony on behalf of PanCAN.

## PREPARED STATEMENT OF THE AMERICAN SOCIETY OF CLINICAL ONCOLOGY

The American Society of Clinical Oncology (ASCO) represents more than 18,000 physicians and other health care providers involved in cancer treatment and research worldwide. Among our highest policy priorities is adequate federal funding for biomedical research generally and for research specifically into the prevention, diagnosis and treatment of cancer. Therefore, ASCO welcomes the opportunity to comment on fiscal year 2003 appropriations for the National Institutes of Health (NIH) and the National Cancer Institute (NCI).

At the outset, we commend the Congress as well as the Bush Administration for continued commitment to the 5-year plan to double the NIH budget. This bipartisan effort represents a model of good government dedicated to advancing human health. We are pleased that the Administration's fiscal year 2003 budget remains on track to achieve the doubling goal and that there appears to be bipartisan support in both Houses of Congress.

In addition, we recommend that funding for NCI be enhanced in accordance with the Institute's plan and budget proposal for fiscal year 2003 (the "Bypass Budget"). As directed by Congress in the National Cancer Act of 1971, each year the NCI delivers a "bypass" budget directly to the President. This process was implemented to ensure that the President and Congress directly receive NCI's scientific recommendations on the best way to appropriate funds to build on research successes, support the cancer research workforce, and ensure that recent discoveries are translated into improved patient care. For fiscal year 2003, the NCI recommends funding of \$5.69 billion, an increase of \$1.4 billion over the fiscal year 2002 appropriation. Funding NCI at this level will allow the Institute to fund promising and innovative investigator-initiated research proposals and facilitate research that capitalizes on important advances in molecular biology. ASCO believes the bypass budget includes a persuasive rationale for boosting the NCI budget to \$5.69 billion, and we urge the Subcommittee to begin the new millennium by implementing this carefully considered budget proposal. Every 3 years, NCI seeks from the extramural research community recommenda-

Every 3 years, NCI seeks from the extramural research community recommendations for unique funding opportunities in cancer research. Once identified, NCI develops specific objectives and plans for each of these "extraordinary opportunities for investment," and incorporates them in its annual budget planning document. In October 2001, ASCO submitted its recommendation that symptom control and palliative care research designate as such a research opportunity for a new 3-year cycle beginning in 2004. As noted recently by the Institute of Medicine report *Improving*  Palliative Care for Cancer, at least half of patients dying with cancer experience a spectrum of symptoms that go untreated—or under-treated—and greatly reduce the quality of their remaining days. Symptom control and palliative care research is a broad-based frontier of inquiry that holds tremendous potential to reduce the burden of cancer for patients and their families. ASCO recommends that this are a receive heightened focus from the cancer research community, particularly NCI. While the overall levels of proposed fiscal year 2003 funding for biomedical re-

While the overall levels of proposed fiscal year 2003 funding for biomedical research are highly commendable, we believe there remain certain imbalances in the distribution of funding that may inhibit rapid diffusion of new technologies into treatment settings for the benefit of patients. Discoveries through basic science about how cancer develops provide many intriguing targets for translational and clinical research. Yet these activities remain underfunded. If we lack the ability to translate basic science discoveries into clinical applications, then our investment in biomedical research will remain unrewarded in terms of patient benefit.

The status of clinical trials provides a good example. Recognizing that the participation rate for cancer clinical trials has remained unacceptably low, the cancer community has undertaken a number of initiatives to address the shortfall. Communication and public education strategies have been implemented, and, in a signal victory, patient advocates working together with clinical researchers have convinced the Medicare program to cover routine patient care costs for beneficiaries enrolled in clinical trials. Overall, participation has improved somewhat, but one important rate-limiting step remains the significant underpayment to physicians for enrolling patients in trials.

In 1998 ASCO initiated studies designed to determine the activities and corresponding costs associated with conducting a well-designed and -executed clinical trial. The ASCO studies found that the average per-patient cost to enroll in a clinical trial is \$2,000. Yet the NCI reimburses at a rate of \$1,500 per patient. Participation in clinical research requires substantial infrastructure investment, including hiring trained research nurses and data managers and purchasing computer equipment. Without adequate payment for the very real costs of managing clinical trials, physicians will not be able to offer clinical trials as an option for their patients. As a result, not only will individual patients' treatment options be limited, but progress against the disease will be restrained.

Aside from adequate funding of ongoing clinical trials, we also believe that NCI should be encouraged to devote more resources to translational research activities through which the many genetic and molecular targets identified by basic science could be developed into concrete therapies that could then be tested in clinical trials. There is a very strong sense among practicing oncologists and clinical cancer researchers that basic science has offered a myriad of such targets, and now it may be time to reassess the balance of research funding among basic, translational and clinical research.

Therefore, as the Appropriations Committee deliberates the specifics of funding for NCI, we urge that the Committee and the Congress consider whether there should be a change in the historical focus of the Institute, moving the emphasis toward development and implementation of new therapies that utilize the basic science research discoveries of the past few decades.

ASCO appreciates the opportunity to submit its views on NIH funding and clinical research. On behalf of oncologists and their patients, we urge Congress to continue its strong support of NIH. We also recommend that special attention be paid to the clinical research enterprise to ensure that basic research findings are promptly brought to the patient bedside.

# PREPARED STATEMENT OF THE NATIONAL COALITION FOR HEART AND STROKE $$\operatorname{Research}$$

My name is Jack Owen Wood. I solicit your support for more aggressive federal funding for research into prevention and treatment of the sister diseases, stroke and heart disease. Strokes and heart attacks are occurring at an alarming rate.

I am representing the National Coalition for Heart and Stroke Research. The coalition consists of 14 national organizations representing more than 5 million volunteers and members united in support for increased funding for heart and stroke research. Members of the Coalition include:

American Academy of Neurology; American Academy of Physical Medicine and Rehabilitation; American Association of Neurological Surgeons; American College of Cardiology American Heart Association; Americans for Medical Progress; Congress of Neurological Surgeons; American Neurological Association; Association of Black Cardiologists; Citizens for Public Action on Blood Pressure and Cholesterol, Inc.;

Mended Hearts, Inc.; North American Society of Pacing and Electrophysiology; Stroke Connection, Inc.; and National Stroke Association. I will deal primarily with one man's personal experience with stroke and its func-

tional and financial costs—my own. I have only the use of my right arm. I was born in 1937, raised in Vicksburg, Mississippi, earned an engineering de-

gree at Mississippi State University and currently reside in Port Orchard, Washington. I worked for the Boeing Company in Seattle, am a former Director of the Washington State Energy Office, served as Director of Cost and Revenue Analysis and as the Forcasting Manager for a major Northwest Area Natural Gas Utility

until May 1, 1995. On May 1, 1995, at the age of 57, I was stricken and severely disabled by my stroke. Two years later I experienced a triple bypass heart operation. You might say I've "been there and done that" for both major cardiovascular diseases. So you see, I am an expert.

Several years ago I was offered an exciting and rewarding volunteer opportunity. I was asked to lead the "JACK WOOD STROKE VICTOR TOUR" for the American Heart Association

The JACK WOOD STROKE VICTOR TOUR was a 5-state lobbying tour. Through it I tried to meet personally with every Northwest Congressional representative on his or her home turf (in Alaska, Idaho, Montana, Oregon and Washington). In each his or her home turt (in Alaska, Idaho, Montana, Oregon and Washington). In each meeting I was joined by local people, stroke survivors and their families and medical professionals. I told my story and asked them to join the Congressional Heart and Stroke Coalition and to support increased federal heart and stroke research funding. I am proud to say I traveled to 18 communities and met personally with 28 mem-bers of our delegation or their staff. Nearly half of our congressional delegation is now members of the Congressional Heart and Stroke Coalition. One of the most powerful memories for me was the frequency in which Members of Congressional staff. One of the most powerful memories for me was the frequency in which Members

of Congress or staff members related their personal experience with stroke. One member I spoke to lost both parents to stroke. I suspect many of you have stories too.

I realize your interest is greater than the physical impact of my stroke. Your con-cern must include the financial impact, not only to me, but also on our country from increased health care costs and lost productivity and its many implications.

I have confronted the difficult and painful task of calculating that cost to me. Be-sides being a man whose stroke took his ability to pick up and play with his grandchildren, his livelihood, and marriage, I remain a statistician at heart. I couldn't re-sist calculating and telling that part of my story. But please remember my story is not dissimilar to that of many of the 4.6 million stroke survivors in the United States. Many of whom were stricken in their prime earning years. Who in a matter of moments, seemingly without warning, are transformed from a contributor and provider to a receiver and patient.

Allow me to highlight three figures that I feel sum up my data and should be important to you. I estimate that my stroke at age 57:

-Reduced my earnings before retirement age 65 by over \$600,000.

- Subsequently, the cost to the federal government in lost income and other taxes, early Medicare payments and Social Security disability payments is over \$320,000.
- My HMO spent approximately \$150,000 to respond to and treat my stroke.

-One man, over \$1 million. About 600,000 Americans will suffer a stroke this year costing this nation an esti-mated \$50 billion in medical expenses and lost productivity.

Earlier I described a stroke as occurring seemingly without warning. All too often as in my case, people either don't know or ignore the signs of a stroke, even one in progress. When my stroke hit I denied it. It took me two days after my stroke to acknowledge it and seek help. Because of research into new treatments, we now have tPA, a clot-busting drug, which if administered within 3 hours of the onset of stroke symptoms, can dramatically reduce the damage of clot-based strokes. Had I recognized and acknowledged my stroke, gone to a hospital with a neurologist on staff and had there been tPA, the impact of my stroke most certainly would have been lessened.

What is even more painful to me is that my impending stroke could have been detected. Unfortunately, we need to create easier and less expensive diagnostic techniques so that effective diagnostics can be given routinely as part of regular health exams. And they must be covered through insurance.

I am not asking for your sympathy. Instead, please think of me as two of the ghosts in the famous Dickens' story. Please don't misunderstand, I'm not casting you as Scrooge. See me as both the ghosts of things past and things yet to be. I too am here to tell you, the future, which I represent, needs not be. It is largely up to you. I hope my story and estimate of the cost of my stroke convinces you that taking on stroke and heart disease through increased research, leading to better prevention, diagnosis and treatment is fiscally responsible. The human and financial costs are astronomical.

Thank you for your past support of research and recent decision to eliminate (at least for now) restrictions on reimbursement for rehabilitation services, essential to those who have experienced a stroke. Please continue and broaden that support.

# PREPARED STATEMENT OF THE DIGESTIVE DISEASE NATIONAL COALITION

### SUMMARY OF FISCAL YEAR 2003 RECOMMENDATIONS

- —A 16 percent increase for the National Institutes of Health as well as a 16 percent increase for all institutes and centers, specifically the National Institute of Diabetes and Digestive and Kidney Diseases and the National Institute of Allergy and Infectious Diseases.
- -Increased focus on Digestive Disease Research and Education at NIH, including: Inflammatory bowel disease, endoscopic research, irritable bowel syndrome, hepatitis, pancreatic cancer, colorectal cancer, celiac disease, gluten intolerance, and hemochromatosis.
- -\$20 million for the Centers for Disease Control and Prevention's National Colorectal Cancer Screening Awareness Program.

Mr. Chairman and members of the subcommittee, thank you for the opportunity to appear before you today. I am Dr. Maurice Cerulli, a practicing gastroenterologist and Chief of Gastroenterology at The Brooklyn Hospital Center and president of the Digestive Disease National Coalition (DDNC). Founded in 1978, the DDNC is a voluntary organization comprised of 28 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 the millions of Americans suffering from both acute and chronic digestive disorders.

Mr. Chairman, the social and economic impact of digestive disease is enormous. Digestive disorders afflict approximately 62 million Americans, resulting in 50 million visits to physicians, 10 million hospitalization, 230 million days of restricted activity, and nearly 200 deaths annually. The total cost associated with digestive diseases has been conservatively estimated at \$60 billion a year. On behalf of the DDNC, I would like to thank the subcommittee for its past sup-

On behalf of the DDNC, I would like to thank the subcommittee for its past support of digestive disease research and prevention programs at the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). With respect to the coming fiscal year, the DDNC joins the Ad Hoc Group for Medical Research Funding in recommending a 16 percent increase for the National Institute of Diabetes and Digestive and Kidney Disease (NIDDK), the National Institute of Allergy and Infectious Diseases (NIAID) and the NIH overall.

#### INFLAMMATORY BOWEL DISEASE

Up to one million people in the United States suffer from Crohn's disease and ulcerative colitis, collectively known as inflammatory bowel disease (IBD). These are serious diseases that affect the gastrointestinal tract causing bleeding, diarrhea, abdominal pain and fever. Complications of IBD can include anemia, ulcers of the skin, eye disease, colon cancer, liver disease, arthritis, and osteoporosis. Crohn's disease and ulcerative colitis are not usually fatal, but they can be devastating. We do not know the cause, and we have no cure.

In recent years we have made significant progress in the fight against IBD. In 1998, the FDA approved the first drug ever specifically for Crohn's disease. The DDNC encourages the subcommittee to continue its support of IBD research at NIDDK and NIAID at a level commensurate with the overall increase for each institute.

Given the recent advancements in treatment for these diseases and the increased risk that IBD patients have for developing colorectal cancer, the DDNC believes that generating improved epidemiological information on the IBD population is essential if we are to provide patients with the best possible care. Therefore, the DDNC, and its member organization the Crohn's and Colitis Foundation of America, encourage the CDC to initiate a nationwide IBD surveillance and epidemiological program in fiscal year 2003.

### ENDOSCOPIC RESEARCH

There continues to be tremendous potential for the development of new diagnostic and therapeutic procedures for gastrointestinal disorders. Without surgery, using endoscopes, we can find bleeding ulcers and stop the bleeding; we can take out stones that are blocking the bile duct; and we can cut out colon polyps to prevent colorectal cancer. The Clinical Outcomes Research Initiative (CORI) program is allowing us to link more than 50 centers around the country to assess the outcomes of endoscopic therapies. The gastroenterology community looks forward to working with the NIDDK to expand its endoscopic research program and we encourage the subcommittee to support this important effort.

# HEPATITIS C: A LOOMING THREAT TO HEALTH

It is estimated that there are over 4 million Americans who have been infected with hepatitis C of which over 2.7 million remain chronically infected. About 10,000 die each year and the Centers for Disease Control and Prevention (CDC) estimates that the death rate will triple by 2010 unless there is additional research, education and more effective treatments and public health interventions. Moreover, liver failure from HCV now accounts for more than half of all the liver transplants performed in the United States and is the leading cause of liver cancer. Unfortunately, the majority of infected individuals are unaware that they have contracted the disease.

The DDNC joins with the liver disease community in recommending an increase of \$66 million in fiscal year 2003 for CDC's Hepatitis C Prevention Strategy program. This new funding will expand the number of states with CDC sponsored hepatitis C prevention coordinators from 16 to 50. In addition, we recommend an appropriation of \$40 million for CDC's Prevention Research Centers program.

#### PANCREATIC CANCER

In 2001, an estimated 28,300 in the United States were found to have pancreatic cancer and approximately 28,200 died from the disease. Pancreatic cancer is the fourth leading cause of cancer death in men and women. Only 2 out of 10 patients will live 1 year after the cancer is found and only a very few will survive 5 years. Although we do not know exactly what causes pancreatic cancer, several risk factors linked to the disease have been identified:

(1) Age.-Most people are over 60 years old when the cancer is found;

(2) Sex.—Men have pancreatic cancer more often than women;

(3) Race.—African Americans are more likely to develop pancreatic cancer than

are white or Asian Americans;

(4) Smoking;

(5) Diet.-Increased red meat and fats; and

(6) Diabetes.

The National Cancer Institute has established a Pancreatic Cancer Progress Review Group charged with developing a detailed research agenda for the disease. The DDNC encourages the subcommittee to provide an increase for pancreatic cancer research at a level commensurate with the overall percentage increase for NCI.

# COLORECTAL CANCER PREVENTION

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. Colorectal cancer affects men and women equally. Although colorectal cancer is preventable and curable when polyps are detected early, a General Accounting Office report issued in March 2000 documented that less than 10 percent of Medicare beneficiaries have been screened for colorectal cancer. This report revealed a tremendous need to inform the public about the availability and advisability of screening and educate health care providers about colorectal cancer screening guidelines.

CDC's National Colorectal Cancer Screening Awareness Program is addressing these needs by partnering with organizations like the DDNC and its coalition partners (AGA, ASGE, ACG, UOA) to develop an advocacy agenda emphasizing the value of early detection. The digestive disease community hopes that this program will do for colorectal cancer screening rates what the CDC's Breast and Cervical Cancer Screening Program has done for mammography and Pap smear screening compliance.

The DDNC has seen first-hand the ambitious agenda that the CDC and its partners have developed to reduce the incidence of colorectal cancer. We are convinced that we can make a significant impact on screening rates across the country if given adequate resources. Therefore, the Coalition encourages the subcommittee to provide CDC with \$20 million for this important program.

### IRRITABLE BOWEL SYNDROME (IBS)

IBS a disorder that affects an estimated 35 million Americans. The medical community has been slow in recognizing IBS as a legitimate disease and the burden of illness associated with it. Patients often see several doctors before they are given an accurate diagnosis.

an accurate diagnosis. Once a diagnosis of IBS is made, medical management is limited because the medical community still does not understand the pathophysiology of the underlying conditions. Living with IBS is a challenge, patients face a life of learning to manage chronic illness that is accompanied by pain and unrelenting gastrointestinal symp-toms. Trying to learn how to manage the symptoms is not easy. There is a loss of spontaneity when symptoms may intrude at any time. Plans made often need to be changed. IBS is unpredictable. One can wake up in the morn-ing feeling fing and within a chart time argument at the point

ing feeling fine and within a short time encounter abdominal cramping to the point of being doubled over in pain and unable to function.

The unpredictable bowel symptoms may make it next to impossible to leave home. It is difficult to ease pair that may repeatedly occur periodically throughout the day. One becomes reluctant to eat for fear that just eating a meal will trigger symptoms all over again. IBS has a broad and significant impact on a person's quality of life. It strikes individuals from all walks of life and results in a significant toll of human suffering and disability.

While there is much we don't understand about the causes and treatment of IBS, we do know that IBS is a chronic complex of symptoms affecting as many as one in five adults. In addition;

(1) It is reported more by women than men.

(2) It is the most common gastrointestinal diagnosis among gastroenterology practices in the United States.

(3) It is a leading cause of worker absenteeism in the United States.
(4) It costs the U.S. health care system an estimated \$8 billion annually.

Mr. Chairman, much more can still be done to address the needs of the nearly 35 million Americans suffering from irritable bowel syndrome and other functional gastrointestinal disorders. We understand the challenging budgetary constraints that this subcommittee is operating under, yet we hope you will carefully consider the tremendous benefits to be gained by supporting a strong research and education program for irritable bowel syndrome at NIH and CDC.

Mr. Chairman, on behalf of the millions of digestive disease sufferers, we appreciate your consideration of the views of the Digestive Disease National Coalition. We look forward to working with you and your staff.

# PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION

# INTRODUCTION

Thank you for the opportunity to submit written testimony regarding fiscal year 2002 appropriations for the National Institutes of Health (NIH), the Centers for Dis-

ease Control (CDC), and for the Health Resources and Services Agency (HRSA). I am Linda Carr, president of the Pulmonary Hypertension Association (PHA). I I am Linda Carr, president of the Pulmonary Hypertension Association (PHA). I became active within PHA when my daughter was diagnosed with primary pul-monary hypertension. Pulmonary hypertension is a rare disorder of the lung, in which the pressure in the pulmonary arteries (the blood vessels in the lungs) rises above normal levels and may become life threatening. Symptoms of pulmonary hy-pertension include shortness of breath with minimal exertion, fatigue, chest pain, dizzy spells and fainting. When pulmonary hypertension occurs in the absence of a known cause, it is referred to as primary pulmonary hypertension (PPH). This term should not be construed to mean that because it has a single name it is a single disease. There are likely many unknown causes of PPH

disease. There are likely many unknown causes of PPH. Secondary pulmonary hypertension (SPH) means the cause is known. Common causes of SPH are the breathing disorders emphysema and bronchitis. Other less frequent causes are the inflammatory or collagen vascular diseases such as scleroderma, CREST syndrome or systemic lupus erythematosus (SLE). Congenital heart diseases that cause shunting of extra blood through the lungs like ventricular and atrial septal defects, chronic pulmonary thromboembolism (old blood clots in the pulmonary artery), HIV infection, liver disease, and diet drugs like fenfluramine and dexfenfluramine are also causes of pulmonary hypertension.

Pulmonary hypertension is frequently misdiagnosed and has often progressed to late stage by the time it is accurately diagnosed. Pulmonary hypertension has been historically chronic and incurable with a poor survival rate. However, new treat-ments are available which have significantly improved prognosis. Recent data indi-

cate that the length of survival is continuing to improve, with some patients able to manage the disorder for 15 to 20 years or longer.

Ten years ago, when three patients who were searching to end their own isolation founded this organization, there were less than 50 diagnosed cases of this disease. It was virtually unknown among the general population and not well known in the medical community. They soon realized that this was not enough and as membership began to grow—driven by a newsletter distributed by doctors—and a community began to form, an 800 number support line was launched, support groups were established, a Scientific Advisory Board (SAB) was formed, a Patient's Guide to Pulmonary Hypertension was written, and a web site was launched. Today, PHA includes:

-An international network of over 50 support groups

-An active and growing patient hotline

- A new and fast-growing research fund (A cooperative agreement has been signed with the National Heart, Lung, and Blood Institute to jointly create and fund, 5-year, mentored clinical research grants and PHA awarded it's first four Young Researcher Grants.)
- -A host of numerous electronic and print publications

# **KEY RECOMMENDATIONS FOR FISCAL YEAR 2003**

# Centers for Disease Control and Prevention

PHA applauds the subcommittee for its leadership in encouraging CDC to initiate a professional and public PH awareness campaign. Currently, we are working with officials from the CDC to establish this important program that will better inform health care professionals and the general public about PH, its symptoms, and treatment options. The following is a description of the specific initiatives we hope to launch in collaboration with CDC.

(1) Increasing awareness and understanding of PH among primary care physi-cians is critically important, because these practitioners are usually the first point of contact for PH patients. If the primary care doctor misses the symptoms, then the chance for early diagnosis depends upon the intuition and persistence of the patient. They have a chance, if they agressively pursue diagnosis by trained and aware specialists. If they are not aggressive, or if they are in a health plan that requires their general practitioner to prescribe the referral, they are more likely to go undiagnosed until it is too late to control their illness. To increases awareness we propose to launch:

- -Written and video diagnostic tools for placement on the Internet. -A postcard mailing to be sent to all primary care physicians, medical schools and medical centers in the United States drawing attention to the new web resources
- A simplified and visually attractive version of the proper diagnostic procedures, which will be sent in a second mailing to all primary care physicians, medical schools, and medical centers in the United States.
- Advertising in publications general practitioners are likely to read. The empha-sis will be the urgency and ease of early diagnosis and the ease of accessing diagnostic tools via the Internet.
- A  $\dot{CD}$ -ROM that explains pulmonary hypertension from a variety of angles. We would like to make 100,000 of these available to the medical community and patients through our web site on an as requested basis and at conferences and through targeted mailings.

(2) Due to the advancements in treatment for PH, it is important that we also focus on educating cardiologists and pulmonologists. Our strategies for reaching cardiovascular specialists include:

- Publication of the first Pulmonary Hypertension Journal focused on educating a wider population of doctors on issues related to the diagnosis and treatment of the illness.
- -Placement of additional detailed information on the illness on the web. The PH Journal and other publications will promote this availability.
- Expansion of PHA's international conference on pulmonary hypertension (the largest PH conference in the world).
- -Expansion of PHA's Pulmonary Hypertension Resource Network. This program

is focused on increasing awareness of PH among nurses through peer education. (3) Finally, PHA is committed to increasing PH awareness among the general public through the development of the following initiatives:

A series of 10, 15, and 30 second public service announcements on PH. These PSAs will be in both audio and video form.

-A PH media relations manual.

-An organ donation Awareness Campaign (unfortunately, many PH patients die before finding a suitable organ donor).

—Expansion of PHA's web site.

We look forward to working with CDC to implement these and other initiatives aimed at increasing awareness of PH in the United States and throughout the world. For fiscal year 2003, we encourage the subcommittee to continue to support the mission of the CDC with an overall appropriation of \$5 billion (an increase of \$800 million over fiscal year 2002). Moreover, we urge you to continue support of the PH public and professional awareness initiative within CDC's Cardiovascular Disease program (a division of CDC's Chronic Disease Prevention program).

### National Heart, Lung and Blood Institute

Mr. Chairman, PHA commends the leadership of the National Heart, Lung and Blood Institute (NHLBI) for its support of PH research. Two years ago, two separate groups of scientists funded by NHLBI simultaneously identified a genetic mutation associated with primary pulmonary hypertension.

The two groups independently reported that defects in the BMPR2 gene, which regulates growth and development of the lung, are associated with PPH. The defects in the gene lead to the abnormal proliferation of cells in the lung characteristic on PPH.

Although both studies suggest that only one gene is involved in PPH, neither group identified the defects in BMPR2 as the sole cause of PPH. In addition, since many people without a known family history of PPH get the disease, both groups suggested that other factors may interfere with control of the tissue growth. Now that we have pinpointed a gene, we can focus on learning how it works. Hopefully, that information will enable researchers to devise better treatments and perhaps eventually a preventive therapy or cure.

Mr. Chairman, PHA would like to thank you and the subcommittee for your leadership in support of funding for the National Institutes of Health. Moreover, we would like to thank the subcommittee for the inclusion of committee recommendations on PH research at NHLBI in the fiscal year 2003 Senate L-HHS report. For fiscal year 2003, PHA joins with the Ad Hoc Group for Medical Research Funding in supporting a 16 percent increase for NHLBI. Finally, we request that the subcommittee provide \$25 million in fiscal year 2003 for PH research at the institute to enhance basic research, gene therapy and clinical trials of promising new therapies.

### Gift of Life Donation Initiative at HRSA

Mr. Chairman, PHA commends the leadership of Secretary Thompson on the success of his promise the, "Gift of Life Donation Initiative." Currently, there are many drugs that PH patients can choose from to help alleviate the effects of PH; however, these drugs are often used until a patient can no longer wait for a heart or more often, a lung transplant. Immediately following diagnosis, many PH patients sign on to a transplant waiting list and continue to take their medication. Unfortunately, for many it is too late, and pass away before they can receive their much needed transplants. This why PHA has started Bonnie's Gift.

Bonnie's Gift was started in memory of Bonnie Dukart, one of the three founding members of PHA, and a PH patient herself. Bonnie battled with PH for almost 20 years until her death in 2001 following a double lung transplant. Prior to her untimely death, Bonnie expressed an interest in the development of a program within PHA related to transplant information and awareness. PHA will use Bonnie's Gift as a way to disseminate information about PH, the importance of early listing, the importance of organ donation to our community and organ donation cards. Consequently, PHA applauds the administration for its "Gift of Life Donation Ini-

Consequently, PHA applauds the administration for its "Gift of Life Donation Initiative," which is designed to increase organ donation rates throughout the country. We look forward to working with the "Gift of Life Donation Initiative" to increase awareness of the importance of organ donation among the PH community, the medical community and the public. Mr. Chairman, PHA supports the president's fiscal year 2003 budget proposal of \$25 million for HRSA's "Gift of Life Donation Initiative."

## CONCLUSION

Mr. Chairman, once again thank you for the opportunity to present the views of the Pulmonary Hypertension Association. We look forward to continuing to work with you and the subcommittee to improve the loves of pulmonary hypertension patients. If you have any questions or would like additional information, please do not hesitate to contact me or the PHA National Office in Silver Spring, Maryland (301) 565–3004.

### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION FOR CANCER RESEARCH

The mission of the American Association for Cancer Research (AACR), the world's oldest and largest professional society of basic, translational, and clinical cancer researchers, is to accelerate the prevention and cure of cancer through research, education, communication, and advocacy. With over 18,000 members worldwide the AACR is the authoritative voice for the overall continuum of cancer research from laboratory discoveries through the development of new medicines and technologies to prevent, detect, and treat cancer.

Cancer is the disease that Americans fear most, and their fears are understandable. As we look forward into this new century, at current rates, it is projected that one-half of men and one-third of women in America today will be diagnosed with cancer in their lifetime, and 25 percent of our population will die from cancer. Since 1990, there have been 12 million new cases of cancer diagnosed, and 5 million Americans have died from their disease. Since cancer rates are approximately 2.2 per 100,000 in people under 65 vs. 22.2 per 100,000 in those over 65 years of age, we can expect the cancer epidemic to increase significantly in the next 10–20 years due to the aging of the "baby boomers" and the changing demographics of America. In addition, at current rates, we also expect cancer incidence and mortality to increase in those groups which suffer a disproportionate burden of cancer—namely, the poor, medically underserved, and minority populations. Cancer cost our nation over \$156 billion in 2001 and unless we move quickly to impact both incidence and mortality from cancer, these costs could more than double on an annual basis by 2010.

These sobering statistics both drive and inspire the members of the AACR to achieve the organization's mission to prevent and cure cancer with a real sense of urgency, and have prompted the Administration and Congress to make the elimination of cancer one of our highest national healthcare priorities. On behalf of all of the members of the AACR, we offer our sincere appreciation for your active support for funding the 4th year of the 5-year strategy to double the budget for the National Institutes of Health (NIH), and specifically thank you for the 2002 budget increase for the National Cancer Institute (NCI). Your leadership is especially gratifying in the face of the tough 2002 budget choices you were required to make following the tragic events of September 11, 2001.

As a result of our past investments, as well as the unified efforts of the Administration and Congress with basic and clinical scientists, cancer survivors and advocates, and the public, the incidence and mortality of several cancers are on the decline for the first time in decades. Unfortunately, the incidence of several of the major cancers (lung, breast, prostate, and colon) is still increasing or remaining stable, and we must do more to conquer these major killers. Looking to the future, it is clear that these past investments in biomedical and

Looking to the future, it is clear that these past investments in biomedical and cancer research are providing scientists with an ever-increasing understanding of the fundamental differences between cancer and normal cells. However, it is also clear that developing the knowledge needed to understand and control cancer cells at the genetic and molecular levels is a "work in progress." As we look forward to 2003 and beyond, we must strengthen our commitment and redouble our support for the basic research required to "fuel" the engine of discovery. Advancing these laboratory discoveries through the myriad of preclinical, clinical, and regulatory steps required to become the new commercial products so badly needed to address the current and future cancer epidemic is called "translational research." or simply "translation." We cannot choose to do one or the other; rather we must parallel our national efforts in basic research with the translational research needed to advance critical scientific breakthroughs from the laboratory into new technologies and drugs to prevent and cure cancer.

Fortunately, results from our prior investments in cancer research have provided the basis for a "sea change" in our understanding of the large number of diseases (over 200) that we refer to as cancer. Completing the sequence of the human genome and advances in complementary areas of biomedical research such as immunology, biochemistry, and informatics over the past 25 years has provided us with a solid foundation for future progress. For example, our increased understanding of the abnormal genes in cancer cells (genomics) and the resulting aberrant proteins that they produce (proteomics) provide exciting new opportunities to discover, develop, and commercialize targeted, non-toxic agents and rational technologies to prevent and cure cancer.

In fact, this past year re-enforced the promise of genetically based targeted thera-pies for cancer by providing the first "proof of concept" for these new agents. The hope is that through a thorough understanding of the abnormal genes (genomics) and proteins (proteomics) in cancer cells, cancers can be targeted on the basis of specific molecular changes. In 2001, the Food and Drug Administration (FDA) approved a new-targeted, non-toxic drug for the treatment of chronic myelogenous leukemia (CML), a disease that is diagnosed in approximately 4700 people each year. kemia (CML), a disease that is diagnosed in approximately 4700 people each year. CML accounts for 15–20 percent of leukemia in adults, and the prior therapy of choice for this cancer was bone marrow transplantation. Several years of funda-mental research by numerous scientists provided the basis for the discovery of the specific molecular pathway in CML patients that is targeted by Gleevec; the drug was ultimately developed through a public-private partnership between a university (Oregon Health Sciences University) and a pharmaceutical company (Novartis). Al-though it is still early in the clinical history of this new drug to measure its poten-tial for long-term cures, it is the first drug to successfully target and block the ab-normal protein responsible for uncontrolled production of white cells in CML. To date, the results in refractory patients are spectacular and unprecedented. date, the results in refractory patients are spectacular and unprecedented. Although we are poised to make real progress toward realizing our vision of pre-

venting and curing cancer, critical problems and barriers to progress exist that must be addressed. In addition to supporting new innovative research ideas, as previously noted, we must also create the national infrastructure and systems required for the "seamless" transfer of technology required to develop the new medicines and tech-nologies that we need to prevent and cure cancer. The following represent some examples of critical problems and/or barriers across the continuum of cancer research, technology transfer, and commercialization that must be addressed through our ap-propriations for the NIH and the NCI in 2003 and beyond: —Improve funding for new research ideas by increasing funding for approved NCI

- grant proposals for individual investigators from the current level of 24 percent to 40 percent.
- -Provide support to train the future cancer workforce, especially the physicians and basic scientists needed to perform translational and clinical research.
- -Build the needed "infrastructure", including capabilities in informatics, to sup-port translational research through existing cancer centers and new-dedicated entities.
- Increase enrollment on clinical trials from the current level of 3 percent to evaluate new cancer therapies and preventives.
- Create responsive public-private partnerships to encourage technology transfer Address the issue of cancer disparities in poor, medically underserved, and mi-
- nority populations.

Addressing these issues and optimizing our opportunity to turn recent advances in biomedical and cancer research into revolutionary new drugs and technologies to prevent and cure cancer will depend in large measure on our willingness to provide appropriate levels of federal funding. The tragic events of September 11, 2001, were devastating, but Americans have emerged united in our resolve to defeat terrorism and defend our way of life, including ensuring the health of our citizens. Cancer affects every family in America, and although setting funding priorities for 2003 will be difficult, it is clear that now is the time to harness the strengths of all of the sectors involved in the continuum of cancer research, commercialization, and deliv-

ery to turn the tide against this tragic disease. The AACR requests that you support the President's budget proposal to complete the doubling of the NIH in 2003, by providing an increase of \$3.7 billion (15.7 per-cent). The AACR also requests you make the eradication of cancer one of American's top healthcare priorities by providing full funding for the NCI's Bypass Budget at the requested level of \$5.69 billion for fiscal year 2003. This budget reflects the funding that the Director of the NCI deems necessary to fully leverage current sci-entific opportunities and hasten the defeat of cancer. It is also important to increase funding for cancer programs at the Centers for Disease Control and Prevention (CDC) to ensure that new drugs and technologies reach all Americans, especially minority and medically underserved populations.

In addition, we must look forward and develop a rational and appropriate strategy for funding the NIH and the NCI in 2004 and beyond. It would be catastrophic to drastically reduce funding for the NIH and the NCI at what the new Director of the NCI recently described as an "inflection point" in our nation's long struggle to to which we provide adequate funding to exploit the fruits of this "age of biology," will determine the rate of our future progress against cancer and other chronic dis-eases. To sustain and increase the advances in cancer research that are needed to

reduce or remove the shadow of cancer from our lives and from the lives of future generations, the AACR recommends that budget increases for the NIH in 2004 and beyond be at a minimum of 10 percent per year and that the NCI Bypass Budget be funded at the requested level for the foreseeable future.

In summary, the promise of new areas of biomedical research such as the genomics and proteomics portend a "paradigm shift" in the way that we detect, treat, and prevent cancer. Thanks in large measure to our strategic investments in cancer and biomedical research, we can now envision a future where we will cure more cancer patients, treat cancer as a chronic illness, and develop rational and effective cancer prevention strategies. The AACR has just completed its Annual Scientific Meeting in San Francisco California, where over 15,000 basic and clinical cancer researchers presented a stunning array of important new laboratory and clinical results in all areas of cancer research. We must unite to seize this momentum in cancer research and leverage these new opportunities to ensure that progress against cancer is optimized for the benefit of all of our citizens. Although the financial costs of cancer are staggering, the real tragedy is in the loss of our families and friends to a disease that inflicts unimagined pain and suffering on its victims. We must deepen our resolve to "win" this war against cancer and act now to capitalize on what can only be described as unimagined opportunities to accelerate progress in all areas of cancer research and patient care.

Thank you for your leadership, and we look forward to achieving the magnitude and continuity of resources required to soundly and finally defeat cancer for all Americans.

# PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION

### INTRODUCTION

Mr. Chairman, thank you for the opportunity to submit written testimony regarding fiscal year 2003 appropriations for the Centers for Disease Control (CDC), National Institutes of Health (NIH), and Health Resources and Services Agency (HRSA).

I am Jack Stibbs, Administrative Vice President for Advocacy of the Pulmonary Hypertension Association (PHA). I became active in PHA when my daughter Emily was diagnosed with pulmonary hypertension (PH).

PH is a rare disorder of the lung in which the pressure in the pulmonary artery (the blood vessel that leads from the heart to the lungs) and the hundreds of tiny blood vessels that branch off from it rises above normal levels and may become life threatening. Symptoms of pulmonary hypertension include shortness of breath with minimal exertion, fatigue, chest pain, dizzy spells and fainting.

When PH occurs in the absence of a known cause, it is referred to as primary pulmonary hypertension (PPH). This term should not be construed to mean that because it has a single name it is a single disease. There are likely many unknown causes of PPH.

Secondary pulmonary hypertension (SPH) means the cause of the disease is known. Common causes of SPH are the breathing disorders emphysema and bronknown. Common causes of SFH are the breating disorders emphysema and bon-chitis. Other less frequent causes are scleroderma, CREST syndrome and systemic lupus. In addition, the use of diet drugs can lead to the disease. Unfortunately, PH is frequently mis-diagnosed and often progresses to late stage by the time it is detected. Although PH is chronic and incurable with a poor survival

rate, new treatments are providing a significantly improved quality of life for patients. Recent data indicates that the length of survival is continuing to improve, with some patients able to manage the disorder for 20 years or longer.

Ten years ago, when three patients who were searching to end their own isolation founded this organization, there were less than 50 diagnosed cases of this disease. It was virtually unknown among the general population and not well known in the medical community. They soon realized that this was not enough and as membership began to grow-driven by a newsletter distributed by doctors-and a community began to form, an 800 number support line was launched, support groups were established, a Scientific Advisory Board (SAB) was formed, a Patient's Guide to Pulmonary Hypertension was written, and a web site was launched. Today, PHA includes:

Over 3,600 patients, family members, and medical professional

An international network of over 50 support groups

-An active and growing patient hotline

A new and fast-growing research fund (A cooperative agreement has been signed with the National Heart, Lung, and Blood Institute to jointly create and

fund five, 5-year, mentored clinical research grants and PHA awarded it's first four Young Researcher Grants.)

# -A host of numerous electronic and print publications

# **RECOMMENDATIONS FOR FISCAL YEAR 2003**

# Centers for Disease Control and Prevention

PHA applauds the subcommittee for its leadership in encouraging CDC to initiate a professional and public PH awareness campaign. Currently, we are working with officials at the CDC to establish this important program that will better inform health care professionals and the general public about PH, its symptoms, and treatment options. The following is a description of the specific initiatives we hope to launch in collaboration with CDC.

(1) Increasing awareness and understanding of PH among primary care physicians is critically important, because these practitioners are usually the first point of contact for PH patients. If the primary care doctor misses the symptoms, then the chance for early diagnosis depends upon the intuition and persistence of the patient. They have a chance, if they aggressively pursue diagnosis by trained and aware specialists. If they are not aggressive, or if they are in a health plan that requires their general practitioner to prescribe the referral, they are more likely to go undiagnosed until it is too late to control their illness. To increases awareness we propose to launch:

- -Written and video diagnostic tools for placement on the Internet.
- -A postcard mailing to be sent to all primary care physicians, medical schools and medical centers in the United States drawing attention to the new web resources.
- —A simplified and visually attractive version of the proper diagnostic procedures, which will be sent in a second mailing to all primary care physicians, medical schools, and medical centers in the United States.
- Advertising in publications general practitioners are likely to read. The emphasis will be the urgency and ease of early diagnosis and the ease of accessing diagnostic tools via the Internet.
- —A ČD–ROM that explains pulmonary hypertension from a variety of angles. We would like to make 100,000 of these available to the medical community and patients through our web site on an as requested basis and at conferences and through targeted mailings.

(2) Due to the advancements in treatment for PH, it is important that we also focus on educating cardiologists and pulmonologists. Our strategies for reaching cardiovascular specialists include:

- -Publication of the first Pulmonary Hypertension Journal focused on educating a wider population of doctors on issues related to the diagnosis and treatment of the illness.
- —Placement of additional detailed information on the illness on the web. The PH Journal and other publications will promote this availability.
   —Expansion of PHA's international conference on pulmonary hypertension (the

-Expansion of PHA's international conference on pulmonary hypertension (the largest PH conference in the world).

 Expansion of PHA's Pulmonary Hypertension Resource Network. This program is focused on increasing awareness of PH among nurses through peer education.
 (3) Finally, PHA is committed to increasing PH awareness among the general public through the development of the following initiatives:

—A series of 10, 15, and 30 second public service announcements on PH. These PSAs will be in both audio and video form.

—A PH media relations manual.

-An organ donation Awareness Campaign (unfortunately, many PH patients die before finding a suitable organ donor).

–Expansion of PHA's web site.

We look forward to working with CDC to implement these and other initiatives aimed at increasing awareness of PH in the United States and throughout the world. For fiscal year 2003, we encourage the subcommittee to continue to support the mission of the CDC with an overall appropriation of \$5 billion (an increase of \$800 million over fiscal year 2002). Moreover, we urge you to continue support of the PH public and professional awareness initiative within CDC's Cardiovascular Disease program (a division of CDC's Chronic Disease Prevention program).

# National Heart, Lung and Blood Institute

Mr. Chairman, PHA commends the leadership of the National Heart, Lung and Blood Institute (NHLBI) for its support of PH research. Two years ago, two separate groups of scientists funded by NHLBI simultaneously identified a genetic mutation

associated with primary pulmonary hypertension. The two groups independently reported that defects in the BMPR2 gene, which regulates growth and development of the lung, are associated with PPH. The defects in the gene lead to the abnormal proliferation of cells in the lung characteristic on PPH.

Although both studies suggest that only one gene is involved in PPH, neither group identified the defects in BMPR2 as the sole cause of PPH. In addition, since many people without a known family history of PPH get the disease, both groups suggested that other factors may interfere with control of the tissue growth. Now that we have pinpointed a gene, we can focus on learning how it works. Hopefully, that information will enable researchers to devise better treatments and perhaps eventually a preventive therapy or cure.

Mr. Chairman, PHA would like to thank you and the subcommittee for your leadership in support of funding for the National Institutes of Health. Moreover, we would like to thank the subcommittee for the inclusion of committee recommendations on PH research at NHLBI in the fiscal year 2003 Senate L-HHS report. For fiscal year 2003, PHA joins with the Ad Hoc Group for Medical Research Funding in supporting a 16 percent increase for NHLBI. Finally, we request that the sub-committee provide \$25 million in fiscal year 2003 for PH research at the institute to enhance basic research, gene therapy and clinical trials of promising new therapies.

#### Gift of Life Donation Initiative at HRSA

Mr. Chairman, PHA commends the leadership of Secretary Thompson on the success of his promise the, "Gift of Life Donation Initiative." Currently, there are many drugs that PH patients can choose from to help alleviate the effects of PH; however, these drugs are often used until a patient can no longer wait for a heart or more often, a lung transplant. Immediately following diagnosis, many PH patients sign on to a transplant waiting list and continue to take their medication. Unfortunately, for many it is too late, and pass away before they can receive their much needed transplants. This why PHA has started Bonnie's Gift.

Bonnie's Gift was started in memory of Bonnie Dukart, one of the three founding members of PHA, and a PH patient herself. Bonnie battled with PH for almost 20 years until her death in 2001 following a double lung transplant. Prior to her untimely death, Bonnie expressed an interest in the development of a program within PHA related to transplant information and awareness. PHA will use Bonnie's Gift as a way to disseminate information about PH, the importance of early listing, the importance of organ donation to our community and organ donation cards

Consequently, PHA applauds the administration for its "Gift of Life Donation Iniwhich is designed to increase organ donation rates throughout the country. tiative," We look forward to working with the "Gift of Life Donation Initiative" to increase awareness of the importance of organ donation among the PH community, the med-ical community and the public. Mr. Chairman, PHA supports the president's fiscal year 2003 budget proposal of \$25 million for HRSA's "Gift of Life Donation Initia-tive."

# CONCLUSION

Mr. Chairman, once again thank you for the opportunity to present the views of the Pulmonary Hypertension Association. We look forward to continuing to work with you and the subcommittee to improve the loves of pulmonary hypertension pa-tients. If you have any questions or would like additional information, please do not hesitate to contact me or the PHA National Office in Silver Spring, Maryland (301) 565 - 3004.

### PREPARED STATEMENT OF THE NEPHCURE FOUNDATION

### SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2003

1. A 16 percent increase for the National Institutes of Health as well as a 16 percent increase for all institutes and centers, specifically the National Institute of Dia-betes and Digestive and Kidney Diseases (NIDDK).

2. Prioritize Glomerular injury research at NIDDK, raise professional and public awareness about Glomerular injury, and encourage more aggressive scientific attention to all kidney diseases.

3. Urge NIDDK to develop programs to attract talented researchers to the field of Glomerular injury.

I am pleased to present testimony on behalf of the NephCure Foundation (NCF). We are a non-profit organization with a mission of supporting research and public awareness on glomerular injury, which is related to the filtering mechanism of the kidney. I am the founder of the foundation and also serve as treasurer. I have a son, who has had glomerular disease since he was 11 months old. Although he is now 25 years old and in remission, 80 percent of those in his situation lose their kidneys or their life by the age of 5.

# What is glomerular injury?

Mr. Chairman, each kidney contains about one million tiny filtering units called nephrons. Nephrons are the key to the kidney's filtering function, processing a constant flow of waste-laden blood, sorting out the vital fluids, from the toxic and unnecessary elements.

When someone suffers from a glomerular disease, this vital process is impaired. In some instances, an individual will lose protein and sometimes red blood cells in the urine, have high cholesterol levels, and experience severe swelling in the body from too much fluid. Incidence of this disruptive Nephrotic Syndrome is increasing, and this perplexes physicians who cannot identify the cause or cure.

Sometimes damage occurs to the nephrons, specifically, scarring of the glomeruli, which are microscopic capillaries in the nephron. The severe form of this glomerular injury is Focal Segmental Glomerularsclerosis (FSGS). Presently, there is no treatment to reverse this damage. FSGS can lead to end stage renal disease—total, or near total, permanent kidney failure. Costly dialysis treatments become necessary and kidney transplants may be required for severe cases.

### The Toll of Glomerular Injury

Glomerular injury affects tens of thousands of patients in the nation, most of them young. While it is unclear exactly how many Americans are impacted, the incidence of glomerular injury is on the rise. Severe forms of glomerular injury are costly to diagnose and treat, and at this time the only relief for these patients is with heavy medication, usually steroids, which have strong and unpleasant side effects.

Problems of misdiagnosis often occur with glomerular injury. Most patients and parents have stories about the unusual length of time between the first symptoms and diagnosis. The early signs of glomerular injury, swollen eyelids, are often mistaken for allergic reactions. Health care professionals do not appear to be fully knowledgeable about this disease.

The pain this disease causes children and young adults from severe facial and body distortion, disrupts friendships, school, and family life. By committing to more scientific research and increasing public and professional awareness, progress can be made towards ending the suffering of these children.

### There is hope for scientific breakthroughs

At a meeting co-sponsored by the NephCure Foundation, preeminent scientists from around the world have shared their findings about the podocyte, a major filtering cell, with tentacle-like feet. The relationship between the podocyte and the glomerulus may be a key to understanding glomerular injury.

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# What needs to be done?

Respectfully, Mr. Chairman, the NephCure Foundation urges this subcommittee to:

1. Continue the support for doubling the National Institutes of Health (NIH) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK).

2. Provide the funding and recommendations for the National Institute of Diabetes and Digestive and Kidney Diseases to aggressively pursue a scientific program which will advance research into glomerular injury, conduct clinical trials, raise public awareness, and recruit talented scientists to this field of research.

Thank you for the opportunity to appear before you today.

Mr. Chairman, I would like to include a statement from someone who has lived with FSGS for more than half of her life. Her name is Melanie Stewart.

My name is Melanie Stewart. I'm 14 years old and have had FSGS since I was 6. I have spent most of my life in the hospital or hooked up to a dialysis machine for 8 hours every day. My kidneys finally died 2 years ago, so my dad gave me one of his. I did my best to keep it by taking 20 pills a day, fighting off infections, hemorrhages, and a blood clot in my heart.

Unfortunately, my dad's kidney eventually failed. Now I am forced to start over again. There are thousands of kids just like me who would like a chance at a normal life. For all of us, I'm asking for your help in finding a cure for this disease.

Thank you for listening.

### PREPARED STATEMENT OF THE MEDICAL LIBRARY ASSOCIATION AND THE ASSOCIATION OF SCIENCES LIBRARIES

#### SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2003

A 16 percent increase for the National Library of Medicine at the National Institutes of Health and Support for NLM's Urgent Facility construction needs.
 (2) Continued support for the Medical Library Community's role in NLM's Out-

reach, Telemedicine, and Pubmed Central Programs.

I am Logan Ludwig, associate dean and director of library and media services at Loyola University Stritch School of Medicine in Maywood, Illinois.

Thank you for the opportunity to testify today on behalf of the Medical Library Association (MLA) and the Association of Academic Health Sciences Libraries (AAHSL) regarding the fiscal year 2003 budget for the National Library of Medicine (NLM).

MLA is a professional organization, headquartered in Chicago, representing over 4,000 individuals and 1,200 institutions involved in the management and dissemina-tion of biomedical information to support patient care, education and research. In 1998, the organization celebrated its 100th anniversary. AAHSL, is comprised of the directors of libraries of 142 accredited United States

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.

Mr. Chairman, the National Library of Medicine, on the campus of the National Institutes of Health in Bethesda, Maryland, is the world's largest medical library. The Library collects materials in all areas of biomedicine and health care, as well as works on biomedical aspects of technology, the humanities, and the physical, life, and social sciences. The collections stand at 5.8 million items—books, journals, technical reports, manuscripts, microfilms, photographs and images. Housed within the Library is one of the world's finest medical history collections of old and rare medical works. The Library's collection may be accessed in the reading room or requested on interlibrary loan. NLM is a national resource for all U.S. health science libraries through a National Network of Libraries of Medicine.

On behalf of the medical library community, I would like to thank the subcommittee for its leadership in securing a 12.7 percent increase for NLM in fiscal year 2002. With respect to the Library's budget for the coming fiscal year, I would like to touch briefly on four issues; (1) NLM's basic services, (2) NLM's outreach and telemedicine activities, (3) NLM's PubMed Central and clinical trials databases, (4) and NLM's facilities needs.

### THE GROWING DEMAND FOR NLM SERVICES

Mr. Chairman, it is a tribute to NLM that the demand for its services continues to steadily increase each year. An average of 250 million Internet searches (30 percent from the general public) are performed annually on NLM's MEDLINE database, which provides access to the world's most up to date health care information. Moreover; medical libraries, academic health centers, hospitals, community health centers, veterans' health care facilities, and private physicians rely heavily on NLM and its National Network of Libraries of Medicine to delivery quality health care everyday.

NLM also plays a critical role in maintaining the integrity of the world's largest collection of medical books and journals. Increasingly, this information is in digital form, and NLM, as a national library responsible for preserving the scholarly record of biomedicine, is developing a strategy for selecting, organizing, and ensuring per-manent access to digital information. Regardless of the format in which the materials are received, ensuring their availability for future generations remains the highest priority of the Library.

Mr. Chairman, simply stated, NLM is a national treasure. I can tell you that without NLM our nation's medical libraries would be unable to provide the type of information services that our nation's health care providers, educators, researchers and patients have come to expect.

Recognizing the invaluable role that NLM plays in our health care delivery system, the Medical Library Association and the Association of Academic Health Sciences Libraries join with the Ad Hoc Group for Medical Research Funding in recommending a 16 percent increase for NLM in fiscal year 2003.

### NLM'S OUTREACH AND TELEMEDICINE ACTIVITIES

### Outreach and education

NLM's outreach programs are of particular interest to both MLA and AAHSL. These activities, designed to educate medical librarians, health care professionals and the general public about NLM's services, are an essential part of the Library's mission.

The need for enhanced outreach activities has grown significantly in recent years following NLM's decision to make its MEDLINE database available for free over the World Wide Web.

The Library has taken a leadership role in promoting educational outreach aimed at public libraries, secondary schools, senior centers and other consumer-based settings. We were pleased that the Committee again last year recognized the need for NLM to coordinate its outreach activities with the medical library community.

Mr. Chairman, we applaud the success of NLM's outreach initiatives and look forward to continuing our work with the Library again in fiscal year 2003 on these important programs.

### Telemedicine

Mr. Chairman, telemedicine continues to hold great promise for dramatically increasing the delivery of health care to underserved communities across the country and throughout the world. NLM has sponsored over 50 telemedicine related projects in recent years, including 21 multi-year projects located in various rural and urban medically underserved communities. These sites serve as models for:

-Evaluating the impact of telemedicine on cost, quality, and access to health care;

-Assessing various approaches to ensuring the confidentiality of health data transmitted via electronic networks;

Testing emerging health data standards.

Mr. Chairman, it is clear that telemedicine will play a major role in the delivery of health care in the 21st Century. Medical librarians and health information specialists have an important role to play in supporting this revolutionary approach to health care and we encourage Congress and NLM to continue their strong support of telemedicine in our nation's medically underserved areas.

# PUBMED CENTRAL/CLINICAL TRIALS DATABASE

The medical library community applauds NLM for its leadership in establishing PubMed Central, an online repository for life science articles introduced in early 2000. PubMed Central evolved from an electronic publishing concept proposed by former NIH Director Dr. Harold Varmus. The site houses articles from the Proceedings of the National Academy of Sciences, the American Society for Cell Biology's journal Molecular Biology of the Cell, and other publications. This new online resource will significantly increase access to biomedical informa-

This new online resource will significantly increase access to biomedical information by health care professionals, students, researchers and the general public. The medical library community believes that health sciences librarians have a key role to play in the further development of PubMed Central. Because of the high level of expertise health information specialists have in the organization, collection, and dissemination of medical literature, we believe our community can assist NLM in issues related to copyright, fair use, and information classification on the PubMed Central site. We look forward to collaborating with the Library as this exciting new project continues to unfold this year.

Mr. Chairman, I also want to comment on another relatively new service offered by NLM—its clinical trails database (ClinicalTrials.gov). This listing of some 5,200 federal and privately funded trials for serious or life-threatening diseases was launched in February 2000. This free service is currently logging more than 2 million page hits a month and is an invaluable resource to patients and families interested in participating in cutting edge treatments for serious illnesses. The medical library community congratulates NLM for its leadership in creating ClinicalTrials.gov and looks forward to assisting the Library in anyway possible to advance this important initiative. This database is a nice compliment to NLM's extremely successful consumer web-site MEDLINEplus, which now covers over 450 health topics.

### NLM'S FACILITIES NEEDS

Mr. Chairman, over the past two decades NLM has assumed several major new responsibilities particularly in the areas of biotechnology, health services research, high performance computing, and consumer health. As a result, the Library has had tremendous growth in its basic functions related to the acquisition, organization, and preservation of an ever-expanding body of biomedical literature. This increase in the volume of biomedical information as well as Library per-

This increase in the volume of biomedical information as well as Library personnel (NLM currently houses over 1,100 people in building built to accommodate 650) has resulted in a serious shortage of space at the Library. In addition, the National Center for Biotechnology Information at NLM builds sophisticated data management tools for processing and analyzing enormous amounts of genetic information critical to advancing the Human Genome Project.

In order for NLM to continue its mission as the world's premier biomedical library, a new facility is urgently needed. The NLM Board of Regents has assigned the highest priority to supporting the acquisition of a new facility. The medical library community is pleased that Congress last year appropriated the necessary architectural and engineering funds for facility expansion at NLM. We encourage the subcommittee to continue to provide the resources necessary to acquire a new facility and to support the Library's health information programs.

### CONCLUSION

Mr. Chairman, thank you once again for the opportunity to present the views of the medical library community. We look forward to working with you and your staff. I would be happy to answer any questions that you or your colleagues may have.

### PREPARED STATEMENT OF THE INFECTIOUS DISEASES SOCIETY OF AMERICA'S

IDSA appreciates the opportunity to provide testimony to the Subcommittee on Labor, Health and Human Services, and Education of the Senate Appropriations Committee concerning the fiscal year 2003 budgets for the Centers for Disease Control and Prevention (CDC), in particular the National Center for Infectious Diseases, National Center for HIV, STD and TB Prevention and National Immunization Program; the National Institutes of Health (NIH), specifically the National Institute of Allergy and Infectious Diseases, Office of AIDS Research, and Fogarty International Center; the Health Resources and Services Administration; and global infectious diseases programs including the Global Fund to Fight AIDS, Tuberculosis and Malaria.

IDSA represents nearly 7,000 physicians and scientists devoted to patient care, education, research, and community health planning in infectious diseases. Nested within IDSA is the HIV Medicine Association (HIVMA) of IDSA, which represents 2,300 physicians who work on the frontline of the HIV/AIDS pandemic by conducting research and administering prevention and clinical programs that provide services to individuals affected by this pandemic. IDSA is the principal organization representing infectious diseases and HIV/AIDS physicians. Our members care for patients with serious infections, including meningitis, pneumonia, heart valve infections, severe bone, joint or wound infections, food poisoning, those with cancer or transplants who have life-threatening infections caused by unusual microorganisms, and, of course, HIV/AIDS. IDSA members share a common focus on epidemiology, diagnosis, prevention, investigation and treatment of infectious diseases. They also work with national leaders in public health and research to develop and implement infectious diseases policies and programs around the globe. IDSA supports its members by advocating for comprehensive and appropriate disease prevention efforts, including immunization of children and adults; biomedical research; mechanisms to control antimicrobial resistance; vaccine and antimicrobial drug development and availability; quality clinical microbiology; food safety; sufficient bioterrorism preparedness and response activities; and global efforts to reduce the incidence and devastating impact of infectious diseases worldwide.

devastating impact of infectious diseases worldwide. This statement speaks to the value of U.S. public health and research activities in the ongoing and evolving global fight against infectious diseases and requests sufficient resources in fiscal year 2003 in order to sustain and improve these important programs.

## ARE WE SUFFICIENTLY PREPARED?

Last fall's anthrax attacks have reminded all of us of the serious threat infectious disease agents pose to the peace and prosperity of our nation and people around the world. These attacks have been the most shocking and frightening bioterrorism events the United States has yet experienced. As devastating as the anthrax events were, however, the loss of human life could have been far greater had the attack been planned and carried out in a more sophisticated and complex manner, had an infectious diseases physician in Florida not quickly detected the infectious agent in his patient, or had our public health system not responded as rapidly as it did. Undoubtedly, mistakes were made, but lessons also were learned. Ultimately, this experience has reminded each of us, and most notably those assigned the role of responding to such events, the value of being prepared.

Since last fall, many infectious diseases experts and public health officials have asked whether we are sufficiently prepared to handle a significant bioterrorism event or infectious diseases outbreak. Many believe the answer is no—as a nation we are not prepared. A recent survey of 300 U.S. county officials, conducted by the National Association of Counties (NAC), clearly illustrates this belief as only 9.7 percent of those polled believed that their communities were prepared to deal with a bioterrorism event.

Infectious diseases are the second leading cause of death and the leading cause of disability-adjusted life years worldwide (one disability-adjusted life year is one lost year of healthy life) and the third leading cause of death in the United States. The World Health Organization estimates that 1,500 people die each hour from an infectious disease. Infectious diseases, such as AIDS, hepatitis, tuberculosis, malaria and pneumonia, as well as new and emerging infectious diseases, continue to cause vast human suffering in this country and around the world. The real and potential implications on human lives and the escalating costs of health care in this country are staggering. In 1999, CDC reported that should an influenza pandemic occur in the United States today with the ferocity of the Spanish Flu virus outbreak of 1918, it would cause an estimated 89,000 to 207,000 deaths, 314,000 to 734,000 hospitalizations; and the economic impact would range from \$71 billion to \$167 billion. If past is prologue, and we know that it is, many more threats lie ahead. If we are to be prepared and respond rapidly and effectively to the emergence of these agents and events, we must focus today on the strengths and weaknesses of our existing research programs and public health infrastructure and make wise investments now for our future and the future of our children.

### NATIONAL INSTITUTES OF HEALTH (NIH)

NIH is the lead U.S. agency for biomedical research and the most distinguished medical research organization in the world. The research that is conducted and supported by NIH has offered promising breakthroughs in preventing and treating many deadly diseases, both within and beyond our borders—breakthroughs that have improved the health and quality of life around the globe.

When it comes to investments in research, opportunities lost can have serious costs. We would not be where we are today in terms of understanding, preventing and treating infectious diseases had it not been for wise, past investments in research. Knowledge is of critical value in improving the art and science of infectious diseases medicine. Basic and clinical research has facilitated the development of the essential tools, i.e. diagnostics, therapeutics and vaccines, needed to fight these diseases. Past investments in research and the knowledge derived from it has improved the health and extended the lives of many Americans. The value of such investments is no less relevant today than it has been in the past. The level of our current investment in U.S. biomedical and prevention research programs will be of pivotal influence to our nation and the world in responding effectively to future disease events.

For this reason, we applaud the Administration's and Congress' continued commitment to double NIH's budget over 5 years to the current proposed level of \$27 billion for fiscal year 2003. We are concerned about what the future holds for such funding beyond 2003, however, and will work with the Administration and Congress to ensure an ongoing, strong investment in research. Continued strong investment is imperative so that we may better understand and combat the microbes that cause deadly and debilitating infectious diseases. Of particular interest to the Society are the proposed budgets for the Office of AIDS Research, National Institutes of Allergy and Infectious Diseases, and John E. Fogarty International Center.

### Office of AIDS Research (OAR)

Several of NIH's Institutes and Centers conduct and support research that targets new treatments for and a better understanding of AIDS and HIV-related diseases. OAR is responsible for overseeing all aspects of NIH's AIDS research activities. OAR also has been instrumental in crafting NIH's annual comprehensive research plan for HIV-related diseases, which identifies a number of key priorities including prevention research to reduce HIV transmission in the United States and around the world; therapeutic research to respond to those already infected; international research priorities and research targeting the disproportionate impact of AIDS on minority populations in the United States. Clearly, it also is vital to continue our research efforts to identify a safe and effective vaccine. This comprehensive approach has greatly assisted the nation in combating this deadly disease and also has prolonged and enhanced the quality of life for many HIV-infected people around the globe. As the United States' investment in AIDS research reaps greater dividends, appropriate resources must be invested to leverage upon and to support these efforts. As such, we recommend a \$384 million increase in AIDS research funding through NIH's Office for AIDS Research for a total commitment of \$2.9 billion in fiscal year 2003. This amount is \$130 million above what the Administration has proposed for AIDS research in fiscal year 2003. We believe that the amount we are recommending will ensure that NIH can adequately implement its fiscal year 2003 AIDS research plan.

# National Institute of Allergy and Infectious Diseases (NIAID)

NIAID provides substantial support to scientists conducting research around that world that will help us to prevent, diagnose, and treat infectious diseases. Infectious disease physicians significantly depend upon knowledge derived from NIAID-supported research to appropriately diagnose and treat infectious diseases in their pa-tients. As such, the Society strongly supports the President's proposed budget of \$3.9 billion for NIAID. We are concerned that the Administration's proposed infusion of \$1.5 billion for bioterrorism-related research may be too inflexible, however, and believe that NIAID should have broad discretion in determining how these funds are spent so that the universe of infectious diseases research may benefit from the knowledge derived from these studies. We are particularly concerned about this issue because the President's proposed budget provides a smaller increase in funding for NIAID infectious diseases (excluding bioterrorism activities) than was expected for fiscal year 2003, given previous increases in this area. While we support research that will help us better understand bioterrorism agents, we believe that such efforts should not come at the expense of other vital infectious diseases research activities. Therefore, we recommend that the Subcommittee provide the National Institute of Allergy and Infectious Disease's scientists with broad discretion to decide how the Administration's proposed increase in bioterrorism-related funding should be spent so that the wide spectrum of infectious diseases research may benefit from this considerable investment.

### Fogarty International Center (FIC)

FIC promotes and supports scientific research and training internationally to reduce disparities in global health. Programs administered through FIC have provided thousands of health professionals from lesser-developed countries the opportunity to receive vital medical knowledge from U.S. health professionals, which enables them to better treat ailing patients in their home countries. An example of the important work FIC has undertaken is demonstrated through its AIDS International Training and Research Program (AITRP). AITRP has been instrumental in building research capacity and expanding technical knowledge in the developing world by providing HIV/AIDS-related biomedical and behavioral research training to scientists and health professionals from developing countries. The program has enabled American schools of medicine, public health, and nursing to train more than 2,000 scientists from more than 100 countries. Many of these trainees have moved into leading positions in laboratories, administration and policy positions in their home countries. The transfer of knowledge FIC facilitates is extremely valuable in the fight against HIV/AIDS and other infectious diseases in sub-Sahara Africa and has assisted in the prevention and treatment of deadly infectious diseases throughout the world. Despite the tremendous benefit of Fogarty programs and the contributions the

Despite the tremendous benefit of Fogarty programs and the contributions the Center has made to global public health efforts, its budget remains relatively small at \$56 million. Expansion of the Center through increased funding would provide more comprehensive and extensive training programs at this critical juncture in the AIDS pandemic and would benefit efforts to eradicate and control other infectious diseases, such as tuberculosis and malaria. Therefore, we ask the Subcommittee to work with NIH's scientists to ensure that the Fogarty International Center's programs are sufficiently funded in the future.

# CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

Complementing the vigorous research activities supported by NIH through a strong and flexible public health infrastructure is the best strategy our nation can undertake to control and contain infectious diseases' threats. CDC is the premier public health agency working to prevent and control infectious diseases around the globe. CDC has been instrumental in achieving many major public health accom-

plishments, including the high vaccination rates for children, and the eradication and control of deadly infectious diseases, like smallpox and the soon- to-be-achieved eradication of polio. Despite these successes, the number of deaths from infectious diseases in the United States and around the world continues to rise.

eradication of polio. Despite these successes, the number of deaths from infectious diseases in the United States and around the world continues to rise. To adequately prepare for the global health challenges of the 21st Century, vital components of the CDC must be strengthened so that the United States can respond quickly and appropriately. We are concerned that the Administration's proposed budget levels for CDC's infectious diseases programs drastically underestimate the many challenges that lie before us, and, if not increased, will impose an additional strain on an already vulnerable system. Of particular interest to IDSA are the proposed funding levels for the National Center for Infectious Diseases, National Center for HIV/AIDS, STD and TB Prevention; and National Immunization Program.

# National Center for Infectious Diseases (NCID)

IDSA is most concerned with the Administration's proposed budget of \$344 million for infectious diseases programs at NCID. This amount represents a decrease of \$10 million below the 2002 level—an amount that will undermine vital, ongoing infectious diseases activities. NCID is the lead agency in preventing illness, disability, and death caused by infectious diseases in the United States and around the world. Among NCID's responsibilities is to help the United States prepare for and respond to bioterrorism attacks. To carry out all of its responsibilities, NCID conducts surveillance, epidemic investigations, epidemiological and laboratory research, training, and public education programs to track and respond to infectious diseases occurrences.

The United States has one of the most sophisticated public health infrastructures in the world. However, the events of last year have revealed some of the deficiencies of our system. During last fall's anthrax events, many segments of the nation's health system were overwhelmed—most significantly, public health laboratories, which were plagued with thousands of requests to rapidly identify potential agents—and health care providers, who were bombarded with requests for prophylaxis to prevent infection as well as for accurate information on anthrax and other bioterrorism agents.

To prepare adequately for future infectious diseases events, and to overcome the deficiencies highlighted by last fall's events, NCID must work to achieve several critical goals. One goal must be to increase our public health system's surge capacity so that we may respond quickly and effectively in crisis situations. To achieve this goal, state and local capacities, communication networks, education and training opportunities for health care personnel, surveillance, and other components of our system must be improved and strengthened. To achieve the most benefit, efforts to increase surge capacity must be undertaken in a manner that is relevant to and compatible with the existing framework for controlling infectious diseases. NCID also must move quickly to strengthen and improve existing information delivery systems so that essential and accurate information may be made available—at a touch of a button—to public health officials and professionals at every level. Making such information available more rapidly will permit health officials and professionals to respond more quickly and effectively during crisis periods and to communicate accurate information to an anxious public.

We applaud Congress' and the Administration's efforts last year to provide significant, new resources that will help NCID to achieve these goals, and, particularly, for supporting new resources for state and local preparedness and response activities. President Bush's proposed budget for fiscal year 2003 also will add additional resources to improve our nation's surge capacity. We are very supportive of the Administration's effort to make additional funds available for this purpose, however, these new funds appear to come at the expense of existing infectious diseases programs. The President's budget too rigidly ties these additional resources to bioterrorism-related activities and does not provide NCID the necessary flexibility to implement its infectious diseases strategy, including bioterrorism activities, in a more holistic and integrated manner. As such, we recommend that the Subcommittee provide the National Center for Infectious Diseases with sufficient new resources to expand and improve both our nation's bioterrorism AND existing infectious diseases prevention and control activities as well as permit NCID broad discretion to decide how these new resources may be best spent within the existing infectious diseases framework.

New Emerging Infections.—The Administration's proposed budget for NCID also is insufficient to address the significant challenges related to new and emerging infectious diseases. In 1997, an avian strain of influenza that had never before attacked humans began to kill previously healthy people in Hong Kong. This crisis raised the specter of an influenza pandemic similar to the one that killed 20 million people in 1918. NCID must have sufficient resources to investigate these significant outbreaks as they have done in the past for HIV/AIDS, hantavirus pulmonary syndrome, and drug-resistant re-emerging diseases such as malaria, tuberculosis, and bacterial pneumonias.

bacterial pneumonias. To prepare the United States for these types of pandemics, CDC scientists have designed a plan, Preventing Emerging Infectious Diseases: A Strategy for the 21st Century, to counter the emergence and resurgence of microbial threats in the new millennium. This plan outlines goals and objectives that will strengthen our nation's capability to prevent, protect and respond to outbreaks by focusing on surveillance and response activities; applied research; infrastructure and training; and prevention and control. NCID has estimated that \$260 million is needed to fully implement this strategy. Under the President's proposed budget, \$164 million has been proposed, leaving a \$96 million shortfall. We urge the Subcommittee to fully fund National Center for Infectious Diseases's emerging infections strategy by appropriating \$260 million for its implementation in fiscal year 2003.

\$260 million for its implementation in fiscal year 2003. Antimicrobial Resistance.—CDC's emerging infections strategy has identified antimicrobial resistance (AR) or drug resistance as a major contributor to infectious diseases challenges in the United States. Infectious diseases physicians and other health professionals are already well aware of the dangers of AR in the United States and around the world. Infectious diseases once contained by antimicrobial agents are becoming increasingly untreatable over time as microbes mutate, adapt and decode these wonder drugs. As a result, AR is a contributing factor to many infectious diseases-related deaths and debilitating outcomes in the United States. The United States must respond to the peristent problem of AB by increasing

The United States must respond to the persistent problem of AR by increasing research efforts, creating surveillance systems, and developing strategies to ensure that newly developed and existing drugs are used effectively and are not misused nor abused. Last year, an interagency task force comprised of CDC, NIH, the Food and Drug Administration (FDA) and the U.S. Department of Agriculture (USDA) of-ficials released A Public Health Action Plan to Combat Antimicrobial Resistance. The plan outlines a number of surveillance, prevention and control, research, and product development activities to address this growing concern. Under the Administration's proposal, CDC will receive \$25 million for AR activities in fiscal year 2003—the same level of funding provided in fiscal year 2002—an inadequate amount if we are to better understand and limit the impact of AR. As such, we urge the Subcommittee to support a specific increase of \$25 million in CDC funding for fiscal year 2003 to implement the Public Health Action Plan to Combat Antimicrobial Resistance, which is vital to improving patient outcomes, and an increase of \$25 million in fiscal year 2007.

The relevance of AR to the practice of infectious diseases medicine has become increasingly more problematic over the past several years as the development of new antimicrobial agents and the availability of existing agents have become compromised by vulnerabilities in the availability of existing agents have become compromised by vulnerabilities in the existing pharmaceutical pipeline. These vulnerabilities include manufacturing deficiencies resulting in FDA enforcement actions; problems in the supply of bulk materials; roadblocks in FDA's approval process, including recent agency debates concerning raising the standards for approving new antimicrobial agents; and decisions by pharmaceutical manufacturers to remove existing, approved drugs from the market due to lack of profits, among other reasons. These vulnerabilities raise strong concerns among IDSA's members about the future availability of products to treat their patients suffering from life-threatening infectious diseases. We all must work together to ensure the continued availability of these important products. IDSA intends to work with the appropriate Senate and House authorizing committees to seek a comprehensive review of how existing regulatory and manufacturing approaches may play a role in limiting the availability of new and approved antimicrobial agents and to ensure that CDC, FDA, and the pharmaceutical industry are taking every reasonable measure to minimize vulnerabilities in the system. We believe that the Subcommittee should be aware that these shortages of antimicrobial agents are occurring and are available to answer any questions that the Subcommittee may have regarding this important matter.

Food Safety.—Despite the fact that America's food supply is among the safest in the world, food safety remains a major public health concern in our nation. Every year in the United States, 76 million cases of food-borne illnesses are reported, contaminated foods send an estimated 325,000 people to the hospital—and 5,000 of those people die. The costs associated with hospital visits are estimated at more than \$3 billion per year. The recent bioterrorism attacks have added another layer of concerns about the security of our food supply. If we are to adequately protect our food supply from microbial contamination, a higher priority must be given to food safety activities across the board. Therefore, we encourage Congress to maintain adequate funding for food safety activities at CDC, FDA and USDA.

# National Center for HIV/AIDS, STD and TB Prevention (NCHSTP)

Until an HIV vaccine becomes available, the key to reducing the spread of HIV/ AIDS is investing resources in HIV prevention programs and epidemiological stud-ies. The Administration has proposed no increase in funding for NCHSTP in fiscal year 2003, supporting a level budget of \$1.14321 billion-an approach that is wholly inadequate for addressing the increasing challenges caused by the AIDS pandemic. Each of the HIV/AIDS programs within CDC's NCHSTP is critical to curtailing the spread of HIV. Surveillance systems play a critical role in identifying trends in new infections in terms of geographic location, mode of transmission and other population demographics-all factors important to informing the development of effective prevention interventions and to accurately targeting resources for clinical care and other supportive services. Community-based prevention programs that target populations at highest risk for HIV infection remain a high priority in light of evidence that there continues to be 40,000 new HIV infections in the United States each year. IDSA also strongly supports NCHSTP's Global AIDS Program. This program is a vital component of our international response to the AIDS pandemic around the world. To reduce the number of new HIV infections occurring annually in the United States and the 14,000 new infections occurring daily worldwide, we strongly support increasing funding for National Center for HIV/AIDS, STD and TB Prevention programs at CDC by \$616.2 million to a total commitment of \$1.759 billion. This amount includes a doubling of CDC's Global AIDS Program to \$287.6 million.

### National Immunization Program (NIP)

Immunizations are among the greatest public health achievements of the 20th Century. Vaccines protect our children and adults against serious and potentially fatal diseases and are one of the most cost-effective tools in preventing disease. For every dollar spent on vaccines, we save up to \$27 in medical and societal costs. Because of vaccines, millions of cases of disease, disability and death have been averted, and billions of dollars have been saved.

Despite this great success, significant challenges remain. For instance, 38,000 adults die each year, from complications from hepatitis B, flu and pneumococcal infection, despite the availability of preventive vaccines. Moreover, many states recently have experienced significant difficulty in obtaining 5 of 8 routinely administered childhood vaccines—DTaP, MMR, PCV-7, varicella, and Td. In addition, the influenza vaccine has been delayed during the past two flu seasons due to manufacturing shortages. Vaccine shortages have been so severe that some states have dropped, or have considered dropping, immunization requirements for daycare and school entry and some providers have been forced to turn children away without vaccinating them.

The United States must seek remedies to improve and sustain immunization coverage so that this public health success story can be maintained and expanded into the 21st Century. To continue this success, IDSA—along with several other organizations, including the American Academy of Pediatrics and the American Public Health Association—is supporting a fiscal year 2003 appropriations level of \$696 million for CDC's NIP. This represents a \$65 million increase above the fiscal year 2002 appropriations level, and includes \$20 million for operations/infrastructure grant awards to the states, consistent with the Institute of Medicine's recommendation in its June 2000 report Calling the Shots, and \$45 million for the purchase of vaccines. The Administration has proposed level funding of \$631 million for NIP in fiscal year 2003, which is inadequate if we are to meet our goal of vaccinating 90 percent of children and adults. We must provide additional resources to states and localities to ensure that those in need of immunizations receive them.

IDSA—along with the American Academy of Pediatrics and American Public Health Association and others—also supports the creation of a 6-month stockpile for all childhood vaccines. Although this stockpile would require a significant upfront investment, the stockpile will pay for itself over time in medical and societal savings.

NIP has achieved a remarkable record of success. But, our effective vaccines can only be as good as our ability to deliver them to children and adults in need. By continuing to improve the system, our nation can gain the full benefits that vaccines have to offer. Therefore, we urge the Subcommittee to provide \$696 million for the National Immunization Program at CDC in fiscal year 2003 as well as such additional resources as may be needed to create a 6-month stockpile for all childhood vaccines.

The Health Resources and Services Administration (HRSA) administers programs that serve a critical role in the health care safety nets of our communities.

## HIV/AIDS Bureau: Ryan White CARE Act

HRSA's HIV/AIDS Bureau funds programs to support a broad spectrum of services from training for health care providers to funding for community health centers. We are particularly concerned with the level of funding proposed by the Administra-tion in fiscal year 2003 for the Ryan White CARE Act (CARE), which determines whether many people with HIV/AIDS receive life-saving prescription drugs and health care services. Adequate funding for this program is particularly crucial at this time because of severe cutbacks in the services that state Medicaid programs are able to provide and the increases in HIV infections in low-income communities where many individuals are uninsured or underinsured.

Since 1990, CARE programs have positively affected the lives of many people with HIV/AIDS in the United States through annual grants to more than 600 community-based programs. These programs provide essential funding for primary medical care, dental services, prescription drugs, diagnostic tests, mental health and sub-stance abuse treatment, as well as enabling social services like case management services that help patients attend medical appointments regularly and take their medications appropriately. CARE programs also funds provider training—a program component that remains essential as the standard of care for HIV disease continues to evolve and change.

Many of our physician members rely on CARE funds to provide life-saving serv-ices to a patient population that is increasingly dominated by individuals who are poor and uninsured and unable to benefit from treatment advances without public-supported programs. Without CARE funds, the outpatient clinics where our memsupported programs. Without CARE funds, the outpatient clinics where our mem-bers treat patients with HIV/AIDS are vulnerable to closure, leaving patients with little or no access to experienced providers able to offer the complex and costly care necessary to keep people with HIV/AIDS healthy and functioning. The Administration has proposed no increase for CARE programs over the fiscal year 2002 funding level of \$1.91 billion. Failure to increase funding for CARE pro-response of \$1.91 billion. Failure to increase funding for CARE pro-

grams essentially represents a reduction in resources as the number of individuals depending on the program grows each year. We believe an increase in CARE funding is essential to maintaining the current level of access to treatment services. Specifically, we support an increase of \$303.7 million for the Ryan White CARE Act pro-gram at HRSA to a total commitment of \$2.2147 billion by increasing:

Title I funding available to metropolitan areas disproportionately hit by the epidemic by \$43 million -CARE component of Title II by \$50 million

- -AIDS Drug Assistance Programs by \$162 million (An increase in ADAP is becoming increasingly important as state Medicaid programs continue to cut back on their prescription drug benefits.)
- -Title III primary care funding by \$14 million -Title IV funding by \$19 million
- Part F funding for the AIDS Education and Training Center by \$9.7 million and funding for dental reimbursement by \$6 million

# National Health Service Corps (NHSC)

The Society would like to express its support for the Administration's proposed increase of \$44 million for HRSA's National Health Service Corps (NHSC) program, which recruits, prepares, and supports health professional students, medical resi-dents, and clinicians to deliver health care in underserved communities within the United States. The Society also supports the establishment of a similar inter-national program that would support U.S. health professionals providing direct care and treatment to individuals suffering from infectious diseases in resource-limited countries. IDSA intends to work with the appropriate Senate and House authorizing committees to establish an International Health Service Corps program similar to the National Health Service Corps program at HRSA and urges the Subcommittee's future support for such a program.

### ADDITIONAL HHS GLOBAL ID PROGRAMS

It is not possible to adequately protect the health of our nation without addressing infectious disease problems that occur elsewhere in the world. In an age of rapid air travel and international trade, infectious pathogens are transported across borders every day, carried by infected people, animals, insects, and contained within commercial shipments of contaminated food. We are heartened that, in addition to the other global programs outlined above, HHS Secretary Thompson recently announced several new bilateral HHS infectious diseases initiatives intended for implementation in resource-limited countries. These new initiatives are important weapons in the fight against infectious diseases globally, and IDSA recommends sufficient funding to support them. As these new initiatives were announced following the release of the Administration's budget, we are concerned that adequate funding may not have been requested for them in the fiscal year 2003 budget. We strongly urge the Subcommittee to support the following new HHS programs by appropriating sufficient resources for each:

# HRSA's International AIDS Education and Training Center (IAETC)

HRSA recently announced a 3-year, \$1.5 million IAETC to provide health care providers in Africa and India with the most up-to-date training and education on caring for people with HIV/AIDS. This is an important initiative that will involve direct participation by infectious diseases experts in the training of health professionals in resource-limited countries. We strongly support this approach as one way to achieve a sustainable impact in the global fight against AIDS and infectious diseases. To create a real and credible impact on AIDS in Africa and India, however, a significantly greater investment in training and education initiatives is needed. We support at least doubling the amount dedicated to HRSA's International AIDS Education and Training Center program in Africa and India to \$3 million in the first year, with substantially greater investments in subsequent years.

#### CDC's Global Strategy to Fight Infectious Diseases

CDC recently released a global strategy, Protecting the Nation's Health in an Era of Globalization: CDC's Global Infectious Disease Strategy, to address infectious diseases around the globe. The strategy defines six priority areas developed in consultation with global public health partners to enhance the fight against infectious diseases: international outbreak assistance, global disease surveillance, applied research, application of proven public health tools, global initiatives for disease control and public health training and capacity building. We support CDC's Global Strategy to Fight Infectious Diseases and urge the Subcommittee to provide the highest level of funding to implement this global strategy.

### Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria

In addition to the bilateral, HHS-supported infectious diseases initiatives listed above, IDSA strongly supports a substantial increase in U.S. funding for the Global Fund to Fight HIV/AIDS, Tuberculosis (TB) and Malaria. After thoughtfully considering the relative value of the multilateral Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria in comparison to domestic infectious diseases initiatives as well as other U.S.-led international infectious diseases initiatives, the Society strongly recommends that the U.S. contribution to the Fund be increased to \$2.5 billion in fiscal year 2003. To put the Society's request into perspective, Congress and President Bush supported nearly \$3 billion in emergency appropriations for fiscal year 2002 for U.S. bioterrorism preparedness and response initiatives, following the deaths of 5 people due to anthrax attacks in the United States last fall. In fiscal year 2003, President Bush has proposed an additional \$5.9 billion for bioterrorism preparedness and response activities, we are convinced that a similar investment must be made to fight global AIDS, TB and malaria, which together account for nearly 6 million deaths per year along with immeasurable suffering and damage to families, communities and economies. AIDS kills 8,000 people each day—that fact alone is staggering. Yes, this is an extremely large investment of U.S. resources. However, when considering the consequences of what will happen if we don't act immediately, we believe that there is simply no other choice.

Finally, the Society would like to bring to the Chairman's attention our concerns about restrictions that have been placed on HHS employees' travel over the past year. Given the events of September 11th and the introduction of new management initiatives under the new Administration, some short-term restrictions are understandable. We are concerned, however, about the long-term impact that these restrictions may be having on U.S. health programs both within and outside the United States as well as on information exchanges between government and nongovernment health professionals at scientific and policy conferences. We ask the Subcommittee members to consider this concern and what impact these restrictions may be having on U.S. public health and scientific goals and objectives.

In closing, we sincerely thank the Chairman and all of the Members of the Subcommittee for your continued, energetic support of the federal research and public health activities being undertaken to make the world safe from infectious diseases. We stand ready at any time to assist you in this goal.

# PREPARED STATEMENT OF MENDED HEARTS, INC.

I am Robert H. Gelenter, the legal representative for the Mended Hearts Inc, a national heart disease patient support group of 25,000 members across the country. We visit patients in about 450 hospitals throughout the United States. I have been appointed by the group to assist in this lobbying effort—a volunteer position.

More than 26 years ago, I was diagnosed with a rare heart disease. After having severe chest pains and trouble breathing for more than 2 years, I was diagnosed with hypertrophic cardiomyopathy, a disease in which the heart enlarges. The heart muscle eventually thickens so much that it can't pump blood effectively and does not grow in the normal parallel patterns. More than 35 percent of young athletes who die suddenly die from this disease. But, it affects men and women of all ages. It is sudden and one of the things known about this disease is sudden cardiac death. There is no cure for this disease. Medication may work and there is surgery that may or may not alleviate the pain. If that doesn't work a patient may need a heart transplant, yet spare organs are scarce. The doctor who made my diagnosis was trained at the National Heart, Lung, and Blood Institute of the National Institutes of Health.

Initially, I received several medications which allowed me to engage in most activities. But, some activities, such as walking up hills, gave me problems like shortness of breath and severe chest pains. But, generally I could function normally. However, after about 10 years, the discomfort was increasing, and it became apparent that I was in serious trouble. I could not walk sixty feet without having to stop to catch my breath. Sometimes the pain was so great that I would almost double over in the middle of the street. My wife told me that my face would become gray. The perspiration would pour off by body. If I was lucky I could find a chair to sit on. The quality of my life had deteriorated so drastically that I knew I needed some treatment.

Finally in 1988, I went to Georgetown University Medical Center for an angiogram—the gold standard for diagnosing heart problems. The cardiologist who performed the angiogram told me that he had bad news and worse news. The bad news was that I had a 95 percent blockage in my left anterior descending heart artery—the so-called "widow makers spot." The worse news was that I had a major chance of having a major heart attack with a less than a 5 percent chance of surviving that heart attack because of the hypertrophic cardiomyopathy. At this point, my wife was quietly crying and I was perspiring profusely. Since Georgetown University Medical Center did not have the expertise to operate on me, they called the NIH to see if they would accept me as a patient. I was sent home pending notice from the NIH.

My parents begged me to go to New York or San Francisco for second opinions. But, I knew that I had run out of alternatives. No matter what the result, I needed treatment and I needed it immediately.

I was accepted by the NIH. After entering the National Heart, Lung, and Blood Institute on February 6th, I was operated on February 11, 1988. No matter how trite the expression—that was the first day of the rest of my life. The surgery, considered drastic and rare, is still considered the gold standard throughout the world for the treatment of hypertrophic cardiomyopathy. The Murrow Procedure, in honor of the creator, was developed and improved at the NIH.

Although this surgery is no longer performed at the National Heart, Lung, and Blood Institute, there is another experimental ongoing protocol in which the same effect is being attempted by using alcohol to deaden the excessive heart tissue.

Now, I am on medication for the rest of my life. My condition is progressive. Six years ago, I was fitted with a pacemaker to insure that my heart beats at the correct rate. I am 100 percent dependent on this pacemaker. Without the pacemaker, there are times when my normal heart beat is so slow that I would die.

I am eternally grateful to the physicians funded by the National Heart, Lung, and Blood Institute, particularly to Dr MacIntosh and his staff, for the gift of life. Because of this marvelous research supported by the NHLBI, I have lived 14 years pain free. I have seen two children graduate from college and three grandchildren born, I have shared these years with a wonderful wife. I have been able to work at my profession—an attorney at law.

I have had the gift of life restored to me. So to express my gratitude for that gift, I visit patients recovering from heart episodes at two hospitals, Washington Hospital Center and Washington Adventist Hospital.

I ask for a doubling of the fiscal year 1998 National Heart, Lung, and Blood Institute budget by fiscal year 2003. As the fifth increment toward reaching that goal, I advocate a fiscal year 2003 appropriation of \$3.2 billion for the NHLBI, including \$1.9 billion for its heart disease and stroke-related budget.

My experience is the proof that the research supported by the National Heart, Lung, and Blood Institute benefits not just the patients at the NIH Clinical Center, but throughout the United States. The benefits go worldwide as well.

Heart attack, stroke and other cardiovascular diseases remain the No. 1 killer and major cause of disability of men and women in the United States. More than 41 percent of people who die in the United States die from cardiovascular diseases. This year, nearly 960,000 Americans will die from cardiovascular diseases, including almost 150,000 under the age of 65.

Thank you for your support of National Heart, Lung, and Blood Institute's heart research.

### PREPARED STATEMENT OF THE CHARLES R. DREW UNIVERSITY OF MEDICINE AND SCIENCE

## SUMMARY OF RECOMMENDATIONS FOR FISCAL YEAR 2003

1. A 16 PERCENT INCREASE FOR THE NATIONAL INSTITUTES OF HEALTH AS WELL AS A 16 PERCENT INCREASE FOR ALL INSTITUTES AND CEN-TERS, SPECIFICALLY THE NATIONAL CENTER FOR RESEARCH RESOURCES (NCRR), THE NATIONAL CENTER FOR MINORITY HEALTH AND HEALTH DISPARITIES (NCMHD), AND THE NATIONAL CANCER INSTITUTE (NCI). INCLUDED IN THE 16 PERCENT, CHARLES R. DREW UNIVERSITY IS

SEEKING

- 54.1NG:
  -\$6 MILLION FROM THE NATIONAL CENTER FOR RESEARCH RE-SOURCES, IN INCREMENTS OF \$3 MILLION PER GRANT CYCLE, FOR BUILD-OUT OF RESEARCH FACILITIES AT DREW UNIVERSITY.
  -\$8 MILLION FROM THE NATIONAL CENTER FOR MINORITY HEALTH AND HEALTH DISPARITIES FOR A BUILDING SHELL TO HOUSE THE CHARLES R. DREW UNIVERSITY OF MEDICINE AND SCIENCE MINOR-ITY HEALTH COMPREHENSIVE CANCER CENTER.
  -\$10 MILLION OVER 5 YEARS FROM THE NATIONAL CANCER INSTITUTE
- 5 YEARS FROM THE NATIONAL CANCER INSTITUTE TO ESTABLISH AND SUPPORT RESEARCH AND PATIENT CARE AT THE CHARLES R. DREW UNIVERSITY OF MEDICINE AND SCIENCE MINOR-ITY HEALTH COMPREHENSIVE CANCER CENTER.

2. URGE NCRR, NCMHD, AND NCI TO COLLABORATE TO SUPPORT THE ESTABLISHMENT OF A NATIONAL MINORITY HEALTH COMPREHENSIVE CANCER CENTER AT A HISTORICALLY MINORITY INSTITUTION.

Mr. Chairman and members of the subcommittee, I am Dr. Charles Francis, President of Charles R. Drew University of Medicine and Science. Charles R. Drew University is one of four historically minority medical schools in the country, and the only one located west of the Mississippi River.

Charles R. Drew University of Medicine and Science is located in the Watts-section of South Central Los Angeles. Our mission is to provide quality medical edu-cation to underrepresented minority students, and, through our affiliation with the University of California Los Angeles (UCLA) at the co-located King-Drew Medical Center, we provide valuable health care services to the surrounding, medically underserved, community. Through innovative basic science, clinical, and health services research programs, Drew University works to address the health and social issues that strike hardest and deepest among inner city, underserved, and minority populations.

The population of this medically underserved community is predominately African American and Hispanic. The majority of these people would be without health care if not for the services provided by the King-Drew Medical Center and Charles R. Drew University of Medicine and Science. This record of service has led Charles R. Drew University (in partnership with UCLA School of Medicine) to be designated as a Health Resources and Services Administration (HRSA) Minority Center of Excellence

### A RESPONSE TO HEALTH DISPARITIES

Racial and ethnic disparities in health care have long been established as a major barrier to successful prevention and treatment of a multitude of diseases in minority and underserved communities. The recent Institute of Medicine report entitled "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care", articulated that this problem is not getting better on its own. For example:

African American males develop cancer 15 percent more frequently than white males.

-African American women are not as likely as white women to develop breast cancer, but are much more likely to die from the disease once it is detected.

-According to the American Cancer Society, those who are poor, lack health insurance, or otherwise have inadequate access to high-quality cancer care, typically experience high cancer incidence and mortality rates.

Despite these devastating statistics, we are still not doing enough to try to combat cancer in our communities.

In response to these disturbing findings, Charles R. Drew University of Medicine and Science recommends that a Minority Health Comprehensive Cancer Center be built on its campus. This proposed Center would specialize in providing not only medical treatment services for the community, but would also serve as a research facility, focusing on prevention and the development of new strategies in the fight against cancer.

# SUPPORT FOR THIS INITIATIVE

Mr. Chairman, the support that this subcommittee has given to the National Institutes of Health (NIH) and its various Institutes and Centers has and continues to be invaluable to our University and our community. The dream of a state of the art facility to aid in the fight against cancer in our community would be impossible without the resources of NIH.

To help facilitate the establishment of a Minority Health Comprehensive Cancer Center at Charles R. Drew University of Medicine and Science, the University is seeking support from the National Institutes of Health's National Center for Research Resources (NCRR), the National Center for Minority Health and Health Disparities (NCMHD), and the National Cancer Institute (NCI).

First, the facility must be constructed. Drew University does meet the Public Health Service Act eligibility requirement for facilities construction grants which maintains that the institution "is located in a geographic area in which a deficit in health care technology, services, or research resources may adversely affect health status of the population of the area in the future, and the applicant is carrying out activities with respect to protecting the health status of such a population." Therefore, the university is seeking Extramural Facilities Construction grants through NCRR in the amount of \$6 million (\$3 million per grant cycle) for build-out of the first floor of the research facility, and subsequent build-out of the second floor.

The University is also seeking \$8 million from NCMHD for the research building shell to house the Charles R. Drew University of Medicine and Science Minority Health Comprehensive Cancer Center.

In addition, the Minority Health Comprehensive Cancer Center cannot become a reality without programmatic funding. Drew University, in collaboration with UCLA, is seeking support from NCI in the amount of \$10 million over 5 years to support the health care and research activities conducted by the Center.

### CONCLUSION

Despite our knowledge about the disparities in diseases and health care, the "gap" continues to widen. Not only are minority and underserved communities burdened by higher disease rates, they are less likely to have access to quality care upon diagnosis. As you are aware, in many minority and underserved communities preventive care and/or research is completely inaccessible either due to distance or lack of facilities and expertise.

Even though institutions like Drew are ideally situated (by location, population, and institutional commitment) to study conditions in which health disparities have been well documented, research is limited by the lack of appropriate research facilities. With your help, this cancer center will facilitate translation of insights gained through research into greater understanding of disparities in cancer incidence, morbidity and mortality and ultimately to improved outcomes.

Mr. Chairman, with your support and the financial resources of NIH, Charles R. Drew University of Medicine and Science can not only be the nation's first Historically Black College or University (HBCU) to have a Comprehensive Cancer Center, but also the first minority medical school in the country to have a comprehensive cancer center focused exclusively on minority health and health disparities.

We look forward to working with you to lessen the burden of cancer for all Americans through greater understanding of cancer, its causes and cures.

Mr. Chairman, thank you for the opportunity to present on behalf of Charles R. Drew University of Medicine and Science.

# PREPARED STATEMENT OF THE NATIONAL MULTIPLE SCLEROSIS SOCIETY

We appreciate the opportunity to submit written testimony on behalf of the National Multiple Sclerosis Society. The Society is the world's largest private voluntary health agency devoted to the concerns of all those affected by MS. Throughout the Society's 56-year history, our number one priority has been research to better understand MS and to apply this knowledge to the development of new treatments or a cure. The Society awarded its first three research grants in 1947, and by the end of 2002, the Society cumulatively will have expended \$350 million on research. Our current annual research budget is \$34 million. Multiple sclerosis is a chronic, often disabling disease of the central nervous sys-

Multiple sclerosis is a chronic, often disabling disease of the central nervous system. Symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or loss of vision. Most people with MS are diagnosed between the ages of 20 and 50, but the unpredictable physical and emotional effects can be lifelong. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are giving hope to those affected by the disease. Today, there are five FDA-approved medications in the United States to help control the course of the disease.

In our testimony of prior years, the National MS Society has emphasized the importance of NIH basic and clinical research to all people with chronic illnesses and disabilities. We have recognized that new discoveries and breakthroughs could come from any area of biomedical research and could apply to the primary concern of our members: ending the devastating effects of MS. Knowing that a well-funded federal research enterprise is of great public benefit, we have encouraged Congress to focus on NIH as a whole, with equal consideration given to the National Institute of Neurological Disorders and Stroke (NINDS) and the National Institute of Allergy and Infectious Diseases (NIAID). NINDS funds 75 percent of the MS-specific research at NIH, while NIAID (the institute primarily responsible for autoimmune disease research, including MS) funds about 25 percent.

We still believe in the need to increase funding for NIH across all institutes, and to continue the effort to double NIH funding over 5 years (fiscal years 1999–2003). However, this year, we wish to bring three specific concerns to the Subcommittee's attention:

-The unresponsiveness to date of the lead NIH institute in MS research to the Society's interest in joint collaborative research projects in MS.

-The lack of uniformity in each NIH institute's coding system that tracks grant expenditures according to disease categories.

-The need to balance funding at NIH to assure that our national security needs are met, but still allow research at all institutes to grow in fiscal year 2003 and beyond.

Collaboration with NIH.—The Society has a substantial, well-run and well-respected research enterprise. We come to the table extremely well equipped to present and discuss collaborative ventures with NIH representatives. Since the inception of NINDS, the Society has had a productive relationship with the institute. In prior years, our testimony detailed the many positive aspects of this longstanding relationship. Nevertheless, over the past several years, NINDS has been unresponsive to our proposals to initiate collaborative research support ventures, and has not been forthcoming with suggestions of other opportunities. After 4 years of substantial funding increases for research at NINDS, there should be fresh ideas or new directions that could be further explored, and possibly explored collaboratively. Some of these were suggested in the Society-sponsored Institute of Medicine study entitled, "Multiple Sclerosis: Current Status and Strategies for the Future," which was completed in 2001. Recommendations from this study were widely distributed in this country and abroad at the time of publication. Collaborative activity leverages the resources of all parties engaged in the effort, and clearly there is great need and great opportunity for improved collaboration in research across government agencies, the public and private sectors, and scientific disciplines.

In contrast to our experience with NINDS, we were pleased last year to report to the Subcommittee our collaborative agreement with NIAID to research "Sexbased Differences in the Immune Response." We expect that this collaboration will extend the reach of the Society's own targeted research initiative on gender differences in MS by encouraging basic and clinical investigation of sex differences in the immune response in MS and related diseases; forging new collaborations to address existing gaps; providing wider visibility of the problem and opportunities; and ensuring increased support for high quality and relevant research. Initiated as an effort with the NIAID, other NIH institutes have come on board as well. Together, we will co-fund research projects relevant to MS, as well as projects related to other autoimmune diseases and to the immune function in general. Over the course of this agreement, up to \$20 million could be spent on this initiative, and of this amount, the Society has committed up to \$4 million. We sincerely thank the Subcommittee for including language in the Committee Report accompanying the fiscal year 2002 Appropriations bill that praised NIAID for its collaborative activity with us.

Appropriations bill that praised NIAID for its collaborative activity with us. However, NINDS is the lead agency with regard to MS-specific research, and in order to leverage the institute's finite federal research investment, we believe collaborative activity is essential. It is time for us to request Congressional intervention in directing NINDS to be more open to discussing and negotiating possible collaborative projects. In this connection, we will be seeking advice and counsel from the members of this Subcommittee and their staff on the best approach to this matter.

Grant Recoding Process.—During our efforts in Fall 2001 to obtain a clearer picture of the level of funding for MS-specific research at NIH, we discovered that several of the institutes had revised or were in the process of revising the coding procedures used to track grants and grant expenditures according to disease categories. Due to the new coding procedures that were implemented at NINDS starting in fiscal year 2000, reported NINDS funding for MS research dropped from \$74.5 million in 1999 to \$40.3 million in 2000, a decline of 46 percent. The recoding at NINDS caused a corresponding drop in the reported level of funding for MS research at NIH overall, from \$96.3 million in 1999 to \$61.9 million in 2000, a decline of 36 percent. It is our understanding that NIAID has not yet initiated the recoding process.

The drop in reported funding is of potential concern to members of the Society, and as a result, we requested a full explanation of the new coding process and its effect on reported support for MS research from the Acting Director of NINDS. We are pleased to report that we have now received a reply from NINDS, and we are currently working through all the information provided to assure ourselves that the new coding procedures and the large drop in reported funding for MS research in no way signal a substantive change in the direction and intensity of MS research at NIH. We will keep the Subcommittee members apprised of our findings. At the moment, our larger concern is that each of the institutes at NIH appears

At the moment, our larger concern is that each of the institutes at NIH appears to be free to change its grant coding procedures without a uniform coding standard. The absence of a standard may well defeat the purpose the recoding is supposed to achieve. This is especially true for complex diseases like MS, where research is conducted by more than one institute. However, for ALL diseases, lack of a uniform standard creates a scenario where the American public cannot easily understand how its primary health research agency is allocating its resources.

We request that the Subcommittee bring this matter to the attention of the new Director of NIH. We would like to see standard coding procedures across the institutes, so that everyone can have a clearer picture of how NIH funds research. We also request that the Subcommittee urge the NIH institutes to consult with interested parties, including patient groups, as these coding procedures are devised and implemented.

NIH Funding in fiscal year 2003.—As Americans, we certainly want our country to be prepared to respond to biological terrorism, and we support increased federal funding for bio-terrorism research at NIH. However, we also must remain concerned about the balance of funding at NIH. In this, the last year of the widely supported effort to double funding for NIH over 5 years (fiscal years 1999–2003), we urge the Subcommittee to carefully weigh the funding allocation so that disease-specific research at all institutes can continue to grow.

The Society also supports funding to continue construction of the John Edward Porter Neuroscience Research Center at NIH. For fiscal year 2003, we support the President's request for \$172 million to complete construction of Phases I and II of the center. We expect that this item will be incorporated into the Building and Facilities Budget, and not compete with research funding. We believe that this center will bring together basic and clinical neuroscientists from across NIH to focus on important cross cutting research themes, such as neurodegeneration, regeneration and repair of neurons, neurogenetics, and pain research.

We applaud the careful attention the Subcommittee has given to advancing the health and well-being of all Americans through substantial investment in biomedical research over the past several years, and we thank the Subcommittee for this opportunity to comment.

# PREPARED STATEMENT OF THE COALITION OF NATIONAL HEALTH EDUCATION ORGANIZATIONS

The Coalition of National Health Education Organizations (CNHEO) is pleased to submit this statement to the Senate Labor, Health and Human Services, and Education Subcommittee concerning appropriations for fiscal year 2003 for the Centers for Disease Control and Prevention (CDC). To accomplish its mission in fiscal year 2003, the CNHEO strongly recommends that the CDC should be funded at the level of at least \$7.9 billion to accomplish its mission, including \$1.1 billion for the National Center for Chronic Disease Prevention and Health Promotion.

The CNHEO is a nonpartisan coalition of nine national professional organizations committed to mobilization of the resources of the Health Education Profession in order to expand and improve health education. Among other activities, the CNHEO serves as a communication and advisory resource for agencies, organizations and persons in the public and private sectors on health education issues. Coalition member groups represent more than 25,000 health education and promotion professionals and students in elementary and secondary schools, universities, state and local health/education departments, community-based organizations, health care facilities, and corporations both nationally and internationally. The organizations comprising this coalition are:

- -American Association for Health Education
- —American College Health Association
- -American Public Health Association/Public Health Education and Health Promotion Section and School Health Education and Services Education
- –American School Health Association
- -Association of State & Territorial Directors of Health Promotion and Public Health Education
- —Eta Sigma Gamma
- -Society for Public Health Education

-Society of State Directors of Health, Physical Education, and Recreation.

Health education is a social science that draws from the psychological, biological, environmental, physical, and medical sciences to promote health and prevent disease, disability and premature death through education-driven voluntary behavior change activities. Health education not only addresses individual behavior change but also community and institutional changes that are necessary to support healthy behaviors. By focusing on prevention, health education reduces the costs (both financial and human) that individuals, employers, families, insurance companies, medical facilities, communities, states, and the nation would spend on medical treatment. More than 250 colleges and universities in the United States offer undergraduate and graduate degrees in school or community health education, health promotion and other related titles. Voluntary credentialing such as a Certified Health Education Specialist (CHES) is available from the National Commission for Health Education Credentialing, Inc, while school heath educators are licensed by the state in which they teach.

The CNHEO gratefully acknowledges the strong bipartisan support that the Senate Subcommittee on Labor, Health and Humans Services and Education has provided to CDC in recent years. The steady increased funding has enabled many states to improve translation of research in disease prevention and health promotion into essential programs and services at the state and local levels. Funding since September 11, 2001 has helped lay the foundation for rebuilding public health infrastructure, including risk communication programs to inform the public.

Tragic events of fall 2001 underscored, more than ever, the essential role of CDC in protecting public health. CDC is the nation's prevention agency. Working in partnership with state and local public health providers, CDC translates scientific and behavioral research into practice to accomplish our nation's health blueprint, Healthy People 2010 Objectives for the Nation. CDC programs improve access to quality health promotion and health education services across the broad diversity of our nation's communities. Given the unprecedented public health challenges now faced by this nation, the CNHEO strongly recommends that CDC should be funded at least \$7.9 billion in fiscal year 2003.

Of particular importance in fiscal year 2003 is increased funding for CDC's National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP). Chronic diseases are the nation's leading causes of morbidity and mortality and account for more than 70 percent of the nation's \$1 trillion spent on health care annually.<sup>1</sup> For example, chronic diseases account for 76 percent of all deaths in Pennsylvania and Iowa; 75 percent in Hawaii and Wisconsin; and 74 percent in Washington

<sup>&</sup>lt;sup>1</sup>CDC National Center for Chronic Disease Prevention and Health Promotion. Reducing the Health and Economic Burden of Chronic Disease. http://www.cdc.gov/nccdphp/upo/intro.htm, April 12, 2002.

and Texas.<sup>2</sup> Moreover, chronic diseases account for the largest part of the health gap between populations. African Americans have higher mortality rates for cardio-vascular disease, stroke, and cancer of the lung, colon/rectum, breast, cervix, and vascular disease, stroke, and cancer of the Inits, controctant, breach, certar, and prostate than Whites, American Indians/Alaska Natives, Asian/Pacific Islanders, and Hispanic Americans.<sup>3</sup> To address these inequities, the CNHEO requests fiscal year 2003 appropriation of \$1.1 billion for CDC's NCCDPHP, including: \_\_\_\_\_\$220 million for breast and cervical cancer programs

- \$128 million for cancer prevention and control programs
- \$130 million for tobacco prevention and control programs
- \$83 million for comprehensive school health programs
- \$60 million for nutrition and physical activity programs

-\$60 million for nutrition and physical activity programs -\$125 million for the Youth Media Campaign According to recent surveys, the public believes preventable disease and injuries are a major health problem and that funding should be increased for disease preven-tion and health promotion programs. Health behavior is complex, and with the in-creasing diversity of our population, there is no "one size fits all" strategy or ap-proach that works with all population groups. Simply advising people to stop smok-ing, start exercising, get a mammogram, or lose weight is ineffective. But science-based programs in health education that combine individual behavior change with community programs policies and practices are effective, thereby saying lives and community programs, policies and practices are effective, thereby saving lives and reducing U.S. health care expenditures.

For example, a new group of studies in Health Promotion Practice shows that successful programs to lessen racial and ethnic health disparities share common traits of establishing strong ties between health providers and the community members they serve.<sup>4</sup> Areas in which innovative programs are having a positive effect are in-fant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV/AIDS and immunization. The most successful interventions in narrowing the gap build community involvement and trust by enlisting the help of community representatives, involve community members in prioritizing issues and address fundamental policy changes at the neighborhood, organizational and institutional levels.

Programs that establish healthy behaviors in our youth represent an investment for the future health of this nation. Tobacco use, poor nutrition, lack of physical ac-tivity, alcohol, and other drug use are risk behaviors, often established during youth, which contribute markedly to heart disease, diabetes, cancer, and injuries. Every day nearly 3,000 young people begin smoking; in the past decade obesity has doubled among children and adolescents; and daily participation in high school physical education classes dropped to 29 percent in 1999.<sup>5</sup> School health programs have the potential to reach 53 million young people and are demonstrated to be cost-effective in promoting healthy behaviors. Yet 29 states, including Pennsylvania, lowa, Texas, Nevada, New Hampshire, and Ohio, do not have coordinated school health programs. The CNHEO requests a fiscal year 2003 appropriation of \$35 million for CDC's Division of Adolescent and School Health (DASH) program separate from HIV/AIDS funds. These funds will support 6 to 9 new state programs, expansion of the 21 existing coordinated school health programs, and funding for Physical Activity, Nutrition, and Tobacco Evaluation Projects in 2 states.

For example, in Maine all teachers in all middle schools were offered training and materials for the Life Skills Training curriculum, designed to help adolescents develop a wide range of personal and social skills. Surveys show that smoking among high school students in Maine has decreased more than 20 percent since the Life Skills Training Program was established in 1997.<sup>6</sup> Increases in the state tobacco excise tax and the introduction of community-based tobacco control programs also contributed to this decrease in smoking rates.

Obesity is a major concern among children and adults alike. In the past 15 years the prevalence of obesity has increased by more than 50 percent among adults and

<sup>&</sup>lt;sup>2</sup> CDC National Center for Chronic Disease Prevention and Health Promotion. Total Deaths and Deaths Due to Chronic Diseases, by State, United States, 1998. http://www.cdc.gov/nccdphp/

<sup>&</sup>lt;sup>3</sup>CDC National Center for Chronic Diseases, by Race and Ethnicity, 1998. http://www.cdc.gov/nccdphp/ugo/ <sup>3</sup>cDC National Center for Chronic Disease Prevention and Health Promotion. "Death Rates for Major Chronic Diseases, by Race and Ethnicity, 1998. http://www.cdc.gov/nccdphp/ugo/ death\_\_rates.htm

death\_rates.htm <sup>4</sup>Roe, KM, Thomas, S. Eliminating Racial and Ethnic Health Disparities: Mapping a Course for Community Action. Health Promotion Practice. 3(2): 106–323, April 2002. <sup>5</sup>CDC National Center for Chronic Disease Prevention and Health Promotion. Division of Ado-lescent and School Health. Healthy Youth: An Investment in our Nation's Future. 2002. http://www.cdc.gov/nccdphp/dash/ataglanc.htm April 10, 2002. <sup>6</sup>CDC National Center for Chronic Disease Prevention and Health Promotion. Division of Ado-lescent and School Health. Programs That Work—Research to Classroom. http://www.cdc.gov/ nccdphp/dash/rtc/index.htm April 10, 2002.

100 percent in children and adolescents.<sup>7</sup> Ten to 15 percent of children and adolescents are overweight and more than half of these children have at least one cardiovascular disease risk factor, such as elevated cholesterol and hypertension. Obesity increases the risk for chronic diseases such as cardiovascular disease, diabetes, and cancer. Less that 30 percent of men and women eat five servings of fruits and vegetables daily and 60 percent of adults do not engage in proper physical activity levels. The overall cost of disease associated with obesity is estimated at \$100 billion per year. The CNHEO requests a fiscal year 2003 appropriation of \$60 million for CDC's Physical Activity and Nutrition Programs. With these funds the CDC will be able to fund Nutrition/Physical Activity programs in all states, territories and tribes and support analyses of the cost effectiveness of prevention and promote policy initiatives to modify diet and physical activity.

The CNHEO requests the fiscal year 2003 appropriation of \$1.67 million for CDC's Bioterrorism Preparedness and Response Program. This request supports CDC's commitment to further define, develop, and implement a nationwide set of public health capacities required at the local, state, and federal levels to prevent, prepare for, respond to, and recover from terrorist acts. With these funds, we request that CDC expand the Centers for Public Health Preparedness Program to assure nationwide coverage and provide nationwide bioterrorism training for health care workers and that states have flexibility to respond to local needs. Only 20 percent of local public health agencies have a comprehensive bioterrorism response plan in place; 10 percent do not have e-mail capabilities; and half lack high-speed data transmission capacity. Most consumers agree that the CDC is very important in protecting public health against biological and chemical weapons and many were supportive of increased funding for preparation and response to such terrorism (9). Brought into focus by the September 11 terrorist attacks and subsequent anthrax attacks, the best strategy to protect civilians against any health threat is a public health infrastructure that is prepared at every level. Having a well-prepared work-force that can be deployed at the community level to support essential public health services will in turn support public health outcomes.

Through many programs and initiatives, the CDC helps countless individuals live healthier, more productive lives. Although research has helped to better understand the causes and risk factors for chronic diseases, effective measures are not being fully implemented at the state and local levels to prevent chronic disease and its devastating and costly consequences. Behavioral and clinical research needs to be effectively promoted and applied at the community level with the guidance of the nation's prevention agency—the CDC. CDC programs need full funding to effectively address challenges of the 21st century, including the threats of bioterrorism. We appreciate the support of this Subcommittee and look forward to working with members of Congress to achieve these goals in fiscal year 2003 and into the future.

#### PREPARED STATEMENT OF THE AMERICAN UROLOGICAL ASSOCIATION, INC.

On behalf of the more than 10,000 members of the AUA and the patients they serve, I am pleased to provide the Subcommittee with our recommendations for fiscal year 2003 funding for urology research at the National Institutes of Health (NIH), in particular the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Cancer Institute (NCI). We are also recommending that the Centers for Disease Control and Prevention (CDC) receive additional funds to expand their efforts to promote public awareness about prostate cancer. I request that this statement be made part of the official hearing record.

AUA thanks Congress and this Subcommittee for its strong support of NIH and CDC. We are on schedule toward doubling the budget for biomedical research. This is welcome news for the medical and scientific communities, and most importantly, for our citizens who will one day benefit from the results of this research. NIH is among our best investments, and the nation needs to strengthen its biomedical research infrastructure if we are to continue to improve the health of our citizens. This Subcommittee has been steadfast in its support for biomedical research, and AUA greatly appreciates those efforts. AUA supports the recommendation of One Voice Against Cancer for a fiscal year 2003 NIH budget of \$27.3 billion which would fulfill the commitment to double the budget over 5 years.

<sup>&</sup>lt;sup>7</sup> CDC National Center for Chronic Disease Prevention and Health Promotion. Division of Nutrition and Physical Activity. Physical Activity and Good Nutrition: Essential Elements to Prevent Chronic Diseases and Obesity. http://www.cdc.gov/nccdphp/dnpa/dnpaaag.htm April 11, 2002.

The burden of urological diseases can fall on anyone, from young children to our most frail elderly. Many urological diseases are age related and the incidence and consequences of urologic disease will become more profound and a greater burden to individuals and our society with the aging of our population. Genito-urinary diseases and conditions result in estimated health care expenditures in the United States of nearly \$50 billion each year. One third of all new cancers in 2002 will involve a urologic organ. Fifty percent of all new cancers in men are urologic in origin.

The effect of these diseases on minority populations and women is significantly greater than the overall effect on the entire population. For example, the incidence of prostate cancer among African American males is twice that of white men. Women suffer from urinary incontinence at twice the rate of men. Unfortunately science cannot adequately explain why these differences exist and how to address them.

In 1990 I had the honor of serving as Deputy Chairman of the National Kidney and Urologic Diseases Advisory Board. I helped author its long-range plan, "Window on the 21st Century", that identified areas of need in urology research and made recommendations on how those challenges could be met. In the intervening decade there has been undoubted progress, but as I reread the report, I am struck by how many of the same issues confront urology research today because no steps have been taken to address them. If the report's recommendations had been followed, I am sure that I could today report on great progress in women's urological issues, in the congenital urologic defects that affect infants and in male infertility, just to name a few areas that badly need the attention of the scientific community. If the advice of the Advisory Board had been followed, we would not have the ongoing debate over whether early detection of prostate cancer saves men's lives. Had we started in 1990 we would know the answer today with certainty.

I view this as a history of lost opportunities, and while I am excited about the progress that our scientists have made, I am greatly disappointed that so much still remains to be done.

We knew what the questions were in 1990. They have not changed. We simply have not taken the opportunity to answer them. The losers have been the American people who still suffer from these diseases.

The funds available for urologic research remain small when compared to those available for other diseases of similar impact. We believe that urological diseases and conditions constitute a major public health problem in this nation; one that is not being adequately met by existing research and public health mechanisms. We hope that the commitment of Congress to foster growth in the overall budget at NIH will translate into real gains in support for urologic research.

#### NATIONAL CANCER INSTITUTE

The American Cancer Society (ACS) estimates that 189,000 new cases of prostate cancer will be diagnosed in 2002. This means that prostate cancer remains the second most commonly diagnosed cancer among men. ACS further projects that 30,200 men will die from this disease this year. This represents a further decline in the death rate that is part of a sustained trend and strongly suggests the effectiveness of early detection. In fact, the change is so statistically significant that it is hard to understand why there is any debate over the importance of early detection of prostate cancer.

However, it is imperative that we improve our ability to detect prostate cancer more accurately at the earliest stages. We also need to be able to determine which cancers will be aggressive and might require more aggressive therapies.

There is no question that we must expand and improve the types of treatments that are available for men with prostate cancer, whether in the early or later stages of the disease. AUA is pleased with the initiatives in prostate cancer that are underway at NCI. If adequate funds continue to be available researchers will unlock even more of the secrets of this cancer. Because of research funded at NCI, with the strong encouragement of this Subcommittee, urologists now have a better understanding of the disease's mechanisms. NCI funded research has opened new doors that could lead to significant new advances in the diagnosis and treatment of this disease.

In order to meet the needs in prostate cancer research, we join with the National Prostate Cancer Coalition and One Voice Against Cancer in asking for \$5.69 billion, the amount of the NCI bypass budget. This amount will assure that NCI will have the \$340 million necessary to implement fully the 5-year prostate cancer investment strategy it submitted to Congress in 1999.

However, we should not forget that the other urologic cancers, including testicular, bladder and kidney cancer, also affect thousands of Americans and their families each year. As the budget for NCI increases, new funds must be allocated to work in these areas. Currently, they are not adequately funded. AUA has previously recommended that NCI develop a comprehensive plan showing how these other urologic cancers can be addressed. Such a plan, worked out with the urologic scientific community, can help Congress and the National Institutes of Health determine the appropriate level of funding for these cancers and assure that federal funds are spent most effectively to combat these diseases. We are pleased that NCI has responded to our request and established progress review groups for both kidney and bladder cancers. We look forward to their recommendations.

## NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

Two years ago the appropriations conference report contained the following commentary on NIDDK, the home of the urology basic science program. "The conferees are concerned that the urology research effort is not addressing the large public health impact of urological diseases and conditions. NIDDK is strongly urged to enhance its research initiatives in urology." Unhappily, this situation remains unchanged.

Congress has provided substantial increases in the budgets of all Institutes, and now is the time for NIDDK to show Congress that it heard the message in the conference report. This means that existing programs must grow along with the overall agency budget. It also means that additional efforts are required because some key areas in urology research have been neglected in the past. It is critical that NIDDK provide this Subcommittee with specific plans for addressing these issues. There is no shortage of unmet need or opportunity in urology research. In addition to providing the needed funds, NIDDK needs to rethink the structure

In addition to providing the needed funds, NIDDK needs to rethink the structure of the urology research program. Currently it is housed in the Division of Kidney, Urology and Hematology. However, the breadth and complexity of urological disease argues strongly for a more flexible arrangement, with direct access to the highest levels of NIDDK leadership. We believe that a separate urology division, reporting to the Director of the Institute, would be such an arrangement and would make sure that there is strong and effective leadership for the urology program at NIH.

Prostate diseases affect far too many men, including cancer, prostatitis and benign prostatic disease. A key issue for each of these conditions is to better understand the factors that regulate prostate growth. Prostatitis is a painful condition affecting younger men and it has been estimated that the cost of this disease exceeds one half billion dollars annually.

BPH affects more than 12 million men over age 50, and twenty percent of them require treatment. Surgical treatment for the symptoms of the disease is the most common operation in the male over 65 years old in the United States. We also need to focus more attention on the bladder and urethral changes in response to the enlarged prostate. Bladder dysfunction and urinary obstruction are important problems associated with BPH, yet the relationships, causes and mechanisms are poorly understood.

There is a pressing need to increase research into the urologic disorders that affect women: urinary incontinence, urinary tract infections, interstitial cystitis (IC) and other problems of the bladder. These diseases affect millions of women of all ages and result in major U.S. health care expenditures. Urinary incontinence is a major cause of nursing home admissions for women. Many of those admissions might be prevented if the right questions were being asked and answered. There is very little funded research that focuses on either the prevention or effective treatment of these diseases. NIDDK has been slow to respond to Congressional efforts to advance clinical and basic research in women's urology.

Three other areas of research need attention, male infertility and impotence, congenital anomalies of the genitourinary tract and kidney stone diseases. In the area of male infertility for example, funding is extraordinarily limited although it is the cause of at least half of infertility in couples. Given the importance we all place on families and raising children, it is astounding that NIDDK funds virtually no research into a major problem affecting couples who cannot have children. Impotence affects as many as 30 million men, yet virtually no research is directed to the problem.

Urology problems that are present at birth result in significant physical and psychological stress for both the parents and the child. Most of these problems are due to congenital errors in the development of the urinary tract. The NIH devotes minimal research dollars to investigating either the genetic origin or effective treatment strategies for these abnormalities. The reality of genetic intervention could provide an entirely new method of understanding the inheritance, the cause and the effective treatment of these defects. We recommend that the NIDDK collaborate with other interested institutes in developing a strategic research plan to address congenital urological disorders in the pediatric age group. We need to initiate new, innovative research projects in these areas, especially such prevalent conditions as ureteral reflux, fetal hydronephrosis, and the effective treatment of the bladder dysfunction of spina bifida.

Urinary stone disease is a common and very painful occurrence for many Americans. Although effective treatments are available, almost no work is being done to advance this field, particularly in areas such as etiology and prevention.

NIDDK is the home of the George M. O'Brien Kidney and Urology Research Centers that have made a significant contribution to progress in these disease areas. We urge continued and increased funding for their activities. In addition, AUA recommends the creation of new urologic centers, which should have a clinical component and a research training component. These new centers could address some of the challenges in male infertility and pediatric urology, for example, that are currently unexamined.

Congress has provided NIDDK significant amounts of money to study diabetes and its complications. Urological complications such as impotence and urinary retention are frequent, yet the Institute is devoting no funds to examining this aspect of diabetes. AUA believes that this is a major oversight and recommends that NIDDK provide the Subcommittee with its plan to address this problem.

NIDDK should also increase research into the effective treatment of bladder dysfunction associated with spinal cord injury and neurological diseases. Bladder dysfunction associated with these disorders is frequently the cause of protracted illness, kidney failure and even death from overwhelming infection. We need to make sure that the most effective methods of treatment and new and innovative approaches to treatment are investigated and utilized.

# CENTERS FOR DISEASE CONTROL AND PREVENTION

Prostate cancer is the second leading cause of cancer death among men in this country. Other than skin cancer, it is the most commonly diagnosed type of cancer, and has considerably higher incidence and mortality rates among African American men. Despite this impact, the importance of providing screening, outreach, education and treatment for men, especially those at higher risk, is neglected. CDC's prostate cancer awareness campaign is an important part of the overall effort. Since prostate cancer does strike African American men at a much higher rate, it is imperative that we conduct prevention and outreach programs within this community to assure early intervention and treatment using the best tools available. CDC is a logical place for such an effort given its experience with similar programs in breast and cervical cancer.

We are pleased that the efforts of Congress to stimulate such a program have succeeded, and a small activity has been developed. This program shows great promise, and we ask that \$20 million be allocated to this effort in order to expand CDC's ability to target high-risk populations for this disease. Education, awareness and early detection are key to reducing the extremely high prostate cancer rates among African American men. Men must be motivated to take advantage of these opportunities, and this is an area in which CDC can play a critical role. As this targeted effort succeeds, it can be expanded in the future to include the broader male population at risk.

However, we must express one concern about the attitudes among some in CDC toward men with prostate cancer and their need for accurate information about their disease. In the Public Health Improvement Act which reauthorized the CDC in 2000, specific language was included directing CDC to seek input from professional societies and other private and public entities as it developed materials on prostate cancer screening measures and appropriate medical treatment. One of CDC's first efforts was to draft a public education brochure on prostate cancer screening. While a meeting was held with representatives from urology and prostate cancer patient organizations, the language that was drafted took in little or none of our recommendations. The language was in fact extremely vague and rambling about the risks of prostate cancer, negative towards the benefits of screening and even questioned whether prostate cancer is a serious health problem. While the booklet has not yet been published, efforts by AUA and many patient groups to implement changes have fallen on deaf ears. I think it is very important to underscore that the groups most unhappy with CDC's efforts are the ones that represent prostate cancer survivors. We urge the Subcommittee to make sure that CDC does not publish such misleading information about a deadly disease.

AUA urges careful consideration of these recommendations and appreciates the opportunity to submit them to the Subcommittee. We urge the Subcommittee to

maintain its efforts on behalf of NIH and to focus greater attention on urologic dis-

eases and conditions in this next fiscal year. Please direct any questions to AUA's Director of Government Relations, Cherie McNett, or Director of Research, Monica Liebert, at 410–727–1100.

#### PREPARED STATEMENT OF THE HEPATITIS FOUNDATION INTERNATIONAL

# SUMMARY OF FISCAL YEAR 2003 RECOMMENDATIONS

-Continue the effort to double the National Institutes of Health (NIH) budget by providing a 16 percent increase for fiscal year 2003. Increase funding for the National Institute for Allergy and Infectious Diseases (NIAID) and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) by 16 percent.

NIH—\$23.7 billion

- -NIAID—\$2.9 billion (non-bioterrorism) -NIDDK—\$1.7 billion
- Provide \$7.9 billion in fiscal year 2003 for the Centers for Disease Control and Prevention (CDC).
- Provide \$41 million in fiscal year 2003 for a hepatitis B vaccination program for high risk adults at CDC as recommended by the National Hepatitis C Prevention Strategy

—Provide \$40 million in fiscal year 2003 for CDC's Prevention Research Centers. Thank you for your continued leadership in promoting better research, prevention, and control of diseases affecting the health of our nation. I am Thelma King Thiel, Chairman and Chief Executive Officer of the Hepatitis Foundation International (HFI), representing members of 425 patient support groups across the nation, the

(HFI), representing members of 425 patient support groups across the nation, the majority of whom suffer from chronic viral hepatitis. Currently, five types of viral hepatitis have been identified, ranging from type A to type E. All of these viruses cause acute, or short-term, viral hepatitis. Hepatitis B, C, and D viruses can also cause chronic hepatitis, in which the infection is prolonged, sometimes lifelong. While treatment options are available for all types of hepatitis, individuals with chronic viral hepatitis (types B, C, and D) represent the majority of liver failure and transplant patients. Treatment options and immunizations are available for most types of hepatitis (see below), however, we do know how to prevent all types of hepatitis.

	Immunization	Treatment
Hepatitis A	Yes	Will Resolve Itself
Hepatitis B	Yes	Drug Therapy
Hepatitis C	No	Drug Therapy
Hepatitis D	Yes	Drug Therapy
Hepatitis E	No	Will Resolve Itself

# HEPATITIS B

Hepatitis B (HBV) claims 5,000 lives every year in the United States, even though we have therapies to both prevent and treat this disease. This disease is spread through contact with the blood and body fluids of an infected individual. Unfortunately, due to both a lack in funding to vaccinate adults at high risk of being infected and the absence of an integrated preventive education strategy transmission of hepatitis B continues to be problematic.

#### HEPATITIS C

Infection rates for hepatitis C (HCV) are in epidemic proportions, unfortunately, as many do not become ill with the disease until several years after infection, we are dealing with an "epidemic of discovery". This creates a vicious cycle, as individuals who are infected continue to spread the disease unknowingly. Hepatitis C is also spread through contact with an infected individual's blood. The CDC estimates that there are over 3.9 million Americans who have been infected with hepatitis C, of which over 2.7 million remain chronically infected, with 10,000 deaths each year. Additionally, the death rate is expected to triple by 2010 unless additional steps are taken to improve outreach and education on the prevention of hepatitis C, new research is undertaken, and more effective treatments are developed. As there is no vaccine for HCV, prevention activities serve as the only tool in halting the spread of the disease.

#### PREVENTION IS THE KEY

Only a major investment in immunization and preventive education will bring these diseases under control today. All newborns, young children, young adults, and especially individuals that participate in high-risk behaviors must be a priority for immunization and outreach initiatives. We recommend that the following activities

- Be undertaken to prevent the further spread of all types of hepatitis:
   —Provide effective preventive education in our elementary and secondary schools helping children avoid the ravages of health problems resulting from viral hepatitis infection
  - -Training health care professionals in effective communication and counseling techniques.
  - -Public awareness campaigns to alert individuals to assess their own risk behaviors, motivate them to seek medical advice, encourage immunization against hepatitis A and B, and to stop the consumption of any alcohol if they have par-ticipated in risky behaviors that may have exposed them to hepatitis C.
  - -Expansion of screening, referral services, medical management, counseling, and prevention education for individuals who have HIV/AIDS, many of whom may be co-infected with hepatitis.

HFI recommends an increase of \$41 million in fiscal year 2003 for further imple-mentation of CDC's Hepatitis C Prevention Strategy. This increase will support and expand the development of state-based prevention programs by increasing the num-ber of state health departments with CDC funded hepatitis coordinators. The Strategy will use the most cost-effective way to implement demonstration projects evalu-ating how to integrate hepatitis C and hepatitis B prevention efforts into existing public health programs. Additionally, HFI recommends that \$10 million be used to train and maintain hepatitic acadimic to the second se

public health programs. Additionally, first recommends that the minimum be used to train and maintain hepatitis coordinators in every state. CDC's Prevention Research Centers, an extramural research program, plays a critical role in reducing the human and economic costs of disease. Currently, CDC funds 26 prevention research centers at schools of public health and schools of medi-cine across the country. HFI encourages the Subcommittee to increase core funding for these provention conters, as it has been decreasing since this program was first. for these prevention centers, as it has been decreasing since this program was first funded in 1986. We recommend the Subcommittee provide \$40 million for the Prevention Research Centers program in fiscal year 2003.

#### INVESTMENTS IN RESEARCH

Investment in the National Institutes of Health (NIH) has led to an explosion of knowledge that has advanced understanding of the biological basis of disease and development of strategies for disease prevention, diagnosis, treatment, and cures. Countless medical advances have directly benefited the lives of all Americans. NIHsupported scientists remain our best hope for sustaining momentum in pursuit of scientific opportunities and new health challenges. For example, research into why some HCV infected individuals resolve their infection spontaneously may prove to be life saving information for others currently infected. Other areas that need to be addressed are:

-Reasons why African Americans do not respond to antiviral agents in the treatment of chronic hepatitis C

-Pediatric liver diseases, including viral hepatitis. -The outcomes and treatment of renal dialysis patients who are infected with HCV

-Co-infections of HIV/HCV positive patients. -Hemophilia patients who are co-infected with HIV/HCV. The Hepatitis Foundation International supports the final year of the NIH doubling effort, which would provide \$23.7 billion for NIH in fiscal year 2003 representing a 16 percent increase. HFI also recommends a comparable increase of 16 percent in hepatitis research funding at the National Institute of Diabetes and Digestive and Kidney Diseases and the National Institute of Allergy and Infectious Diseases.

Victims of hepatitis suffer emotionally as well as physically. They experience discrimination in employment, strained personal relationships and severe depression when treatments fail to control their illness as well as during their treatment. We look forward to working in collaboration with CDC, NIH, health departments and other voluntary organizations to bring viral hepatitis under control.

Thank you for providing this opportunity to present our testimony.

#### The Hepatitis Foundation International

The Hepatitis Foundation International (HFI) is dedicated to the eradication of viral hepatitis, a disease affecting over 500 million people around the world. We

seek to raise awareness of this enormous worldwide problem and to motivate people to support this important—and winnable—battle.

Our mission has four distinct parts:

-Teach the public and hepatitis patients how to prevent, diagnose, and treat viral hepatitis.

Prevent viral hepatitis by promoting liver wellness and healthful lifestyles.

-Serve as advocates for hepatitis patients and the related medical community worldwide.

-Support research into prevention, treatment, and cures for viral hepatitis.

#### PREPARED STATEMENT OF ONE VOICE AGAINST CANCER

On behalf of One Voice Against Cancer (OVAC), a collaboration of more than 40 public interest groups representing 15 million Americans impacted by cancer, we are writing to urge you to make cancer research and its application a priority during consideration of the fiscal year 2003 Labor, Health and Human Services and Education (LHHS) Appropriations bill.

Congress has shown exemplary leadership in mounting an aggressive war on cancer, as demonstrated by Congressional commitment to double the National Insti-tutes of Health (NIH) budget by 2003. We have been pleased to work with you to secure the necessary funding for NIH, the National Cancer Institute (NCI), and the Centers for Disease Control and Prevention (CDC) in the past and look forward to doing so again this year. Your continued support and leadership is imperative to winning the war on cancer.

The facts are sobering: cancer claimed the lives of more than 500,000 Americans last year, while another 1.2 millions are newly diagnosed with cancer annually. We are aware of the many worthy priorities deserving of Congressional support in this difficult fiscal environment and hope that you will prioritize the importance of lifesaving cancer research and application programs.

We encourage you to devote the resources needed to benefit those on the front lines battling cancer-the researchers and health professionals striving every day to defeat cancer, the person without access to adequate cancer screening, the family with a loved-one who has been newly diagnosed with the disease. Research holds the key to improved prevention, early detection, diagnosis and treatment, late effects of treatment and subsequent follow up care. To complement our nation's ongoing investment in research, increased funding also is needed to enhance vital cancer prevention, awareness, and early detection programs at the CDC to ensure that these research applications benefit all Americans.

Therefore, OVAC asks that Congress include the following funding levels in the fiscal year 2003 Labor, Health and Human Services and Education Appropriations

- bill (see attached summary):
  \$27.3 billion for the NIH in fiscal year 2003. This will fulfill the commitment to double NIH funding by fiscal year 2003.
  \$5.69 billion for the NCI, the amount the NCI Director is requesting for a comprehensive effort to win the war against cancer. This "bypass budget" represents the best change for Americans who will be newly diagnosed with cancer resents the best chance for Americans who will be newly diagnosed with cancer this year, many of whom will have deadly forms of cancer of which we still know too little and for which we must offer new research opportunities and new hope
  - \$199.6 million for the NIH Center for Minority Health and Health Disparities to enable the Center to fulfill its important mission, particularly as it concerns the disproportionate incidence, morbidity, and mortality that cancer has in many racial and ethnic minority populations. Specifically, we call upon Con-gress to double the financial commitment to the Center over the course of the next 3 fiscal years. This will be attained through 26 percent increases in each year and will allow the Center to meet emerging priorities made even more ap-parent by the doubling of the overall NIH budget during the past five years.
  - \$348 million for cancer education, outreach, prevention and screening efforts through the CDC which applies the important research done at NIH to those touched by cancer. CDC's Cancer Prevention and Control programs provide vital cancer education, outreach, prevention and screening efforts that have a posi-tive impact on the lives of all Americans. Application of NIH and NCI research conducted by CDC is proving to be particularly critical in saving lives, and we urge Congress to continue this important support.

Funding for all of these critical programs must be efficiently and effectively utilized so that all Americans reap clear and rapid benefits from research and its appli-

cation. To that end, we look forward to working with you to ensure that these federal agencies responsibly meet their obligations. One Voice Against Cancer encourages you to take these vital steps to help the

nation defeat cancer. Please contact any of the organizations listed below if we can be of assistance or provide additional information regarding our funding requests. We thank you for your continued work on behalf of our nation in these critical days.

American Cancer Society; American Foundation for Urologic Disease; American Society of Hematology; American Urological Association; Asian & Pacific Islander American Health Forum; Association of Community Cancer Centers; Breast Cancer Resource Committee, Inc.; Cancer Research Foundation of America; Candlelighters Childhood Cancer Foundation; Children's Oncology Group; Coali-tion of National Cancer Cooperative Groups; Colorectal Cancer Network; Inter-cultural Cancer Council; Intercultural Cancer Council Caucus; Kidney Cancer Association; Leukemia & Lymphoma Society; Men's Health Network; National Alliance for Hispanic Health; National Melanoma Foundationl; Oncology Nursing Society; Ovarian Cancer National Alliance; Pancreatic Cancer Action Network; Society of Gynecologic Oncologists; United Ostomy Association, Inc.; and US TOO International, Inc

SUMMARY OF ONE VOICE AGAINST CANCER FUNDING REQUESTS-FISCAL YEAR 2003

National Institutes of Health (NIH)—\$27.3 billion

This is the amount necessary to fulfill the commitment to double the NIH budget over 5 years.

National Cancer Institute (NCI)-\$5.69 billion

This is the NCI Director's fiscal year 2003 Bypass Budget.

National Center for Minority Health and Health Disparities—\$199.6 million

This amount will put the nation on course to double the Center's budget over the course of 3 years.

Centers for Disease Control and Prevention (CDC)

Comprehensive Cancer Control Initiative-\$10 million

National Cancer Registries Program-\$55 million

Colorectal Cancer Screening, Education and Outreach—\$25 million Prostate Cancer Awareness Campaign—\$20 million National Breast and Cervical Cancer Early Detection Program—\$220 million Ovarian Cancer Program-\$8 million

Skin Cancer Program—\$10 million

#### PREPARED STATEMENT OF THE UPPER COUNTY BRANCH, MONTGOMERY COUNTY, MARYLAND STROKE CLUB

### A STROKE SURVIVOR: A PERSONAL STORY

Hello. My name is Susan Emery. I am the presiding officer of the Upper County Branch of the Montgomery County Stroke Club and I'm a stroke survivor.

Our club conducts education and support activities for stroke survivors, their famly members, and caregivers. We serve people in the Maryland suburbs of Wash-ington, DC, and are fortunate to be in the same county as the National Institutes of Health. We have benefited on many occasions by the participation of NIH staff members in our membership meetings. They have been generous in sharing infor-

mation about their research into stroke prevention and treatment with us. On December 26, 1965 at the age of nine, I was playing a new game with my brother and a few friends at the kitchen table. That's the last thing that I remember. I was unconscious for the next two days. My mother first learned, incorrectly, that I had spinal meningitis. I was transferred to another hospital where my mother was told that I had little chance of survival. Yet I'm here, more than 36 years later, and I've survived a stroke.

People seldom associate strokes with children. These strokes are rare, but they do happen. There are about three cases of stroke per year in every 100,000 children under age 14. One of the difficulties in dealing with strokes in children is getting the right diagnosis quickly. There are often delays in diagnosis of childhood stroke.

I spent 2 weeks in the hospital and the following 4 months in intensive physical therapy. My tenth birthday was spent in the hospital, and I have a picture in my photo album of myself with my mother and a new friend. My right eye is turned down, my mouth is turned down, but I'm still smiling. During the 4 months in therapy at Holy Cross in Detroit, I learned the basics: how to walk, how to talk, and how to move the fingers on my right hand. My mother followed the doctor's instructions and sent me back to school very quickly, where classmates helped me button and unbutton my coat and carry my books, and teachers taped papers to the desk so I could learn to write again. I survived that 4 months, and would never wish to repeat it.

Twe been in therapy six times in my life. I need to tell you about the one time that was the most important to my family. I was 26 years old and had just had my first child. I kept her safe, for I knew my limitations. I always used my left hand to support her. But when she was 6 months old, she got to be a little heavy, and twice, as I was putting her on the floor to change her diaper, my right hand slipped from under her buttocks. She fell only inches in both cases and didn't even notice. But I noticed. I went in for 2 or 3 months of therapy close to Denver, Colorado, where I was living at the time. Here for the first time, they helped my right hand and arm dexterity through occupational therapy. I also learned that I had aphasia the inability to speak, write or understand spoken or written language because of brain injury—because I called things like cornucopias, unicorns instead of fruit baskets. Instead of the word being the same, I picked a word that sounded the same. These therapists in Colorado worked with my mind and my body and I will forever be in their debt.

Close to 14 years ago, I made a new life for myself in Maryland. Here, I've been an outpatient at the National Rehabilitation Hospital three times: once for my right foot, once for my Achilles tendon and once for my right knee. I've seen numerous physiatrists, all of whom are excellent in their field. I've also seen my fair share of therapists. Since I've had therapy off and on for most of my life, I can honestly say that the first few times you go in to see a therapist, you'll come out hurting more than when you went in. But in the long run, they help tremendously. On a work related note, I received a Bachelor of Science in 1978 from Michigan

On a work related note, I received a Bachelor of Science in 1978 from Michigan State University in Computer Science and worked for 12 years in the field. I started working in the telecommunications industry in 1990, and got a Master of Science from the University of Maryland, University College in Telecommunications Management. I now work for ITT Industries as a senior engineer on a contract supporting the Federal Aviation Administration's leased telecommunications activities, and have worked there for more than 5 years. I've done more than survive. I've become a productive member of society.

Stroke research has changed my life. Without the research carried out 40 to 50 years ago, I would not have benefited from electric shock therapy that made me understand the muscles that moved my fingers. Without research done 30 years ago, I may not have been able to understand how to exercise my hand for dexterity. Without research performed 10 years ago, the people around me would not understand that they need to get me to the hospital quickly if ever I have another strokes before they happen or how to make current stroke survivors live healthier lives.

Stroke remains America's No. 3 killer and a major cause of permanent disability. About 4.6 million Americans live with the consequences of stroke and 1 of 4 is permanently disabled. Yet, stroke research receives 1 percent of the National Institutes of Health budget. I strongly urge you to significantly increase funding for the National Institutes of Health-supported stroke research, particularly for National Institute of Neurological Disorders and Stroke-supported stroke research. NIH stroke research is essential to prevent strokes from happening to children and adults in the first place, and to advance recovery and rehabilitation of those who survive this potentially devastating illness.

# PREPARED STATEMENT OF THE AMERICAN THORACIC SOCIETY AND THE AMERICAN LUNG ASSOCIATION

#### Summary of Funding Recommendation

#### [In millions of dollars]

National Institutes of Health	27,259.0
National Heart, Lung, and Blood Institute	2,988.7
National Institute of Allergy and Infectious Disease	2,943.6
National Institute of Environmental Health Sciences	661.2
Fogarty International Center	66.3
National Institute of Nursing Research	
Centers for Disease Control and Prevention	7,900.0
National Institute for Occupational Safety and Health	336.5

Office on Smoking and Health	130.0
Environmental Health: Asthma Activities	70.0
Tuberculosis Control Programs	528.0

The American Thoracic Society (ATS) and American Lung Association (ALA) are pleased to present our recommendations for programs in the Labor Health and Human Services and Education Appropriations Subcommittee purview.

The American Thoracic Society, founded in 1905, is an independently incorporated, international education and scientific society which focuses on respiratory and critical care medicine. The Society's members help prevent and fight respiratory disease around the globe through research, education, patient care and advocacy. The Society's long-range goal is to decrease morbidity and mortality from disorders and life-threatening acute illnesses.

The American Lung Association is the oldest voluntary health organization in the United States, with a National Office and constituent and affiliate associations around the country. Founded in 1904 to fight tuberculosis, the American Lung Association today fights lung disease in all its forms, with special emphasis on asthma, tobacco control and environmental health. The Lung Association is funded by contributions from the public, along with gifts and grants from corporations, foundations and government agencies. The American Lung Association achieves its many successes through the work of thousands of committed volunteers and staff.

#### MAGNITUDE OF LUNG DISEASE

Each year, an estimated 341,500 Americans die of lung disease. Lung disease is America's number three killer, responsible for one in every seven deaths. More than 25 million Americans suffer from a chronic lung disease. This year, lung diseases cost the U.S. economy an estimated \$94.9 billion.

Lung diseases represent a spectrum of chronic and acute conditions that interfere with the lung's 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 cancer, tuberculosis, pneumonia, influenza, sleep disordered breathing, pediatric lung disorders, occupational lung disease, sarcoidosis and asthma. The American Thoracic Society and American Lung Association are pleased that

The American Thoracic Society and American Lung Association are pleased that the Administration has proposed completing the effort to double the National Institute of Health (NIH) budget in fiscal year 2003. We look forward to working with this committee to bring this important investment in the health of all Americans to its fruition. Mr. Chairman, while our comments today will focus on selected parts of the Public Health Service, the American Thoracic Society and American Lung Association are firmly committed to appropriate funding for all sectors of our nation's public health infrastructure.

### COPD

Chronic Obstructive Pulmonary Disease, or COPD, is a growing health problem. Yet it remains relatively unknown to most Americans and much of the research community. COPD is an umbrella term used to describe the airflow obstruction associated mainly with emphysema and chronic bronchitis. COPD is the fourth leading cause of death in the United States and worldwide. While the exact prevalence of COPD is not well defined, it affects tens of millions of Amoricans and can be an extremely debiliteding condition. It has been estimated

While the exact prevalence of COPD is not well defined, it affects tens of millions of Americans and can be an extremely debilitating condition. It has been estimated that 16 million patients have been diagnosed with some form of COPD and as many as 16 million more are undiagnosed. New government data based on a 1998 prevalence survey suggest that three million Americans have been diagnosed with emphysema and nine million are diagnosed with chronic bronchitis. Emphysema affects more men than women, while chronic bronchitis affects more women than men. In 1999, 119,524 people in the United States died of COPD. During the period 1979– 1998, the number of deaths from COPD rose almost 126 percent. COPD costs the U.S. economy an estimated \$30.4 billion a year. Today, COPD is treatable but not curable. Fortunately, promising research is on

Today, COPD is treatable but not curable. Fortunately, promising research is on the horizon for COPD patients. Research in the genetic susceptibility underlying COPD is making progress. Research is also showing promise for reversing the damage to lung tissue caused by COPD.

Despite these promising research leads, the ATS/ALA feel that research resources committed to COPD are not commensurate with the impact COPD has on the United States and the world. The ATS/ALA strongly recommend that the NIH and

other federal research programs commit additional resources to COPD research programs.

## ASTHMA

Asthma is a chronic lung disease in which the bronchial tubes of the lungs become swollen and narrowed, 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.—A 1998 survey found that an estimated 26 million Americans (including 8.6 million children under the age of 18) have at some point in their lifetime been told by their doctor that they have asthma. 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, 75 percent will require life-long treatment and monitoring of their condition.

some children appear to out grow their astima when they reach additional, to per cent will require life-long treatment and monitoring of their condition. *Asthma is expensive.*—The growth in the prevalence of asthma will have a significant impact on our nation's health expenditures, especially Medicaid. Currently, asthma costs the United States \$12.7 billion annually, including \$8.1 billion in direct medical expenditures. Asthma attacks bring nearly two million people to the emergency room each year. Asthma also kills. In 1998, 5,438 people in the United States died as a result of an asthma attack. That is a 109 percent increase from 1979. A disproportionate share of these deaths occurred in African American families.

## Federal Response to Asthma

The federal response to asthma has three components: research, programs and planning. We are pleased to report that, with support from the subcommittee, we are making progress on all three fronts.

## Federal Response to Asthma—Research

As the prevalence of asthma has grown, so has asthma research. Researchers are developing better ways to treat and manage chronic asthma. Research supported by National Heart, Lung and Blood Institute (NHLBI) has shown that using corticosteroids to treat children with mild to moderate asthma is safe and effective. For several years there had been concern that corticosteriods would stunt the growth of children who used them. This 5-year study showed that children had a 1-year small reduction in their growth rate. But they had normal growth rates compared with children who did not use corticosteriods for the following 4 years. Children who used corticosteroids did suffer fewer asthma attacks and made fewer trips to the emergency room.

Genetic research is also providing insights into asthma. Physicians have noticed that while most people respond well to inhaled beta-agonists—a commonly prescribed drug to treat asthma—some patients do not response or have worse asthma using inhaled beta-agonists. Researchers in the NHLBI supported Asthma Clinical Research Network have discovered that a genetic variation in the beta-adrenegric receptor determines how well asthma patients will respond to inhaled beta-agonists. This discovery will enable physicians to better target the drugs they proscribe to treat asthma.

Basic research is also learning more about asthma. 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 asthma's onset, severity and long-term consequences.

#### Federal Response to Asthma—Programs

Last year, Congress provided approximately \$35 million for the Centers for Disease Control and Prevention (CDC) to conduct asthma programs. CDC will use these funds to conduct asthma outreach, education and tracking activities. In Ohio, Case Western University and Rainbow Babies and Children's Hospital have been awarded funds to conduct an asthma intervention program. However, at the current level of funding, less than half the states have funds to respond to asthma. The ATS/ALA recommend that CDC be provided \$70 million in fiscal year 2003 to expand its asthma programs.

## Federal Response to Asthma—Planning

Last year, Congress enacted legislation that directs the National Asthma Education and Prevention Program (NAEPP) at NHBLI to develop a plan for the federal government to respond to the growing asthma epidemic in the United States. The plan will include recommendations on research, public health, tracking, education and treatment activities. The ATS/ALA support this planning process and look forward sharing the recommendations of the NAEPP Federal Asthma Plan with this subcommittee in the near future.

## TUBERCULOSIS

Mr. Chairman, tuberculosis has been with us since the dawn of time. It is an airborne infection caused by a bacterium, *Mycobacterium tuberculosis* (TB). TB primarily affects the lungs but can also affect other parts of the body, such as the brain, kidneys or spine.

TB is spread through coughs, sneezes, speech and close proximity to someone with active tuberculosis. People with active tuberculosis are most likely to spread TB to others they spend a lot of time with, such as family members or coworkers. It cannot be spread by touch or sharing utensils used by an infected person.

There are an estimated 10 million to 15 million Americans who carry latent TB infection. Each has the potential to develop active TB in the future. About 10 percent of these individuals will develop active TB disease at some point in their lives. In 2001, there were 15,991 cases of active TB reported in the United States. The Institute of Medicine (IOM) recently published a report, entitled *Ending Neglect: The Elimination of Tuberculosis in the United States.* The report documents

The Institute of Medicine (IOM) recently published a report, entitled *Ending Ne*glect: The Elimination of Tuberculosis in the United States. The report documents the cycles of attention and progress toward TB elimination, the periods of insufficient funding and the re-emergence of TB. The ATS/ALA are pleased to note that, for the time being, TB rates in the United States are declining. From a high in 1992 of 26,673 new cases, we have seen 9 straight years of decline. However, the drop in 2001 was reportedly only 2 percent, indicating a leveling off of the overall decline in cases and a cause for concern within the public health community. This is no time to lower our defenses in funding TB programs.

time to lower our defenses in funding TB programs. While declining overall TB rates is good news, the emergence and spread of multidrug resistant TB poses a significant threat to the public health of our nation. Continued support is need if the United States is going to continue progress toward the elimination of TB.

The IOM report provides the United States with a road map of recommendations on how to eliminate TB in the United States. The IOM report identifies needed detection, treatment, prevention and research activities. The ATS/ALA have endorsed the IOM report and its recommendations. We estimate it will cost \$528 million for the CDC Tuberculosis Elimination Program to implement the report recommendations.

The NIH also has a prominent role to play in the elimination of TB. Currently there is no highly effective vaccine to prevent TB transmission. However, the recent sequencing of the TB genome and other research advances has put the goal of an effective TB vaccine within reach. The National Institutes of Allergy and Infectious Disease have developed a Blueprint for Tuberculosis Vaccine Development. ATS/ ALA encourage the subcommittee to fully fund the TB vaccine effort.

# Fogarty International Center TB Training Programs

The Fogarty International Center (FIC) at NIH provides training grants to U.S. universities to teach AIDS treatment and research techniques to international physicians and researchers. The goal is to develop a cadre of health professionals in the developing world who can begin controlling the global AIDS epidemic. Because of the link between AIDS and TB infection, FIC has created supple-

Because of the link between AIDS and TB infection, FIC has created supplemental TB training grants for these institutions to train international health care professionals in the area TB treatment and research. This supplemental program has been highly successful in beginning to create the human infrastructure to treat the nearly two billion people who have TB worldwide.

However, we believe TB training grants should not be offered exclusively to institutions that have received AIDS training grants. The TB grants program should be expanded and open to competition from all institutions. The ATS/ALA recommend Congress provide an additional \$3 million for FIC to expand the TB training grant program from a supplemental grant to an open competition grant.

#### NIOSH—RESEARCHING AND PREVENTING OCCUPATIONAL LUNG DISEASE

The ATS/ALA are extremely concerned that the president's budget proposes to cut the National Institute of Occupational Safety and Health (NIOSH) extramural research program. The ATS/ALA strongly encourage this subcommittee to reject the Administration's proposed cut to the NIOSH research program. Occupational safety and health research are valuable and deserve additional funding.

Protecting the health of our nation's workforce will require research, training, tracking and new technologies. The ATS/ALA recommend that the subcommittee

provide a \$60 million increase for the NIOSH budget including \$25 million for the NIOSH National Occupational Research Agenda (NORA). NORA represents a partnership research plan for occupational disease. The NORA agenda was developed with input from labor, business and the health community. The ATS/ALA recommend an additional \$10 million for the National Personal

The ATS/ALA recommend an additional \$10 million for the National Personal Protective Technology Laboratory. In addition to improving workers safety, investments in protective technology will help our nation respond to the growing threat of bioterrorism. The ATS/ALA also recommend an additional \$10 million for NIOSHsponsored prevention, intervention and information programs. These programs respond to existing workplace health programs, conduct prevention education programs and work with labor and industry groups to lower the risk of workplace injury and illness.

A recent IOM Report, Safe Work in the 21st Century: Education and Training Needs for the Next Decades Occupational Safety and Health Personnel, identified a growing shortage of trained occupational health professionals in the United States. Unlike the majority of medical subspecialties, occupational health professionals do not receive Medicare training support. We recommend \$5 million to increase training opportunities for occupational health professionals at NIOSH-sponsored Centers of Excellence. The ATS/ALA believe more funds are needed to track the incidence of serious work-related illnesses and injury. We recommend \$10 million for surveillance data on workplace safety.

#### LUNG-DISEASE OPPORTUNITIES AND ADVANCES

Previously, the ATS/ALA reported that NHLBI-supported researchers found that retinoic acid can reverse the effects of emphysema in laboratory rats. The ATS/ALA are pleased to report that studies have gone from rats to non-human primates and that results continue to be encouraging. NHLBI is taking steps to test retinoic acid treatment in people. We appear to be one step closer to finding a way to reverse the effects of emphysema—what has been considered an irreversible, debilitating disease.

Researchers studying black, white and Hispanic groups in a search for genetic links to asthma found genes on chromosomes 5, 8, 12, 14, and 15 that are associated with asthma, regardless of a patient's ethnic background. Therefore, understanding the genetic variations of asthma is likely to have a major influence on improving available therapeutic options, especially for minority patients. LAM is a rare and devastating lung disease that primarily affects young women and course an ourgrowth of smooth muscle like cells in the lungs. Becoardbore hours

LAM is a rare and devastating lung disease that primarily affects young women and causes an overgrowth of smooth muscle-like cells in the lungs. Researchers have found a link between LAM and another, more common, inherited condition known as tuberous sclerosis complex (TSC). Many women with TSC also have a mild form of LAM and often develop benign kidney tumors containing typical LAM cells. Understanding the influences of specific genes in LAM, as well as the roles of specific proteins, should aid in identifying new therapeutic targets and developing new treatments for this debilitating disease.

NHLBI is continuing its support for sleep-related research. Investigators studying nearly 700 adults found that weight gains of 5 per cent to 20 percent over 4 years increase the risk of developing sleep apnea 2.5- to 37-fold. More important, weight loss was associated with reduced sleep apnea severity and decreased likelihood of developing moderate to severe sleep apnea. Sleep apnea, a prevalent and potentially serious medical condition, is characterized by repeated episodes of airway obstruction during sleep and excessive daytime sleepiness and may lead to cardiovascular disease.

In conclusion, Mr. Chairman, 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. Overall, lung disease and breathing problems constitute the number one killer of babies under the age of 1 year. Worldwide, tuberculosis kills 3 million people each year, more people than any other single infectious agent. Mr. Chairman, the level of support this committee approves for lung disease programs should reflect the urgency illustrated by these numbers.

# PREPARED STATEMENT OF THE PUBLIC POLICY COUNCIL

This statement is submitted on behalf of the Public Policy Council (PPC) that 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 forces 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, clinical and heath services research, and for the training of future pediatric bench and clinical investigators.

### PEDIATRIC RESEARCH

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. Infants and children are leading healthier lives. However, there are still many pediatric diseases that are not preventable or for which treatment may not exist, may only be palliative or are simply inadequate.

However, there are still many pediatric diseases that are not preventable or for which treatment may not exist, may only be palliative or are 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.

Improvements in pediatric medicine and research will have far-reaching implications on the societal and economic costs of disease in adults. For example, 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 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? A strengthened investment in pediatric research is clearly needed and necessary.

search is clearly needed and necessary. 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. 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. Are 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.

# 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 a child 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, the pediatric research community is 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 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.

# PROMOTING PEDIATRIC RESEARCH AND PRESERVING THE TRAINING OF PEDIATRIC INVESTIGATORS

The pediatric community applauds the ongoing commitment of Congress, through the leadership of this Subcommittee, to increase NIH funding. The Public Policy Council supports the \$27.3 billion fiscal year 2003 recommendation presented by the Ad Hoc Group for Medical Research Funding, that calls for an increase in funding for the NIH as the final year of doubling the NIH budget.

This Subcommittee and full Committee has helped make pediatric research a priority at the highest level of the NIH by establishing a Pediatric Research Initiative in the Children's Health Act of 2000. The Public Policy Council encourages the Committee to continue and to increase funding for this initiative to at least \$10 million in fiscal year 2003. The pediatric academic societies endorse the Friends of NICHD Coalition's recommendation for the National Institute of Child Health and Human Development (NICHD) of \$1.284 billion and the overall fiscal year 2003 Public Health Service funding recommendations of the Coalition for Health Funding. The PPC recognizes the difficulty in achieving all of these goals under the current spending limits. However, the PPC encourages the Committee to explore all possible options to identify the additional resources needed to support this recommendation.

Furthermore, the PPC urges 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, and provide opportunities for mentoring by experienced clinical investigators as well as enhance the quality of our mentors. The PPC also continues to support and urges the expansion of available funding for the clinical research and the pediatric research loan repayment programs. The Public Policy Council strongly believes that we must not shortchange our children from receiving care from well-trained and qualified pediatric investigators.

The Public Policy Council also supports the Agency for HealthCare Research and Quality, 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, including pediatricians. The PPC joins with the Friends of AHQR to recommend funding of \$390 million for AHQR in fiscal year 2003.

#### INCLUSION OF CHILDREN IN CLINICAL TRIALS

The Public Policy Council commends 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." Implementation of these guidelines began in October 1998. As pediatric investigators, the Public Policy Council anticipates that significant advances will be gained in understanding the mechanism and improving the treatment of pediatric diseases. This policy is an excellent initial step. Moreover, it reflects an important partnership and the com-mitment 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, a process should be established to assess the efficacy (or lack thereof) of the policy in generating data about and therapeutic advances for children. The pediatric research community will continue to work with the NIH on these and other implementation issues of these important guidelines. Moreover, the PPC encourages this Committee to maintain its oversight on the assessment of this policy as its implementation evolves over time.

Finally, we all must recognize that the benefits for children and society in securing properly studied and dosed medications are considerable. This includes: the reduction of medical errors and adverse drug effects; the reduction of health care costs through fewer hospitalizations and shortened hospital stays; and the availability of more child-friendly formulations for infants and children. The PPC urges you to provide and ensure the adequacy of funding for the NIH that will provide \$200 million for the NIH to establish a fund to study generic (off-patent) and selected on-patent drugs for pediatric use.

#### 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. The Public Policy Council supports the increased investment in research in general and the new pediatric initiative in particular.

#### PREPARED STATEMENT OF THE DYSTONIA MEDICAL RESEARCH FOUNDATION

## SUMMARY OF FISCAL YEAR 2002 RECOMMENDATIONS

-Continue to double the budget for the National Institutes of Health (NIH) by providing a 16 percent for fiscal year 2003. Increase funding for the National Institute of Neurological Disorders and Stroke (NINDS) and the National Institute of Deafness and other Communication Disorders (NIDCD) by 16 percent.

#### Fiscal Year 2003 Recommendations for NIH

#### [In billions of dollars]

NIH	23.700
NINDS	1.540
NIDCD	.397

-Continue to accelerate funding for extramural dystonia research at NINDS.

-Provide funding for NINDS to conduct an epidemiological study and to increase public and professional awareness of dystonia. Continue to expand NIDCD's intramural

and extramural research on dysphonia.

Chairman Harkin, thank you for the opportunity to describe for the Subcommittee how dystonia has affected our lives and our recommendations for fiscal year 2003 federal funding of dystonia research

My name is Rosalie Lewis, president of the Dystonia Medical Research Foundation. Three of my four sons have dystonia, and my fourth son is a carrier of the DYT1 gene that is responsible for generalized dystonia, which begins in childhood. As there is no cure for dystonia, and only in the past 30 years has research given way to treatments other than brain surgery, my sons have had some benefit from oral medication and botulinum toxic injections. Although we are fortunate to have these treatments available, the various drugs have significant cognitive side-effects.

Dystonia is a neurological movement disorder characterized by involuntary muscle contractions and postures. There are several different types of dystonia, including: focal dystonias, affecting specific parts of the body, such as the arms, legs, neck, jaw, eyes, vocal cords; and generalized dystonia, affecting many parts of the body at the same time. Some forms of dystonia are genetic and others are caused by injury or illness. Dystonia does not affect a person's consciousness or intellect, but is a chronic and progressive physical disorder for which, at this time, there is no cure. We estimate that some form of dystonia affects about 300,000 people in North America.

In the past few decades, dystonia researchers have made several exciting scientific advancements and have been able to rapidly turn laboratory and clinical research into diagnostic examinations and treatment procedures, directly benefiting those affected. Genetics, in particular, is opening up new understanding into the cause and pathophysiology of the disorder. Thus far, 12 dystonia related genes have been identified. In 1997, the DYT1 gene for childhood onset dystonia was identified, and we now have a genetic test available for this particular type of dystonia.

#### RESEARCH, AWARENESS, AND SUPPORT

It is an exciting time to be involved in dystonia research and awareness. Researchers are becoming more interested in movement disorders and dystonia at the National Institutes of Health (NIH), and research is yielding promising clues for better understanding and management of this disorder.

One way the Dystonia Foundation has advocated for more research on dystonia, is by funding "seed" grants to researchers. Thus far, the Dystonia Foundation has funded 338 grants, and 3 fellowships, totaling more than \$17 million. Due to our advocacy there are a growing number of talented researchers dedicated to under-standing the biochemistry of dystonia, genetic causes, new therapeutics and the ramifications of an epidemiology study.

Another primary goal of the Dystonia Foundation is education of both lay and medical audiences. Every year the Foundation conducts several medical workshops and regional symposiums to present, discuss, and disseminate comprehensive medical and research data on dystonia. In January 2001, NINDS co-sponsored a genetics and animal models meeting, designed to involve not only prominent researchers but inviting junior investigators to participate in the discussions. Additionally, in October 1996, the NIH was one of our co-sponsors for an international medical symposium, which featured 60 papers on dystonia and 125 representatives from 24 countries

Since 1995, over 3,000 educational medical videos have been distributed to hospitals, medical and nursing schools, and at medical conventions. Now, we have a children's video to increase public awareness of this devastating disorder. Media awareness is conducted throughout the year, and especially during Dystonia Awareness Week, observed nationwide from October 14 through 20. The Dystonia Foundation has over 200 chapters, support groups, and area contacts across North America. In addition, there are 15 international chairpersons whose mission is to increase awareness, children's advocacy, development, extension to be been advocation and the supersonal devastion on the provide the devastion of the supersonal devastion of

The Dystonia Foundation has over 200 chapters, support groups, and area contacts across North America. In addition, there are 15 international chairpersons whose mission is to increase awareness, children's advocacy, development, extension, the Internet, leadership, medical education, an on-line news group, and symposiums. Furthermore, patient symposiums are held regionally to provide the latest information to dystonia patients and others interested in the disorder. Last year we held over eight regional symposiums reaching approximately 2,000 affected families.

#### DYSTONIA AND THE NATIONAL INSTITUTES OF HEALTH

The Dystonia Medical Research Foundation recommends an increase to \$23.7 billion or 16 percent for NIH overall, and a 16 percent increase for NINDS and NIDCD or \$1.54 billion and \$397 million respectively. This increase reflects a request to double the NIH budget in 5 years. However, we request that this increase for NIH does not come at the expense of other Public Health Service agencies.

Dystonia is the third most common movement disorder after Parkinson's and tremor, and effects six times more people than better known disorders such as Huntington's, muscular dystrophy and ALS or Lou Gehrig's Disease. We ask that NINDS fund dystonia-specific extramural research at the same level that it supports research for other neurological movement disorders.

research for other neurological movement disorders. We urge the Subcommittee to recommend that NINDS provide the necessary funding for extramural research and a large scale dystonia epidemiological study and increase its efforts to educate the public and medical community about dystonia through co-sponsorship of workshops and seminars. We also encourage the Subcommittee to support NIDCD in its efforts to revamp its strategic planning process by implementing a Strategic Planning Group which will help NIDCD as they: consider applications for high program priority; develop program announcements and requests for applications; and develop new research areas in the Intramural Research Program.

The ultimate goal of the Dystonia Foundation is a cure for dystonia. Until that goal is realized, we are hungry for any knowledge about the nature of dystonia and for more effective treatments with fewer side-effects. We have amassed many exceptional and diligent researchers, committed to our goal, and our top priority is funding their very important research. But the Foundation cannot do it alone. We need federal support though NIH, NINDS, and NIDCD to continue to fund good research and eliminate this debilitating disease.

We ask that you aggressively support medical research, specifically for movement disorders and brain research. By doing so, you are doing a tremendous service for myself and my family and to the hundreds of thousands of people and families affected by dystonia.

Thank you very much.

## PREPARED STATEMENT OF THE NATIONAL CAUCUS AND CENTER ON BLACK AGED

The National Caucus and Center on Black Aged (NCBA) appreciates the opportunity to present written testimony for the fiscal year 2003 Labor-HHS-Education Appropriations Act.

NCBA urges the Subcommittee to approve a \$40-million funding level for the Older Americans Act Title IV Training, Research, and Discretionary Projects program for fiscal year 2003. This is \$1.727 million above the current appropriation: \$38.723 million. In addition, NCBA calls upon the Subcommittee to approve report language to direct the Administration on Aging (AoA) to "allocate Title IV Training, Research and Discretionary Project funds equitably to minority aging organizations with a proven track record in delivering services to low-income minority persons."

Title IV minority report language should be inclusive in the same manner that it has been historically to assure that all elderly minority groups benefit from Title IV initiatives, rather than a limited number. Older minorities share many common problems and challenges. The inclusive report language will help to assure that AoA addresses the needs of all major elderly minority groups.

NCBA strongly favors a \$2.5-million earmark within the Research, Demonstra-tions, and Evaluation account for the Centers for Medicare and Medicaid Services (CMS) to fund a demonstration program to improve the minority aged's participa-tion in Medicare and Medicaid, as well as their understanding of these vital pro-

tion in Medicare and Medicaid, as well as their understanding of these vital pro-grams. The Subcommittee should include report language to direct CMS "to utilize national minority aging organizations that have a proven track record in serving older minorities to carry out these demonstration programs." Recent polls show that there is substantial confusion and misunderstanding among older Americans concerning Medicare Plus (+) Choice, as well as other changes adopted for Medicare in recent years. This situation is compounded for sen-iors suffering from economic, cultural, language, and/or other barriers that hinder their participation in or fundamental understanding of these programs. The new demonstrations can help CMS to develop innovative best practice models to make demonstrations can help CMS to develop innovative best practice models to make Medicare and Medicaid more user friendly and more responsive to the needs of older Americans.

NCBA is encouraged that the Fiscal Year 2002 Labor-HHS-Education Appropriations Act had report language mandating certain federal agencies to improve the co-ordination of service delivery for older Americans, as part of the Harkin aging initia-tive. Specifically, the report directs the Secretary of HHS to establish an Inter-agency Task Force on Aging Programs, comprised of the Departments of HHS, HUD, Labor, Agriculture, and Transportation. The primary mission of this Task Force is to maximize the impact of existing services, reduce and eliminate duplica-tion for both service provision and the process for older parents to some tion for both service provision and the process for older persons to access the services, and minimize regulatory burdens and costs at the local level. NCBA is also encouraged that the Fiscal Year 2002 Labor-HHS-Education Appro-

NCBA is also encouraged that the Fiscal Year 2002 Labor-HHS-Education Appropriations Act earmarked a significant proportion of Title IV funding to support naturally recurring retirement communities. However, there was no funding targeted to organizations traditionally serving the major aging minority groups: African Americans, Hispanics, Asians, Pacific Islanders, and Native Americans. NCBA requests the Subcommittee to provide sufficient Title IV funding to broaden the scope of this highly promising, innovative, and worthwhile activity to serve the needs of the major elderly minority population groups as well. NCBA supports a 10-percent funding hike for the Older Americans Act Title V Senior Community Service Employment Program (SCSEP), to \$490 million in fiscal year 2003 from \$445.1 million in fiscal year 2002. This increase is necessary for several reasons. First, it will help to enable Title V to catch up with inflation for the many years that this successful program was level funded. Second, the funding hike

many years that this successful program was level funded. Second, the funding hike will increase the number of authorized positions by about 6,275 (in round numbers), to more than 68,500 in fiscal year 2003 from the projected level of approximately 62,225 for fiscal year 2002. Finally, this proposal can provide an effective and dig-62,225 for fiscal year 2002. Finally, this proposal can provide an energy end and ing-nified means for low-income older Americans to escape from poverty. Persons 65 years of age or older who worked at some time during 2000 were four times less likely to be poor than aged individuals who did not work during the year. Older Americans who did not work at all during 2000 had an 11–7-percent poverty rate, compared to 2.9 percent for those who worked either part-time or full-time. NCBA understands that the Department of Labor (DoL) is considering a proposal

to put out for competition the entire national sponsors' share of the funding for the SCSEP. If DoL moves forward with this possible proposal, it would run counter to the bipartisan agreement for the 2000 OAA Amendments, which reauthorized OAA programs, including the Title V SCSEP, for 5 years. The essence of the agreement was that the existing national sponsors would continue to administer the SCSEP, which the existing national sponsors would continue to administer the SCSEP. provided they met the performance standards and other applicable requirements to be a suitable grantee. If a national sponsor failed to meet these requirements, the national sponsor would have an appropriate opportunity to take necessary corrective action after a proper and timely notification from the Department of Labor (DoL). If the national sponsor performed unsatisfactorily after the notification, then DoL could put out for competitive bidding a portion of the national sponsor's grant or all of it. A primary reason for this approach was to prevent disruption for enrollees. In addition, the existing national sponsors had an excellent record in administering the SCSEP

Competitive bidding would also create problems for host agencies administering SCSEP projects at the local level. For example, competition could result in enrollees moving from one host agency to another or perhaps out of the entire community if another sponsor became a grantee. Members of Congress wanted to avoid the negative impact of these potentially disruptive products from competition for low-income enrollees, the communities they serve, and the host agencies administering the program locally.

Program performance will almost assuredly decline if competitive bidding produces new entrants for administering the SCSEP. This is because the new sponsor must focus more attention on launching projects and concentrating on administrative matters, rather than programmatic objectives.

New national applicants will quite likely have very limited or no expertise in serving older workers. On the other hand, the existing national sponsors have a long and respected record in working with older workers. In addition, they have considerable expertise concerning other programs that may impact SCSEP enrollees, such as Social Security, Supplemental Security Income, Medicare, Medicaid, and VA (Veterans' Affairs) income maintenance and health programs.

Competitive bidding could create an administrative nightmare for DoL. As a practical matter, the existing DoL staff that administers the SCSEP consists of 6 professional staff members and 1 support person. This very small staff is stretched very thin in overseeing a \$445.1-million program that operates in all 50 states, the District of Columbia, and elsewhere.

For these reasons, NCBA urges the Labor-HHS-Education Appropriations Subcommittee to incorporate language in the report to direct DoL to follow the statutory language in the 2000 OAA Amendments to comply with the carefully crafted bipartisan agreement to minimize disruption for enrollees and host agencies participating in the extraordinarily successful SCSEP.

#### PREPARED STATEMENT OF THE SUDDEN INFANT DEATH SYNDROME ALLIANCE

#### SUMMARY OF FISCAL YEAR 2003 RECOMMENDATIONS

- --Continue the effort to double the National Institutes of Health (NIH) budget by providing a 16 percent increase for fiscal year 2002, to \$23.7 billion. Within NIH, provide proportional increases of 16 percent to the various institutes and centers, specifically, the National Institute of Child Health and Human Development (NICHD). We request NICHD's budget to be increased by 16 percent to \$1.29 billion.
- -Continue to fund the third Sudden Infant Death Syndrome (SIDS) Five-Year Research Plan at NICHD, which focuses on research and educational opportunities on SIDS.
- -Continue to fund the SIDS and Other Infant Death Program Support Center at the Maternal and Child Health Bureau, within the Health Resources and Services Administration.

-Fund 3 SIDS death scene protocol demonstration projects at the Centers for Disease Control and Prevention (CDC), to provide a nation-wide protocol for dealing with SIDS death scenes.

Thank you for the opportunity to address this subcommittee and explain what Sudden Infant Death Syndrome (SIDS) and the importance of federal funding for SIDS programs and research means to me. My wife and I lost our son Chandler in 1997, and we are compelled to do everything and anything possible to ensure no one has to suffer the loss of a child again. Mr. Chairman, we need your help, your commitment, and your support to help solve the mystery that is SIDS.

Despite the fact that SIDS cases have been documented for years, organized scientific research into SIDS only began in the mid 1970's. Three decades later scientists are now beginning to make significant progress in unraveling the enigma of SIDS. For instance, we now know that in many SIDS related deaths there is an abnormality in a region of the brain which is thought to control heart and lung functions. In these cases, this irregularity may have hampered normal respiratory activity, and while not the sole cause of SIDS, it may have contributed to a larger respiratory problem leading to death. As a direct result of SIDS research and the "Back to Sleep" educational and

As a direct result of SIDS research and the "Back to Sleep" educational and awareness campaign, SIDS deaths have been reduced by 38 percent since 1992, concurrent with the increase in awareness regarding infants being placed on their backs to sleep—leading to the greatest decline in infant mortality rates in over 20 years.

However, our research and educational campaign is far from finished. Each year more than 3,000 infants in the United States die from SIDS and it continues to be the number one cause of death for children between 1 month and 1 year of age. SIDS is a major component of the United States infant mortality rate. In spite of

this fact, we do not yet understand the causes of SIDS nor do we possess a guaranteed method for its prevention.

The primary federal agency responsible for conducting SIDS research and the "Back to Sleep" public awareness campaign is the National Institute of Child Health and Human Development (NICHD) at the National Institutes of Health. In addition to federal funding of SIDS research, there are other federal agencies involved in the SIDS effort. Since 1975, the Maternal and Child Health Bureau (MCHB) within the Health Resources and Services Administration (HRSA) has supported specific programs for SIDS family counseling and for public and professional education about SIDS. The Centers for Disease Control and Prevention (CDC) has established a standardized death scene investigation protocol for SIDS incidents. Additionally an Interagency Panel on SIDS has been established, which includes: NIH, HRSA, CDC, Indian Health Services, Food and Drug Administration, U.S. Consumer Products Safety Commission, Department of Defense, Administration for Children and Families, and the Department of Justice to help coordinate all federally funded SIDS activities.

The SIDS Alliance is grateful for the Subcommittee's past support of SIDS activities, especially the support of NICHD. We urge you to again provide the additional funding necessary for the second year of the third Five Year SIDS Research Plan to ensure that NICHD can continue to address critical SIDS research initiatives. Specifically the SIDS Alliance is supporting a funding increase to \$23.7 billion or 16 percent for NIH overall, and a 16 percent increase for NICHD to \$1.29 billion. We ask that the increases for NIH do not come at the expense of other Public Health Service Agencies. Further research is essential to find the reasons for, and means of preventing the tragedy of SIDS.

I urge the Subcommittee to support SIDS educational, awareness, and counseling activities that take place at the MCHB, and the death scene investigation protocol demonstration projects at the CDC. These programs are a vital "flip-side" to the good research that NICHD does. Without prevention awareness, counseling and standardized investigation procedures, good research does not translate into meaningful advances for SIDS victims and their families.

#### HIGHLIGHTS OF FEDERALLY FUNDED SIDS ACTIVITIES

#### National Institute of Child Health and Human Development (NICHD)

Childcare has become increasingly important in the social fabric of the United States, so have child care centers and homes. To address this issue the NICHD has initiated the "Back to Sleep Child Care Project," sending publications and other "Back to Sleep" materials to over 280,000 child care centers and licensed homes throughout the United States. Response to these mailings has been overwhelming, resulting in a 20 percent increase in the volume of requests for Back to Sleep materials.

Studies on the risk factors for SIDS among African American and American Indian populations conducted in collaboration with the CDC and the Indian Health Service have yielded valuable information for targeted interventions to reduce infant mortality in these communities. SIDS among minority populations continues to be a top priority for the NICHD. Surveys show that the proportion of African Americans placing their infants to sleep on their stomachs continues to decrease, however, African Americans are still twice as likely to place infants on their stomachs as compared to other populations. Discussion groups are underway in African American communities across the country to assess the "Back to Sleep" campaign message, and to improve message delivery. In addition, during fiscal year 2001, the NICHD established new initiatives on health disparities in minority populations. SIDS and related fetal and infant deaths are part of the initiatives targeted at eliminating health disparities in infant mortality.

related fetal and infant deaths are part of the initiatives targeted at eliminating health disparities in infant mortality. A new component of the "Back to Sleep" campaign focusing on reducing SIDS among African American's was launched in late 1999. The goal is to develop and implement a community-based initiative. The National Black Child Development Institute (NBCDI) joined with the NICHD, the campaign sponsors, and several other organizations in the outreach initiative. A culturally appropriate resource kit, which includes a training guide, has been developed, and the first national training workshops have been held.

The mechanism of SIDS is still unknown; there are no clinical or biologic tests to identify a newborn at high risk of succumbing to SIDS; and more work is needed to increase the implementation of "Back to Sleep" among all caregivers and in communities with high rates of infant death. To address and focus its efforts on these challenges, the NICHD has developed and is implementing its third SIDS Research

Five-Year Plan. The plan is divided into five parts: Introduction, Etiology/Pathogenesis, Prognostics and Diagnostics, Prevention, and Health Disparities. Research initiatives in fiscal year 2002 include (1) continued research on mecha-

nisms of pathogenesis through studies in animal models, postmortem tissue, and high-risk infants. This includes a prospective study to define a battery of physiologic and genetic markers that will predict SIDS and to determine whether SIDS is part of a larger family of autonomic nervous system disorders; (2) analysis of epidemiological and physiological data collected during the second five year research plan to improve our understanding of environmental and intrinsic risk factors; (3) a community-linked health disparities initiative to investigate related aspects of mortality from late fetal life through early childhood; (4) improve risk reduction and efficacy of "Back to Sleep" through continued research, monitoring, and outreach in at risk communities.

# Maternal and Child Health Bureau (MCHB)

The MCHB supports a number of SIDS and Other Infant Death related services and programs, including the following activities: —National SIDS Resource Center, a major source of current information about

- SIDS
- Maternal and Child Health Service Block Grant (MCH), which grants funds to states providing a range of services to SIDS families. Block grant funds support activities like: contact families immediately after death, discussion of autopsy results with the family, and support and counseling through the first year of bereavement. Unfortunately, in many jurisdictions across the country, funds for these services have been decreased or eliminated due to budgetary difficulties.
- Field training and curriculum to health care providers for case management of families who have experienced an infant death, and the development of model families who have experienced an infant death, and the development of model programs, particularly for the underserved and minorities. Demonstration grants have been established in four states to target services for specific popu-lations: California, Massachusetts, Missouri, and New York. -National SIDS & Infant Death Program Support Center to address SIDS service issues at the federal level on an ongoing basis. The SIDS Alliance was chosen to run this center, which opened in 1999, and has experienced notable success.

#### Centers for Disease Control and Prevention (CDC)

To develop a better statistical figure on SIDS cases, Congress recommended in 1993 the establishment of a standard death scene protocol to offset discrepancies on unexplained infant deaths between states. It was hoped that this protocol would be adopted by states not only for statistical measure, but to help avoid awkward and emotionally charged misunderstandings at the death scene. In 1996, CDC published the protocol, and since that time several states have adopted the standard. It is SIDSA's long term goal to ensure that all states fully adopt the protocol. To help realize this goal, SIDSA would like CDC to heed Congress' recommendations for the past 2 years and implement demonstration projects that follow these guidelines in several communities nationwide. We would also encourage CDC to implement a nationwide survey to measure how many locales have implemented the protocol independently and to analyze the results thus far.

In conclusion, we are all too painfully aware that SIDS has historically been a mystery, leaving in its wake devastated families and bewildered physicians. Not only have there been no answers on the cause of SIDS, but there have been no answers on how to effectively prevent its occurrence. Today we are beginning to find some of the answers on cause and prevention, and therefore reduce the risk of SIDS. Because of the "unknown", however, babies are still vulnerable even when parents and care givers take the cautionary steps to prevent SIDS deaths. This tragedy will continue if research efforts are stalled or halted, especially when we are at the point where so much progress has been made. Now is the time for a re-energized effort against this tragic syndrome.

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 parents, we ask for your support, and thank you again for allowing us to present this testimony. If you have any questions, please do not hesitate to contact us.

## THE SUDDEN INFANT DEATH SYNDROME ALLIANCE

The SIDS Alliance is an organization of parents and friends of SIDS victims along with medical, business, and civic groups who are concerned about the health our this nation's children. The Alliance is engaged in ongoing efforts to expand its scientific program, strengthen services for families, and provide public education and advocacy opportunities. An important goal is to improve community understanding and elevate SIDS to the level of societal concern appropriate to one of our nation's major causes of infant mortality.

## PREPARED STATEMENT OF THE INTERNATIONAL FOUNDATION FOR FUNCTIONAL GASTROINTESTINAL DISORDERS

### SUMMARY OF FISCAL YEAR 2003 RECOMMENDATIONS

-Continue the effort to double the National Institutes of Health (NIH) budget by providing a 16 percent increase for fiscal year 2002, to \$23.7 billion. Within NIH, provide proportional increases of 16 percent to the various institutes and centers, specifically, the National Institute National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). We request NIDDK's budget to be increased by 16 percent to \$1.7 billion.

-Continue to accelerate funding for extramural clinical and basic functional gas-trointestinal research at NIDDK. -Provide funding for NIDDK to conduct a prevalence study on and to increase public and professional awareness of irritable bowel syndrome (IBS).

Thank you for the opportunity to present this written statement regarding the im-

My name is Nancy Norton, and in 1991, I founded the International Foundation for Functional Gastrointestinal Disorders (IFFGD), in response to my own experiences as a patient. I'm proud to say that 11 years later my organization serves millions of people in need each year, providing information and support to patients and physicians. The largest organization of its kind in the United States, IFFGD works with consumers, patients, physicians, providers and payers to broaden under-standing about fecal incontinence, irritable bowel syndrome (IBS), gastroesophageal reflux disease (GERD), pediatric disorders and numerous other gastrointestinal disorders. Additionally, it has been my personal vision and goal to see a greater investment in research on functional gastrointestinal and motility disorders, a subject that has often been left behind.

I have lived with IBS most of my adult life and due to an obstetrical injury 16 years ago I also live with bowel incontinence. Incontinence, in particular, is often thought of as something that affects us when we are frail and elderly, perhaps something that is part of the aging process. Incontinence is neither part of the age-ing process nor something that affects only the elderly. Incontinence crosses all age groups from the pediatric community to the older adult. It also is a symptom that is associated with many different diseases that are neurologically based and the aftermath of many cancer treatments. Yet we rarely hear about the bowel disorders associated with multiple sclerosis, diabetes, colon cancer, uterine cancer, and a host of other diseases, let alone as a complication of an episiotomy with vaginal delivery. IFFGD has become the resource and hope for millions of people as they try to regain IFFGD continues to speak about and raise awareness for disorders and diseases

that many people are uncomfortable and embarrassed to talk about. The prevalence of fecal incontinence and irritable bowel syndrome is underestimated in the United

States. These conditions are truly hidden in our society. Not only are they are mis-understood, but the burden of illness and human toll has not been fully recognized. Given that we have been diligently working for the past 11 years it is an exciting time to lead the IFFGD, not only are we serving more and more people, but we are beginning to be able to privately fund research, with our first grant announcement next year. Additionally, more treatment options are being researched and becoming available for all types of FGI diseases and disorders, although many more are needed

Since its establishment the IFFGD has been dedicated to increasing awareness of functional gastrointestinal disorders and motility disorders, among the public, health professionals, and researchers. In March of 2001 we hosted the Fourth International Symposium on Functional Gastrointestinal Disorders, which was a great success in bringing scientists from across the world together to discuss the current science and opportunities in irritable bowel syndrome and other functional gastro-intestinal disorders. The Fifth International Symposium will be held in April 2003. Additionally, this November, we are hosting a conference on fecal and urinary incontinence. The IFFGD has become known for our professional symposia. We consistently bring together a unique group of international multidisciplinary investigators to communicate new knowledge in the field of functional gastroenterology

The majority of the diseases and disorders we address have no cure. We have yet to understand the pathophysiology of the underlying conditions. Patients face a life

of learning to manage chronic illness that is accompanied by pain and an unrelenting myriad of gastrointestinal symptoms. The costs associated with these diseases is enormous, conservative estimates range between \$25-\$30 billion annually. The human toll is not only on the individual but also on the family. Economic costs spill over into the workplace. In essence these diseases reflect lost potential for the individual and society.

#### FECAL INCONTINENCE

At least 6.5 million Americans suffer from fecal incontinence. This disorder affects people of all ages—children as well as adults, but is more common among women and in the elderly of both sexes. Fecal incontinence is not normal in the aging process, and can be caused by: damage to the anal sphincter muscles; damage to the nerves of the anal sphincter muscles or the rectum; loss of storage capacity in the rectum; diarrhea; or pelvic floor dysfunction. People who have fecal incontinence may feel ashamed, embarrassed, or humiliated. Some don't want to leave the house out of fear they might have an accident in public. Most try to hide the problem as long as possible, so they withdraw from friends and family. The social isolation is unfortunate but may be reduced because treatment can improve bowel control and make incontinence easier to manage.

# IRRITABLE BOWEL SYNDROME (IBS)

Irritable Bowel Syndrome affects approximately 30 million Americans. This chronic, non-life threatening disorder is characterized by a group of symptoms, which can include abdominal pain or discomfort associated with a change in bowel pattern, such as loose or more frequent bowel movements, diarrhea, and/or constipation. Although the cause of IBS is unknown, we do know that this disease needs a multidisciplinary approach in research and treatment. Currently, methods to treat IBS are limited to over-the-counter medications, which is problematic due to the overuse and then misuse of the regimen.

Similar to fecal incontinence and depending on severity, IBS can be emotionally and physically debilitating. Because of bowel irregularity individuals who suffer from this disorder may distance themselves from social events, work, and even may fear leaving their home.

#### GASTROESOPHAGEAL REFLUX DISEASE (GERD)

Gastroesophageal reflux disease, or GERD, is a very common disorder, which results from the back-flow of acidic stomach contents into the esophagus. GERD is often accompanied by persistent symptoms, such as chronic heartburn and regurgitation of acid. But sometimes there are no apparent symptoms, and the presence of GERD is revealed when complications become evident. Symptoms of GERD vary from person to person. The majority of people with GERD have mild symptoms, with no visible evidence of tissue damage and little risk of developing complications. Periodic heartburn is a symptom that many people experience. There are several treatment options available for individuals suffering from GERD.

#### ESOPHAGEAL CANCER

Approximately 13,000 new cases of esophageal cancer are diagnosed every year in this country. This type of cancer is more prevalent in individuals who have a specific type of GERD. Diagnosis usually occurs when the disease is in an advanced stage, early screening tools are currently unavailable, and therefore an estimated 13 percent of whites and 9 percent of non-whites survive beyond 5 years.

#### PEDIATRIC FGI AND MOTILITY DISORDERS

A larger number of children each year are diagnosed with functional gastrointestinal disorders and motility disorders. The most common disorders found in children are: Chronic intestinal pseudo-obstruction Functional diarrhea Gastroesophageal reflux (GER) Irritable Bowel Syndrome (IBS) Gastroesophageal reflux disease (GERD) Functional bowel disorders Hirschsprung's disease Infant dyschezia Intestinal neuronal dysplasia (IND) Functional constipation Cyclic Vomiting Syndrome Functional fecal retention Functional abdominal pain Non-retentive fecal soiling

## FGI AND MOTILITY DISORDERS AND THE NATIONAL INSTITUTES OF HEALTH

The International Foundation for Functional Gastrointestional Disorders recommends an increase to \$23.7 billion or 16 percent for NIH overall, and a 16 percent increase for NIDDK, or \$1.7 billion. This increase reflects a request to double the NIH budget in 5 years. However, we request that this increase for NIH does not come at the expense of other Public Health Service agencies.

We urge the subcommittee to provide the necessary funding for the expansion of the NIDDK's research program on FGI and motility disorders, this increased funding will allow for the growth of new research, a prevalence study on IBS, and increased public and professional awareness of FGI and motility disorders.

A primary tenant of IFFGD's mission is to ensure that clinical advancements concerning GI disorders result in improvements in the quality of life of those affected. By working together, this goal will be realized and the suffering and pain millions of people face daily will end.

Thank you.

## PREPARED STATEMENT OF THE NATIONAL MENTAL HEALTH ASSOCIATION

Thank you for this opportunity to testify before the Subcommittee and to address the important issue of mental health. I am the President and CEO of NMHA, the country's oldest and largest advocacy organization addressing all aspects of mental health and mental illness, representing more than 54 million children and adults who have a mental disorder. We have a diverse and broad membership—representing over 340 affiliates throughout the country—and are uniquely positioned to speak to the entire mental health and substance abuse portfolio including prevention, early intervention, treatment, and research.

Before I start, I want to thank Chairman Harkin and Senator Specter for your leadership and for your strong support in winning increases last year for mental health programs. I hope to make the case why we need even greater increases for fiscal year 2003. In fact, I believe that increased funding for mental health services and general public health is consistent with our critical national goals particularly those related to Homeland Security. The subcommittee has an especially critical role this year given that the public health safety net is vanishing before our eyes. Medicaid, for example, is unable to cover the mental health service needs in many states and is in a fiscal crisis, leading legislatures in many states to look for ways to cut benefits. With the prospect of sweeping Medicaid cutbacks, our already overburdened mental health system is being set up to fail adults and children with mental disorders.

#### BACKGROUND

In building our case for increased funding, we have a solid science base and effective tools to promote mental health and treat mental disorders in both adults and young people. And we have effective federal programs to bring those tools and services to our communities. Thanks to the commitment of this subcommittee, we know what works. We know we can be most effective by taking a comprehensive approach that recognizes the importance of providing a full continuum of services—prevention, early intervention and treatment services. We also need to acknowledge the stigma long associated with mental illness and the role that stigma has played in the relatively limited federal funding provided for mental health programs. What we lack is an investment in the application of proven services and tools that is commensurate with the need.

The backdrop for our requests is an unprecedented need for mental health services. Let me give you a brief snapshot of the mental health crisis in this country. Mental illness is the second leading cause of disability and premature mortality in the United States. One in five adults will experience a mental illness in a given year. About 5 percent of the population suffers from a severe and persistent mental illness such as schizophrenia, bipolar disorder, or major depression. Fewer than onethird of adults and only one in five children who need mental health services receive treatment. And between 50 to 75 percent of incarcerated youth have a diagnosable mental health disorder.

As Senator Bill Frist recently noted, "For the last 20 years we've neglected public health," and have recently been shocked "into realizing how dependent we are on the system."

Given all those considerations, the President's Budget for fiscal year 2003 is both disappointing and troubling. In the midst of underfunded, severely strained state and local mental health systems, the Administration's budget calls for stagnant funding for most mental health programs, while cutting \$17 million in current funding for improved community mental health. Worse, the budget would actually cut, without rationale, all federal funding for a number of proven, evidence-based mental health programs, the budget leaves people with mental health needs in ever greater jeopardy.

The proposed fiscal year 2003 budget doesn't take into account the magnitude of our nation's mental health crisis. Although the budget provides for welcome, though isolated increases in mental health and substance abuse funding, most mental health programs have been targeted for cuts. The Substance Abuse and Mental Health Services Administration (SAMHSA) budget, for example, would increase funding for the PATH program (Projects for Assistance in Transition from Homelessness) by \$7 million. But funding for priority "Programs of Regional and National Significance" within the Center for Mental Health Services would shrink by \$17 million. SAMHSA's Substance Abuse block grant would win an additional \$60 million and substance abuse treatment funding (principally for targeted capacity expansion) would increase by \$67 million. Yet the Center for Substance Abuse Treatment funding for "best practices" would shrink by \$43 million, and substance abuse prevention funding (through the Center for Substance Abuse Prevention) would be cut by \$45 million. The budget does propose a substantial \$105 million increase in funding for the National Institute of Mental Health, but that increase falls well short of the double-digit increase in the overall budget for National Institutes of Health.

#### COMMUNITY MENTAL HEALTH

Among these cuts, the budget would end all funding next year for the five centers that provide technical assistance to help mental health consumers and family members around the country achieve independence through recovery from mental illness. The budget offers virtually no explanation for decimating consumer-support programs, currently drawing only \$2 million, or less than 1 percent of the SAMHSA's discretionary funding for "Programs of Regional and National Significance." The decision to terminate federal funding for the modestly funded centers that assist consumer-run self-help programs and support consumers and family members ignores not only the significant body of evidence that such programs provide valuable support and assistance for people in their recovery from mental illness but also the report language in last year's Labor, Health and Human Services appropriations bill which highlights the value of these TA centers and expresses Congress's confidence in this program.

Another very disturbing casualty of this budget is the community action grant program. These modest grants, ranging from \$50,000 to \$150,000, are a catalyst for local communities to improve mental-health service delivery by implementing proven, evidenced-based practices for adults and children with mental disorders. Despite the modest \$5.5 million investment currently being made through this program, these grants significantly advance the Olmstead process as it relates to people with mental illness, since they are designed to implement effective community-based services. Yet this budget would eliminate this critical source of community grant funding in fiscal year 2003. Terminating funding for this program is particularly inexplicable given such positive outcomes as reduced hospitalizations and increased employment for adults with serious mental illness. I strongly urge you to reject the \$17 million cut to PRNS at CMHS and the proposed termination of funding for such proven CMHS programs as Community Action Grants and Consumer Technical Assistance Center funding. We urge instead that you provide an increase in funding for these programs.

#### RESEARCH MISSION

One of SAMHSA's core missions is to develop an evidence base on the effectiveness of services and service delivery mechanisms. Inexplicably, this budget cavalierly abdicates further responsibility for fostering the development of knowledge on mental health and substance abuse service delivery and programming. While basic medical research by the National Institutes of Health has yielded tremendous dividends in the area of mental health and substance abuse, SAMHSA plays a critical role in developing systems and programs to translate those mental health research findings to community practice. The budget justification provides no rationale for what amounts to abdication of a statutory responsibility. Indeed the budget implicitly acknowledges the importance of such research, but simply suggests that NIH institutes would fund it. Based on our experience, such research has not been, and is not likely to become, an NIH priority. It is critical, therefore, that SAMHSA continue to be funded to support such research to develop evidence-based "best practices" and that this Committee reject SAMHSA's proposal that it discontinue needed health services research. I urge you to maintain knowledge development as a key component of SAMHSA's mission.

# COMMUNITY-BASED CARE

In areas that were level funded under the fiscal year 2003 spending plan for the Center for Mental Health Services, double-digit medical inflation effectively transforms "flat funding" into real cuts in mental health services. These funding levels are not consistent with the Administration's support of the New Freedom Initiative to increase community-based services under *Olmstead* v. LC, a Supreme Court case brought on behalf of people with mental illnesses. Over the last several decades, the public mental health system has appropriately shifted its emphasis from institution-based care to community integration. However, there has not been a commensurate increase in funding for community-based mental health care. That transition can NOT happen without an investment of new dollars.

Without additional federal funding, many state and local governments, struggling with budget shortfalls, are likely to consider severely cutting services for people with mental illnesses. In many areas, including nearby Montgomery County, Maryland—one of the wealthiest counties in the country—the situation is already critical. Viewed in this context, a budget plan that generally freezes or cuts the limited support for an agency whose mission is "to ensure access and availability of quality mental health services to improve the lives of all adults and children in this Nation" is shocking.

#### CHILDREN'S MENTAL HEALTH

Tragically, our mental health system is failing not only adults but also our children, who often fall through the cracks of fragmented child-serving agencies. With its limited funds, a Children's Mental Health Services Program (administered by the Center for Mental Health Services at SAMHSA) targeted at youth with serious emotional disorders can serve only a very small fraction of communities needing help. We strongly urge you to expand funding for the Children's Mental Health Services Program (to \$140 million) as well for school and community-based violence prevention initiatives (to \$150 million). Programs that address the emotional and behavioral needs of youth—and engage parents, students, schools and communities to work together—are critical to preventing youth violence and promoting more positive youth development. We know programs like Safe Schools/Healthy Students (SS/HS) work, as evidenced by the tragedy averted in Fort Collins, CO when plans for a "Columbine" event were exposed due to skills learned in the SS/HS program.

While making every effort to provide mental health services for children and adolescents in schools, there should be a parallel track to make those services as widely available in communities across America. Buttressed by a vast network of health providers including community maternal and child health clinics, the Human Resources Services Administration (HRSA), in collaboration with SAMHSA, is in a position to expand the availability of mental health services such as mental health screening, referrals, and treatment. We support increased funding for HRSA that expands the delivery of prevention, early intervention and treatment services to individuals with, or at risk of, mental illness.

Our country is failing children and adolescents by not addressing or treating their mental and emotional health. We're failing because we are not addressing the issues that keep children and adolescents from receiving appropriate care: these include the stigma of mental illness; the fragmentation of services; the lack of investment in prevention; the shortage of providers with sufficient expertise; the limited access to treatment and services; and the failure to engage families and children in mental health and substance abuse prevention and treatment efforts. Sadly, even the limited research information we possess about children's mental health is not being translated into clinical practice. If we do not change this trajectory, we will continue to foster a cycle of emotional and behavioral problems for our children resulting in school failure, substance abuse, violence, imprisonment—and most tragically, wasted lives that could have been changed.

#### CONSEQUENCES OF INADEQUATE FUNDING

Failure to provide adequate mental health services to children who need them can increase risk of school failure, involvement with the criminal justice system, dependency on social services and even suicide. For example, each year millions of our nation's youth come into contact with the juvenile justice system and hundreds of thousands of these youth are put into correctional facilities, yet only a very small number of them have committed serious offenses. We have gone from one institution—psychiatric wards—to another institution—juvenile justice facilities. In fact, children and teenagers with mental health disorders in New Mexico who were sent to juvenile detention facilities last year were detained without access to care for more than 2 weeks on average because mental health facilities were unavailable, according to a congressional report released this week. The report found that 718 youths were incarcerated for a collective 31.3 years waiting for openings in mental health treatment facilities. That is shameful and ought to be unacceptable to this subcommittee.

#### NATIONAL TRAGEDY

Our national mental health system could not adequately meet the needs we faced before the events of September 11th, and is entirely unprepared to address the mental health issues associated with the ongoing trauma of threatened domestic terrorism. Our public mental health system is also entirely unequipped to address the human toll on people whose lives are upended by the strains of unemployment and recession. With all these challenges, already overburdened mental health systems are further imperiled by state and local budget shortfalls.

Mental health professionals across the country say the psychological fallout from the September 11 terrorist attack is strikingly pervasive. Many mental health professionals and drug and alcohol abuse counselors report that they are seeing more serious problems now—and more evidence of a widespread anxiety—than they did in the immediate aftermath of the attacks, which they attribute to a delayed reaction now that the initial shock of the attacks has worn off. In addition, 6 months after the attacks, experts say the struggle for hundreds of rescue workers to lift themselves out of depression, fear and sorrow has just begun. Based in part on the experience of rescue workers after the Oklahoma City bombing, counselors expect problems with emotional recovery to rise in the next few months as the physical recovery work at the site nears completion and rescue workers return to their normal duties. Such difficulties are likely to peak around 1 year or 18 months after the event—and to continue more than 5 years later, the experts say. If Oklahoma City is any indication, we can anticipate large numbers to be at risk for post-traumatic stress disorder.

Again, we are particularly concerned that those most affected by the tragedy of September 11th may be our nation's children. Children at risk include those directly affected by the attacks, as well as those who have lost a parent or other loved one in the past; children with parents going through a divorce or other domestic instability; those who have a history of previous exposures to trauma or who suffered a recent loss; those who suffer from chronic physical or emotional problems; and those who live under adverse circumstances including poverty, discrimination, or the absence of one or both parents. We need to do more for these vulnerable children.

## NEXT STEPS

Proposed cuts and frozen funding for mental health programs are compounded by proposed reductions in funding for juvenile justice prevention, housing supports, Veteran Affairs health care, and school-based mental health services—including elimination of the Elementary and Secondary School Counseling Program. These cuts would simply exacerbate the ever-increasing difficulty people have in gaining access to effective mental health services. For millions across the country, a budget laden with cuts, frozen funding, and termination of effective mental health programs is an unwitting formula for despair, joblessness, interaction with the justice system, poor academic performance, and even suicide.

More than ever, we need your resolve to counter this grave outlook and pledge your commitment to improve the availability, accessibility, and quality of mental health services through increased federal investment in federal mental health programs. We urge you to reject the proposed \$17 million cut in SAMHSA funding for CMHS Programs and to increase substantially federal support for community-based mental health early intervention, prevention and treatment services. And while other key federal programs such as juvenile justice reside outside the purview of this subcommittee, we urge you, as members of the full committee, to take every opportunity to increase funding for those programs vital to people with mental health service needs.

Finally, I would like to thank members of this subcommittee for their support of the Mental Health Parity amendment last year and your encouraging report language. I encourage all of you to support S. 543, parity legislation by Senators Domenici-Wellstone. With your help, we can enact parity this year.

I'll conclude by stating that we concur with the view expressed by Secretary Tommy Thompson in a November address in New York that the country needs additional resources to fund a vast, well-coordinated network of mental health support to battle the anxiety that follows tragedies. Thank you for considering our views.

# PREPARED STATEMENT OF THE IOWA SUBSTANCE ABUSE PROGRAM DIRECTOR'S ASSOCIATION

My name is Ardis Glace and I am the Executive Director of the Iowa Substance Abuse Program Director's Association (ISAPDA), an organization that represents the directors of alcohol and drug treatment and prevention agencies that serve all of Iowa's 99 counties. Thank you for this opportunity to submit testimony in support of increased fiscal year 2003 funding for alcohol and drug treatment, prevention, education, and research programs in the Department of Health and Human Services and the Department of Education. Today I am representing the views of ISAPDA, the State Associations of Addiction Services (SAAS), composed of 27 state associations of treatment and prevention agencies, and the Legal Action Center, a nonprofit law and policy organization specializing in alcohol, drug, HIV/AIDS, and criminal justice issues and representing the interests of drug and alcohol treatment and prevention providers and consumers of those services.

Thank you, Mr. Chairman and members of the subcommittee, for last year's increases for alcohol and drug treatment, prevention, education, and research programs. However, as I am sure you are aware, the unmet need for alcohol and drug treatment and prevention services in America is overwhelming, and the tragedies of September 11, 2001 have made this situation worse. While between 13 million and 16 million people need treatment for alcohol and drug problems in any given year, only 3 million or 20 percent receive care, and the terrorist attacks in September have heightened the need for services. Drug and alcohol treatment and prevention providers are reporting increased national demand for their services, and disaster research indicates that the demand for these services should be expected to increase in the months and years to come. For example, a University of Oklahoma study examining the health effects of the Oklahoma City bombing found that alcohol consumption was three times higher in the metropolitan area as compared to a similar control community in the year after the attack. Additionally, the study found that the community as a whole was affected—not just direct victims. According to reports issued by the National Institute on Drug Abuse and the federal Center for Substance Abuse Treatment, the widespread trauma and stress associated with disasters significantly increases the risk for alcohol and drug use that can lead to addiction.

## TREATMENT AND PREVENTION NEEDS IN IOWA

Like all states, Iowa has implemented successful treatment and prevention programs, but finds that the demand for services outstrips the current capacity of providers. In 1999, the last year for which data are available, 105,000 Iowans had drug or alcohol dependence. In the same year, 32,845 Iowans that needed treatment for drug use were unable to receive it, according to estimates by the White House Office of National Drug Control Policy (ONDCP). Admissions for methamphetamine addiction treatment have dramatically increased in Iowa over the past decade, accounting for only 1 percent of admissions in 1992 and 11 percent of admissions in 2001. Methamphetamine addiction is best treated in specialized treatment requiring many resources, and the increase in methamphetamine-addicted clients has required some providers to shift resources away from the treatment of other addiction disorders to meet this pressing need. Increased resources, provided by the State of Iowa and the federal government, have been targeted to specialized treatment for methamphetamine use. More are needed, however, to address this growing problem and to meet the treatment needs of people with other forms of drug and alcohol abuse and addiction.

#### TREATMENT AND PREVENTION NEEDS IN PENNSYLVANIA

Pennsylvania also offers a picture of the serious public health issues that states face as a result of alcohol and drug dependence. In 1999, 421,000 Pennsylvanians had drug or alcohol dependence, and ONDCP estimates that in that year, 160,117 Pennsylvania residents were in need of treatment for illicit drug use and were unable to obtain it. Additionally, a sampling of news headlines from the past several months reveals the public attention and urgency placed on this issue: "Luzerne Overdoses Kill More People than [automobile] Crashes," Patriot-News; "Last Year, Someone in Allegheny County Died Nearly Every Other Day from a Drug Overdose," Post-Gazette; and "Philadelphia Area has 2nd Most Drug Deaths in Nation," Philadelphia Inquirer. The availability of less expensive, higher-quality drugs has contributed to overdose deaths and increased use of high-risk drugs by youth.

#### FISCAL YEAR 2003 RECOMMENDATIONS FOR FEDERAL PROGRAMS

For providers to supply these essential services in Iowa, Pennsylvania, and throughout the nation we need your support. We urge Congress to adopt the following increases in fiscal year 2003 funding for alcohol and drug treatment, prevention, education, and research programs in the Substance Abuse and Mental Health Services Administration (SAMHSA), the Department of Education, and the National Institutes of Health. These are wise investments that will provide desperately needed services in communities across the country:

- -\$2.0 billion for the Substance Abuse Prevention and Treatment Block Grant to continue closing the treatment and prevention services gap.
- -\$360 million for the Center for Substance Abuse Treatment (CSAT) and \$360 million for the Center for Substance Abuse Prevention (CSAP), to expand Targeted Capacity Expansion (TCE) programs that target services to emerging drug epidemics and underserved populations and to support programs that develop best practices to improve service delivery and effectiveness.
- -\$737 million for the Safe and Drug Free Schools and Communities Program, increasing the State Grants portion of this program by \$68 million to support local, community-based prevention initiatives.
- -\$475 million for research at the National Institute on Alcohol Abuse and Alcoholism (NIAAA) and \$1.064 billion for research at the National Institute on Drug Abuse (NIDA).

# The Treatment and Prevention Services Gap: The Human and Fiscal Costs

As mentioned above, while between 13 million and 16 million people need treatment for alcohol and drug problems in the United States in any given year, only 3 million or 20 percent receive care. In addition, young people are widely exposed to alcohol and drugs: a 2001 University of Michigan national study of youth drug use found that 54 percent of high school seniors reported using an illicit drug by the time they left high school and 11 percent indicated that they had used marijuana in the last 30 days. To reverse these trends, every adolescent should have access to alcohol and drug prevention services, but many communities are unable to provide these critical services.

Additionally, Alcohol and drug problems exact tremendous costs to society. According to a 2001 study by the Office of National Drug Control Policy, the societal cost of drug abuse in the United States in 1998 was \$143 billion, and was projected to be \$161 billion in 2000. Costs to society in 1998 included lost productivity in the workplace (\$98.5 billion), healthcare expenses (\$12.9 billion), and criminal justice and social welfare system costs (\$32.1 billion).

# Treatment and Prevention Services are Effective and Cost Effective

Drug and alcohol treatment and prevention services save lives and money. Numerous studies have demonstrated the effectiveness of treatment and prevention in reducing alcohol and drug addiction and use. For example, the National Treatment Improvement Evaluation Study (NTIES), a study of 4,411 individuals receiving federally funded treatment services throughout the country, found sustained reductions in post-treatment drug use. One year after completing treatment, overall drug use declined by 52 percent, crack use by 50 percent, cocaine use by 45 percent, and heroin use by 54 percent. NTIES also found a 78 percent decrease in violent crime, a 19 percent increase in employment, and an 11 percent decrease in welfare dependence. The treatment effectiveness findings of this comprehensive study are similar to the findings of other comprehensive studies. In a 1998 review of the research literature, the General Accounting Office found that several studies of the effectiveness of drug treatment had "evaluated the progress of thousands of people" and "concluded that drug abuse treatment was effective when outcomes were assessed

1 year after treatment." Prevention has also been shown to be effective in reducing alcohol and drug use and the risk of dependency. CSAP has identified 38 model prevention programs backed by research findings of effectiveness. An example of one successful program, the Life Skills Training program, teaches drug resistance and social skills in the classroom. A study of 6,000 participating students in 56 schools found that smoking, alcohol use, and marijuana use was 44 percent lower 6 years after an initial assess-ment, and the use of multiple drugs was 66 percent lower. In addition to reducing drug use, treatment and prevention are cost-effective. A 1994 study of state-funded treatment programs in California found that each \$1 in-

Vested in drug and alcohol treatment and prevention saves taxpayers \$7. A 1995 Operation PAR cost-benefit analysis of prevention programs nationwide found a \$15 savings on every dollar spent on drug abuse prevention. These savings resulted from increased productivity and reduced health care, criminal justice, and social services costs.

#### Closing the Gap: Increasing the Investment in Drug and Alcohol Treatment, Prevention, and Éducation, and Research

Federal programs provide significant funding for treatment and prevention services nationwide. I urge Congress to help improve access to and the effectiveness of services by increasing support for the Substance Abuse and Mental Health Services Administration (SAMHSA), the Safe and Drug Free Schools and Communities Act program, the National Institute on Alcohol Abuse and Alcoholism (NIAAA), and the National Institute on Drug Abuse (NIDA). We urge Congress to help close the gap further by increasing support for a number of programs. Substance Abuse Prevention and Treatment Block Grant—SAMHSA/CSAT.—The

Substance Abuse Prevention and Treatment Block Grant is the cornerstone of the nation's treatment system. Overall, public funding-federal, state, and local-accounts for 64.3 percent of the nation's annual spending for alcohol and drug treatment. The Substance Abuse Prevention and Treatment Block Grant represents the foundation of this support, providing about 47 percent of all public funding for treat-ment services. In 1998, it provided treatment for over 300,000 persons nationwide. The Block Grant also provides crucial support for the states' prevention programs, designating 20 percent of the total funding for this purpose. To help meet the pressing need for treatment and prevention services, we urge Congress to fund the Block Grant at \$2.0 billion for an overall increase of \$275 million over fiscal year 2002 funding.

Targeted Capacity Expansion and Best Practices Development and Dissemina-tion—SAMHSA/CSAT & CSAP.—Funding at the Centers for Substance Abuse Treatment and Prevention is directed toward two major activities: Targeted Capacty Expansion (TCE) and best practices development. In the TCE programs, targeted funding allows CSAT and CSAP to fill service gaps in underserved communities and to quickly respond to emerging drug epidemics. TCE programs have helped states, such as Iowa, develop new capacity to address changing treatment needs. CSAT's TCE program has responded to Iowa's growing methamphetamine problem by sup-porting a specialized case management program that enhances existing services. The program has proven successful in addressing methamphetamine use: 6 months after treatment, 71 percent of program clients reported being abstinent and only 9 percent reported an arrest during the follow up period, as compared to 24 percent reporting an arrest among a comparison group of clients who received treatment without specialized services.

Best practices development improves service quality by translating the findings of research studies into effective service delivery that can be implemented in real-world settings. For example, CSAP's High Risk Youth program has helped service providers implement and evaluate strategies that research has shown to reduce problem behavior in youth. A national cross-site evaluation of more than 10,000 youth at 48 High Risk Youth programs found that the programs were successful in reducing alcohol and drug use. To help CSAT and CSAP continue their critical Tar-geted Capacity Expansion and best practices development work in fiscal year 2003, I urge Congress to appropriate \$360 million each for CSAT and CSAP, a \$68 million increase for CSAT and a \$162 million increase for CSAP.

Safe and Drug Free Schools and Communities Act Program (SDFSC)-Department of Education.—Research has demonstrated that school and community-based prevention programs that assist the personal development of youth and teach them re-fusal skills can significantly reduce alcohol and drug use. The federal Safe and Drug Free Schools and Communities Program is the backbone of prevention efforts in the United States, and it is having a significant impact in many states. For example, in Kentucky, significant increases in abstinence were reported over a 6-month pe-riod in 1999 for young people involved in SDFSC programs: from 32 percent to 70 percent for marijuana; from 26 percent to 56 percent for beer drinking; and from 51 percent to 86 percent for liquor drinking. For fiscal year 2003, we urge Congress to appropriate \$737 million for the Safe and Drug Free Schools and Communities Program, including a \$68 million increase for the State Grants portion of this program to support local, community-based prevention initiatives

National Institute on Drug Abuse & National Institute on Alcohol Abuse and Alcoholism/National Institutes of Health.—Research into the causes, costs, treatment, and prevention of alcoholism and drug dependence plays an important role in improving the quality of services. Over the past several years, NIDA has made extraordinary scientific advances in understanding the nature of addiction, such as those made through the use of imaging technologies like positron emission tomography (PET scans), and addiction has begun to be conceptualized as a brain disease. Research on addiction as a disease has been useful in the development and testing of new science-based therapies. NIAAA also has conducted breakthrough research that has improved clinical practice, with much of this research focusing on the genetics, neurobiology, and environmental factors that underlie alcohol dependence. NIAAA also has sought to use new information about alcohol use to promote education and an effective public health response to this problem. For example, the NIAAA Task Force on College Drinking commissioned and widely disseminated a study that found drinking by college students 18–24 years old contributes to an estimated 1,400 deaths, 500,000 injuries, and 70,000 cases of sexual assault or date rape each year. To expand our knowledge of addiction and how best to treat and prevent it, we urge Congress to appropriate \$475 million for NIAAA, a \$91 million increase, and \$1.064 billion for NIDA, a \$176 million increase.

#### CONCLUSION

Alcoholism and drug dependence continue to be among our nation's most serious and costly public health problems. The programs I have discussed this afternoon must be strengthened because they are America's first line of defense against alcohol and drug dependence. Thank you.

#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF IMMUNOLOGISTS

The American Association of Immunologists (AAI), a non-profit professional association of more than 6,000 research scientists and physicians dedicated to understanding the immune system-resulting in the prevention, treatment, and cure of -appreciates this opportunity to express its views on the President's fiscal disease year 2003 Budget Request for the National Institutes of Health (NIH). Before we do, we would like to express our deep appreciation to the members of this sub-committee, and in particular, to the Chairman and ranking member of this subcommittee, Senators Tom Harkin and Arlen Specter, for their extraordinary support for biomedical research. Last year, AAI was delighted to present Chairman Harkin and Senator Specter with our 2001 Public Service Award in recognition of their "outstanding leadership, achievements, and advocacy on behalf of Biomedical Re-search and the National Institutes of Health." While it comes as no surprise that we find ourselves 1 year later witnessing again the leadership and commitment of Senators Harkin and Specter, we are no less grateful to you both for your con-tinuing dedication and for the depth of understanding that you bring to government sponsored biomedical research and the scientists this funding supports.

#### IMMUNOLOGY

The study of immunology spans a wide range of diseases and conditions which affect the lives of every American. Our scientists use grants from the NIH, and in particular from the National Institute of Allergy and Infectious Diseases (NIAID),<sup>1</sup> to understand the workings of the immune system. This information allows for delineating the causes of disease and discovering treatments and potential cures. Immunologists are currently engaged in many such activities, including: —developing effective vaccines against HIV/AIDS, influenza, and other infectious

and chronic diseases;

<sup>&</sup>lt;sup>1</sup>Many AAI members also receive grants from the National Cancer Institute (NCI), the National Institute on Aging (NIA), the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the National Heart, Lung, and Blood Institute (NHLBI), and other NIH institutes and centers.

- --discovering new defenses against emerging and re-emerging bacteria (such as tuberculosis) and drug resistant bacteria (including antibiotic-resistance);
- —regulating autoimmune diseases such as diabetes, myasthenia gravis, and lupus;
- -discovering the causes of cancer and promising new treatments; and
- -developing treatments to prevent the rejection of transplanted organs and bone marrow.

With all of this research ongoing, AAI members are poised to embrace a new and unexpected research challenge posed by the fiscal year 2003 budget: bioterrorism research. AAI members include the nation's preeminent immunologists, many of whom will conduct the research that will be at the forefront of the nation's urgently needed vaccine development and related bioterrorism research efforts. The efforts of immunologists will be critical in understanding both the mechanism of infectious diseases and recovery from them. As we discuss this year's budget, we would also like to discuss the unique role that we believe immunologists can play in the national effort to combat bioterrorism.

#### DOUBLING THE BUDGET OF THE NATIONAL INSTITUTES OF HEALTH (NIH)

AAI strongly supports the President's budget request for \$27.3 billion for fiscal year 2003 for the NIH—an increase of 15.7 percent (\$3.99 billion) over fiscal year 2002. This request, if funded, would complete the doubling of the NIH budget over 5 years—a bipartisan effort made by Congress under the leadership of the then—Chairman and Ranking Member of this subcommittee, Senators Arlen Specter and Tom Harkin, and former Rep. and House Subcommittee on Labor, Health and Human Services, and Education Chairman John Porter (R-10th, IL, ret.). This doubling effort has been endorsed and fulfilled by President Bush in his fiscal year 2002 and fiscal year 2003 budget requests.

Prior years' funds have already increased the funding of grants to about 30 percent of all submitted applications, allowing for more quality research and for a greater likelihood of successful grant applications. The fiscal year 2003 budget would build on this foundation. Most Institutes and Centers would receive an average increase of 9 percent, with the NIAID increasing by 52 percent and the NCI increasing by 11 percent. NIH expects that the fiscal year 2003 budget would fund a total of 9,854 new, competing research grants, resulting in the highest annual total ever (38,038 awards). In addition, intramural research would increase by about 15 percent over fiscal year 2002.

AAI believes that this increase in funding will allow more quality research to be funded, leading to more translational opportunities and swifter clinical application. It will also help attract young students to research careers and help retain young scientists who might otherwise leave academia or government for better funding opportunities with pharmaceutical or biotech companies.

#### BIOTERRORISM FUNDING

As the members of this subcommittee know, a significant portion of this year's budget increase-\$1.75 billion-is devoted to bioterrorism research, with \$1.5 billion of that total directed to the National Institute of Allergy and Infectious Diseases (NIAID). AAI strongly supports the President's extraordinary commitment to research evidenced by this funding request. And while we as scientists generally oppose specific funding earmarks-preferring instead to allow the investigator initiated research to lead us to the next scientific discoveries-we recognize the responsibility of the President and the Congress to address urgent national needs and to direct funding to areas where scientists may not currently be focusing their atten-tion or efforts. A previous example was the advent of AIDS in the 1980s, when little or nothing was known of the disease. During a tumultuous period lasting through much of that decade, the scientific community was asked to focus on this emerging pandemic. And while we are still a long way from curing AIDS, the research that has been done on the cause, epidemiology, and prophylaxis has prevented untold numbers of new cases of AIDS; and advanced treatments have enabled millions of people with AIDS or HIV to live longer, healthier lives. It was the NIAID, under the averaging for the treatment is the state of the section of the exceptional leadership of Dr. Anthony Fauci, together with thousands of scientists who are funded by the NIAID, that changed the course of the fight against AIDS/HIV. AAI members firmly believe that Dr. Fauci and the NIAID will be able to lead the national research effort against bioterrorism as successfully as they did the fight against AIDS, and we feel confident—as a significant portion of the MAID's grantees—that we can undertake with purpose and commitment the re-search challenges that Dr. Fauci and the NIAID have laid out for us.

## THE ROLES FOR IMMUNOLOGISTS IN THE NATIONAL RESPONSE TO BIOTERRORISM.

Because immunologists study the immune system in health and disease, we have both a special interest and expertise in the nature of infections. We have a unique ability to study the normal immune response to the bacteria and viruses which could be used as weapons of bioterrorism. An important aspect of the normal immune response is defining the "targets" (i.e., antigens or epitopes) the immune system uses to recognize and destroy invading pathogens. In immunologic terms, this means defining the chemical nature of the epitopes recognized by the major defenders of the immune system—T and B lymphocytes. The mechanisms of defining epitopes are well known, but have not been applied to some pathogens which could be used as weapons of bioterrorism; these will need to be defined in the test tube, in animal models,<sup>2</sup> and finally, in humans. Once we understand the human immune response, we will be prepared to develop life-saving therapies and preventive vaccines. Collaboration between microbiologists, who understand the biology of infectious agents, and immunologists, who understand he biology of infectious agents, and immunologists, is critical.

Many diseases have serious health consequences that can reappear years after the primary infection (e.g., some autoimmune syndromes). Many of these disorders are related to immune responses to persistent infection. It is important to understand these possible negative effects of immune system protection. An understanding of the biology of these negative effects will allow physicians to predict the likely side effects and/or long-term consequences of both vaccination and contracting the disease itself. The benefit of these studies includes the following:

1. These studies will lead to the production of safe and effective vaccines. This information will allow vaccines to target the correct parts of the pathogens and make the vaccine more effective, while at the same time less likely to induce side effects.

2. Immunologists will provide tools for clinicians to aid in the rapid diagnosis and prognosis of infected individuals. This could include both monoclonal antibody-based tests to detect the presence of an infectious agent as well as assessments of immune status to aid in the determination of the course of infection.

3. The course of the disease will itself suggest effective treatments. Understanding the disease process will define targets for drug therapy that are specific, e.g., antitoxin treatment used for tetanus. Once these targets are identified, the real strengths of the American pharmaceutical industry (rapid drug screening and development) can be utilized.

### RESEARCH, MANAGEMENT AND SERVICES (RM&S) BUDGET

AAI applauds the President and the leadership at NIH for recommending a budget which recognizes that significant new funding requires additional administrative staff to ensure that the money is well and properly spent. While the Research, Management and Services (RM&S) budget supports the management, monitoring, and oversight of intramural and extramural research activities (including ensuring the continuation of NIH's excellent and highly regarded peer review process), it has not been able to keep pace with the increasing size and complexity of the NIH budget. We are particularly pleased, therefore, that the RM&S budget receives an overall increase of 17 percent in fiscal year 2003, with an average 9 percent increase for most Institutes and Centers and a larger increase for the NIAID and NCI to support their significant funding increases. AAI believes that proper stewardship will be the best guarantee the taxpayer and the Congress have that the appropriated funds will support the best research and lead to the most promising results. We strongly support this increase in the RMS budget and hope that hiring procedures can be streamlined and if necessary, amended, so that hiring can be accomplished in time for the upcoming grant cycles and new funds can be awarded expeditiously.

<sup>&</sup>lt;sup>2</sup>Immunologists depend heavily on the use of animal models in their research. Without the use of animals, theories about immune system function and treatments that might cure or prevent disease would have to be tested first on human subjects, something our society—and our scientists—would never countenance. Despite the clear necessity for animal research, people and organizations that oppose such research are threatening scientists who use animal models. The legal and extra-legal methods used by these groups to further an animal-rights/anti-medical research agenda are diverting precious resources from our work, threatening the personal safety and security of scientists, and delaying the progress of important research that is already underway.

# ATTRACTING BRIGHT STUDENTS TO BIOMEDICAL RESEARCH AND RETAINING YOUNG RESEARCHERS

AAI has long been concerned about science's ability to attract bright young students to careers in biomedical research to ensure the future supply of biomedical researchers. In particular, we have worked to advance the plight of post-doctoral fellows who are significantly underpaid and under-compensated for their critical work. We were delighted, therefore, when the NIH announced in March of 2001 that it intended to implement recommendations of the National Academy of Sciences' Committee on Science, Engineering, and Public Policy (COSEPUP) regarding the need for better compensation and employment benefits for post-doctoral fellows. (See NIH NOT-OD-01-027). The final NIH plan included increasing the stipends for National Research Service Award (NRSA) recipients over a 5 year period by 10 percent per year or until entry level post-docs reach \$45,000 per year (from its fiscal year 2002 level of \$31,092). During fiscal year 2002, NIH did raise stipends by 10 percent and intended to raise them again during fiscal year 2003 by 10 percent. The President's budget, however, permits only a 4 percent increase for fiscal year 2003. We strongly urge this subcommittee to allow NIH to proceed with its plan to in-

We strongly urge this subcommittee to allow NIH to proceed with its plan to increase NRSA post-doctoral stipends and to further explore ways to provide important employ ment benefits—including health insurance, pensions and Social Security, and vacation/leave time—to both NRSAs and the post-doctoral fellows supported by NIH extramural grants. While we understand that this may result in the hiring of fewer post-docs, we believe that it is essential to provide a living wage and basic employment benefits if we are to attract and retain the best and brightest students who often encounter multiple job opportunities with significantly more attractive compensation packages. NIH and the National Science Foundation have both recognized this reality facing the nation's scientific community and have attempted to address this problem directly—we urge the Congress to enable NIH to move forward with its post-doctoral stipend plan.

#### POST-DOUBLING BUDGETS

AAI members are grateful for the extraordinary support for biomedical research that the Congress has shown through the successful and nearly completed effort to double the NIH budget. While we recognize that such generous funding increases are unlikely to continue in future years given the many important competing programs and needs, we strongly urge the Congress to preserve and build upon the many scientific advances that have been—and will continue to be—made during the doubling period by ensuring adequate funding increases in the post-doubling era. While AAI has not yet formulated a recommendation regarding reasonable funding increases for future years, we note that NIH Acting Director Ruth Kirschstein, M.D., in testimony to this subcommittee on March 21, 2002, indicated that current scientific opportunities "lend themselves to an 8–10 percent [annual] increase" in funding in the post-doubling years. We urge the Congress as a prudent investment in providing healthier, better, and safer lives for all Americans.

#### CONCLUSION

While ongoing hearings in both the Senate and House of Representatives continue to explore details of the President's fiscal year 2003 biomedical research budget that AAI has not yet studied, we regard the President's fiscal year 2003 budget for NIH as evidencing an extraordinary commitment to advancing not only our nation's defenses against bioterrorism, but also to the fight against the more common diseases which afflict every family in America and around the world, and wreak havoc—one person—and one family at a time. We look forward to embracing the many research areas that will open to our scientists and plan to work with the NIAID to help educate bench scientists about the scientific needs and opportunities that lie before us. We hope that the members and staff of this subcommittee will look to us as a resource on any matters involving the immune system, vaccine development, or biomedical research in general. We appreciate having this opportunity to express our views.

#### PREPARED STATEMENT OF THE POPULATION ASSOCIATION OF AMERICA AND THE ASSOCIATION OF POPULATION CENTERS

Thank you 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 2003 funding for the National Institutes of Health (NIH), specifically the National Institute on Aging (NIA), and the National Institute of Child Health and Human Development (NICHD). In addition, our comments focus on the Centers for Disease Control's (CDC) National Center for Health Statistics (NCHS).

PAA is a scientific and educational society of professionals working in demographic research. APC is a consortium of 32 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. Two population research centers are based in Pennsylvania—one in Philadelphia and one in State College. In addition, there is a population center on aging located at the University of Iowa.

Demographic research focuses on many of the issues important to our nation, such as retirement, health disparities, disability and long term care, child care, immigration and migration, labor force participation, worker retraining, family formation and dissolution, and population forecasting. The United States is undergoing farreaching shifts in its demographic composition and distribution. Such changes are not always recognized or understood until they confront society with new and immediate needs—often requiring federal and state expenditures. By tracking such changes, demographic, social and behavioral research provides for more coherent and efficient planning and policy implementation.

The National Institute of Child Health and Human Development (NICHD) and the National Institute on Aging (NIA) provide primary support for demographic research at NIH. The National Center for Health Statistics (NCHS) serves as the federal government's main vital statistics agency. We would like to take this opportunity to share information concerning research findings and funding levels of all three of these programs.

### NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENT (NICHD)

NICHD has a well established and successful population research program, currently funded at \$1.1 billion, with approximately \$252.7 million of that budget dedicated to research funded through the Demographic and Behavioral Sciences Branch in fiscal year 2002. Among the many areas of demographic research supported by NICHD are families and household composition; 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 combine conceptual innovations, with improvements in data collection, measurement, and analysis to address emerging questions, often involving cross disciplinary research. In addition, the centers are the major training ground for future demographers.

This testimony relating to NICHD focuses on two main areas of research: welfare reform and the National Children's Study.

#### Welfare Reform Effects on Children and Families

This year the Welfare Reform Act of 1996 comes up for reauthorization. This act marked a major shift in welfare programs and remains a national priority. NICHD supports a wide range of research that examines how communities, families and children are interrelated and adapting to changes in social policy and macroeconomics. One such research effort is the Fragile Families and Child-Well Being Study, which started collecting data in 2000 and will continue through 2004. The study follows a cohort of mostly unwed parents and their children for a 4-year period. Initial waves of data will provide the basis for research on prenatal care, mother-father relationships, expectations about fathers' rights and responsibilities, marriage attitudes, social support and knowledge of local policies and community resources and networks.

#### The National Children's Study

NICHD, along with the National Institute of Environmental Health Sciences, CDC and the United States Environmental Protection Agency, is participating in a landmark study that will assess how environmental factors may affect child health. This study was prompted by a recommendation of the Developmental Disabilities Work Group of the President's Task Force on Environmental Health Risks and Safety. PAA and APC join in supporting this study, as children are particularly vulnerable to environmental influences. This is largely because a child's immunology system is not yet fully developed. The National Children's Study will examine how low level contaminants, such as lead, combined with other aspects of their social and built environments, such as poverty, affect the well being and health of children. In addition to environmental factors, the study will analyze biological and social factors that may impede child development.

#### 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 the aging of the American population for our country. Currently, the NIA is funded at \$893 million, with \$221.3 million of that budget dedicated to the Behavioral and Social Research Program. This figure includes training, career development, and demographic, economic and epidemiological research in fiscal year 2002. As the U.S. population ages and Congress contemplates sweeping changes in Medicare and Social Security, the demography of the elderly is increasingly 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 is the NIA-supported Health and Retirement Study (HRS).

#### Health and Retirement Study (HRS)

The Health and Retirement Study (HRS) was launched in 1992 with baseline interviews for a representative sample of persons born between 1931 and 1941. These respondents were interviewed again in 1994, 1996, 1998 and 2000. HRS 2002 is now underway and includes new material on how the events of 9/11 affected the overall sense of security of mid and late-life Americans as well as their financial resources.

In 1993, the HRS was augmented by the AHEAD (Asset and Health Dynamics of the Oldest-Old) which sampled the cohorts born before 1924, individuals who are the oldest-old segment of our population with high rates of chronic disease, disability, and health care costs. The older AHEAD respondents were interviewed again in 1995, 1998 and 2000. In 1998, samples of two other cohorts were added, those born between 1924 and 1930, the so-called children of the Depression, and those born between 1942 and 1947, or the "early baby-boomer cohort". With the addition of these cohorts, HRS becomes nationally representative of the U.S. population over age 50. Since 1998, the entire study is referred to as the HRS.

The original HRS focused on mid-life work and health dynamics. Biennial data are now available for all respondents on health, disability, work, health insurance, pensions and retirement plans, and transfers of time and financial help across generations of the family. The HRS has been used by NIA-supported researchers to explore issues such as the effect of changes in physical and cognitive health on the age of retirement, the prospects for late-life financial security, and the relationship of the use of health care services and the type of private and Medicare insurance coverage. Data provided by very old respondents has been useful for studying how families redistribute their resources across generations, and whether public benefits drive out private, family transfers. These data inform policy decisions on initiatives such as Medicare/Medicaid coverage, prescription drug benefits, and the redistribution of wealth across three or four generations of American families.

## Health Status and Health Care

We have long known that Americans are living longer than ever before, and new research shows that older Americans are living better as well. A recent NIA funded study showed that while memory problems increase with age, fewer seniors were identified as having significant memory or cognitive problems in 1998 than in 1993. Men and women experienced improvements over the past decade and marked improvements were seen in those over 80. These preliminary findings suggest that severe cognitive impairment in the senior population has declined over time. Numerous factors contribute to this decline, including: improvements in physical and cognitive health; greater ability to diagnose chronic illness at an earlier stages; innovations in preventive medicine, and treatment of disabling illnesses; improved diagnoses of mental health disorders; the emergence of a broad continuum of living and care arrangements; and expanded elder care programs. The decline in disability yields cost benefits as well. These benefits can be measured in terms of higher rates of labor force participation for caregivers to frail elderly, reduced rates of nursing home admissions, and a slow down in the increases in public payments for personal care.

## NATIONAL CENTER FOR HEALTH STATISTICS (NCHS)

Located within CDC, the National Center for Health Statistics (NCHS) is the principal source of data on the health of the U.S. population. A unique public resource for health information, NCHS provides data on current public health challenges and monitors the extent to which the country is meeting important public health goals, such as closing racial and ethnic health disparities. These data are used by policy makers and members of the health care industry to recognize emerging health problems and evaluate public health initiatives. NCHS is currently funded at \$130.7 million. After years of small increases, the President's budget proposes to shave over half a million dollars off of NCHS' budget for fiscal year 2003.

## Data on Families and their Health Status

NCHS is the source of a wealth of information on family formation, reproductive health, adoption, and family planning—essential data for understanding demographic and social trends. For example, unintended pregnancies and births are declining; adoptions are holding steady even though relinquishments are decreasing; contraceptive use is increasing for each age group including teens, and infertility appears to be holding steady despite the common perception that it is increasing. This information on family formation and adoption comes from the National Survey of Family Growth, a survey conducted by NCHS in partnership with NICHD and others. These data not only provide important information to policy-makers, but are widely used by population researchers.

In collaboration with the U.S. Department of Education and other federal agencies, NCHS is also participating in a study that will provide data on child development, education, health and early life care. The Early Childhood Longitudinal Study will track 15,000 children from their 9th month of age through first grade. Such studies are critical to ensuring that the President's goal of "leaving no child behind" is monitored and met.

## Data on Life Expectancy and Social Trends

Through data on births and deaths, NCHS is able to track critical trends in infant mortality, life expectancy, causes of death, teen pregnancy, and out-of-wedlock births. Thus, NCHS has documented recent declines in teen pregnancy, the upward trend in births to unmarried women, as well as changes in the number of children women would like to have, continuing reductions in infant mortality (despite the 2:1 disparity between white and black populations), record highs in U.S. life expectancy, the downward trends in AIDS mortality and in cancer mortality (since 1993). This information is crucial for national policy—for example, mortality data are essential for projecting the health of our Medicare and Social Security Trust funds; birth data are used to track the success of programs to reduce teen pregnancy; and birth data are used to evaluate the success of state efforts to reduce out-of-wedlock births through welfare programs. NCHS collects birth and death information through the NCHS is the lead agency for collecting reliable health data for all aspects of our population through flagship programs including the National Health Interview Survey and the National Health and Nutrition Examination Survey.

## Conclusion

PAA and APC commend President Bush and Congress for their commitment to double the NIH budget by the end of 2003. Not all NIH Institutes and programs, however, have benefited equally from the substantial NIH budget increases. PAA and APC urge an increase in the range of 11 percent to 12 percent to sustain the momentum of demographic research at both NICHD and NIA. NICHD efforts, such as the National Survey of Family Growth, and NICHD training programs risk collapse because of partial funding. A funding increase will also allow NICHD to sustain and capitalize on the research programs of the Centers. Recently, NICHD suspended funding to three such population centers because of inadequate funds. In addition, an 11 percent to 12 percent increase at NICHD would allow expansion of programs to study immigration and population movement programs, including work on how immigration policies affect racial and ethnic composition of neighborhoods, as well as the residential patterns of legal and illegal immigrants in both urban and rural areas. At NIA, additional funding would support the expanding program on biodemography and analyses of the two major prospective panel studies, the Health and Retirement Study and the National Long Term Care Study. These studies have already yielded important policy dividends charting changes in the age and timing of disability transitions and the increased duration of healthy life, even at the extremes of old age.

PAA and APC urge restoration of the \$600,000 funding cuts for NCHS that are reflected in President Bush's fiscal year 2003 proposed budget.—Without such restoration, combined with a substantial increase of 20 percent for NCHS, there will be a major reduction in the data generated from NCHS' existing data systems. Timeliness, sample size, ability to look at smaller groups within population, will all be adversely affected without restored and increased funds for NCHS. Both the National Health Nutrition and Examination Survey and the National Health Interview

Survey will be compromised if not fully funded. In addition, a reduction in funds will severely undermine the scientific integrity of both. Within NCHS' programs on vital statistics (e.g. annual estimates of birth and death rates, and marriage and divorce rates), budget cuts are likely to diminish the reliability of data used to monitor trends in out of wedlock births, causes of death and health disparities. Indeed, one of the major NCHS surveys itself would have to be suspended without such increases in funding. Of all developed countries over the last decade, only Russia has reduced its investment in these most fundamental programs of data collection.

PAA and APC thank you for the opportunity to present these recommendations. Demographic data and research are important tools for policymakers that can both save public funds and promote more informed decision-making. If this vital program is to continue providing reliable and timely data for the country, as a whole and the states, adequate funding and Congressional support are needed.

## PREPARED STATEMENT OF THE AMERICAN CHEMICAL SOCIETY

The American Chemical Society (ACS) would like to thank Chairman Tom Harkin and Ranking Member Arlen Specter for the opportunity to submit testimony for the record on the Labor, Health and Human Services, and Education Appropriations bill for fiscal year 2003.

As you may know, ACS is a non-profit scientific and educational organization, chartered by Congress, representing more than 163,000 individual chemical scientists and engineers. The world's largest scientific society, ACS advances the chemical enterprise, increases public understanding of chemistry, and brings its expertise to bear on state and national matters.

Advances in science and engineering have produced more than half of our nation's economic growth in the last 50 years. Each field of science contributes to our diversity of strengths and capabilities and has given us the flexibility to apply science in unexpected ways. Together, science and engineering and the highly trained people who work in these fields remain the most important factor in the productivity increases responsible for economic growth and rising living standards, economists agree. Increased attention to national security and counter-terrorism activities and the bipartisan commitment to double the budget of the National Institutes of Health over 5 years led to record investments in federal research and development (R&D) in fiscal year 2002. Nevertheless, the R&D investment in some federal agencies is still inadequate for them to achieve their missions. Opportunities to perform highquality research, recruit U.S. students to science and engineering fields, and fully will evode in the long term as a result. For fiscal year 2003, Congress and the administration will be challenged by the costs of the war on terrorism, budget deficits, and an uncertain economic outlook. As these challenges are confronted, strength in science should remain a key national objective.

## NIH BUDGET RECOMMENDATIONS

The American Chemical Society (ACS) commends Congress and the Administration for its continued support of the effort to double NIH's budget by fiscal year 2003. ACS urges Congress and the Administration to continue this effort by funding NIH at \$27.3 billion for fiscal year 2003, a 15.8 percent increase over fiscal year 2002. As the major supporter of biomedical research in the United States, NIH is the primary source of new biomedical discoveries that will lead to longer, healthier lives due to prevention, early detection, and more effective treatment of disease. NIH-supported research contributes to U.S. leadership in biomedical research. This research provides training opportunities for new scientists and stimulates technological advances in the pharmaceutical and biotechnology industries, both of which contribute positively to the nation's balance of trade.

Physical sciences contribute to fundamental advances in biomedical research. As the largest source of federal funding for basic research, NIH must do more to provide strong support for areas of physical science that are critical for sustained advances in biomedicine.

## NATIONAL INSTITUTE OF GENERAL MEDICAL SCIENCES

ACS believes it is essential that the National Institute of General Medical Sciences (NIGMS) receive increases that are at least proportional to the other NIH institutes. NIGMS supports quality, non-disease-specific basic research and training that underpins advances in other institutes. NIGMS plays a central role in gener-

ating basic knowledge across science disciplines, strengthening the roots of innovation in the biomedical community, and fostering tomorrow's breakthrough discov-eries. ACS supports NIGMS' promotion of interdisciplinary research programs. These programs would allow chemists to collaborate with other scientists to study new research areas

## NATIONAL CENTER FOR RESEARCH RESOURCES

The National Center for Research Resources (NCRR) provides support for stateof-the-art research infrastructure, including the expansion, remodeling, and con-struction of extramural research facilities. The Center facilitates the development of new technologies and techniques for scientific inquiry. NCRR provides grants such as the Shared Instrumentation Grants program, which provides a cost-effective mechanism for groups of NIH-supported investigators to obtain commercially available, technologically sophisticated equipment costing more than \$100,000. ACS urges that this program be funded at its authorized level of \$100 million.

ACS also supports NCRR's High Cost Instrumentation grant program for instruments that cost between \$750,000 and \$2 million. Instruments in this category include structural and functional imaging systems, high-resolution NMR spectrom-eters, electron microscopes, and supercomputers. Through these contributions, NCRR offers the potential for revolutionary approaches to health-related research. This program should receive the same proportional increase as other NIH programs.

## NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES

ACS supports the research programs of the National Institute of Environmental Health Sciences and the National Toxicology Program. NTP is well-suited to encour-age and support changes in the synthesis and manufacture of pharmaceuticals and their intermediates in ways that are more benign to human health and the environ-ment. NIEHS and NTP should be encouraged to integrate the emerging area of green chemistry, which involves the use of more benign chemicals and technologies, into their portfolio of synthetic methods development.

## PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF STATE ALCOHOL AND DRUG ABUSE DIRECTORS

Thank you for the opportunity to provide testimony regarding fiscal year 2003 appropriations. My name is Dr. Lewis Gallant, and I am the Executive Director of the National Association of State Alcohol and Drug Abuse Directors (NASADAD).

NASADAD's members are responsible for administering the Substance Abuse Pre-vention and Treatment Block Grant and assuring the quality and effectiveness of substance abuse prevention and treatment services. In addition, our members certify substance abuse professionals, accredit treatment programs, contract with community based providers, collect, manage analyze and report on data, and work to ensure quality performance.

## NASADAD'S FISCAL YEAR 2003 APPROPRIATIONS PRIORITIES

I would like to quickly highlight NASADAD's appropriations priorities for fiscal year 2003 contained in the bill funding the Departments of Labor, Health and Human Services (HHS), and Education. NASADAD is joined by other members of the substance abuse community in recommending the following: —\$2 billion for the Substance Abuse Prevention and Treatment Block Grant,

\$360 million for the Center for Substance Abuse Prevention,

\$360 million for the Center for Substance Abuse Treatment,

\$540 million for the State Grants portion of the Safe and Drug Free Schools and Communities Program within the Department of Education,

\$1.064 billion for the National Institute on Drug Abuse, and \$475 million for the National Institute of Alcoholism and Alcohol Abuse.

[In billions of dollars]

	Fiscal year			
Program	2002 appropriation	2003 President's request	2003 NASADAD recommenda- tion	
Substance Abuse Prevention and Treatment Block Grant (SAPT) Center for Substance Abuse Treatment (CSAT)	1.725 .292	1.785 .358	2.000 .360	

54	0

[In billions of dollars]

	Fiscal year				
Program	2002 appropriation	2003 President's request	2003 NASADAD recommenda- tion		
Center for Substance Abuse Prevention (CSAP)	.198	.153	.360		
Safe & Drug Free Schools & Communities Program (SDFSC) <sup>1</sup>	.747	.644	.747		
State Grants (SDFSC subtotal)	.472	.472	.540		
National Institute on Drug Abuse (NIDA)	.888	.968	1.064		
National Institute on Alcohol Abuse and Alcoholism (NIAAA)	.384	.418	.475		

<sup>1</sup> Includes funds newly authorized under Public Law 107-110, the No Child Left Behind Act of 2001.

## PRESIDENT BUSH: SUBSTANCE ABUSE SERVICES MUST BE A NATIONAL PRIORITY

President Bush reminded us all that more must be done to elevate substance abuse treatment and prevention issues to the forefront of our national agenda. In particular, the President noted, "In this struggle, we know what works. We must aggressively and unabashedly teach our children the dangers of drugs. We must aggressively treat addiction wherever we find it. And we must aggressively enforce the laws against drugs at our borders and in our communitiesà America cannot pick and choose between these goals. All are necessary if any are to be effective." I could not agree more.

The President issued a call to action—and for good reason. The National Household Survey on Drug Abuse (NHSDA) estimates that 14 million Americans (or 6.3 percent of the U.S. households' population age 12 and over) need treatment in any given year. We know that certain substances, including the "club drug" Ecstasy and the non-medical use of Oxycontin, are impacting our communities at alarming rates. Studies also show that alcohol and other drug addiction cost the nation as much as \$400 billion per year. These costs stem lost job productivity, health care needs, accidents, crime, welfare and child welfare and other factors. But no sterile statistic, or gross dollar estimate, can accurately capture the toll substance abuse takes on citizens across the country. We all know a friend, family member, co-worker or even celebrity impacted by substance abuse. We are all too familiar with the havoc addiction wreaks on citizens across the nation. As the President noted, substance abuse "threatens everything that is best about our country."

In an ambitious move to address substance abuse problems in the U.S., President Bush announced last year his commitment to dedicate \$1.6 billion over 5 years to help erase the treatment gap. In February, Mr. John Walters, Director of the Office of National Drug Control Policy (ONDCP), announced the release of the Administration's 2002 National Drug Control Strategy, which set a goal of reducing illegal drug use by 25 percent over the next 5 years. More recently, Mr. Charles Curie, Administrator of the Substance Abuse and Mental Health Services Administration (SAMHSA), unveiled his agency's priorities and reiterated his commitment to work collaboratively to improve substance abuse services across the country. We applaud each of these leaders, and commend them for their vision. We also look forward to working closely with the Administration, Congress and others in order to ensure that the \$1.6 billion in new, cumulative funding will be effectively used to help the lives of Americans across the country.

## BACKBONE OF STATE ADDICTION SYSTEMS: SUBSTANCE ABUSE BLOCK GRANT

NASADAD enthusiastically supports the Administration's call to increase funding for the Substance Abuse Block Grant. While NASADAD and others would prefer a total of \$2 billion in fiscal year 2003 funding for the Block Grant, we commend the Administration's proposal to increase this program by \$60 million.

The Substance Abuse Block Grant is a crucial funding stream that assists States in maintaining a foundation for their respective service delivery systems. In particular, Block Grant funds help provide assistance to vulnerable populations—including youth and pregnant and parenting women—who either have, or at risk of having, a substance abuse problem. Also, the Substance Abuse Block Grant maintains and creates linkages with other public programs to maximize the impact of available resources. These linkages are vital due to the many year-to-year pressures impacting State substance abuse systems. For example, States across the country are facing severe budget cuts due to the economy and the homeland security costs related to the tragic events of September 11. The National Governors Association (NGA) and the National Association of State Budget Officers (NASBO) estimate that there is a \$50 billion State budget gap nationwide.

# TRANSITIONING TO A PERFORMANCE PARTNERSHIP GRANT: RESOURCES FOR DATA NEEDED

As you may know, federal law mandated a shift away from the Substance Abuse Prevention and Treatment Block Grant into a Performance Partnership Grant. This transition is designed to provide States more flexibility in the use of funds while instituting a system of accountability based on performance. NASADAD is working closely with SAMHSA, led by Administrator Curie, on this complicated transition. We share SAMHSA's idea that the Performance Partnership Grant should be viewed as a "quality improvement" mechanism versus a punitive approach that could threaten the flow of much needed resources to our already strained substance abuse system.

As part of the transition, Public law requires the Secretary of Health and Human Services (HHS) to submit a plan to Congress by October 17, 2002, on the details of the switch to a Performance Partnership Grant. NASADAD is working with SAMHSA regarding the many details that must be contained in this blueprint, including (1) a description of the flexibility that would be given to the States under the plan; (2) the common set of performance measures that would be used for accountability; (3) the definitions for the data elements to be used under the plan; (4) the obstacles to implementation of the plan and the manner in which such obstacles would be resolved; (5) the resources needed to implement the performance partnerships under the plan; and (6) an implementation strategy complete with recommendations for any necessary legislation.

It is clear that the transition to a Performance Partnership Grant will require substantial resources. Adequate federal funds will be needed in order to help each State meet the new requirements set forth in the Performance Partnership Grant. One priority that must begin to be addressed in fiscal year 2003 and future fiscal years relates to data management. Funds are needed, for example, to help States assess current data information capacity in view of the transition. Resources are also needed to help States build systems that will collect, track, refine, manage, analyze and disseminate accurate data in accordance with the requirements set forth in the new Performance Partnership Grant. In a report written in November 2001 by NASADAD for SAMHSA, research found

In a report written in November 2001 by NASADAD for SAMHSA, research found that the total State expenditures for the operation and maintenance of alcohol and other drug (AOD) systems for 2001 was \$35,359,000 or \$698,000 per State. As a result, we know that substantial resources are already being spent on State substance abuse data management. The implementation of the Performance Partnership Grant, however, mandates a new set of corresponding requirements from the States. Without additional federal funds, the timeline for the transition away from the Substance Abuse Block Grant would be severely delayed. Further, the implementation of the Performance Partnership Grant is predicated on the current system of providing adequate and baseline funding levels to each State for substance abuse prevention and treatment services. Any changes to this system would endanger the ability of States to participate successfully in the Performance Partnership.

# CENTER FOR SUBSTANCE ABUSE TREATMENT

NASADAD recommends \$360 million for SAMHSA's Center for Substance Abuse Treatment (CSAT) for fiscal year 2003. Over the years, tremendous gains have been made to help address the treatments needs of our nation. We know, for example, that criminal activity decreases by as much as 80 percent when treatment is administered. We know that infants whose mothers receive substance abuse treatment avoid low birth weight, premature delivery and death at rates better than the national average. We know that welfare recipients who need addiction treatment, and undergo a complete treatment cycle, are more likely to get a job and earn more money than those who receive only minimal treatment services. Simply put—we know treatment works.

However, the data also shows that we have many more challenges ahead of us. For example, there is an "invisible epidemic" taking place among our senior citizens, where an estimated 17 percent of our seniors have a substance abuse problem. In addition, 70 percent of families with a child in protective care struggle with addiction. The tragedies of September 11 have heightened the need to expand substance abuse services as providers report increased demand for their assistance. The events of September 11 also highlight the impact trauma has on substance use and abuse.

We would like to take this opportunity to publicly thank Mr. Charles Curie, Dr. H. Westley Clark, Director of CSAT, and Dr. Joseph Autry, Deputy SAMHSA Administrator, for their leadership during—and immediately after—the terrorist attacks. SAMHSA acted quickly to provide a series of emergency grants to States impacted by the events. Subsequently, SAMHSA organized a national summit in New York City to examine and enhance the local, State and federal role in addressing the mental health and substance abuse needs of individuals and communities before, during, and after acts and threats of terrorism. We would encourage Congress—and SAMHSA—not to lose focus on the link between trauma and substance abuse as other related initiatives are developed and implemented.

## CENTER FOR SUBSTANCE ABUSE PREVENTION

NASADAD recommends \$360 million for SAMHSA's Center for Substance Abuse Prevention (CSAP) for fiscal year 2003. NASADAD and other national organizations are extremely concerned with the Administration's proposal to reduce funding for CSAP in fiscal year 2003 by \$45 million. CSAP is the sole Federal organization with responsibility for improving accessibility and quality of substance abuse prevention services. Led by Dr. Ruth Sanchez-Way, CSAP provides national leadership in the development of policies, programs, and services to prevent the onset of illegal drug use, along with underage alcohol and tobacco use.

There is no doubt that we must remain committed to the prevention of substance abuse problems before they occur. Projections in drug abuse treatment need made by the NHSDA demonstrate a compelling point: The study found that if current initiation rates continue at the same levels we are experiencing now, demand for drug treatment will more than double (an increase 57 percent) by 2020. Even if we managed to cut current initiation rates today by 50 percent, demand for treatment would simply remain constant by 2020. The good news is that studies also show that federally funded substance abuse programs for "high-risk youth" yield reduced rates of alcohol, tobacco and marijuana use. Prevention can and does work—and we must continue to invest federal funding in prevention programs in order to avoid more problems in the future.

NASADAD supports CSAP's State Incentive Grant (SIG). The SIG program is a successful initiative that links different systems in new and exciting ways to help enhance service delivery and capacity. These competitive grants (there have been 33 funded to date) flow through the Governors' offices, where care is taken to involve other important State systems, and are provided to community coalitions in a more inclusive and comprehensive manner. The SIG program is an effective mechanism designed to "bridge" formerly disparate government entities (e.g., the State AOD agencies, criminal justice agencies, child welfare agencies, education agencies, enforcement agencies, etc.) to provide thorough substance abuse prevention services.

CSAP's Decision Support System—launched less than 2 years ago—has already proven to be a remarkable, cutting-edge tool that makes use of the World Wide Web platform. This user-friendly interactive system enables the individual to access not only the registry of effective model programs, but also offers general technical assistance, information on State-supported prevention systems (via State "portals"), and assessment tools relevant to the measurement of risk and protective factors within a target population. In an era of increased accountability and performancebased reporting, such an interactive Web-based tool becomes invaluable to the substance abuse prevention community.

As previously mentioned, the dissemination of model programs is proving to be a useful mechanism in assisting States and communities in replicating and adopting evidence-based practices that are specifically tailored to various demographic target populations. The database created by CSAP, the National Registry of Effective Prevention Programs, is the primary national repository for scientifically validated prevention programs.

NASADAD is concerned with the impact the proposed budget will have on "services research"—or knowledge development. Administration officials note that SAMHSA and the National Institutes of Health (NIH) plan to collaborate to promote the study, dissemination, and implementation of research findings that improve the delivery and effectiveness of substance abuse and mental health services. This collaboration, according to SAMHSA, will involve the National Institute on Alcohol Abuse and Alcoholism (NIAAA), the National Institute on Drug Abuse (NIDA), and the National Institute of Mental Health (NIMH), and seek to produce a comprehensive "Science to Services" agenda that is responsive to the needs of the field. Over the next year, SAMHSA will seek to define and develop a "Science to Services" cycle that reduces the time between the discovery of an effective treatment or intervention and its adoption as part of community-based care. NASADAD would like to work with SAMHSA and NIH to ensure that the emerging plan for services research is crafted to include a portfolio that directly addresses the needs of State systems. In looking at the overall budget, NASADAD is extremely concerned with the proposed \$45 million to CSAP. We believe that more funding is needed—not less—and should be directed to the projects outlined above and others in order to maintain our strong investment in much needed prevention services.

## UNDERAGE TOBACCO USE: SYNAR AMENDMENT

As noted by the National Governors Association (NGA), States are strongly com-mitted to reducing youth smoking and restricting underage access to tobacco. In turn, States have committed substantial resources and time for the enforcement of what is known as the "Synar amendment"—requiring States to enact laws prohib-iting tobacco sales to minors and to achieve an 80 percent compliance rate among tobacco vendors. HHS issued regulations for Synar enforcement that established baseline annual target rates for each State. Despite good-faith efforts, many States have experienced serious challenges to implementing, enforcing, achieving and maintaining compliance with the Synar statute. The penalty for noncompliance with Synar is a severe 40 percent cut to the State's Substance Abuse and Prevention Treatment Block Grant. NASADAD opposes this punitive penalty that severely

threatens those who are most vulnerable. We agree with NGA in noting that Congress has taken an important first step in creating effective Synar enforcement by inserting language into the fiscal year 2000, 2001, and 2002 appropriations bills that would prevent Sates that commit substantial resources to the goals of Synar from suffering severe penalties to their Block Grant. NASADAD agrees with NGA in calling for substantial, longterm changes in the administration of the law and the statute itself. These changes are needed in order to ensure that States and the federal government work together to meet their common goal of reducing tobacco sales to minors without penalizing populations in need of substance abuse prevention and treatment services. In particular, we support NGA's position that calls for the establishment of a Synar enforcement structure that does not threaten, interrupt or eliminate critical substance abuse prevention and treatment services. NASADAD looks forward to working with Congress, the Administration, and others on this important issue.

#### NATIONAL INSTITUTE OF DRUG ABUSE AND NATIONAL INSTITUTE ON ALCOHOLISM AND ALCOHOL ABUSE

NASADAD recommends \$1.064 billion for NIDA and \$475 million in fiscal year 2003 for NIAAA. Increased funding for substance abuse research is vital, as mentioned above, and should include initiatives relevant to our State systems.

## SAFE AND DRUG FREE SCHOOLS AND COMMUNITIES PROGRAM

NASADAD recommends \$540 million in fiscal year 2003 funding for the newly re-authorized State Grants portion of the Safe and Drug Free Schools and Communities Program within the Department of Education. This important program serves as a vital source of funding to States for prevention programming. Thank you for considering these requests. Should you have any questions, or re-

quire additional information, please do not hesitate to contact me or have your staff contact Robert Morrison, Director of Public Policy, at (202) 293-0090 x 106 or email at rmorrison@nasadad.org.

## PREPARED STATEMENT OF THE FACIOSCAPULOHUMERAL MUSCULAR DYSTROPHY 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 as President & Chief Executive Officer (CEO) of the Facioscapulohumeral Muscular Dystrophy Society (FSH Society, Inc.) and as an individual who has this devastating disorder.

Facioscapulohumeral muscular dystrophy (FSHD) is the third most prevalent form of muscle disease. FSHD is a neuromuscular disorder that is inherited and transmitted genetically by 1/20,000 people affecting 12,500-37,500 persons in the United States. Additionally, FSHD can occur at any time by new mutations in the chromosome and 20-30 percent of people affected by FSHD are this type of spontaneous congenital mutation. For men and women, the major consequence of inheriting FSHD is a clinically unpredictable and 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. Retinal and cochlear disease can often be associated with FSHD although the pathogenesis and causative relationship to FSHD remains unknown. FSHD wastes the skeletal muscles and gradually but surely brings weakness and reduced mobility. Many with FSHD are severely physically disabled and spend the last 30 years of their lives in a wheelchair. The toll and cost of FSHD physically, emotionally and financially is enormous. FSHD is a life long disease that has an enormous cost-ofdisease burden and is a life sentence for the innocent patient and involved persons and their children and grandchildren as well.

The FacioScapuloHumeral (FSH) Society, incorporated in 1991, solely addresses specific issues and needs regarding facioscapulohumeral muscular dystrophy (FSHD). We promote public awareness of FSHD by providing research, education, and advocacy on FSHD. The FSH Society actively represents more than 10,000 patients with FSHD. The Society to date has invested more than \$750,000 into new research initiatives for this common muscle disease.

A decade of progress in FSHD has led to the discovery of many novel genetic phenomena never seen before in human disease and genomics that are of great significance and consequence to medicine and science. Genetic and physical mapping of the FSHD chromosome 4q35 region identified a DNA rearrangement associated with the disease. A polymorphic monomeric 3.3 kilo base pair (kb) repeat array, called D4Z4, when shortened to less than 9 repeats in length causes FSHD. The "FSHD mutation" was identified in 1990–1992. Despite having identified this molecular defect or mechanism there are no gene(s) that have been associated with or linked to FSHD to date. The repeats themselves may contain a gene or genes or some transcription mechanism that is disrupted. FSHD could be caused by a position effect variegation (PEV) mechanism. A PEV is caused by a shortening of the repeat array (DNA) causing structural and folding changes in the chromosome leading to altered expression of genes nearby or genes on other chromosomes. PEV causes DNA in one part of the genome to affect DNA in other parts of the genome. In FSHD, DNA at the very end of the chromosome. FSHD may be the first human disease known to be caused by a deletion-mutation of a stretch of chromosome causing PEV. Incredibly, as well, another level of complexity occurs due to a crossover of subtelomeric DNA between chromosomes (4 and 10) in both normal individuals and diseased individuals. Researchers know that FSHD is a complex human disease entangled in a dynamic molecular genomic evolution and many insights are being gleaned about the evolution of species. In recent months, researchers have presented preliminary data of a potential major breakthrough detailing the molecular switch that turns FSHD on and off via the repeats.

Despite remarkable genetic insight and immense progress by a small team of scientists worldwide, the nature of the gene product(s) remain enigmatic and the biochemical mechanism and cause of this common muscle disease remains absolutely unknown and elusive. The same is true for any treatment, therapy or cure—none exist.

The National Institutes of Health (NIH) spent approximately \$19 million (fiscal year 2000), \$21 million (fiscal year 2001), \$23.4 million (fiscal year 2002) and has budgeted \$25.4 million (fiscal year 2003) for research on all nine forms of muscular dystrophy including FSHD. Of the 23.4 million (fiscal year 2002) spent on all nine forms of muscular dystrophy, conservatively \$1.7-\$1.9 million (fiscal year 2002) is currently being spent on the third most prevalent and third largest disease of muscle, FSHD. One one-hundredth of 1 percent of the NIH budget will be spent on a very large and significant group of disease. Compared to other disease research areas at the NIH, muscular dystrophy is drastically under-funded.

areas at the NIH, muscular dystrophy is drastically under-funded. Nearly a decade ago, we appeared before this Committee to testify for the first time. The Appropriations Committees have repeatedly instructed the NIH to enhance and broaden the portfolio in FSHD. Due to the Appropriations Committees' interest, FSHD research has taken a number of steps forward this past year. I am pleased to report that three major programs to directly accelerate funding and research on FSHD have been initiated by the NIH. Admittedly, at first the NIH was slow to respond. However, in the past year we have been heartened to see the Directors of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), the National Institute of Neurological Disorders and Stroke (NINDS), the Office of Rare Disease (ORD) and the National Institute for Child Health and Human Development (NICHD) bring their considerable talents to bear on shaping meaningful approaches to solving the puzzle of FSHD. To date, the funding is still a fraction of what is needed to establish a comprehen-

To date, the funding is still a fraction of what is needed to establish a comprehensive and competent research platform for FSHD. \$12–18 million is needed for FSHD and \$65–85 million is needed for the entire class of disease called muscular dystrophy. Last year, the United States Congress passed the "Muscular Dystrophy Community Assistance, Research and Education Act" (The MD-CARE Act of 2001). The purpose of the MD CARE Act is to develop research that will broaden the base of inquiry on muscular dystrophy and FSHD and to bring that research to the clinic. The FSH Society has worked very hard to make this a reality. The NIH is working rapidly to implement the MD CARE Act. This is evidenced by the unprecedented partnership between the public agencies and patient groups

The NIH is working rapidly to implement the MD CARE Act. This is evidenced by the unprecedented partnership between the public agencies and patient groups concerned with muscular dystrophy. The closer and tighter cooperation between public and private agencies working together has led to remarkable progress in understanding the gravity of the situation of extreme lack of muscular dystrophy research and in particular FSHD research.

The Congress, the NIH and the volunteer health agencies are to be commended for the rapid and efficient progress. We hope that the MD CARE Act will yield a solid research strategy among the scientific, patient and government agencies.

However, we are concerned with the actual and estimated research funding figures from the NIH. These figures anticipate budgets of \$21, \$23.4, and \$25.4 million for fiscal year 2001–2003 respectively on all muscular dystrophy. Even with the enormous increases Congress has provided to the NIH over the last several years, the muscular dystrophy research portfolio at the NIH is only an 8.55 percent increase for next year. Surely, the public, patients, volunteer health agencies and the Congress envisioned the MD CARE Act as a strong statement to raise the level of muscular dystrophy funding from \$25 million to \$60, \$85, or even \$100 million beginning as early as 2003. The intent was to give the NIH much needed resources to move ahead quickly. We need to look at the present rate of growth and expansion and more importantly beyond the present.

We are very concerned that the enormous scientific progress on FSHD and muscle disease internationally and the unprecedented collaboration between the public and private agencies is not reflected in the budget as presented by the NIH.

Thanks to the Appropriations Committees, the NIH and the FSH Society held a research planning Conference in May 2000. It developed a sound and comprehensive research strategy on FSHD. Now, that plan is about 25 percent completed. We urge the Committee to maintain the momentum which that effort generated and to continue to express your support for the establishment of a broad portfolio of research grants in FSHD.

Mr. Chairman, we trust your judgement on the matter before us. Please remember that we need your help to ensure that the sun is rising on FSHD and all muscular dystrophy.

Mr. Chairman, again, thank you for providing this opportunity to testify before your Subcommittee.

## PUBLIC HEALTH SERVICE

## PREPARED STATEMENT OF THE AMERICAN MEDICAL ASSOCIATION

As you continue the Committee's hearings on the fiscal year 2003 Budget for the Department of Health and Human Services, the American Medical Association (AMA) would like to share its insights on the Administration's fiscal year 2003 Budget Proposal submitted to Congress. As the Committee moves forward in considering the Administration's requests, we hope you will seriously weigh our concerns related to the issues listed below.

User Fees.—Through its budget proposal, the Administration has proposed user fees for physicians who submit claims on behalf of their patients. As background, several years ago, Congress enacted legislation requiring physicians treating Medicare patients to submit these claims to the Medicare program on behalf of their patients. Congress has repeatedly rejected the Administration's attempts to shift such additional Medicare program costs onto physicians through user fees. These user fees are nothing but a tax on the physician community, which is currently facing unprecedented payment cuts from the Medicare program, and we urge you to again reject these fees.

The Administration's budget would tax physicians \$1.50 for each paper claim submission. This has the potential to impact up to 21 percent of all Part B Medicare claims, and along with the tax cited below would impose \$130 million in fees on physicians in fiscal year 2003. This would be an extraordinary cost for physicians to bear simply because their offices have not been linked to an electronic network. This tax is especially unwarranted since many physicians may feel more comfortable submitting hard copies of claims to their carriers given the negative experiences that some physicians have had with their carriers and the issues surrounding confidentiality of patient records. The budget proposal would also penalize physicians by taxing them \$1.50 for each resubmitted claim even when payment was seriously overdue or when the contractor has rejected the claim for trivial or inappropriate reasons. The AMA objects to requiring a physician to pay to resubmit claims to the Medicare program. The AMA strongly urges the Committee to reject these user fees.

Loan Consolidation.—The AMA is adamantly opposed to any proposal that would end fixed-rate consolidation of federal student loans. If implemented, this proposal would prevent thousands of student loan borrowers from consolidating their education loans at significantly lower interest rates.

Physicians enter their residency with an average of \$97,750 in student loan debt. At 4.5 percent (the projected 2002 fixed rate for student loan consolidation), borrowers with a debt of \$106,000, and a standard 10-year repayment period, pay \$1,098 per month or a total of \$131,828 (\$25,828 in interest) over the life of the loan. At a rate of 6.8 percent, (projected variable rate based on Congressional Budget Office projections over the next 10 years) these same borrowers would pay \$1,220 per month or a total of \$146,382 (\$40,382 in interest) over the life of the loan. This increase would be unjustified and would rest squarely on the backs of our nation's students.

The AMA believes that students should be able to avail themselves of the best possible loan terms when seeking to refinance their debt. The high level of educational indebtedness serves as a deterrent for many medical school graduates considering whether to practice medicine in an underserved area, enter the public health service, or start a career in medical education or research. We strongly urge the Committee to reject this proposal as it would effectively raise the interest on education loans for millions of American students.

health service, or start a career in medical education or research. We strongly urge the Committee to reject this proposal as it would effectively raise the interest on education loans for millions of American students. *Limited English Proficiency Requirements*—The previous Administration issued guidance stating that since physicians treating Medicaid patients receive "federal financial assistance," they are required to provide medical interpreters for all of their non-English speaking patients. Since the cost of providing interpreter services usually exceeds the payment made for the physician visit, many physicians may simply opt not to treat the most needy patients because of this requirement. The AMA believes that the Center for Medicare and Medicaid Services (CMS) should instead fund toll-free interpreter services that would be available to patients or physicians needing interpreter services. The AMA believes that action on this item is imperative to ensure that it does not become an economic disincentive for physicians to provide care to non-English speaking patients. *Bioterrorism and Emergency Preparedness.*—The events of September 11th and

Bioterrorism and Emergency Preparedness.—The events of September 11th and the subsequent anthrax attacks have demonstrated that it is imperative for our nation to invest in its public health infrastructure and disaster response system, including an investment in the readiness of our nation's physicians. The AMA has identified the following critical steps to ensure that our health care system is prepared to respond to any future threat. We urge the Committee to recognize the role of organized medicine in:

(1) The adaptation of existing medical education curricula on disaster medicine, the medical response to terrorism, and the development of information resources for civilian physicians and other health care workers. As curricula teaching the medical response to terrorism and other disasters already exist, the need is to adapt curricula to physician audiences and then disseminate to target audiences, as well as to support the costs of continuing medical education (CME) programs. Congress should support this effort by ensuring that organized medicine has adequate funding via federal education and training grants;

(2) The development of model plans for community medical response to disasters, including terrorism, that incorporate physicians into community planning efforts; and

(3) The development of a national communications infrastructure that will address the issues of reliable, timely and adequate sharing of information on dangerous diseases by community physicians to public health authorities. This effort should rely to the largest extent possible on existing systems. Any such system also must take into account the burdens placed on physicians and hospitals in reporting such information.

The appropriate level of funding should also be dedicated to ensuring that increased stockpiles of vaccines and antibiotics are available, that more research occurs, and to support an industrial base to insure the production of new antiviral and antibiotic treatments. The AMA also requests the Committee to give careful consideration to funding mental health services for those affected by terrorism.

Liability for Physician Volunteers.—In 1996, the Congress wisely enacted legislation which promotes free clinics around the country by reducing the professional liability exposure of physicians who volunteer their time and medical skills. The AMA urges the Committee to appropriate the necessary funds for the implementation of Section 194 of the "Health Insurance Portability and Accountability Ac of 1996" (HIPAA) as soon as possible. This Section designates physicians who work in free clinics without receiving reimbursement as federal Public Health Service employees. As such, if a medical malpractice claim arises, the physician's legal defense is as-sumed by the federal government. Without this provision, the enormous increases in malpractice insurance may force physicians to stop volunteering at these free clinics, many of which are in areas with physician shortages.

The AMA believes that it is especially important to encourage physician vol-unteerism in free clinics and in other critical need areas, and we hope the Com-mittee will appropriate the funds authorized under Section 194 of HIPAA, which are necessary to implement this important program and promote free clinics. HIPAA Educational Efforts.—Beginning in October of 2002, physicians and other

covered entities will be required to make major changes to their administrative sys-tems to accommodate the provisions of the privacy portion of HIPAA and the trans-action and code set standards established as a result of HIPAA. Significant edu-cational efforts will be necessary to ensure effective implementation of the new standards. The AMA believes that the Department should devote an appropriate level of resources (the level spent on Y2K educational efforts may be a suitable guide) to ensure that the health care community properly submits and receives payments based on the new HIPAA rules.

Title VII/Title VIII Funding for Physician Training.—Through loans, loan guar-antees, and scholarships to students, and grants and contracts to academic institu-tions and non-profit organizations, Title VII and VIII health professions programs are designed to:

- -meet the nation's needs to increase the supply of primary medical and dental care providers, public health and allied health professionals, and nurses; -educate and train more health professionals in fields experiencing shortages, such as the current shortages in nursing, pharmacy, dentistry, public health, and allied health:

-improve the geographic distribution of health professionals and nurses; -increase access to health care for underserved populations; and -enhance minority representation in the practicing health professional workforce. The AMA strongly urges the Committee to retain or increase fiscal year 2002 lev-els for the Title VII and Title VIII programs. The Administration's budget proposal would zero out funding for the Primary Care Medicine and Dentistry Program and would cut the Health Professions Program by 75 percent (from \$378 million to a total of \$94 million). Title VII is the only federal program designed to increase the number of primary care physicians and to increase the number of individuals providing health care to underserved populations. In fact, a study by the Robert Graham Center for Policy Studies shows that medical schools receiving Title VII funds produced higher numbers of students that metrical schools receiving fine vin funds produced higher numbers of students that practiced family medicine or pri-mary care, practiced in rural areas, or practiced in a whole county primary care health professions shortage area. We urge the Committee to act to ensure continued funding of the Title VII and Title VIII programs.

Pilot Testing New Evaluation and Management (E&M) Procedure Codes.—Pay-ments for E&M codes represent approximately one-third of all payments made to ments for E&M codes represent approximately one-third of all payments made to the physician community. A private sector workgroup has been working with CMS to refine these codes. However, it will be necessary to pilot test any new documenta-tion guidelines prior to national implementation. We urge the Committee to provide CMS with specific funding to pilot test any new E&M documentation guidelines. *National Health Service Corps.*—The AMA has been a long time supporter of the National Health Service Corps (NHSC), a program that recruits and retains primary care physicians and other healthcare providers into underserved rural areas within

care physicians and other healthcare providers into underserved rural areas within our great nation. The AMA is extremely committed to the continuation of the NHSC and its objectives.

The NHSC recruits, prepares, and supports dedicated students and clinicians through a variety of programs and services. In fact, more than 2,300 NHSC clinicians provide primary and preventive health care to some 3.6 million people in rural and urban communities. The goal is not only to recruit physicians and health care professionals to remote areas, but to retain them in these areas. To date, more than 50 percent of physicians and health care providers remain in underserved areas.

The AMA strongly supports the Administration's request for a 32 percent increase in the fiscal year 2003 NHSC budget. This funding level is extremely important to the millions of individuals who will be well served through the NHSC's preservation and growth.

Agency for Healthcare Research and Quality (AHRQ)-The AMA is very concerned about the Administration's proposal to decrease AHRQ funding by \$48 million or 16 percent of its fiscal year 2002 budget. AHRQ has played a vital role in improving patient safety and reducing medical errors, providing health care access for persons with chronic disorders, and reducing health care costs. The AMA believes that the agency's work is extremely valuable to both patients and to the health care system on a larger scale.

The proposed budget would result in AHRQ not being able to undertake any new projects and would mean that non-patient safety research spending would be reduced by 50 percent. This reduction in research would significantly reduce the knowledge and understanding of how to provide cost-effective quality health care. We strongly urge the Committee to restore the AHRQ budget to its fiscal year 2002 level to ensure the continuation of its essential work.

Office on Smoking and Health (Centers for Disease Control and Prevention (CDC)).—The AMA strongly encourages the Committee to increase CDC funding from its fiscal year 2002 level to ensure that it has an appropriate level of funds to conduct its tobacco work. The CDC would use additional funding to expand the scope of its current activities to study the effects of exposure to environmental tobacco smoke (ETS) and to educate the public about the benefits of reducing ETS exposure. Additional funds would be used by CDC to learn more about ETS, educate the public about exposure to ETS, and evaluate which programs work to reduce ETS exposure. Additional funds would be used to research cessation techniques, establish a "tobacco quitline," and to evaluate and expand tobacco cessation programs. We strongly urge the Committee to increase CDC funding to ensure the expansion of these programs.

Medicare Contractor Reform Impact Analysis.—In December, the House of Representatives passed H.R. 3391, the "Medicare Regulatory and Contracting Reform Act of 2001" which could significantly alter the number of Medicare carriers and intermediaries and how they pay, review, and serve physicians and providers of care. The AMA strongly supports this legislation, and we believe that the CMS should conduct an impact analysis prior to changing the number and responsibilities of Medicare contractors. This analysis would aid in avoiding unnecessary disruptions in the way the program is administered.

In addition, we urge the Committee to ensure that local carrier advisory committees (CACs) continue to function in each state to ensure that local medical review policy reflects the consensus of the local physician community. All changes in local medical review policy (whether through a change in contractor or through the consolidation of existing contractors) should be subjected to the normal review and comment process with the local CAC. This would prevent a new contractor from simply transporting a new policy from one geographic region to another without subjecting that policy to CAC review in the new geographic area. *Immunization Activities.*—The AMA supports the CDC's efforts to expand the na-

Immunization Activities.—The AMA supports the CDC's efforts to expand the nation's immunization system. The CDC provides technical assistance, training, and education for health care practitioners providing vaccines. Among its many immunization activities, the Center also provides grants to all fifty states, six cities, and eight current or former territories to reduce the instances of disability and death from vaccine-preventable diseases.

The AMA believes that vaccines are one of the best methods of protecting children and the general population from vaccine-preventable diseases. It is inexcusable that 1 million 2-year olds in the United States have not received all of the recommended vaccinations. In the adult population, more than 38,000 adults die annually from complications associated with hepatitis B, influenza, and pneumococcal infections despite the availability of vaccines.

despite the availability of vaccines. We urge you to ensure that CDC receives increased funding to safeguard its current program activities and to expand its functions so as to guarantee that an everdiminishing proportion of our population falls victim to these devastating diseases. Antimicrobial Resistance.—The appearance of numerous bacterial and viral spe-

Antimicrobial Resistance.—The appearance of numerous bacterial and viral species resistant to the very treatments that, in the past, effectively cured patients, has left physicians with a decreased number of options in the battle against diseases caused by organisms such as salmonella, staphylococcus, streptococcus, and HIV. The AMA has had a longstanding interest in the problem of antimicrobial resistance and supported the Public Health Action Plan to Combat Antimicrobial Resistance, which coordinated the different federal agencies' efforts to combat this important public health problem.

The AMA believes that antimicrobial resistance can only be solved through coordinated, cooperative efforts involving both public and private sectors. This activity must receive appropriate funding for the Food and Drug Administration (FDA) and the CDC to execute its action items under the Action Plan. There is very strong support among the medical and public health communities for efforts to combat antimicrobial resistance, and we urge you to support CDC funding levels and to ensure that such activities occur.

We appreciate the opportunity to submit this statement to the Committee, and we look forward to working with the Committee as this process moves forward. Please feel free to contact our Washington DC office with any questions you may regarding these or other matters.

# PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR MICROBIOLOGY

The American Society for Microbiology (ASM), representing over 40,000 members in the microbiological sciences, supports the recommendation of the Centers for Disease Control and Prevention (CDC) Coalition to fund the CDC at a level of \$7.9 billion in fiscal year 2003. The Coalition's budget proposal will strengthen CDC's programs in infectious disease, surveillance, control and prevention, will help to rebuild the nation's public health system, and will improve the role of public health in national security.

The CDC plays a critical role in reducing death, illness and disability, both in the United States and globally. Increased funding for the CDC is warranted in fiscal year 2003 to sustain and expand the CDC's ability to respond promptly and effectively to outbreaks of new and emerging diseases, public health threats, national preparedness for a potential bioterrorism attack, and a growing international presence in combating infectious diseases. New resources are critical to ensure that CDC has a well trained, well staffed, fully prepared public health work force; expanded laboratory capacity to produce timely and accurate results for diagnosis and investigation; strengthened epidemiology and surveillance to enable rapid detection of health threats; and improved information systems to communicate, analyze and interpret health data and to provide timely and accurate public access to health information.

The United States and other countries face increasing threats and challenges from infectious diseases. Infectious diseases persist as the third leading cause of death in the United States. Worldwide they cause 25 to 30 percent of the more than 50 million deaths each year. Chronic diseases are linked increasingly to infectious agents, including more than 30 microbes to date. The cost to both human health and economic resources continues to spiral upward. Infectious disease problems around the world are inextricably linked because an infectious microbe that emerges in any part of the world has the potential to spread across borders, especially because of increased international travel and trade. The CDC has an increasing role to play in responding to new, highly dangerous, drug-resistant or reemerging diseases have been identified since 1973. Disease outbreaks endanger U.S. citizens at home and abroad, threaten U.S. armed forces and exacerbate political instability in nations. CDC must also respond to established diseases, such as HIV/AIDS, tuberculosis, and malaria, which continue to cause high morbidity and mortality.

The threat of the use of biological weapons is increasing. The CDC's role in national bioterrorism response and preparedness was tested in its response to the tragedy of September 11, 2001, and the bioterror event caused by anthrax mailed through the postal system. Public health workers from CDC, including microbiologists, epidemiologists, and others responded with immense dedication, skill and sacrifice to addressing a complex, difficult and unprecedented situation involving epidemiologic and forensic investigation and a high level of public concern. Adequate resources will be needed for CDC to further define, develop and implement public health capacities at local, state and federal levels to prepare for, respond to and recover from a deliberate disease attack on U.S. citizens.

#### RESPONDING TO INFECTIOUS DISEASES AND EMERGING INFECTIOUS DISEASES

The ASM recommends that \$260 million be allocated in fiscal year 2003 to implement fully the high priority CDC strategic plan to prevent emerging infectious diseases, which is currently funded at a level of \$164 million. In 1994, the CDC launched the first phase of a nationwide program to revitalize the national capacity to protect the public from infectious diseases. The second phase of CDC's effort was released in 1998, with the publication of the strategy for "Preventing Emerging Infectious Diseases: A Strategy for the 21st Century." In March, 2002, CDC announced its new Global Infectious Disease Strategy, which includes specific items to address the need for a more international strategy to control infectious diseases. Additional resources will be needed for the implementation of the proposed activities. CDC's efforts to prevent and control emerging diseases support a multi-layered, interconnected approach of disease surveillance, epidemic investigations, scientific research and training, and public education. Recently the CDC established seven domestic and global surveillance networks to detect and monitor various emerging diseases, provided epidemiologists to advise the global antimalaria campaign, and deployed specialists to nations now faced with outbreaks of Ebola hemorrhagic fever, hantavirus pulmonary syndrome, and other emerging viral diseases. The agency predicts that an influenza pandemic could kill between 90,000 and 210,000 people just in the United States, and that of all emerging infections, influenza could be the most serious threat to public health. In response, the CDC conducts domestic and worldwide surveillance of the disease, in collaboration with the World Health Organization, to facilitate early detection and response to influenza.

Just in the United States, and that of all emerging infections, influenza could be the most serious threat to public health. In response, the CDC conducts domestic and worldwide surveillance of the disease, in collaboration with the World Health Organization, to facilitate early detection and response to influenza. About 75 percent of CDC funding reaches state and local health departments to collect information and to implement health programs. More than 3,000 county, city, and tribal health departments and 59 state and territorial health departments, receive funding through the CDC. CDC has significantly expanded state capabilities to monitor new pathogens like hepatitis C virus and West Nile virus. In the United States, food borne diseases affect an estimated 76 million victims each year and cause up to 5,000 deaths. The CDC last year provided training to all state health departments in DNA fingerprinting of bacteria causing food borne illnesses, especially *E. coli* O157:H7, *Salmonella typhimurium*, and *Listeria monocytogenes*, part of the PulseNet network that quickly recognizes food borne outbreaks throughout the nation.

## ANTIMICROBIAL RESISTANCE

The ASM recommends \$25 million in new funding in fiscal year 2003 for CDC to implement the interagency Public Health Action Plan to Combat Antimicrobial Resistance, which was released in 2001. The CDC has joined with the FDA and the NIH to lead a new national effort against antimicrobial resistance. Antimicrobial resistance is increasing and the emergence of antimicrobial resistance among just six common bacteria adds about \$660 million annually to U.S. hospitalization costs. The CDC has established clinical guidelines for health professionals on improved antimicrobial use and initiated state-level surveillance systems to track this growing problem. New activities proposed in the Action Plan to increase antimicrobial surveillance, prevention and control and extramural research to expand the peerreviewed applied research program depend on an infusion of new funding.

## GUARDING AGAINST BIOTERRORISM, BUILDING NATIONAL SECURITY

The ASM endorses the fiscal year 2003 proposed \$1.6 billion for the CDC's Bioterrorism Preparedness and Response Program. The proposed budget includes: \$940 million to upgrade state and local capacity, including training, laboratory, surveillance and epidemiological capacity, and communication and information systems; \$300 million to enhance the National Pharmaceutical Stockpile; \$100 million for efforts to counter the effects of smallpox; \$18 million for anthrax research and evaluation; \$120 million for biosecurity improvements and facilities; and \$159 million to upgrade CDC's emergency response and preparedness efforts, including increasing biological and chemical laboratory capacity, rapid response teams, Epidemic Intelligence Service officers and the Emerging Infectious Diseases Laboratory Fellowship Program.

The deliberate release of pathogenic microorganisms is no longer a hypothetical possibility, but a potent and grim reality. The CDC already had begun extensive bioterrorism-related research and planning before the anthrax release last fall, including expansion of vaccine and pharmaceutical stockpiles and research to develop better diagnostics and treatments for suspect pathogens. The CDC also categorized lists of possible bioterrorism agents based on their potential lethality, to better advise local health authorities and focus federal resources. Following the attacks, CDC responded by initiating a 24-hour Emergency Operations Center, activated nation wide information networks for health officials, and deployed an unprecedented number of Epidemic Intelligence Service officers and other staff to New York City and elsewhere. The ASM applauds the rapid and effective reaction by the CDC to these horrendous events, but remains concerned about deficiencies identified by the CDC within the public health system.

The fiscal year 2003 budget request will assist with efforts to repair weaknesses in public health programs. The nation's ability to respond to a bioterrorist attack, which unlike an explosive or chemical attack can unfold gradually and silently, depends on the preparedness of its public health infrastructure and medical care systems. The number of deaths and serious illnesses in a bioterrorist attack is directly related to the speed and accuracy with which doctors and laboratories can correctly diagnose and report their findings to public health authorities. Programs are needed to specifically train medical and laboratory personnel. There is also a shortage of laboratories with the capability to identify biothreat agents. With new resources, the CDC will be able to expand its comprehensive and coordinated emergency planning and training program, in support of all states and certain cities that could become bioterrorism targets. This program includes the Centers for Public Health Preparedness based in schools of public health, integration of the CDC's high-tech Epidemic Information Exchange network into state and local surveillance plans, the National Laboratory System, the Laboratory Response Network, and dozens of other specific and science-based efforts to prepare all health agencies for possible bioterrorist at-tack.

The ASM urges the Congress to recognize that efforts to protect the nation against bioterrorism must function within a federal agency that also is strong in all other aspects critical to public health. The high consequence implications of bioterrorism place it in a special category that requires immediate and comprehensive response. At the same time, naturally occurring infectious diseases caused by emerging pathogens seriously threaten the health and security of the United States and other countries on an existing and continuing basis. Building the health infrastructure to respond to bioterrorism should also increase our ability to respond to naturally occurring and reemerging infections

# TRACKING POTENTIALLY DANGEROUS BIOLOGICAL AGENTS

Congress mandated CDC to implement and enforce regulations for monitoring the acquisition and transfer of biological agents within the United States under authority of the Antiterrorism and Effective Death Penalty Act of 1996. Section 511 of the Act, Regulatory Control of Biological Agents, is intended to protect the safety of the public while not imposing undue restrictions on scientific research needed to develop new therapeutics for deadly pathogens.

The ASM has recommended that the CDC be provided adequate resources for implementation of the select agent rule. Congress is presently considering legislation that will expand the mandate to track the acquisition, transfer and possession of select agents and to now register laboratories which possess select agents. The new regulations include safeguard and security requirements, the collection of information for law enforcement and a process for alerting authorities about unauthorized attempts to acquire select agents. The ASM recommends that Congress determine the resources that will be needed for implementation of an expanded select agent program and provide the necessary new funding to ensure proper administration of the program.

## IMPROVING BUILDINGS AND FACILITIES

The ASM recommends that Congress appropriate \$250 million for CDC buildings and facilities in fiscal year 2003, an amount equal to the fiscal year 2002 funding. Current research and management facilities used by the CDC are very inadequate. Some agency personnel experiment with pathogenic microorganisms in laboratories constructed as temporary facilities almost 60 years ago. Other structures are neither entirely efficient nor completely secure. Modern demands on CDC infrastructure grow more urgent and complex, and the agency must be supported in its long-range plans for updating old laboratories and constructing new buildings. It is critical that CDC research and management activities be consolidated into up-to-date and physically secure facilities, and that certain projects proceed quickly—such as completion of the new Infectious Disease Laboratory, the Scientific Communication Center, the Environmental Toxicology Laboratory and a replacement for the aging vector-borne infectious disease laboratory in Fort Collins, Colorado, where researchers study plague bacteria, West Nile virus, and other deadly pathogens.

## PREPARED STATEMENT OF THE PULMONARY HYPERTENSION ASSOCIATION

## INTRODUCTION

Thank you for the opportunity to submit written testimony regarding fiscal year 2003 appropriations for the Centers for Disease Control (CDC), National Institutes of Health (NIH), and Health Resources and Services Agency (HRSA).

I am Jack Stibbs, Administrative Vice President for Advocacy with the Pulmonary Hypertension Association (PHA). I became active in PHA when my daughter Emily was diagnosed with pulmonary hypertension (PH).

PH is a rare disorder of the lung in which the pressure in the pulmonary artery (the blood vessel that leads from the heart to the lungs) and the hundreds of tiny blood vessels that branch off from it rises above normal levels and may become life threatening. Symptoms of pulmonary hypertension include shortness of breath with minimal exertion, fatigue, chest pain, dizzy spells and fainting. When PH occurs in the absence of a known cause, it is referred to as primary pulmonary hypertension (PPH). This term should not be construed to mean that because it has a single name it is a single disease. There are likely many unknown causes of PPH.

Secondary pulmonary hypertension (SPH) means the cause of the disease is known. Common causes of SPH are the breathing disorders emphysema and bronchitis. Other less frequent causes are scleroderma, CREST syndrome and systemic lupus. In addition, the use of diet drugs can lead to the disease.

Unfortunately, PH is frequently mis-diagnosed and often progresses to late stage by the time it is detected. Although PH is chronic and incurable with a poor survival rate, new treatments are providing a significantly improved quality of life for patients. Recent data indicates that the length of survival is continuing to improve, with some patients able to manage the disorder for 20 years or longer.

Ten years ago, when three patients who were searching to end their own isolation founded this organization, there were less than 50 diagnosed cases of this disease. It was virtually unknown among the general population and not well known in the medical community. They soon realized that this was not enough and as membership began to grow-driven by a newsletter distributed by doctors-and a community began to form, an 800 number support line was launched, support groups were established, a Scientific Advisory Board (SAB) was formed, a Patient's Guide to Pulmonary Hypertension was written, and a web site was launched.

Today, PHA includes:

- Over 3,600 patients, family members, and medical professional
- An international network of over 50 support groups
- -An active and growing patient hotline
- A new and fast-growing research fund (A cooperative agreement has been signed with the National Heart, Lung, and Blood Institute to jointly create and fund five, 5-year, mentored clinical research grants and PHA awarded it's first four Young Researcher Grants.)
- -A host of numerous electronic and print publications

# **RECOMMENDATIONS FOR FISCAL YEAR 2003**

# PH awareness at the Centers for Disease Control and Prevention

PHA applauds the subcommittee for its leadership in encouraging CDC to initiate a professional and public awareness campaign focused on PH. Currently, we are working with the CDC to establish this important program that will better inform health care professionals and the general public about PH, its symptoms, and treatment options. The following is a description of the specific initiatives we hope to launch in collaboration with the CDC.

## Awareness among primary care providers

Increasing awareness and understanding of PH among primary care physicians is critically important, because these practitioners are usually the first point of contact for PH patients. If the primary care doctor misses the symptoms, then the chance for early diagnosis depends upon the intuition and persistence of the patient. They have a chance, if they aggressively pursue diagnosis by trained and aware spe-cialists. If they are not aggressive, or if they are in a health plan that requires their general practitioner to prescribe the referral, they are more likely to go undiagnosed until it is too late to control their illness. To increases awareness among primary care physicians we hope to collaborate with the CDC on the following: —Written and video diagnostic tools for placement on the Internet.

- -A postcard mailing to be sent to all primary care physicians, medical schools and medical centers in the United States drawing attention to the new web resources
- A simplified and visually attractive version of the proper diagnostic procedures which will be sent in a second mailing to all primary care physicians, medical schools, and medical centers in the United States.
- -Advertising in publications general practitioners are likely to read. The empha-sis will be the urgency and ease of early diagnosis and the ease of accessing diagnostic tools via the Internet.
- A CD–ROM that explains pulmonary hypertension from a variety of angles. We would like to make 100,000 of these available to the medical community and

patients through our web site on an as requested basis and at conferences and through targeted mailings.

## Awareness among specialists

Due to the advancements in treatment for PH, it is important that we also focus on educating cardiologists and pulmonologists. Our strategies for reaching cardiovascular specialists include:

- Publication of the first Pulmonary Hypertension Journal focused on educating a wider population of doctors on issues related to the diagnosis and treatment of the illness
- -Placement of additional detailed information on the illness on the web. The PH Journal and other publications will promote this availability.
- Expansion of PHA's international conference on pulmonary hypertension (the largest PH conference in the world).
- Expansion of PHA's Pulmonary Hypertension Resource Network. This program is focused on increasing awareness of PH among nurses through peer education.

# Awareness among the general public

Finally, PHA is committed to increasing PH awareness among the general public through the development of the following initiatives: —A series of 10, 15, and 30 second public service announcements on PH. These

PSAs will be in both audio and video form. –A PH media relations manual.

An organ donation Awareness Campaign (unfortunately, many PH patients die before finding a suitable organ donor). Expansion of PHA's web site.

We look forward to working with CDC to launch these initiatives aimed at increasing awareness of PH throughout the United States. For fiscal year 2003, we encourage the subcommittee to provide \$1 million within CDC's Cardiovascular Dis-ease program (a division of CDC's Center for Chronic Disease and Health Promotion) for this important initiative

## PH research at the National Heart, Lung and Blood Institute

Mr. Chairman, PHA commends the leadership of the National Heart, Lung and Blood Institute (NHLBI) for its support of PH research. Two years ago, two separate groups of scientists funded by NHLBI simultaneously identified a genetic mutation associated with primary pulmonary hypertension.

The two groups independently reported that defects in the BMPR2 gene, which regulates growth and development of the lung, are associated with PPH. The defects in the gene lead to the abnormal proliferation of cells in the lung characteristic on PPH

Although both studies suggest that only one gene is involved in PPH, neither group identified the defects in BMPR2 as the sole cause of PPH. In addition, since many people without a known family history of PPH get the disease, both groups suggested that other factors may interfere with control of the tissue growth. Now that we have pinpointed a gene, we can focus on learning how it works. Hopefully, that information will enable researchers to devise better treatments and perhaps eventually a preventive therapy or cure. Mr. Chairman, we would like to thank the subcommittee for the inclusion of im-

where the inclusion of the subcommittee for the inclusion of in-portant committee recommendations on PH research at NHLBI in the fiscal year 2002 Senate Labor-HHS report. For fiscal year 2003, PHA joins with the Ad Hoc Group for Medical Research Funding in supporting a 16 percent increase for NHLBI and NIH overall. Finally, we request that the subcommittee provide \$25 million in for PH research at NHLBI to enhance basic research, gene therapy and clinical trials of promising new therapies.

## Organ donation at the Health Resources and Services Administration

Mr. Chairman, one of the difficult realities that PH patients have to live with is the knowledge that one day they may need a heart or a lung transplant. As you know, there is a critical shortage of organ donors in the United States, and consequently many end-stage PH patients run out of time while waiting for a transplant. PHA has vowed to do to something about this unnacceptable situation through its "Bonnie's Gift" program.

"Bonnie's Gift" was started in memory of Bonnie Dukart, one of the three found-ing members of PHA. Bonnie battled with PH for almost 20 years until her death in 2001 following a double lung transplant. Prior to her untimely death, Bonnie expressed a strong interest in the development of a program within PHA related to organ donation and transplantation. PHA will use "Bonnie's Gift" as a vehicle to disseminate information about the importance of organ donation in our community,

and the importance of early listing on transplant waiting lists by PH patients. PHA applauds the Department of Health and Human Services for its "Gift of Life Donation Initiative." This important program within the Health Resources and Services Administration (HRSA) is designed to increase organ donation rates throughout the country. Last year, PHA entered into a partnership with HRSA's Division of Transplantation (Public and Professional Education Branch) to promote the goals of the Gift of Life program as well as the unique donation and transplantation challenges facing the PH community. We look forward to expanding this successful collaboration this year and would welcome the support of the subcommittee. For fiscal year 2003, PHA encourages the subcommittee to provide \$30 million (an increase of \$10 million over fiscal year 2002) for the "Gift of Life Donation Initiative" at HRSA.

Mr. Chairman, once again thank you for the opportunity to present the views of the Pulmonary Hypertension Association. I would be pleased to respond to any questions that you may have.

## PREPARED STATEMENT OF THE AMERICAN SOCIAL HEALTH ASSOCIATION

The American Social Health Association requests an fiscal year 2003 funding level of 247.4 million, an increase of \$80 million, for the STD prevention, treatment and surveillance programs of the Centers for Disease Control and Prevention. These funds will significantly enhance the CDC's ability to reduce STD rates across the country. Funds are sought to improve services in the following areas:

## [In millions of dollars]

Infertility prevention	41.5
Syphilis elimination	13.0
STD treatment to enhance HIV prevention	5.5
Herpes and human papillomavirus prevention	9.5
Prevention among adolescents	7.5
Clinical services	3.0

For more than 85 years, the American Social Health Association has sought to eliminate sexually transmitted diseases (STDs) and their harmful effects on individuals, communities, and families. ASHA greatly appreciates the leadership this Com-mittee has shown by consistently providing increased resources to our nation's STD prevention efforts. We urge the Committee to continue to provide critically needed resources to prevent STDs. Protecting our nation from the devastating consequences of STDs has been a bipartisan commitment that we hope will continue with this Committee.

ASHA appreciates this opportunity to provide the Subcommittee with information about the health crisis caused by the skyrocketing rates of STDs in America and about the programs of the Centers for Disease Control and Prevention (CDC) that combat these diseases.

combat these diseases. Every year, approximately 15.3 million Americans contract a sexually transmitted disease (STD). The United States has the highest STD rate in the industrialized world. In 1 year, our nation spends over \$8.4 billion to treat the symptoms and con-sequences of STDs. Women and adolescents are disproportionately affected by the long-term consequences of STDs. By age 24, at least one in three sexually active people will have contracted an STD and approximately 1 million women will have a severe case of pelvic inflammatory disease due to STDs. Hundreds of babies will be born with congenital syphilis, which leads to physical deformities, mental retar-dation and death dation and death.

We will be able to significantly reduce both health care costs and illness, particu-larly among adolescents and women, if the STD epidemic is addressed NOW.

In the past 5 years, the CDC has developed innovative programs that have signifi-cantly reduced STD rates and the associated costs to society. However, without ad-ditional funds, the CDC can not establish these programs in all 50 states.

Following are the recommendations of the American Social Health Association: Infertility Prevention Program.—Currently, this highly successful prevention program of screening for chlamydia has been differentially implemented in the states. Thirty states have screening coverage for less than 20 percent of the women at risk and 20 of the states cover 45-50 percent of at risk women. These differentials affect primarily women who are marginalized and African American. Where it has been established, the program has reduced chlamydia rates by 66 percent and decreased treatment costs by over 80 percent. The ASHA recommends a \$41.5 million increase to expand the Infertility Prevention program and provide parity for chlamydia screening at 50 percent of at risk women across the states.

- -Syphilis Elimination.-Prevention efforts have eliminated syphilis from 73 percent of U.S. counties. Since 1998, the CDC has implemented enhanced community-based prevention efforts to eliminate syphilis from all areas of the country. ASHA recommends a \$13 million increase to expand the Syphilis Elimination program, which will focus on regions with epidemic rates of syphilis. Syphilis historically has peaked in 10-year cycles, with the last peak occurring in 1990. We have a window of opportunity to eliminate the disease from these areas and we need to act now, before another upsurge of the disease.
- —STD Treatment to Enhance HIV Prevention.—Research has shown that individuals infected with an STD are as much as 500 percent more likely to acquire HIV infection during a single encounter. In addition, states with high syphilis rates have higher HIV infection rates among young women. The ASHA recommends a \$5.5 million increase to provide STD screening and treatment in HIV clinics and to build connections with community based organizations that serve populations at risk.
- -Human Papillomavirus and Herpes—the Viral STDs.—In a recent study, over 50 percent of college-age women screened were infected with human papillomavirus, an infection that can lead to cervical cancer without appropriate screening and follow-up treatment. Over 45 million Americans are infected with the herpes virus. Because there is not a cure for these diseases, the CDC must expand relevant education and prevention activities. ASHA recommends a \$3 million increase to develop demonstration projects, applied research, and educational messages for viral STD infections.
- —*Prevention Related to Adolescents.*—For numerous reasons, ranging from biological to behavioral, adolescents are at high risk of STDs. ASHA recommends \$7.5 million increase to enhance or expand integrated multi-level intervention trails for STD approaches among adolescents, including programs involving families, schools, media and faith communities.
- --Clinic Services.--STD clinics all over the country have been forced to shorten treatment hours and some have even closed their doors. It is critical that state level communications, surveillance and evaluation programs---our nation's STD infrastructure---strong. ASHA recommends a \$3 million increase to provide support to the state STD programs so that core STD treatment and prevention activities can be strengthened and services expanded in managed care settings.

Effective STD screening, diagnostic, and prevention programs will benefit the health and well being of all Americans, particularly women, adolescents and children. The ASHA urges the Committee to make a significant investment in STD prevention to reduce the transmission of HIV, to save over \$8 billion per year in direct health care costs, and to reduce the occurrence of infertility, ectopic pregnancy, cervical cancer, and pelvic inflammatory disease.

ASHA would appreciate an opportunity to discuss these recommendations and other issues related to STD prevention, research, and treatment. To discuss these issues, please contact: Deborah McNeal Arrindell, Senior Director of Health Policy, American Social Health Association, 1275 K Street, NW Suite 1000, Washington, DC 20005.

## PREPARED STATEMENT OF RESEARCH TO PREVENTION

Research To Prevention is a national coalition committed to improving the nation's health through prevention. It is comprised of the nation's premier voluntary health organizations, including: American Cancer Society, American Diabetes Association, American Heart Association, Arthritis Foundation, Association of State and Territorial Chronic Disease Program Directors, Epilepsy Foundation and the National Health Council. Our entire membership list is included in this testimony.

The mission of Research to Prevention is to make prevention and control of chronic diseases and disability a national policy and funding priority by educating policymakers and advocating for vital funding increases for comprehensive public health programs that address the nation's leading causes of death and disability. Research to Prevention is seeking a \$350 million increase in funding in fiscal year 2003 for chronic disease prevention and control programs at the Centers for Disease Control and Prevention (CDC). We are also supporting a \$75 million increase in the Preventive Health and Health Services Block Grant and a \$12 million increase in the Racial and Ethnic Approaches to Community Health (REACH) initiative. Our total request for increases in funding for chronic disease programming is \$436 million increase above fiscal year 2002, which is included in a chart in this testimony. The leading causes of death have changed markedly over the last century. In

The leading causes of death have changed markedly over the last century. In 1900, the leading causes of death were infectious diseases and were responsible for one-third of all deaths. In 2000, the leading killers and causes of disability are chronic diseases—diseases such as arthritis, cancer, diabetes, epilepsy, heart disease and stroke. Chronic diseases are responsible for more than 70 percent of all deaths and more than 70 percent of all health care expenditures in the United States. Recent studies by Johns Hopkins University and the Robert Wood Johnson Foundation tell us that 125 million Americans live with some form of chronic disease, the most costly and preventable of all health problems. Chronic diseases impact almost every American family and these families confront the death of a loved one, long-term illness and disability, and, in many cases, the heavy economic costs of these conditions.

Chronic diseases are among the most prevalent, costly, and preventable of all health problems. Yet as a nation we invest only \$1.25 per person annually attempting to prevent the number one killers and the states lack the money to combat these leading causes of death. Chronic diseases and conditions account for more 70 percent of the \$1 trillion spent on health care year in the United States. One-third, or approximately \$300 billion, of the Nation's health care budget is spent on older Americans who often have preventable or controllable chronic diseases and conditions. Much of the disability in old age can be delayed or prevented altogether, potentially improving quality of life and saving the Nation billions of dollars in health care expenditures and the costs of long-term care.

Some of the leading chronic diseases, namely heart disease, cancer, stroke, diabetes and arthritis cost the Nation more than \$500 billion in health care expenditures and lost productivity. Without immediate prevention strategies, including nutrition and physical activity interventions, we can expect a rapid proliferation in chronic diseases associated with obesity. The total costs of obesity in the United States in 1995 was estimated to be nearly \$100 billion. Similarly, tobacco costs the Nation more than \$100 billion in direct and indirect medical expenses. Each year, nearly 3,000 young people across our country will begin smoking regularly. One in three of these young people will lose their life prematurely to diseases caused by smoking. By the year 2020, chronic disease expenditures will reach \$1 TRILLION, or 80 percent of health care costs.

To curb the excessive burden of chronic diseases, both in human and economic terms, the Nation must ensure that research advances are applied, evaluated and implemented at the state and local level with comprehensive, sustainable prevention programs. As the nation's leading prevention agency, CDC plays an important role in translating and delivering at the community level what is learned from research—especially ensuring that those populations disproportionately affected by chronic disease and disabilities receive the benefits of our nation's investment in medical research. Key elements of these programs include surveillance, public and provider education, communications campaigns, early detection and screening as appropriate, and prevention research.

In addition to prevention programs that address heart disease, cancer, stroke, diabetes and arthritis, a better understanding and substantial investment in other serious chronic diseases is needed. Such diseases include, but are in no way limited to, oral diseases, chronic lung and other respiratory diseases (e.g., asthma), chronic neurological disorders (e.g., epilepsy, multiple sclerosis, Alzheimer's and Parkinson's disease) and musculoskeletal diseases other than arthritis (e.g., osteoporosis). Additional, effective interventions need to be developed and implemented to reduce diseases and conditions with disabling consequences that include blindness, kidney failure, paralysis, fractures, joint deterioration and limb loss.

- While states have minimal funding to attack several of these conditions, to date: —Only 6 states receive comprehensive funding for programs to prevent and control heart disease, stroke and other cardiovascular diseases, the leading killer
- of Americans.
- -Only 16 states have comprehensive diabetes programs.
- -No state has a comprehensive arthritis program.
- -While only 12 states have core grants for planning, no state has a comprehensive physical activity and nutrition program to prevent chronic disease.
- -While only 12 states have core grants to target preventing tooth decay among children, no state has a comprehensive program to prevent oral cancer, periodontal disease and permanent tooth loss among adults.
- -No state has a comprehensive colorectal cancer program.
- -No state has a comprehensive cancer registry.
- -No state has a comprehensive school health program to address chronic disease.

Our nation has benefited immensely from our past investment in biomedical re-search at the National Institutes of Health (NIH). Research to Prevention's mem-bers have actively supported and participated in the NIH doubling effort. As a nation, we must ensure that the full promise of our research discoveries is realized by translating these discoveries into practical medicine and public health solutions and interventions for everyone. The member organizations of Research to Preven-tion are committed to ensuring that the comprehensive public health programs that address the nation's leading causes of death and disability receive the vital funding increases needed to lower the burden of these diseases and conditions on our families and loved ones.

Last year, two health reports were released that documented successful preven-tion studies and provided conclusive evidence of the need to translate important re-search findings into prevention strategies. The first study, on diabetes risk, outlined search maings into prevention strategies. The first study, on diabetes risk, outlined findings from the first major clinical trial confirming that at least 10 million Ameri-cans who are at high risk for type 2 diabetes can sharply lower their chances of getting the disease with diet and exercise. The findings of this multi-year clinical trial, referred to as the "Diabetes Prevention Program", were so definitive and im-portant to the health of the American public that the trial was ended a year early in an effort to rapidly deliver the news that lifestyle interventions can significantly reduce the onset of type 2 diabetes. The study showed a greater headfield effort reduce the onset of type 2 diabetes. The study showed a greater beneficial effect from a diet-and-exercise regimen than from use of drug therapy. Department of Health and Human Services Secretary Thompson stated in a NIH news release, "In view of the rapidly rising rates of obesity and diabetes in America, this good news couldn't come at a better time. So many of our health problems can be avoided through diet, exercise and making sure we take care of ourselves. By promoting healthy lifestyles, we can improve the quality of life for all Americans, and reduce health care costs dramatically.

Results from the second study, "A Randomized Trial of Physical Activity Counseling in Primary Care for Inactive Adult Patients: Results for the Activity Counseling Trial," found that brief counseling by health professionals can improve sed-entary adults' physical fitness. Lack of physical activity is a major risk factor for many chronic diseases. With increased federal support, these strategies can be implemented to improve America's public health and reduce the burden of these chronic diseases.

With a \$350 million increase in chronic disease prevention and control funding at the CDC, we will be ensuring that out biomedical investments have paid off. This increase will allow CDC to enhance its efforts with states to effectively address these leading killers and causes of disability. Some examples include:

Enable 42 states to plan or expand their cardiovascular disease.

-Provide all 50 states with comprehensive diabetes control programs.

-Enable 10 states to launch comprehensive cancer control programs.

-For the first time-begin to fund comprehensive arthritis programs in states. Establish model epilepsy demonstration programs.

The 20th century was a time of amazing public health accomplishments, which left a legacy of vastly improved health for Americans. The 21st century will be judged by its ability to deliver new discoveries and advances in health science and technology to all Americans to prevent and control chronic diseases, extending their lifespan, while making these added years as healthy and productive as possible. Making prevention of disease and disability a national funding and policy priority gives all Americans the opportunity to live longer, healthier lives and ensures the practical application of the Nation's investment in research.

Research to Prevention stands ready to work with the Members of this Subcommittee to help make it possible for every state in the nation to develop and deliver programs to address chronic diseases and disability. By committing a minimum increase of \$350 million, we can work to make this a reality. Thank you for your support for the chronic disease programs at CDC.

## **RESEARCH TO PREVENTION**

[In thousands of dollars]

	2002 enacted	2003 President	2003 President v. 2002	2003 R2P targets	2003 R2P v. 2002
Chronic Disease Prevention and Health Promotion: Arthritis Breast & Cervical Cancer Cancer Prevention and Control	14,089 194,171 77,207	14,000 203,278 76,548	- 89 9,107 - 659	24,500 220,000 128,000	10,411 25,829 50,793

# **RESEARCH TO PREVENTION**—Continued

[In thousands of dollars]

	2002 enacted	2003 President	2003 President v. 2002	2003 R2P targets	2003 R2P v. 2002
Cancer Registries	40,310	39,937	- 373	55,000	14,690
Colorectal Cancer	12,076	11,985	- 91	25,000	12,924
Comp. Cancer Control	4,384	4,352	- 32	10,000	5,616
Ovarian Cancer	4,618	4,591	- 27	8,000	3,382
Prostate Cancer	14,158	14,042	- 116	20,000	5,842
Skin Cancer	1,661	1,641	- 20	10,000	8,339
Cardiovascular Diseases	37,728	37,571	- 157	60,000	22,272
Stroke registry	4,500	?		5,000	500
Community Health Promotion	15,384	20,318	4,934	38,000	22,616
Aging	2,800	2,800	0	10,000	10,000
BRFSS	3,000	2,891	- 109	10,000	7,000
Comm health prom/vision	9,693	14,627	4,934	18,000	8,307
Diabetes	62,321	62,062	- 259	100,000	37,679
Epilepsy	6,527	6,527	0	11,000	4,473
Iron Overload	477	477	0	500	23
Nutrition/Physical Activity	27,758	27,642	-116	60,000	32,242
Global micronutrients	5,000	5,000	0	5,000	0
Oral Health	10,939	10,893	- 46	18,000	7,061
Prevention Centers	26,423	26,313	-110	40,000	13,577
Safe Motherhood/Infant Health	51,256	51,043	- 213	65,000	13,744
School Health	59,033	58,787	- 246	83,000	23,967
HIV/AIDS	47,621	47,621	0	47,621	0
Non HIV/AIDS	11,412	11,166	- 246	35,379	
Tobacco	101,999	101,576	- 423	130,000	28,001
Subtotal, Chronic base	685,312	697,035	11,723	978,000	292,688
Medial Campaign	68,400	0	- 68,400	125,000	56,600
Total, Chronic	753,712	697,035	- 56,677	1,103,000	349,288
Preventive Health Block Grant	135,000	135,000	0	210,000	75,000
REACH	37,800	37,800	0	50,000	12,200
TOTAL	926,512	869,835	- 56,677	1,363,000	436,488

# PREPARED STATEMENT OF TRUST FOR AMERICA'S HEALTH

Thank you for the opportunity to submit testimony on the importance of investing

more resources in our nation's public health system. Trust for America's Health (TFAH) is a non-profit public health organization whose mission is to protect the health and safety of all communities, especially those most at risk of environmental and other public health threats.

In the war on terrorism, our military troops are armed with top-notch training, state-of-the-art equipment and facilities, and valuable intelligence. Leadership is strong, and the chain of command is clear.

strong, and the chain of command is clear. Unfortunately, the same cannot be said about our homeland defenses protecting Americans today from health threats. It is no secret: Our public health system, which was once the world leader in stamping out diseases like polio, typhoid and smallpox, is inadequately prepared for today's challenges. After decades of under-investment, our health system lacks the resources they it needs to tackle the full range of public health threats, from potential chemical or biological attacks, to the serious ongoing challenges like chronic diseases. —Our major priority for this appropriations cycle is to increase funding for the

Our major priority for this appropriations cycle is to increase funding for the Nationwide Health Tracking Network to \$100 million in the Public Health Improvement line at the Centers for Disease Control and Prevention (CDC). -Given the importance of CDC for protecting the public's health, we would also like to be on record in our support for restoring at least fiscal year 2002 funding levels to all programs at the CDC and rebuilding the public health infrastructure at the local, state and federal level.

## NATIONWIDE HEALTH TRACKING NETWORK

As we debate how best to prepare for possible terrorist threats, we we must recognize that there is a large gap in our public health knowledge. And the September 11 attacks have made this gap more obvious and dangerous than ever. Although this Congress has allocated one-time funds to track the health of first responders at Ground Zero, the New York City firefighter unions are seeking federal funding for "lifelong [health] monitoring" for firefighters who worked at Ground Zero. The firefighter union leaders are calling for federal funding of the proposal because they suspect there will be long-term health effects from environmental exposures.

The truth is there should have been a baseline of health information in place long before the September 11 attacks. Had we been routinely tracking where and when people were getting sick and whether there was a relationship to factors in the environment, public health officials would not have had to resort to tracking pharmaceutical sales such as Kaopectate in New York City to gauge possible illnesses from exposures. How much more would we know if we actually tracked people's health and their exposures instead of tracking how fast over-the-counter medicine is sold and monitoring the air in one location that may or may not represent actual human exposures?

exposures? The targeted health tracking of the New York City first responders is an important and necessary step, but we must do more. This is health information that would benefit everyone. Communities have the right to know what might be making them sick.

A Nationwide Health Tracking Network is critical for responding to the full spectrum of health concerns: chemical terrorism, biological terrorism and chronic disease., we already know the number This investment would serve the dual purpose of protecting us from terrorist threats and from chronic disease which is the number one killer of Americans today.

Chronic diseases including some cancers, asthma and diabetes are on the rise. But we do not know why because we do not perform the most fundamental of all public health practices—tracking and monitoring where and when diseases occur and their potential links to environmental factors. Chronic illnesses They already affect more than 100 million men, women and children in the United States, more than onethird of our population. These illnesses are responsible for 70 percent of all deaths in the United States and cost more than \$325 billion a year in health care and lost productivity.

Most Americans are shocked to learn there is no nationwide network to track where and when chronic diseases occur. In fact, our public opinion research suggests that almost 90 percent of respondents—in every region, age group, and party affiliation—express serious concern when told about this. Our research also shows that people are more worried about the threat of chronic disease than about terrorist threats. And it is not hard to understand why—seven out of 10 Americans die from these diseases.

The majority of Americans also support increased spending when it comes to public health. In fact, almost no one thinks we should spend less on these important activities that protect the public from illness. Our budget priorities this year and for the foreseeable future should ensure that our public health system has all the tools it needs to prevent the full range of health threats, including those posed by chronic diseases and potential terrorist threats.

chronic diseases and potential terrorist threats. Health tracking is an essential element of that dual preparedness, and we are pleased to see that recognition beginning to take hold in Congress and the Administration. We appreciate that almost \$30 million was appropriated for health tracking in fiscal year 2002, including \$12 million to monitor the health effects of the September 11 attacks on emergency responders and \$17.5 million for state pilot programs to begin health tracking. We are encouraged that the Administration in its budget request to Congress called health-tracking a "major focus" of its environmental health program.

But these are only first steps. Congress should expand funding to provide not just 1 year of health tracking for a few states, but a nationwide network would serve as an early warning of disease.

Every year health agencies receive thousands of requests from the public to investigate disease clusters. But those officials lack the resources to respond. With health tracking, we could respond and act to prevent future illnesses. More than 80 public health, health, environmental and consumer groups agree, and have endorsed the concept of a nationwide health tracking network. The list of supporters includes the American Heart Association, the American Water Works Association, the March of Dimes, the Catholic Health Association of the United States, and the Association of State and Territorial Health Officials. The Trust for America's Health estimates that a comprehensive nationwide health-tracking system would cost \$275 million—about \$1 for every American and a fraction of the costs these diseases impose on our society and families. Recognizing budget limitations and the need to ramp up such a system, we are asking Congress and the Administration to support \$100 million for health tracking in fiscal year 2003.

#### REJECT BUDGET CUTS FOR CDC

A health tracking network would build on the good work already being done by the Centers for Disease Control and Prevention (CDC). CDC is one of the most important players in our public health system and the primary federal agency responsible for improving the public's health. is the Centers for Disease Control and Prevention (CDC). Yet, the Administration has proposed a \$1 billion cut in CDC funding in fiscal year 2003. Although additional funds are proposed for emergency preparedness and response to bioterrorism, the overall budget is reduced.

This comes at a time when our country needs better health protection, not less. These funds must be restored. We join with the CDC Coalition, a group of more than 100 organizations committed to the mission of CDC, in calling for at least \$7.9 billion for the CDC in fiscal year 2003.

#### THE BIG PICTURE

Improving the public health system to meet the wide range of threats facing the American public requires efforts to build up the public health system to respond to all of these threats. The same "early warning" systems that would be used to detect and respond to a chemical or biological terrorist act could also help experts identify possible links between long-term exposures to factors in the environment and local disease clusters.

Investing in the fundamentals of public health will help us prepare for all threats to the public's health whether from criminal acts or unexplained chronic diseases.

We must invest significant resources in four areas: more and better-trained public health professionals; better-equipped laboratories; state-of-the-art early-warning systems and communication networks; and a nationwide health tracking network to track chronic diseases like cancer, asthma, Alzheimer's and birth defects, and to monitor environmental exposures that might be related to those diseases.

Preparing our country to meet emerging and existing health threats will require more than a year's worth of increased appropriations. It will require a sizable, multi-year commitment to the foundation of a quality public health system.

The initial funding approved [for fiscal year 2002], \$865 million, is a good start for improving state and local public health capacity. Nonetheless, everyone recognized that this was an initial investment. The Trust for America's Health urges a federal commitment of \$10 billion over 10 years to improve the capacity of state and local public health systems.

## THE NEED FOR STRONGER LEADERSHIP

In addition to increased financial resources, the United States needs strong leadership and a clear chain of command in the public health domain. Although there are more than 50 federal offices involved in protecting the public's health, no single individual or agency is in charge. Better coordination and leadership would improve the nation's public health preparedness and emergency response, and would strengthen our ability to prevent chronic disease.

At the moment, there are no confirmed leaders in place at the CDC; the National Institutes of Health; the Food and Drug Administration; and the Office of the Surgeon General. These vacancies mean we are without the "Generals" we need to safeguard our health on the home front. Last month, the Trust for America's Health and 20 other health organizations sent a letter to President Bush, urging him to act quickly to nominate qualified individuals to fill these vacancies. We were pleased when, a few weeks later, the President nominated qualified candidates for Surgeon General and director of the NIH.

However, the underlying fact remains that no one official is in charge of federal health protection efforts, and years of budget-cutting under both Democratic and Republican leadership have weakened our public health system, especially the office of the Surgeon General. We believe the time has come to reverse years of decline in the power and resources of the Surgeon General and give the office the assignments and backing it needs to spearhead federal efforts to safeguard the health of all Americans.

#### SUMMARY

Investments in our country's public health system will save lives and prevent illness for thousands, even millions, of Americans.

It is more than a one-shot deal, and it requires both a sustained financial commitment and strong, clear leadership.

## PREPARED STATEMENT OF THE HELEN KELLER NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS

#### PRELIMINARY STATEMENT

With the help of this Committee and the Congress, the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) will embark upon a new and important initiative in fiscal year 2003. As part of its long-range plan, HKNC needs financial support for the establishment of a major research, development, and training component. HKNC urges the Congress to appropriate a total of \$9,492 million for fiscal year 2003, an increase of \$775,000 over the President's budget. Of the amount of increase, \$175,000 would enable the Center to offset cost of living increases; \$100,000 would be used to continue the expansion of the nationwide affiliate program and the remaining \$500,000 would support the research and training initiative.

HKNC received level funding for fiscal year 2002, and the President's budget requests a level funding increase in HKNC's appropriations for fiscal year 2003. Within the constraints of funding received last year, we are moving to establish a national registry of deaf-blind individuals; embark on our capital repair and plant improvement program; and to expand our national network to provide more services to deaf-blind young people, adults and the elderly. The HKNC budget is very small in Federal budgetary terms, but through your leadership, it will enable hundreds of deaf-blind Americans to live independently, including employment in productive jobs.

## BACKGROUND

The Helen Keller National Center was established, and is maintained and operated pursuant to its enabling statute, the Helen Keller National Center Act, 29 U.S.C. §1901–1908. It 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. It also provides a national program of technical assistance and training to state vocational rehabilitation agencies and other service entities. From its headquarters in Sands Point, Long Island, New York, the Helen Keller National Center administers a national network of 45 affiliate agencies. HKNC provides financial support and technical assistance to these agencies to enable deaf-blind children, youth, and adults to be served in their own home states.

The mission and responsibilities of the Helen Keller National Center, established by Congress in 1967, have expanded over the years. In 1998, the Helen Keller National Center Act was extended and amended. Additional responsibilities—and additional costs—have been imposed on HKNC. For example, the Center is now required to train family members of individuals who are deaf-blind. The definition of deafblindness was expanded in the 1992 amendments. The result has been the opening up of the rehabilitation system to serving additional deaf-blind clients.

## LONG-RANGE PLANNING

HKNC finds itself at a momentous juncture in its capacity to provide services to America's deaf-blind population: the number of deaf-blind individuals is increasing, but the capacity to serve additional people is not. Deficiencies exist which must be corrected in the near term, and a number of actions must be taken over the next 5 years to equip HKNC to do the job the Congress has mandated it to do. We need to create a substantial capacity in research, development, and training. A critical review of the HKNC nationwide service delivery system has determined that our regional representatives are spread too thin—ten individuals are now expected to coordinate service delivery to all fifty states. Consequently, when deaf-blind individuals trained for meaningful employment at HKNC's New York Center return home, the infrastructure which is meant to provide continuity of support often does not exist, and the value of concentrated training is diminished. One objective is to establish a HKNC representative in all 50 states to strengthen the coordination of essential, individualized services. Within 5 years we hope to have established 20 regional offices (doubling the current number), each with a professional representative responsible for two to three states. At the same time, HKNC hopes to be in a position to provide financial incentives for improved service coordination through joint grants to state rehabilitation agencies and developmental disabilities councils. Such grants would be twice the size of the current grants to state VR agencies.

## THE HKNC RESEARCH, TRAINING, AND DEVELOPMENTAL INITIATIVE

Due to chronically limited funding, the Helen Keller National Center necessarily has focused its resources upon the development of services, and the network to provide them. One undesirable result of this attention has been the lack of adequate research, training, and development in the field of deaf-blindness. If the preponderance of deaf-blind youths and adults is to be served adequately, we must not delay in building the infrastructure to make such services more effective and efficient.

HKNC is the world's premier institution serving deaf-blind youths and adults. Through the Helen Keller National Center Act, Congress has vested in HKNC the research and training authority in this field. It is vitally important now to fund the initiative that will make HKNC's research capability a reality. The \$500,000 we seek for this purpose would enable HKNC to address critical deficiencies in professional training; to develop new technology for deaf-blind children and adults, including assistive listening devices and low vision aids; and to conduct research in many other important areas.

The universe of trained personnel in deaf-blindness is small. Part of the reason is the low incidence and population of deaf-blind persons. Because of the low incidence of deaf-blindness, this complex disability does not receive the level of attention needed. There is a critical shortage of trained professionals in all areas of service to deaf-blind adults: orientation and mobility instructors, rehabilitation teachers, rehabilitation counselors, interpreters, job coaches, placement specialists, group home providers, independent living center staff, and others. Existing training programs in blindness do not address adequately the special requirements of deaf-blind persons.

In the research and development field, existing Rehabilitation Research and Training Centers have neither the resources nor the expertise to focus on issues related to deaf-blindness. However, HKNC has obtained commitments from a number of universities to collaborate on research initiatives if and when a program is developed through HKNC. Areas in need of quality research include interpreting for individuals who are deaf-blind; placement and supported employment; interveners and service support providers for deaf-blind people; needs of older blind persons experiencing age-related hearing loss; new employment opportunities through application of technology; improved communication techniques; specialized orientation and mobility techniques; the genetics of Usher's Syndrome; and the late emerging manifestations of Congenital Rubella Syndrome. Research results in a number of these areas will be translated into training of professionals who will utilize the improvements to better serve deaf-blind youths and adults.

## 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 more than a quarter century, the Helen Keller National Center has operated as the only organization in the United States which provides, directly and indirectly,

For more than 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 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 \$9.492 million for the Helen Keller National Center for fiscal year 2003. As the largest animal protection organization in the country, we appreciate the opportunity to provide testimony to the Labor, Health and Human Services, and Education Subcommittee on fiscal year 2003 funding items of great importance to The Humane Society of the United States (HSUS) and its 7 million supporters nationwide:

- -\$5 million to expand the work of the Interagency Coordinating Committee on the Validation of Alternative Methods (ICCVAM), authorized by Public Law 106-545, coupled with Committee Report language encouraging federal agencies to avail themselves of ICCVAM's expertise and efficient review process;
- -\$2.5 million for the National Center for Research Resources to sponsor research and development focused on identifying and alleviating pain and distress in laboratory animal subjects.

#### CHIMPANZEE SANCTUARIES

We are grateful to the Committee for providing \$5 million in fiscal year 2002 to begin construction of the National Chimpanzee Sanctuary System, as authorized by Congress in Public Law 106–551. This statute, originally introduced by Senators Bob Smith (R-NH) and Richard Durbin (D-IL) and Representative Jim Greenwood (R-PA), earned the bipartisan support of 24 cosponsors in the Senate and 143 cosponsors in the House, and had the endorsement of more than 100 scientists, many of whom are renowned experts in the field of chimpanzee research. It was approved by unanimous voice vote in both chambers and signed into law in December 2000.

by unanimous voice vote in both chambers and signed into law in December 2000. This common-sense law is designed to help animals who are deemed by the Secretary of Health and Human Services to be "surplus" for medical research, but who are still being warehoused in expensive federally-supported laboratory cages. As determined by the Congressional Budget Office (CBO), the sanctuaries envisioned by this law will provide a much higher quality of life for these animals. They will also serve American taxpayers well, by saving millions of dollars over the course of the next several years. These savings are primarily due to the fact that sanctuary facilities, which offer a more naturalistic environment and opportunities for social interaction, can be built and operated at significantly lower cost than laboratory facilities. Housing chimpanzees in sanctuaries is estimated to cost \$8-\$15 per day per animal, compared to the \$20-\$30 per day per animal that the federal government currently spends to house them in lab cages. In addition, the statute creates a public-private partnership, requiring private sector matching dollars to complement the federal government's share (the private match is 10 percent of construction costs and 25 percent of operating costs).

The statute follows the recommendations of a National Research Council (NRC) report commissioned by the National Institutes of Health (NIH) and released in 1997, *Chimpanzees in Research: Strategies for Their Ethical Care, Management, and Use.* In 1986, NIH launched an initiative to breed chimpanzees—mistakenly thought to be useful models for AIDS research—creating a surplus of several hundred chimpanzees who are no longer used in medical research. According to the NRC report, the government is spending more than \$7 million annually on maintenance of chimpanzees. The report recommends a breeding moratorium and opposes euthanasia of chimpanzees as a means of population control, noting that "Islome of the best and most caring members of the support staff, such as veterinarians and technicians would, for personal and emotional reasons, find it impossible to function effectively in an atmosphere in which euthanasia is a general policy, and might resign." The report also specifically recommends: "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."

To continue timely and efficient implementation of this law, we ask that the Committee direct NIH to allocate \$8 million in fiscal year 2003 for the next phase of construction of the national chimpanzee sanctuary system. The President's budget recommends \$5 million for fiscal year 2003 toward this goal. While we are pleased to have the Administration's support of this program, we respectfully request \$8 million, in order to achieve the cost-benefits of scale as quickly as possible. Fiscal year 2002 funds will allow site preparation, establishment of infrastructure and installation of utilities in a 200-acre site, and housing for 50–75 of the estimated 600 chimpanzees that the Secretary may identify as no longer needed for research. To optimize cost effectiveness, a sanctuary site must house 200–300 chimpanzees. \$8 million in fiscal year 2003 will reduce daily operating expenses per chimpanzee by allowing Phase II construction of housing for an additional 125–150 chimpanzees.

#### INTERAGENCY COORDINATING COMMITTEE ON THE VALIDATION OF ALTERNATIVE METHODS (ICCVAM)

We are also very pleased that Congress enacted Public Law 106–545 by unanimous voice vote in both chambers. This legislation, introduced by Senator Mike DeWine (R-OH) and Representatives Ken Calvert (R-CA) and Tom Lantos (D-CA), earned the bipartisan support of 5 Senate cosponsors and 73 House cosponsors, and was also signed into law in December 2000. This statute strengthens and makes permanent the Interagency Coordinating Committee on the Validation of Alternative Methods (ICCVAM). We hope the statute will increase acceptance of more animal-friendly test methods by streamlining the process by which these methods are validated and easing institutional barriers within federal agencies that discourage their use.

ICCVAM performs an invaluable function for regulatory agencies, industry, public health, and animal protection organizations by assessing the validation of new, revised and alternative toxicological test methods that have interagency application including methods that replace, reduce, and refine the use of animals in testing. After appropriate independent peer review of a test method, ICCVAM provides its assessment of the test to the federal agencies that regulate the particular endpoint that the test measures. In turn, the federal agencies maintain their authority to incorporate the validated test method as appropriate for the agencies' regulatory mandates. This streamlined approach to assessment of validation of new, revised and alternative test methods has reduced the regulatory burden of individual agencies, provided "one-stop shopping" for industry, animal protection, public health and environmental advocates to consider test methods, and set uniform criteria for what constitutes a validated test method.

ICCVAM arose from an initial mandate in the NIH Revitalization Act of 1993 for the National Institute of Environmental Health Sciences (NIEHS) to "(a) establish criteria for the validation and regulatory acceptance of alternative testing methods, and (b) recommend a process through which scientifically validated alternative methods can be accepted for regulatory use." In 1994, NIEHS established an ad hoc ICCVAM to write a report that would recommend criteria and processes for validation and regulatory acceptance of toxicological testing methods that would be useful to federal agencies and the scientific community. Through a series of public meetings, interested stakeholders and agency representatives from 14 regulatory and research agencies developed NIH Publication No. 97–3981, Validation and Regulatory Acceptance of Toxicological Test Methods. This report has become the "sound science" guide for consideration of new, revised and alternative test methods by the federal agencies and interested stakeholders. After publication of the report, the ad hoc ICCVAM moved to standing status under the NIEHS' National Toxicology Program Interagency Center for the Evaluation of Alternative Toxicological Methods (NICEATM). Representatives from federal regulatory and research agencies have continued to meet, with advice from NICEATM's Advisory Committee and independent peer review committees, to assess the validation of new, revised and alternative toxicological test methods.

Since then, three methods have undergone rigorous assessment and been deemed scientifically valid and acceptable. The first method, Corrositex, is a replacement for animal-based dermal corrosivity tests for some chemicals. The second, the Local Lymph Node Assay, is a reduction and refinement of an animal test for the skin irritation endpoint. The third, the Up and Down Method, is a reduction and refinement of the LD50 Test for acute oral toxicity.

The open public comment process, input by interested stakeholders, and the continued commitment by various federal agencies have led to ICCVAM's success so far. Now, under Public Law 106–545, ICCVAM is poised to accomplish even more in terms of streamlining the validation of other new, revised and alternative test methods. For the past few years, NIEHS has provided approximately \$1 million annually to NICEATM for ICCVAM activities. In order to ensure that federal regulatory agencies and their stakeholders can more fully benefit from the work of ICCVAM, we respectfully urge the Committee to direct NIEHS to allocate \$5 million for ICCVAM activities in fiscal year 2003. Funding at this level will cover FTEs, independent peer review assessment of test methods, meeting expenses, and other activities as deemed appropriate by the Director of the NIEHS. To accomplish this, we respectfully request the following Committee report language:

"The Committee supports the assessment of scientific validation of new, revised and alternative toxicological test methods by ICCVAM. The Committee supports the use of ICCVAM to streamline consideration of new, revised and alternative toxicological test methods. The Committee also urges the incorporation of scientifically validated new, revised and alternative test methods into federal regulations, requirements and recommendations in an expeditious manner. To this end, the Committee has provided \$5 million to support ICCVAM's activities."

## PAIN AND DISTRESS RESEARCH

An estimated 40 percent of the National Institutes of Health (NIH) budget—or currently more than \$8 billion—is devoted to some aspect of animal research. At this time, no funding is set aside specifically for research into alternatives that replace or reduce the use of vertebrate animals in research or that reduce the amount of pain and distress to which research animals are subjected. NIH may receive in excess of \$27 billion in fiscal year 2003 if Congress fulfills the President's budget request. Out of this funding, we seek \$2.5 million (.00925 percent) for research and development focused on identifying and alleviating animal pain and distress. We recommend that this R&D be conducted under the National Center for Research Resources (NCRR, responsible for NIH extramural funding). We also urge the Committee to specify in report language that NCRR should conduct this research in conjunction with, or "piggy-backed" onto, ongoing research that already causes pain and distress. No pain and distress should be inflicted solely for the purpose of this research, given the volume of existing research (we estimate a minimum of 20–25 percent of all animal research) that already involves moderate to significant pain and/ or distress.

In 1987, NIH announced a program to award grants for "research into methods of research that do not use vertebrate animals, use fewer vertebrate animals, or produce less pain and distress in vertebrate animals used in research." Many of the 17 program awards made from 1987 to 1989, totaling approximately \$2.4 million, involved research on non-mammalian models, including projects on frogs, mollusks, and insects. Other awards included mathematical modeling and computer studies. This program, which was managed out of the Division for Research Resources (the precursor to NCRR), no longer exists at NIH, and it has not been replaced by any similar program.

A recent survey conducted by an independent polling firm indicates that concern about animal pain and distress strongly influences public opinion about animal research in general. Public support for animal research declines dramatically when pain and distress are involved: 62 percent support animal research when pain and distress are minimal, only 34 percent when moderate, and an even smaller 21 percent when animal suffering is severe. Despite this public concern, NIH has not continued to sponsor R&D exploring how to minimize animal suffering and distress in the laboratory.

During the past 4 years, The Humane Society of the United States has been reviewing institutional policies and practices with respect to pain and distress in animal research. We have found that research institutions have inconsistent policies due to the lack of information on this subject, and that standards vary greatly from one institution to another. Painful techniques, such as the use of carbon dioxide to euthanize rats and mice, are widely practiced and approved even though studies indicate that carbon dioxide exposure for only a few seconds causes acute distress to humans. The federal standard for determining laboratory animal pain specifies that, if a procedure causes pain or distress to humans, it should be assumed to cause pain and distress to animals. While human experience can and should provide a useful guide in some cases, there are others in which humans are never subjected to the conditions facing laboratory animals. Information on pain and distress that animals themselves actually experience is important. For many accepted laboratory practices there is no scientific data regarding the painful or distressing effects on either people or animals.

A lack of data on the recognition, assessment, alleviation, and prevention of pain and distress in laboratory animals is commonly cited by scientists as a rationale for either not reporting pain and distress or not acting to mitigate it. This lack of data is obviously detrimental to the welfare of animals used in research, but it is also detrimental to the quality of science produced. Uncontrolled, undetected, and unalleviated pain, physical distress, or psychological distress result in alterations in physiologic and behavioral states, and confound the outcome of scientific research. Ultimately, the lack of information on pain and distress leads to misinterpretation of research results that could result in harmful effects in human beings when preclinical animal research results are applied to humans in clinical trials.

Our nation takes pride in leading the world in biomedical research, yet we lag behind many other countries in our efforts to minimize pain and distress in animal subjects. For example, the United Kingdom, Sweden, Switzerland, Germany, the Netherlands and the European Union all have committed funds specifically for the "three R's" (replacing the use of animals, reducing their use, and refining research techniques to minimize animal suffering). We urge the Committee to make this small investment of \$2.5 million to promote animal welfare and enhance the integrity of scientific research.

Again, we appreciate the opportunity to share our views and priorities for the Labor, Health and Human Services, and Education Appropriation Act of fiscal year 2003. We hope the Committee will be able to accommodate these three requests affecting animals across the United States. Thank you for your consideration.

#### PREPARED STATEMENT OF ELDER LAW OF MICHIGAN, INC.

Elder Law of Michigan, Inc. has operated the Legal Hotline for Michigan Seniors for 12 years. In that time, we have found the Hotline to be a tremendous resource for the low income and middle income seniors who seek out our services. Aging is a complex process with many decisions and choices to be made. Providing citizens with the opportunity to ask questions to make informed decisions is a cornerstone of modern and enlightened democracy. The Michigan Hotline served over 4,000 seniors in calendar year 2001. Help is

The Michigan Hotline served over 4,000 seniors in calendar year 2001. Help is provided on housing issues, consumer issues, health insurance issues, the quality of long term care services, powers of attorney, guardianship, and issues relating to personal freedom. 65 percent of our clients have incomes under 200 percent of the federal poverty level. Over 35 percent consider themselves to be disabled in some way. Most are highly vulnerable due to poverty, geographic isolation, limited education or frailty (mental or physical health problem). We receive less than 10 percent of our funding from the State of Michigan and currently 35 percent from a federal demonstration grant. The rest must raised annual from attorneys, private citizens, foundations and corporations. This is no easy task post 9/11 when competition for funds from private donors is fierce.

While we are lucky to have had the Legal Hotline for Michigan Seniors in our state, each year it is a struggle to secure the funding needed to continue its operation. We ask that Congress provide at least \$6 million from the Administration on Aging Title IV appropriation for aging research, training, and discretionary programs to fund a nationwide program of statewide senior legal hotlines. This could be done by establishing and maintaining at least one senior legal hotline program in each of 50 states, the District of Columbia, and Puerto Rico. Existing senior hotlines should be maintained in states that have them and new ones added in the states that do not. For the states with the largest senior populations, California, Florida, New York, Texas and Pennsylvania, it would be prudent for the Administration on Aging to award larger grants of \$200,000-\$250,000 or fund two smaller hotlines for a total of \$250,000.

## PREPARED STATEMENT OF THE ASSOCIATION OF PUBLIC HEALTH LABORATORIES

## INTRODUCTION

Mr. Chairman and distinguished members of the subcommittee, my name is Dr. Mary Gilchrist. I am the Director of the University Hygienic Laboratory in Iowa City, IA. I also serve as the president of Association of Public Health Laboratories (APHL), representing state and local public health laboratories across this nation. This testimony is being submitted on behalf of APHL. The Association of Public Health Laboratories (APHL) is a professional associa-

The Association of Public Health Laboratories (APHL) is a professional association that represents its member national, state, city, and local public health, environmental, and international laboratories on issues of public health importance. APHL's mission is to promote the role of public health laboratories in support of national and global objectives, and to promote policies and programs that assure continuous improvement in the quality of laboratory practices. As such, APHL is dedicated to protecting and preserving the health of our nation, and to promoting technology transfer in laboratory practices in order to foster better health globally. To fulfill its mission, APHL works collaboratively with a diverse array of national,

To fulfill its mission, APHL works collaboratively with a diverse array of national, international, public and private sector partners in formulating sound public health and environmental policies, offering training and fellowship programs designed to prepare future leaders in public health laboratory practice, and improving public health laboratory practices nationally and internationally. APHL is recognized nationally and internationally for its excellence in the provision of cost-effective training and continuing education programs offered through its National Laboratory Training Network (NLTN).

APHL is pleased to have the opportunity to outline the critical role that public health laboratories play in our nation's public health system. From bioterrorism response to emerging infectious diseases to responding to environmental health threats, our nation's public health laboratories are on the frontlines.

Today's testimony will concentrate on three important programs that are funded through the Centers for Disease Control and Prevention (CDC): The Public Health Response to Terrorism/Laboratory Infrastructure; Emerging Infectious Diseases; and the Environmental Health Laboratory. These three programs each have a strong public health laboratory component and funding is urgently needed to ensure that state public health laboratories will have the capacity and capability to protect the health of our citizens.

## THE PUBLIC HEALTH RESPONSE TO TERRORISM/LABORATORY INFRASTRUCTURE

During last year's anthrax attacks the state public health laboratories shouldered the lion's share of laboratory testing for potential bioterrorism. Many of our labs worked around the clock processing specimens to ensure that the public's health would be secure. Importantly, the testing that occurred in the state public health laboratories controlled panic and fear and reduced excess costs to health care and our economy.

The availability of laboratory testing for packages, powders and environmental specimens is essential in a crisis. Laboratories must stand ready to identify a broad range of potential agents including organisms that could be used to compromise the food supply, water or air. APHL is grateful for the attention this subcommittee has given to this important topic. Last year a total of \$940 million was appropriated to upgrade state and local public health capacity. For fiscal year 2003, APHL respectfully requests that you continue to fund this program at the \$940 million level. These funds will help modernize the overall public health infrastructure and assist our laboratories to be better prepared for bioterrorism. The Department of Health and Human Services determined that out of last year's emergency supplemental appropriations, 13 percent could be used to enhance the state public health laboratories be allocated additional funds beyond 13 percent of the total for laboratory upgrades. In late February 2002 the CDC issued the following document—"Guidance for Fis-

In late February 2002 the CDC issued the following document—"Guidance for Fiscal Year 2002 Supplemental Funds for Public Health Preparedness and Response for Bioterrorism Announcement Number 99051—Emergency Supplemental." All of the state public health laboratories have worked closely with their governors and state health officers to come up with proposals that better prepare state public health systems for bioterrorism.

The funds provided through the "emergency supplemental" will build a foundation that will develop our nation's public health infrastructure. To assist in this process our laboratories are working closely with their public health counterparts in the state agencies to ensure overall preparedness planning and readiness, improved surveillance and epidemiology capacity, improved communications and information technology, and better education and training.

These funds will also enhance the public health laboratories that are part of the Laboratory Response Network (LRN) by ensuring safe and secure facilities, trained personnel, modern equipment and other important components of a well-equipped laboratory. The LRN is composed of county, city, state, and federal public health laboratories, and was established to help public health laboratories across the nation prepare for and respond to acts of terrorism. It is a joint program of the CDC and the Association of Public Health Laboratories and was begun about 3 years ago. This network of laboratories can accept specimens and samples from hospitals, clinics, the Federal Bureau of Investigation (FBI) and other law enforcement groups, emergency medical services, the military, and other agencies.

The "emergency supplemental" also directed the state public health laboratories to develop connectivity with the private clinical and hospital laboratories. Both types of laboratories have independent yet complementary roles to safeguard public health. Through improvements in communication, collaboration, and coordination, the public health laboratories are implementing plans to provide links to the public and private sectors necessary for an effective response to bioterrorism. Unfortunately, the "emergency supplemental" did not contain a substantial sec-

Unfortunately, the "emergency supplemental" did not contain a substantial section that would allow states to better prepare for chemical terrorism and response. The likelihood that chemical agents will be used for terrorist purposes is high. Unlike biological agents, chemical agents can produce immediate effects; chemical agents are cheap, easy to use, stable, and can be precisely delivered; and can be easily, efficiently, and rapidly dispersed. Terrorists can use thousands of commercially available chemicals. These chemicals can be synthesized or purchased throughout the world. These include herbicides, blood agents, choking agents, blistering agents, and nerve agents.

To prepare for chemical terrorism our states need containment laboratories, trained personnel and equipment to perform rapid screening for toxic chemicals. For Chemical Terrorism Preparedness and Response, expanding the number of laboratories able to handle chemical agents and agents present in environmental samples is essential. It is important that this year's appropriations allow states to enhance and expand public health laboratories testing human specimens for chemical terrorism agents as well as to implement a program of testing for environmental samples. Currently there is no program in place to test environmental samples and this is a major gap in testing.

is a major gap in testing. In fiscal year 2002 CDC provided \$3.1 million to five state public health laboratories (New York, Virginia, New Mexico, California and Michigan) for chemical detection in human (blood and urine) samples. In addition to funding, these laboratories have received training from the CDC, and are beginning to serve as "surge capacity" laboratories for CDC chemical terrorism analyses of clinical specimens. At present there are no official, state based efforts to provide coordinated laboratory testing of environmental samples for evidence of terrorist attacks. Preparing for chemical terrorism must become a public health priority. APHL urges the Committee to ensure that chemical terrorism is a priority in the fiscal year 2003 Appropriation.

Overall, the funds provided by Congress last year are helping prepare our nation's public health system for a bioterrorist attack. It is important that we sustain the improvements to the public health infrastructure that are underway. Many of our state public health laboratory directors have expressed concerns that a one-time infusion of funds will not allow states to sustain the improvements that they are making to their laboratories. For example, personnel that are hired will need to be retained, equipment that is purchased and systems that are put in place will need to be maintained and updated. Therefore, we urge the committee to continue to provide support for this program at last year's level.

## EMERGING INFECTIOUS DISEASES

Infectious diseases are a continuing threat to all Americans, regardless of age, gender, lifestyle, ethnic background, or socioeconomic status. Between 1973 and 1999, more than 35 newly emerging infectious diseases were identified. Although modern advances, such as antibiotics and vaccines have conquered some diseases, new ones are constantly emerging (such as HIV/AIDS, Legionnaires' disease, Lyme disease, hantavirus pulmonary syndrome and West Nile Virus). Other infectious diseases reemerge in drug-resistant forms (such as tuberculosis and bacterial pneumonias) or through bioterrorism (anthrax). Because we do not know what new diseases will arise, laboratories and public health agencies must always be prepared for the unexpected.

Last year a total of \$354 million was appropriated for the emerging infectious diseases programs at the National Center for Infectious Disease (NCID). For fiscal year 2003 APHL requests that this program be funded at a \$425 million level. This increase will allow states and the CDC to expand and improve essential public heath programs that focus on infectious diseases.

In total, infectious diseases cost our society more than \$120 billion each year. An influenza pandemic would cause an estimated 90,000 to 200,000 deaths in the United States alone; the cost of the pandemic could reach as high as \$167 billion. NCID has utilized the funds you provide to establish domestic and global sentinel surveillance sites to facilitate the early detection of influenza virus variants that are used each year for vaccine development. Additional support would expand the number and international surveillance sites for influenza to support vaccine decisions.

The Epidemiology and Laboratory Capacity program (ELC) at NCID is helping to build laboratory capacity in state and local health departments by providing funds and technical assistance to all states. The funds provided through the ELC have allowed all states to acquire pulsed-field gel electrophoresis capability. In 2002 all states are now part of a national molecular fingerprinting surveillance network called PulseNet that helps prevent kidney failure and/or death by detecting contamination in foods before large outbreaks occur. Additional support for this program is essential if we are to improve and expand the capability of public health laboratories to rapidly diagnose foodborne disease outbreaks and communicate laboratory findings. The support you provide is also improving the laboratory detection of antibiotic resistant microbes. This helps reduce the transmission of antimicrobial resistance through improved surveillance and outbreak investigations. It also assists in the promotion of the judicious use of antimicrobial drugs by physicians and the public

Additional support for the programs at NCID would allow state and local health departments to build further capacity focusing on new activities such as surveillance for vCJD and antimicrobial resistance, influenza preparedness and response, West Nile Virus surveillance and response, hepatitis C prevention and control, and other under funded public health priorities. NCID could expand the activities of the Emerging Infections Program (EIP) network, which is uniquely designed to address new infectious disease problems whenever they arise.

Improved laboratory capacity and capability for the detection of infectious diseases is an extremely important component of our nation's public health system. Support for continued development and utilization of rapid, sensitive molecular detection assays will be critical to surveillance and control of new and reemerging diseases. Therefore, we urge this Committee to increase your support of the infectious disease programs at CDC.

## ENVIRONMENTAL HEALTH LABORATORY

The CDC Environmental Health Laboratory program is located at the National Center for Environmental Health (NCEH). The Environmental Health Lab develops and applies laboratory science and works with state and local health departments to prevent cancer, birth defects and other disease resulting from exposures to toxic substances.

Last year a total of \$157 million was appropriated for the environmental health programs at NCEH. For fiscal year 2003 APHL respectfully requests a modest increase to fund this program at a \$203 million level. This funding will allow states to begin to implement important biomonitoring programs and provide support for state/local environmental health investigations, and allow NCEH to respond to requests from state health departments regarding chemical emergencies.

NCEH is nationally and internationally recognized for its expertise in biomonitoring, which is the direct assessment of human exposure to toxic substances by measuring them in human blood or urine. Biomonitoring improves exposure assessment; reduces uncertainty in risk assessment; identifies exposures that cause cancer, birth defects and other disease; evaluates the effectiveness of interventions to reduce human exposure; provides individual exposure information for children and persons at risk of dangerous exposures; saves money and needless anxiety by recognizing exposures of negligible health consequence; and provides essential exposure data needed for medical management of persons exposed to toxic substances.

In 2001 NCEH awarded 25 planning grants totaling \$5 million to 33 states to develop, and expand state-based monitoring programs to help prevent disease from exposure to toxic substances. Individual states, as well as consortia comprising several states, received funding. Grants are designed to help states strengthen their public health infrastructure. States will also be able to plan how they will track exposure trends and assess effectiveness of efforts to reduce exposure to toxic substances. Finally, states will be able to increase their capacity to measure many toxic substances in people, including such vulnerable groups as children, the elderly, and women of childbearing age. Planning for this project is well underway and states are hopeful that sufficient funds will be available for the implementation phase. State and local health departments regularly investigate clusters of diseases and expresence to toric substances. NCEH

State and local health departments regularly investigate clusters of diseases and exposures to toxic substances. Each year, NCEH supports the investigations of state and local health departments, using its biomonitoring capabilities to provide individual exposure information for more than 200 toxic substances. This information is essential for health officials determine what is the magnitude of the public health problem, who has had dangerous exposures, and what are the appropriate public health actions to manage the current problem and prevent disease. Additional funding for this program is needed to support investigations at the state and local level

ing for this program is needed to support investigations at the state and local level. Newborn screening is one of the largest disease prevention programs reaching 4 million infants each year. Each year, 3,000 babies with severe disorders are detected by newborn screening programs. The outcome of a false-negative test can result in injury or death, therefore demanding a high level of testing accuracy. The Newborn Screening Quality Assurance Program (NSQAP), a voluntary, non-regulatory program operated by NCEH serves over sixty domestic newborn laboratories and fortyfive international laboratories by conducting research on materials development and quality assurance for dried blood spots (DBS) screening tests.

State health departments test blood spots collected from newborns for up to ten metabolic and genetic diseases such as phenylketonuria (PKU), hypothyroidism, galactosemia, and sickle cell disease. Health departments and laboratories participate in this comprehensive quality control (QC) and performance evaluation (PE) program for dried blood spot screening tests to receive training on quality assurance practices, guidelines and standards for DBS screening tests, technical assistance, proficiency testing and reference materials.

NCEH is also called upon to respond to requests from state and local health departments and foreign governments to assess exposure of persons affected by chemical emergencies—such as pesticide poisoning, mercury food poisoning, or an industrial explosion. Often, the laboratory has to develop new methods to assess exposures to toxic substances involved in the emergency. For these emergencies, the laboratory analyzes toxic substances in blood and urine to determine what chemicals are involved, who has been exposed, how much exposure each individual has had and what is the likely health risk. This information is used to guide the medical management of persons affected and determine what public health follow-up is appropriate for exposed groups of people.

#### CLOSING REMARKS

In closing, I want to thank the members of the Committee for your support of the nation's public health infrastructure and for this opportunity to testify.

## PREPARED STATEMENT OF THE NATIONAL CENTER FOR HEALTH EDUCATION

The National Center for Health Education Organizations (NCHE) is pleased to present this statement concerning appropriations for fiscal year 2003 for the Centers for Disease Control and Prevention (CDC).

The National Center for Health Education, created by a presidential commission under President Richard Nixon in 1975, is a private, non-profit entity whose sole responsibility is to advance the nation's private-sector efforts in health education. Our organization also works in conjunction with the Friends of School Health and the Coalition of National Health Education Organizations,\* a group of 9 professional membership organizations that represents approximately 25,000 professionals who are especially skilled in the use of health promotion and disease prevention to advance the nation's Healthy People 2010 goals and objectives.

I want first to thank you for your past support of programs and initiatives that invest in our nation's youth. But, I am submitting this statement on behalf of the National Center for Health Education to sound a "wake-up call" for more substantial Federal investment in what are proven, cost-effective coordinated school health programs and comprehensive school health education. Specifically, I am here to request that the Centers for Disease Control and Prevention (CDC) should be funded at \$35 million for fiscal year 2003 in order to provide the states with infrastructure grants for such programs.

Perhaps more than at any other time in our nation's history, children and adolescents in our society are facing challenges that can have a profound impact on health. Data from the CDC Youth Risk Behavior Survey 1 and other studies have shown that:

More than 3,000 young people begin smoking each day.<sup>2</sup>

-Obesity has doubled among children and adolescents in the last decade, making it now a national epidemic. Ten to 15 percent of children and adolescents are overweight and more than half of these children have at least one cardiovascular disease risk factor, such as elevated cholesterol, hypertension, and risk

<sup>\*</sup>American Association for Health Education, American College Health Association, American Public Health Association/Public Health Education & Health Promotion Section and School Health Education & Services Section, American School Health Association, Association of State & Territorial Directors of Health Promotion and Public Health Education, Eta Sigma Gamma, National Commission for Health Education Credentialing, Society for Public Health Education, and the Society of State Directors of Health, Physical Education and Recreation.

<sup>&</sup>lt;sup>1</sup>U.S. Centers for Disease Control and Prevention. Youth Risk Behavior Surveillance—United States, 1999. *Morbidity & Mortality Weekly Report. June 9, 2000; 49 SS-5): 1-96.* <sup>2</sup>U.S. Centers for Disease Control and Prevention. Youth Tobacco Surveillance—United States, 2000. Morbidity & Mortality Weekly Report. November 2, 2001; 50(SS04):1–84.

for Type II diabetes.<sup>3</sup> Yet, daily participation in high school physical education classes dropped from 42 percent in 1991 to 29 percent in 1999.

- Two-thirds of eighth-graders have experimented with alcohol and 28 percent have been drunk at least once.
- Seven percent of ninth-grade students report carrying a weapon to school in the previous month, with 135,000 bringing a gun to school every day; violent homi-cide is now the second leading cause of death among people 15 to 24.<sup>5</sup> -Motor vehicle accidents result in over 30 percent of the deaths among young
- people ages 1 to 24.6

Young people from throughout the United States are among these statistics. For example, in Ohio, 73 percent of youth report ever having smoked cigarettes, 56 per-cent drank alcohol during the last month, 72 percent did not participate in moderate physical activity, and 81 percent ate fewer than 5 servings of fruits and vegetables daily during the past 7 days.<sup>7</sup> Tobacco use, poor nutrition, lack of physical activity, alcohol use and other drug use constitute major risk behaviors, which when established during youth today, lead to tomorrow's adult premature death and disability, including heart disease, cancer, diabetes, and injuries.<sup>8</sup> Our children and adoles cents fall victim to these chronic diseases when we fail to provide them with prevention strategies that we now have in hand and know that work. And we are failing them in almost each and every community. The cost to the nation of not doing more than we are currently doing is intolerable. The cost is measured both in terms of lives lost to premature death and unnecessary medical expenses. And the burden of these costs is borne disproportionately in communities where racial minorities predominate.

What those of us at NCHE and I find so disturbing about these statistics is that something can be done. As a national non-profit entity whose sole responsibility is to advance the nation's private-sector efforts in health education, we are already working in partnership with CDC's Division of Adolescent and School Health (DASH) and other government agencies, as well as health-related voluntary associa-tions and national and state-level school organizations in the private sector, to ad-dress these problems and other health concerns of children and their families through the implementation of comprehensive health education and other initiatives in schools throughout the United States. By comprehensive, I mean curriculum approaches that are sequential, age-appropriate, and help young people to apply un-derstandings across a broad range of content areas and behaviors that influence health.

For example, NCHE's Growing Healthy®, a comprehensive school health edu-cation<sup>9</sup> curriculum for grades K-6, helps young people acquire the knowledge and skills they need for good health, academic success, and productive adult lives. Over the past 25 years, Growing Healthy has reached over 5 million students in 15,000 schools in more than 40 states in the United States and Canada. Through a Federally-funded cooperative agreement that enables NCHE to work in partnership with CDC DASH, we also are currently working with teachers, parents, and school leaders across America to coordinate development of locally-based school health councils that can contribute to building community capacity for healthy schools. These coun-cils allow communities to take ownership of their schools and youth, the very youth that will comprise the future workforce and community support.

Our Growing Healthy curriculum is an interdisciplinary approach that has been demonstrated effective at giving young people in Kindergarten through 6th grade

<sup>&</sup>lt;sup>3</sup>U.S. Department of Health and Human Services. The Surgeon General's Call to Action to Prevent and Decrease Overweight and Obesity 2001. [Rockville, MD]: U.S. Department of Health and Human Services, Public Health Service, Office of the Surgeon General; [2001]. Avail-

<sup>&</sup>lt;sup>4</sup>Simons-Morton B, Eitel P, Small ML, School physical education: Secondary analyses of the School Health Policies and Programs Study. Journal of Health Education. 1999; 30:558–564. <sup>5</sup>Anderson M, Kaufman J, Simon TR, Barrios L, Paulozzi L, et al. School-associated violent deaths in the United States, 1994–1999. Journal of the American Medical Association. 2001; accessor or propagation. 286:2695-2702.

<sup>&</sup>lt;sup>200:2095–2702.</sup> <sup>6</sup>Everett SA, Shults RA, Barrios LC, Sacks JJ, Lowry R, Oeltmann J. Trends and subgroup differences in transportation-related injury risk and safety behaviors among high school stu-dents, 1991–1997. Journal of Adolescent Health. 2001; 28:228–234. <sup>7</sup> U.S. Centers for Disease Control and Prevention. Division of Adolescent and School Health. Youth Risk Factor Behavioral Surveillance. Ohio. www.cdc.gov/nccdphp/dash/yrbs.pies99/oh.htm.

 <sup>&</sup>lt;sup>8</sup>U.S. Department of Health and Human Services. Healthy People 2010. Washington, DC:
 <sup>9</sup>LOhrmann DK, Wooley SF. Comprehensive school health education. In Marx E, Wooley SF, Northrop D, Eds. Health is Academic: A Guide to Coordinated School Health Programs. New York: Teachers College Press, 1998.

the understandings and skills they need to resist peer pressures to engage in health-risky behavior. We can prevent much of the disease burden that is associated with poor health behaviors by exposing young people to such understandings and skill development. Growing Healthy, which has been recognized as a promising program for Safe, Disciplined and Drug-Free Schools by the U.S. Department of Education, is especially valuable in this effort because it is one of the few school-based programs that can easily be integrated into other subject areas, allowing students to create, apply, and use knowledge gained in many different situations. In addition to meeting all of the National Health Education Standards,<sup>10</sup> our curriculum meets a generous number of performance objectives in other major subject areas, including Social Studies, Science, Literacy, and Language Arts. Yet, despite the existence of promising and effective programs such as NCHE's Growing Healthy, which can not only improve students' health and reduce their participation in harmful activities, but also improve their language and computational skills, health education is often tacked on, taught by teachers with little or no background in health, and taught with few or no resources.11

As the chief executive officer of a non-profit entity, parent, and American who has become alarmed by the prevalence of these problems and doing something about them, I know that most schools, most educators, and most communities in America are woefully unprepared to help young people avoid the costly consequences of poor health decisions and complex health problems. Schools look to the states for help with teacher training, curriculum development and selection, and obtaining resources for health education. State-level capacity in the education departments to support such local school programming has been seriously eroded in recent years. Despite generous tobacco settlements and rising rates of obesity and Type II diabetes among youth, fewer than half the states support implementation of school health education programs that target tobacco and promote physical activity and good nu-trition because they do not have access to CDC infrastructure funds. This is unfor-tunate because we know that smoking, lack of exercise, and lack of a sound diet constitute the three major risk factors for several chronic diseases.<sup>12</sup>

Although many Federal and state programs exist to provide basic services such as immunization, nutritious meals, and physical education programs, most are frag-mented and uncoordinated. Funds for such programs come from a variety of Federal agencies—Education, Agriculture, Health and Human Services. Yet, fewer than half of America's schools have the capacity to review, prioritize, and coordinate the di-verse programs and services that are available. Expanded funding authorized by Congress could help states strengthen their efforts to establish and replicate local school-community partnership with state education departments and state public health agencies, as well as organizations in the private sector, to develop and sustain coordinated—rather than piecemeal—school health programs. Coordinated school health programs provide youth with the information and skills, environmental changes, parent and teacher education, and other resources to avoid risky behaviors.<sup>13</sup> In addition, expanded funding would enable CDC to continue moni-toring risk behaviors among youth and thus document progress toward meeting the national health promotion and disease prevention objectives for the nation.

For example, in Rhode Island, the State Department of Education has developed a partnership with Kids First, a community-based agency dedicated to improving the health and education of children. Together, they have provided nutrition education in schools throughout the state, and helped to address risk factors related to physical activity and obesity. From May 1998 through September 2000, Rhode Island provided nutrition services and programs to more than 40,000 children and their parents, 2,100 teachers, and 700 school food-service staff in more than 220 schools. Through its nutrition-education program, Rhode Island is helping its young people establish healthy eating habits at an early age and thus reducing their risk for devastating chronic diseases both now and later in life.14

<sup>&</sup>lt;sup>10</sup>Joint Committee on National Health Education Standards. Achieving Health Literacy: An

 <sup>&</sup>lt;sup>11</sup>Kann L, Brener ND, Allensworth DD. Health education: Results from the school health policies and programs study 2000. Journal of School Health. 2001; 71:266–278.
 <sup>12</sup>U.S. Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion. Unrealized Prevention Opportunities: Reducing the Health and Economic Burden of Chronic Disease. Atlanta: U.S. Department of Health and Human Services, Dublic Mealth 2007.

Economic Burden of Chronic Disease. Atlanta: U.S. Department of Health and Human Services, Public Health Service, March 1997. <sup>13</sup>Marx E, Wooley SF, Northrop D, Eds. Health is Academic: A Guide to Coordinated School Health Programs. New York: Teachers College Press, 1998. <sup>14</sup>U.S. Centers for Disease Control and Prevention. Division of Adolescent and School Health. Programs that Work. www.ced.gov/nccdphp/dash/rtc/index.htm. April 13, 2002.

Similarly, in Illinois, the Cook County Department of Public Health has utilized a CDC school health program infrastructure grant to fund a bold initiative to bring about systemic change in an effort to improve child health in an economically depressed African-American community in south suburban Cook County. With the support of school superintendents and the Illinois Board of Education, two county tax-support of school superinternations and the finite Defined of the state human services agency created The Healthy Schools Partnership. The first activity was to begin implementation of comprehensive, age-appropriate and sequential health instruction. The grant paid for teachers in three schools to receive training to use NCHE's Grow-Ine grant paid for teachers in three schools to receive training to use NCHE's Grow-ing Healthy, and enough curriculum materials for one school year. When the grant ended the following year, the curriculum materials were not able to be purchased. Since then, the school board has established a line item in their budget to continue purchasing the curriculum for all schools, and to maintain teacher training. The school nurse became a Fellow of the American Cancer Society's National School Health Coordinator Leadership Institute Initiative. Empowered by leadership train-ing and with support from the superintendent the school purse has initiated ing and with support from the superintendent, the school nurse has initiated wellness activities for students, their families and staff, and has created an annual event to assure that children are immunized prior to the beginning of the school year.15

The framework for efforts like these and others is simple, but could not have been put into place without CDC funds. That is why the expansion of infrastructure grants to establish school health programming that can effectively promote healthy behavior aimed at preventing tobacco use, fostering physical activity and improving nutrition is so critical. Doing so is especially important if we are to expand such programs in the early grades and in economically disadvantaged communities. In short, implementation of high-quality, comprehensive education by certified health education specialists is critical if we want to make a difference.<sup>16</sup>

education specialists is critical if we want to make a difference.<sup>16</sup> In fiscal year 2002, CDC provided 20 states with support to facilitate coordinated school health programs. These programs resulted in improvements to the health en-vironment in schools, including healthier food choices and tobacco-free schools, deliv-ery of effective health education, and opportunities for physical education that pro-mote the recommended levels of physical activity. Yet, none of these 20 states have had sufficient funds to support implementation of effective programs such as NCUEY: Converte Use the conductive programs for the CDC. NCHE's Growing Healthy, and many states receive no funding. Moreover, the CDC school health program, which was funded at a level of \$9.7 million in fiscal year 2002, is virtually unchanged from the \$9.6 million appropriated in fiscal year 2001, which is about the level of funding that has occurred in the last 10 years. Failure to provide an increase is tantamount to sliding backwards. With increased dollars, CDC would be able to increase funding to 2 of the cur-

rently funded states to establish physical activity, nutrition, and tobacco evaluation programs; fully fund the remainder of the 18 existing states; and fund an additional 6-9 states to do what Illinois and Rhode Island have begun to do. This would result in a total of 27–30 states receiving funding. These funds would foster critical part-nerships between departments of education and health and other related agencies in states, allowing high-level, state-directed coordination across programs. This would help ensure that students not only receive effective health instruction in nuhealth services, quality physical education, nutritious school meals, and counseling and social services that, when integrated into a coordinated school health program,

and social services that, when integrated mode coordinated school health programs, can contribute to students' overall learning and academic success. In addition to enabling CDC to provide infrastructure support for school health programs in additional states, funding for CDC's coordinated school health initiative can serve as a foundation for other Federal categorical funding programs as well as state-specific funding. For example, in Tennessee, coordinated school health fund-ing provided the basis for a \$1 million appropriation from the state legislature for school health in rural, underserved areas. In states that also receive the CDC school health funding, coordination of various categorical programs eliminates duplication of services, more effectively allows states to leverage resources to fill gaps, and maximizes each program's effectiveness by ensuring that students receive consistent messages and exposure across programs and services.

I am not alone in my view that we need to do this. Independent surveys have consistently demonstrated that the public supports school health programs; a recent Gallup poll found 7 of 10 adults rated health information as important for students

 <sup>&</sup>lt;sup>15</sup> Personal communication with Elaine Ricketts, April 14, 2002.
 <sup>16</sup> U.S. Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion. Coordinated school health programs make a difference. Chronic Disease Notes & Reports. Winter 2001; 14(1):6-9.

to learn before graduating from high school.<sup>17</sup> School health programs have the potential to reach 53 million young people in schools across America and have been demonstrated to be cost-effective in promoting healthy behaviors.<sup>18</sup> Thus, we are only scratching the surface of the number of schools in America that should be co-ordinating the implementation of coordinated school health programs and com-prehensive school health education. That is why NCHE supports a fiscal year 2003 appropriation of \$35 million for the CDC DASH school health program, separate from DASH HIV/AIDS funding. In addition to expanding the funding base for co-ordinated school health programs at the state level, this \$25 million increase would help state and local agencies that receive these monies to leverage local tax-based funding to better coordinate the many categorical health education programs that This is an investment in our future. Limiting the burden of chronic disease for

our nation's health care system will pay enormous dividends in Federal dollars saved in coming decades. Improving health outcomes for children and youth can also improve their educational success as students, providing the educational foundation that fosters productive citizens. Finally, ensuring a healthy start for our young peo-ple lessens the eventual physical and emotional burden of chronic disease on our citizens and their families.

In closing, I want to say that I understand the constraints under which all of the agencies of our Federal government must operate. But, I believe that, when it comes to the health of our children, the diagnosis is clear and a treatment is readily at hand. Expanding funding of school health programs is an efficacious and cost-effective prescription for the health of our children, one that will ensure our nation's future.<sup>19</sup> It is a prescription that this committee should write for the American people.

#### PREPARED STATEMENT OF THE MARCH OF DIMES BIRTH DEFECTS FOUNDATION

The March of Dimes is pleased to have the opportunity to submit testimony on behalf of its 1,600 staff and over 3 million volunteers, and share with you the Foundation's federal funding priorities for fiscal year 2003. As you may know, the March of Dimes is a national voluntary health agency founded in 1938 by President Franklin D. Roosevelt to prevent polio. Today, the Foundation works to improve the health of mothers, infants and children by preventing birth defects and infant mortality through research, community services, education, and advocacy. The March of Dimes is a unique partnership of scientists, clinicians, parents, members of the busi-ness community, and other volunteers affiliated with 55 chapters and 263 divisions in every state, the District of Columbia and Puerto Rico.

The statistics on birth defects and developmental disabilities are very disturbing and illustrate a serious health problem facing our nation. Of the four million babies born each year in the United States, approximately 150,000 are born with one or more serious birth defects. Birth defects are the leading cause of infant mortality and responsible for about 30 percent of all pediatric hospital admissions. The lifetime economic costs of caring for infants born in a single year with a serious birth defect have been estimated at \$8 billion. To be more specific, approximately 12 out of 1,000 school children have some discernable level of mental retardation; it has been estimated that as many as 2 in 1,000 children under age 15 may have an autism spectrum disorder; and as many as 2 in every 1,000 children have a moderate to severe hearing impairment in both ears. By adequate funding of the programs described below, Congress can take a significant step towards improving the health of mothers, infants and children.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the CDC began operation a year ago with the mission to improve the health of children and adults by preventing the occurrence of birth defects and developmental disabilities; and promoting health and wellness among children and adults with disabilities. The March of Dimes urges this Subcommittee to increase funding for the Center to \$115 million in fiscal year 2003. This modest increase of \$25 million will

<sup>&</sup>lt;sup>17</sup>Marzane R, Kendall J, Cicchinelli L. What Americans believe students should know, a survey of U.S. adults. 1999: Aurora, CO: McREL. <sup>18</sup>Collins J, Robin L, Wooley S, Fenley D, Hunt P, Taylor J, Haber D, Kolbe L. Programs-that-work: CDC's guide to effective programs that reduce health-risk behavior of youth. Journal of School Health. 2002; 72:93–99. <sup>19</sup>U.S. Centers for Disease Control and Prevention. Healthy Youth: An Investment in Our Na-tion's Future, 2002 [At-a-Glance]. Atlanta: CDC, 2002.

provide the resources necessary to expand the following activities supported by the Center.

# Regional Centers for Birth Defects Research and Prevention

NCBDDD currently funds regional "Centers for Birth Defects Research and Prevention" in Arkansas, California, Iowa, Massachusetts, New Jersey, New York, and Texas. Each center receives approximately \$900,000 per year. The March of Dimes recommends adding \$6 million (\$12.3 million total funding) to the budget for these regional centers. This increase will allow these centers to expand and intensify their groundbreaking research on genetic and environmental causes of birth defects. These seven centers and the eighth site at the CDC participate in the National Birth Defects Prevention Study, one of the largest studies ever conducted on the causes of birth defects. Each center has been collecting information about "cases" that have a major birth defect and "controls" which are infants with no birth de-fects. The mothers of both "case" and "control" infants complete an extensive telephone interview about their pregnancy and medical history, occupational and envir ronmental exposures, lifestyle, diet, and medication use. These centers are also collecting cells from cheek swabs which are used to study genetic factors. Now, with 5 years worth of information collected, these data are being used in studies that will help identify the causes of birth defects. For example, the current studies focus on the effectiveness of various methods for the primary prevention of birth defects, the teratogenicity of various drugs, the environmental causes of birth defects, and the genetic factors that make people susceptible to birth defects, the behavioral causes of birth defects, and the costs associated with birth defects. This is exciting, leading edge research that merits additional support.

## State Cooperative Agreements to Improve Birth Defects Tracking

NCBDDD also funds the development, implementation, and expansion of state birth defects tracking systems, programs to prevent birth defects, and activities to improve access to health services for children with birth defects. CDC is now funding 28 cooperative agreements ranging in size from \$100,000 and \$200,000 a year for each of 3 years. The March of Dimes encourages the Subcommittee to add \$3.4 million (\$7.5 million total funding) to state-based birth defects surveillance activities. As you may be aware, resources have not been adequate to fund all the states seeking CDC assistance. These additional resources are needed to help all the states seeking CDC assistance and to increase the level of assistance to states already receiving support.

#### Folic Acid Education Campaign

Tracking and research are needed to develop and implement programs to prevent birth defects and developmental disabilities. Currently, NCBDDD is conducting a national education campaign designed to increase the number of women taking folic acid daily. Each year, an estimated 2,500 babies are born with neural tube defects (NTDs). NTDs are birth defects of the brain and spinal cord, including anencephaly and spina bifida. CDC estimates that the annual medical care and surgical costs for persons with spina bifida in the United States exceed \$200 million, and that up to 70 percent of NTDs could be prevented if all women of childbearing age consume 400 micrograms of folic acid daily, beginning before pregnancy. As a result of fortification of the grain supply with folic acid and increased educational outreach programs, CDC reports the rates of NTDs are down 19 percent since 1996. Increased funding will allow CDC to expand its folic acid campaign to reach more women of childbearing age and their health care providers. The March of Dimes recommends an appropriation of at least \$5 million for fiscal year 2003 to promote this lifesaving intervention.

#### ADDITIONAL CDC PROGRAMS

## National Immunization Program

CDC's National Immunization Program provides grants to all 50 states to reduce the incidence of disability and death resulting from vaccine preventable diseases. The March of Dimes encourages the Subcommittee to approve an fiscal year 2003 appropriation of \$696 million for the National Immunization Program. Increasing the funding by \$65 million over fiscal year 2002 (\$20 million increase for operations/ infrastructure grants awards to states and \$45 million increase for the purchase of vaccines) would help ensure that those in need of immunizations receive them and we are able to meet our goals of vaccinating 90 percent of children and adults.

## Polio Eradication

The March of Dimes was founded to find ways of preventing poliomyelitis. Although success in developing the Salk and Sabin vaccines enabled the Foundation to take on a new set of challenges, we continue to support completing the task of polio eradication worldwide. Global polio eradication will save lives and reduce unnecessary health-related costs. The March of Dimes supports a funding level of \$106.4 million for CDC's fiscal year 2003 global polio eradication activities. If approved, the additional \$4 million would help cover the costs associated with a 33 percent increase in the price of the polio vaccine in 2001 that has reduced the amount of doses that CDC has been able to procure.

#### NATIONAL INSTITUTES OF HEALTH (NIH)

In keeping with this Committee's 5-year goal of doubling funding for the National Institutes of Health, the March of Dimes supports the President's proposed \$27.3 billion appropriation for NIH in fiscal year 2003. However, the Foundation is concerned with some allocations recommended by the Administration and suggests the following adjustments.

## National Institute for Child Health and Human Development (NICHD)

The mission of NICHD is closely aligned with that of the March of Dimes. The Foundation recommends an increase of 16 percent for NICHD, bringing total funding for this Institute to \$1.296 billion. With this increase in funding, NICHD could expand research in several areas that are crucial to the health of mothers and children. Additional funds would permit expansion of research into the causes of birth defects, and also the causes of prematurity. Increased funding would also enable NICHD to accelerate the timetable for implementing a much-needed analysis of environmental influences on child health and development that will be conducted as part of the National Children's Study authorized by the Children's Health Act of 2000.

#### National Human Genome Research Institute

Finally, the March of Dimes supports the important work of the National Human Genome Research Institute. The Human Genome Project has identified the sequence of DNA comprising human genes, but this is just the beginning; now, researchers are working to identify every gene, learn their functions, learn how they contribute to disease and determine what can be done to prevent and treat disease more effectively. Obviously, with the enormity of the task ahead, additional funding would expedite the remaining work associated with this proposal. The Foundation supports the President's requested funding level for the National Human Genome Research Institute and urges the committee's support.

## HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA)

#### Maternal and Child Health Block Grant

The Maternal and Child Health (MCH) block grant funds community-based services such as home visiting and respite care for children with special health care needs. MCH complements Medicaid and the State Children's Health Insurance Program by providing "wrap-around" services and by targeting underserved areas. The March of Dimes recommends fully funding the block grant at the authorized level of \$850 million. Additional funding would enable states to expand prenatal and infancy home visitation programs, a proven prenatal care strategy that helps improve birth outcomes. The 900,000 children with special health care needs who use MCH services would also benefit as increased resources would enable states to raise spending limits for durable medical equipment, home visiting, respite care, physical and occupational therapy visits, and other supportive health services.

#### Newborn Screening

One of the great advances in preventive medicine has been the introduction of newborn screening. Newborn screening is a public health activity used to identify certain genetic, metabolic, hormonal and/or functional conditions in newborns. As the Committee members know, such disorders, if left untreated, can cause death, disability, mental retardation and other serious problems. Although nearly all babies born in the United States undergo newborn screening tests for genetic birth defects, the number and quality of these tests vary from state to state. The March of Dimes recommends that every baby born in the United States receive, at a minimum, a core set of 10 screening tests.<sup>1</sup> The March of Dimes proposes an appropriation of \$25 million to support HRSA's

The March of Dimes proposes an appropriation of \$25 million to support HRSA's work with states to implement the heritable disorders (newborn screening) program authorized in Title XXVI of the Children's Health Act of 2000. This program is designed to strengthen states' newborn screening programs; to improve states' ability to develop, evaluate, and acquire innovative testing technologies; and to establish and improve programs to provide screening, counseling, testing and special services for newborns and children at risk for heritable disorders.

In addition, the March of Dimes is deeply concerned that the President's fiscal year 2003 budget proposal eliminates funding for the Universal Newborn Hearing Screening program at HRSA. There is clear evidence that children who are identified early and receive intensive early intervention perform as much as 20–40 percentile points higher than children who do not receive such intervention on school related measures (reading, arithmetic, vocabulary, articulation, percent of the child's communication understood by non-family members, social adjustment and behavior) than children who do not receive such early intervention. This program is funded at a level of \$10 million this year. The Foundation recommends a \$1 million increase to \$11 million for fiscal year 2003.

## Consolidated (Community) Health Centers

The March of Dimes also supports the Consolidated (Community) Health Centers program because these centers are an important source of obstetric and pediatric care for nearly 11 million individuals, 4.5 million of whom are uninsured. The Foundation would like to be on record in support of additional funding sufficient to increase both the number of Centers and to improve the scope of perinatal services offered. Additional funds would be consistent with the President's 5-year plan to create new or expand health center sites in 1,200 communities and increase the number of patients served annually to more than 16 million.

#### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

The March of Dimes is deeply concerned by the President's proposed \$48 million cut in funding for the Agency for Healthcare Research and Quality (AHRQ). AHRQ supports research designed to improve the quality of healthcare, reduce its cost, improve patient safety, decrease medical errors, and broaden access to essential health services. If approved, this decrease in funding would endanger the completion of many vitally important studies on children's health. Two examples specifically related to the mission of the March of Dimes are a study focusing on racial/ethnic variations in managing prematurity and infant mortality and the development of quality-of-care measurements for high-risk (very low birthweight) infants. The March of Dimes supports a fiscal year 2003 budget allocation of \$390 million for the Agency for Healthcare Research and Quality, a \$90 million increase over fiscal year 2002 and a \$138 million increase above the President's budget request. The research conducted by AHRQ is more relevant and more needed than ever.

Thank you for the opportunity to testify on the programs of highest priority to the March of Dimes. The staff and volunteers of the March of Dimes look forward to working with members of the Subcommittee to improve the health of mothers, infants and children.

#### PREPARED STATEMENT OF ROTARY INTERNATIONAL

Rotary International appreciates this opportunity to submit testimony in support of the polio eradication activities of the U.S. Centers for Disease Control and Prevention (CDC). The effort to eradicate polio has been likened to a race—a race to reach the last child. As in any race, discipline, commitment, and endurance are indispensable elements of success. This race requires the discipline to remain focused on the task at hand. We cannot allow ourselves to become complacent as we approach the finish line. Though we sense victory is near, a single misstep could jeopardize all we have accomplished. This race requires the commitment to make the sacrifices necessary to achieve success. The major partners in the global polio eradication effort have joined with national governments around the world in an unprece-

<sup>&</sup>lt;sup>1</sup>The March of Dimes recommends that every baby born receive the following ten newborn screening tests: phenylketonuria (PKU); congenital hypothyroidism, congenital adrenal hyperplasia (CAH); biotinidase deficiency; maple syrup urine disease; galactosemia; homocystinuria; sickle cell disease; medium-chain acyl-CoA dehydrogenase (MCAD) deficiency; and hearing screening.

dented demonstration of commitment to this historic public health goal. As the initiative runs its course, total victory can only be guaranteed through continued and unwavering commitment to the goal of a polio-free world. This race requires the endurance necessary to maintain our current activities. We cannot allow the great distance we have traveled to diminish our resolve. Though we may be weary from a race that has now lasted years, our adversary is weakening. The victory over polio is closer than ever!

Rotary International is extremely grateful for the committee's tremendous commitment to this effort. Without your support of the CDC's polio eradication activities, the battle against polio would be impossible.

The global eradication strategy is working. In 1985, when Rotary began its PolioPlus Program, 125 nations around the world were polio-endemic. At the end of 2001, only 10 countries remained polio-endemic. The Western Hemisphere has now been polio-free since 1991, and the Western Pacific region was certified poliofree in October of 2000. The European Region is expected to be certified polio-free later this year. Today polio is confined only to seven African countries and three countries of South Asia (Exhibit A).

Thanks to polio eradication efforts, more than four million children who might have been polio victims are walking and playing normally. Tens of thousands of public health workers have been trained to investigate cases of acute flaccid paralysis and manage massive immunization programs. Cold chain, transport and communications systems for immunization have been strengthened. A network of 147 polio laboratories has been established to analyze suspected cases of polio and monitor transmission of polio. This network will continue to support the surveillance of other diseases long after polio has been eradicated.

Although we are running the final miles of the race against polio, significant challenges lie before us. Continued political commitment is essential in polio endemic countries, to support the acceleration of eradication activities, and in donor countries, so that the necessary human and financial resources are made available to polio-endemic countries. Access to children is needed, particularly in countries affected by conflict. Truces must be negotiated if National Immunization Days (NIDs) are to proceed in these countries. Polio-free countries must maintain high levels of routine polio immunization and surveillance. The continued leadership of the United States is critical if we are to overcome these challenges.

Since 1985, Rotary International, a global association of more than 30,000 Rotary clubs, with a membership of over 1.2 million business and professional leaders in over 160 countries, has been committed to battling this crippling disease. In the United States today there are some 7,500 Rotary clubs with nearly 400,000 members. All of our clubs work to promote humanitarian service, high ethical standards in all vocations, and international understanding. Rotary International stands beside the United States Government and governments around the world to fight this disease by providing local volunteer support of National Immunization Days, raising awareness about polio eradication, and contributing significant financial support for the initiative. In 2002, members of Rotary clubs around the world have committed to raising an additional U.S. \$80 million beyond the over U.S. \$460 million already committed to ensure the goal of global polio eradication is achieved. Rotary International firmly believes that that the vision of a world without polio can be realized and that the time for action is now.

national firmly believes that that the vision of a world without point can be realized and that the time for action is now. In the United States, Rotary has formed the United States Coalition for the Eradication of Polio, a group of committed child health advocates that includes Rotary, the March of Dimes Birth Defects Foundation, the American Academy of Pediatrics, the Task Force for Child Survival and Development, the United Nations Foundation, and the U.S. Fund for UNICEF. These organizations join us in expressing our gratitude to you for your staunch support of the international program to eradicate polio. Over the past several years, you have steadily increased your appropriation for the polio eradication activities of the Centers for Disease Control and Prevention, and for fiscal year 2002 you appropriated a total of \$102.4 million for the CDC's overseas polio eradication efforts. This investment has made the United States the leader among donor nations in the drive to eradicate this crippling disease.

## FISCAL YEAR 2003 BUDGET REQUEST

For fiscal year 2003, we respectfully request that you provide \$106.4 million for the targeted polio eradication efforts of the Centers for Disease Control and Prevention—a \$4 million increase from the fiscal year 2002 funding level. This \$4 million increase is necessary to respond to the rising cost of oral polio vaccine, which has increased by about 33 percent since 1999. In addition, we must continue to meet the enormous costs of eradicating polio in its final stronghold—sub-Saharan Africa. The underdeveloped and conflict-torn countries of Africa represent the greatest challenges to the success of the global Polio Eradication Initiative. This appropriation will allow the CDC to help African nations accelerate polio eradication activities, improve surveillance for polio and other diseases, and support peace-building ceasefires for National Immunization Days. Without the additional \$4 million, we may not be able to purchase sufficient levels of oral polio vaccine, prolonging the need to continue expensive NIDs and routine immunization worldwide. The time for the final assault against polio is now.

In 1998 the Chairman of the House Committee on International Relations commissioned the General Accounting Office to investigate the soundness of WHO cost estimates for the eradication or elimination of seven infectious diseases. The United States was a major force behind the successful eradication of the smallpox virus, and the GAO concluded that the eradication of smallpox has saved the United States some \$17 billion to date. Although polio-free since 1979, the United States' public and private sectors currently spend about \$350 million annually to protect its newborns against the threat of importation of the poliovirus, in addition to its investment in international polio eradication. Globally, over \$1.5 billion U.S. 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, the possibility of discontinuing polio vaccination and applying the resources elsewhere can be considered.

#### PROGRESS IN THE GLOBAL PROGRAM TO ERADICATE POLIO

Thanks to your leadership in appropriating funds, the international effort to eradicate polio has made tremendous progress.

- —Since the global initiative began in 1988, more than 4 million children in the developing world, who otherwise would have become paralyzed with polio, are walking because they have been immunized.
- -The number of polio cases has fallen from an estimated 350,000 in 1988-of which 35,000 were reported-to less than 1,000 in 2001 (Exhibit B). More than 200 countries and territories are polio-free, including 4 of the 5 most populous countries in the world (China, United States, Indonesia and Brazil). Bangladesh, the world's eighth most populous country, experienced its first year without polio in 2001.
- without polio in 2001. —Almost 2 billion children worldwide have been immunized during NIDs in the last 5 years, including 150 million in a single day in India.
- -Less than 1,000 confirmed polio cases were reported to WHO for 2001. As a result of routine polio immunization, NIDs and house-to-house mopping-up activities, there has been a 99 percent decline in reported polio cases since 1988.
- Of the three types of wild poliovirus, Type 2 has not been seen since October of 1999, and appears to have been eradicated.
- —All polio-endemic countries in the world have conducted NIDs. The achievement of successful NIDs and implementation of Acute Flaccid Paralysis (AFP) surveillance in Somalia and Sudan shows that polio eradication strategies can be implemented even in countries affected by civil unrest.

#### THE ROLE OF THE U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION

Rotary commends the CDC for its leadership in the global polio eradication effort, and greatly appreciates the Subcommittee's support of the CDC's polio eradication activities. For 2002, the Subcommittee appropriated a total of \$102.4 million for the CDC's global polio eradication activities. Because of Congress' unwavering support, in 2001 the CDC is:

- -Supporting the international assignment of more than 110 long-term epidemiologists, virologists, and technical officers to assist the World Health Organization and polio-endemic countries to implement polio eradication strategies, and 16 technical staff to assist UNICEF and polio-endemic countries. This includes 30 CDC staff on direct assignment to WHO and UNICEF.
- —Providing nearly \$60 million to UNICEF for approximately 590 million doses of polio vaccine and \$9 million for operational costs for NIDs in some 60 countries in Asia, Eastern Europe, the Middle East and Africa. A 33 percent increase in polio vaccine costs in 2001 has reduced the number of doses that can be procured with CDC funds. Many of these NIDs would not take place without the assurance of the CDC's support.
- providing over \$16 million to WHO for surveillance, technical staff and NIDs' operational costs, primarily in Africa. As successful NIDs take place, surveil-

lance has emerged as a critical need to determine where polio cases continue to occur. Effective 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 and public health laboratory support. The CDC's Atlanta laboratories serve as a global reference center and training facility.
- -Providing the largest volume of both operational (poliovirus isolation) and technologically sophisticated (genetic sequencing of polio viruses) lab support to the 147 laboratories of the global polio laboratory network. CDC has the leading specialized polio reference lab in the world.
- Spectralized point relative that in the world. Serving as the primary technical support agency to WHO on scientific and programmatic issues regarding: (1) laboratory containment of wild poliovirus stocks following polio eradication, and (2) when and how to stop polio vaccination worldwide following global certification of polio eradication in 2005.

#### OTHER 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 vaccinepreventable infectious diseases. Already, with the exception of one country (Venezuela), Latin America is free of measles, due in part to improvements in the public health infrastructure implemented during the war on polio. The disease surveillance system—the network of laboratories and trained personnel established during the Polio Eradication Initiative—is now being used to track measles, rubella, yellow fever, meningitis, and other deadly infectious diseases. NIDs for polio have been used as an opportunity to give children essential vitamin A, which, like the polio vaccine, is administered orally. 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. Additionally, the unprecedented cooperation between the public and private sectors serves as a model for other public health initiatives. Polio eradication is the most cost-effective public health investment, as its benefits accrue forever.

#### RESOURCES NEEDED TO FINISH THE JOB OF POLIO ERADICATION

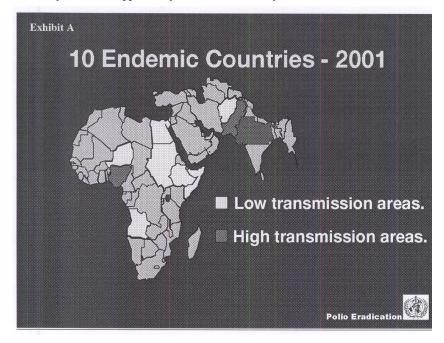
The World Health Organization estimates that \$1 billion is needed from donors for the period 2002–2005 to help polio-endemic countries complete the polio eradication strategy. Great strides have been made in meeting the financial requirements of the polio eradication initiative, but it will take the continued political and financial commitment of both donor nations and polio-endemic countries to overcome the challenges posed in these final years. In the Americas, some 80 percent of the cost of polio eradication efforts were borne by the national governments themselves. However, as the battle against polio is taken to the poorest, least-developed nations on earth, and those in the midst of civil conflict, many of the remaining polio-endemic nations can contribute only a small percentage of the needed funds. In some countries, up to 100 percent of the NID and other polio eradication costs must be met by external donor sources. We are asking that the United States continue to take the leadership role in supporting the polio eradication initiative.

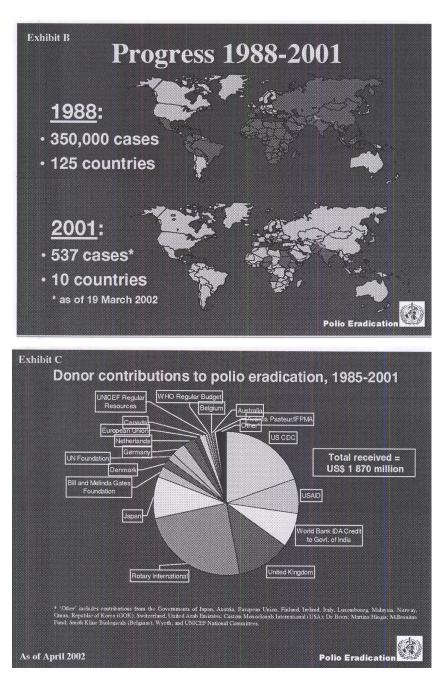
The United States' commitment to polio eradication has stimulated other countries to increase their support (Exhibit C). Thanks to the leadership of the United States government, the per capita contributions to the global polio eradication initiative of several countries, including the United Kingdom, The Netherlands, and even the tiny country of Luxembourg now exceed \$1. Other countries that have followed America's lead and made special grants for the global Polio Eradication Initiative include Japan, which has expanded its support to polio eradication efforts in Africa. Germany has made major grants that will help India eradicate polio. In 2001 the United Kingdom announced two multi-year grants totaling U.S. \$135 million for polio eradication efforts in India and have committed to providing an additional U.S. \$70 million in global funds. Since May 2000, the Netherlands has committed \$110 million for global polio eradication.

By the time polio has been eradicated, Rotary International expects to have expended more than \$500 million on the effort—the largest private contribution to a public health initiative ever. Of this, \$462 million has already been allocated for polio vaccine, operational costs, laboratory surveillance, cold chain, training, and social mobilization in 122 countries. 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.

Your discipline, commitment and endurance have brought us to the brink of victory in the great race against this ancient scourge. Polio cripples and kills. It deprives our children of the capacity to run, walk and play. Other great health crises loom on the horizon. The work you have done and that which we ask you to continue will ensure that today's children possess the strength and vitality to run the race on behalf of future generations.

Thank you for this opportunity to submit testimony.





## PREPARED STATEMENT OF THE NATIONAL COALITION OF STD DIRECTORS

The National Coalition of STD Directors is a coalition of directors of state and local STD programs and is dedicated to reducing the incidence of sexually trans-

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mitted disease in the United States and territories. NCSD provides national leadership in the development of responsible public policies to achieve this goal. One of the challenges that we in the STD community face when asking for resources is that the term STD is almost a misnomer. When we speak about STD, we speak of not just one disease, but many—each with its own clinical course, its own treatment and its own consequences. Our budget request for \$247.4 million—an \$80 million increase—for fiscal year 2003 reflects some of the public health fronts of STDs. Our two top STD priorities for fiscal year 2003 are infertility/chlamydia preven-

Our two top STD priorities for fiscal year 2003 are infertility/chlamydia prevention and syphilis elimination. The reasons are summarized below and expanded upon in the following pages.

- --Chlamydia is the number one most commonly reported disease in the United States--eople contract chlamydia each year; the annual cost of direct treatment for chlamydia is nearly \$400 million.
- -Although preventable and curable, chlamydia is the leading cause of infertility among women.
- -After a decade of decline, rates were on the increase in 2001. This increase can be seen in almost every region of the country.
- -With current programs in place we are reaching only 28 percent of women at risk in our 30 most populous states. In the remaining 20 states, we reach 50 percent of women at risk.
- Provent of women at risk. –NCSD is asking for a \$13 million increase for syphilis elimination; if this figure is reduced or diluted, then syphilis elimination cannot and will not be achieved and CDC will be forced to abandon the National Plan to Eliminate Syphilis.
- —Syphilis elimination is a time sensitive effort and needs to be done when rates are low and we are right now at a historic low. The current window is closing as we are once again seeing an increase in syphilis outbreaks in a few areas of the country. History teaches us that our next chance to eliminate syphilis will not be for another 10 years. Resources are needed now. Otherwise, next year we will be talking about syphilis control, not syphilis elimination.

## INFERTILITY PREVENTION

The Infertility Prevention Program (IPP) is a CDC demonstration project that has become an STD success story. In the areas where it has been implemented, this program has been hugely successful in reducing rates of chlamydia—the chief cause of infertility in the United States—and has increased the extent of chlamydia screening and treatment services available to women who were in need of such but had little or no access to it.

According to the CDC, chlamydia has become the most frequently reported infectious disease in the United States and a primary cause of infertility among young women. We know with some precision the extent to which this effort is cost effective: for \$1 spent on screening and treatment of chlamydia, we save \$12 in complications that result from untreated chlamydia. In the northwestern United States, where the Infertility Prevention Program began, chlamydia rates have dropped by 62 percent over 5 years; in the Mid-Atlantic States, the number of new cases declined by one-third. However, in the rest of the country, current resources only allow for the testing of less than 20 percent of women who present at STD and family planning clinics.

A new generation of laboratory test provides us with a more powerful tool to identify more of these infections. New technologies allow us to test people at high risk who are less likely or unable to come to clinics. Although these new technologies are not cheap, they allow us to expand the testing net and identify many cases that would previously have gone undetected.

#### Request for Infertility Prevention—\$41.5 million increase

Expand chlamydia screening to 75 percent of at-risk women in each of 65 CDCfunded STD project areas across the United States, conduct applied research to enhance chlamydia and gonorrhea screening and prevention and enhance gonorrhea screening and surveillance activities across the United States.

## SYPHILIS ELIMINATION

Among the array of unique STDs, syphilis is singular for the following reason: with the exception of a few isolated pockets, it is now virtually non-existent in most areas of the country and we stand poised on the brink of eliminating this scourge. However syphilis control is not a success story. Rather, the fact that it still is prevalent in a number of areas highlights a glaring failure in the American public health system and illustrates the gaps in our capacity to control infectious diseases.

This is not the first time we have been at the brink of syphilis elimination. Since the introduction of penicillin and the organization of a national STD control pro-gram in the 1940s, we have stood on this brink not once but several times. Every one of those near-elimination moments has been followed by a national syphilis epidemic, each one more serious than the one before.

demic, each one more serious than the one before. We are currently at a point in time in which the number of reported cases is close to historic lows. These lows signal yet another opportunity to eliminate syphilis. But history has taught us that this will not last—not without a focused national effort and resources. We are beginning to see increased numbers of cases in some cities; use of the Internet is one of several factors. We need to address these without delay. Congress has been very supportive of the CDC's efforts to eliminate syphilis transmission in the United States. The current plan to eliminate syphilis incor-porates the strengths of previous efforts and addresses their shortcomings by spe-cifically including affected communities in creating local solutions.

#### Request for Syphilis Elimination Campaign—\$13.0 million increase

Replicate projects based on the success of demonstration sites located in Nash-ville, TN; Indianapolis, IN; and Raleigh, NC, expand Rapid Response capabilities and establish enhanced surveillance, outbreak response, health promotion, and community involvement to address reemerging syphilis and new increases among Hispanics.

## VIRAL STDS

Viral STDs, like herpes simplex virus (HSV) and human papillomavirus (HPV), virus (HSV), and the united territories for STD programs. Over 45 million Americans—al-most 26 percent of the United State population—are infected with herpes simplex virus (HSV), a treatable but incurable viral STD. We estimate that HSV costs the United States \$208 million in direct medical costs alone each year. An estimated 20 million Americans are infected with HPV, the cause of about 90

percent of all cervical cancer cases. In the United States, we see approximately 14,000 cases of cervical cancer each year and 5,000 deaths. It is estimated that HPV costs the United States \$1.6 billion in direct medical costs alone each year. Thus, primary prevention programs for HPV infections can become a new and powerful tool for cervical cancer prevention. Improved screening and treatment of HSV and HPV is fundamental to reduce the rates of transmission. Enhanced funding will increase the availability of new screening tools and allow for an increase in public and provider awareness campaigns to reduce the spread of HSV and HPV. In 1997, the attendant treatment costs of HPV alone were estimated to be nearly \$4 billion.

Development of primary prevention programs for viral STDs is critical. We need to improve availability and delivery of screening tests; make treatment more avail-able; develop and evaluate model educational and prevention messages; and, test new surveillance methods that can be used by all STD prevention programs nationally.

# Request for Building a Response to non-HIV Viral STDs—\$9.5 million increase

Establish four demonstration projects focusing on health promotion and clinical services for HSV prevention, develop HSV surveillance and evaluation capacity, and applied research on HSV to inform development of national efforts to address non-HIV viral STDs, develop and evaluate HPV educational messages and expand HPV sentinel surveillance efforts.

### STD PREVENTION AND ADOLESCENTS

Adolescents are at an increased risk for STDs due to biology, behavior, and social factors. More than half of teenagers aged 15–19 years are sexually experienced, and more than one quarter of all new cases of STDs occur in adolescents. By age 24, at least one in three sexually active people will have contracted an STD. There are already numerous programs funded through multiple funding streams to explain the sexual section. already numerous programs funded through multiple funding streams to conduct disease and pregnancy prevention interventions among adolescents across parents, medical care providers, schools, media and other domains such as community-based organizations and faith communities. The component that many of these attempts are lacking is the availability of clinical care and laboratory screening services. Promoting health-service-seeking behaviors through targeted education-education that includes abstinence-is not going to be successful unless the services for screening and treatment are readily available.

#### Request for STD Prevention related to Adolescents—\$7.5 million increase

To expand integrated intervention trials for STD approaches among adolescents across parents, medical providers, schools, media, and faith communities to increase access and utilization of health service and facilitate healthier sexual behaviors; increase STD screening of adolescents, and strengthen surveillance activities.

## STD TREATMENT TO ENHANCE HIV PREVENTION

This component of our budget request focuses on the causal link between STD and HIV. A person with a pre-existing STD has a three to five fold greater risk of acquiring HIV/AIDS. A recent study has shown that testing and treating STDs resulted in a 43 percent reduction in HIV rates. Funding earmarked for STD treatment to enhance HIV prevention will assist in establishing five demonstration projects to provide on-site STD screening, treatment, and related services in settings serving HIV infected and at-risk individuals. Without adequate funding, program constraints inhibit these critical joint activities.

## Request for STD Treatment to Enhance HIV Prevention-\$5.5 million increase

Establish five demonstration projects to provide on-site STD screening, treatment, and related services in settings serving HIV infected and at-risk individuals; augment HIV Community Planning Groups to focus on STD data issues, detection, and treatment in project areas with syphilis or gonorrhea rates above the Healthy People 2000 targets; expand community-based organization efforts currently focusing primarily on HIV; expand STD clinical services in HIV treatment and referral facilities to address STD increases among gay men and Hispanics.

#### STRENGTHEN CORE STD SERVICES

One of our most pressing needs is adequate funding for surveillance, treatment and partner referral. While these terms sound benign, and do not seem to have the same urgency as the words "chlamydia" or "herpes", they incorporate our most essential services—testing, treating, training and referrals are cornerstones of STD prevention. We have seen a dramatic rise in the number of people seeking services from our clinics and a drop in our ability to provide them with services. A 1996 CDC survey indicates that less than 50 percent of local health departments in the U.S. provide clinical services for STDs and only 40 percent of existing clinics are able to provide services to clients on the same day they seek care. We know how to deal with most of these diseases but we are hamstrung by lack of funding for our basic services.

# Request to Strengthen Core STD Services—\$3.0 million increase

To establish and expand training and partner services capacity as it relates to the expansion of STD-related services provided in managed care settings. Establish and strengthen health communications, surveillance, evaluation, and applied research related to the most efficient delivery of partner services in different settings including "safety net settings." Establish and expand training and partner services capacity as it relates to the expansion of STD-related services provided in managed care settings.

## PREPARED STATEMENT OF THE UNITED CEREBRAL PALSY ASSOCIATIONS

The United Cerebral Palsy Associations (UCP) is one of the nation's largest disability organizations, serving more than one million Americans annually. UCP appreciates this opportunity to submit our recommendations for Fiscal 2003 appropriations for the Departments of Labor, Health and Human Services, and Education.

Our nation must now pay for a war on terrorism. Yet we also must invest in our citizens with disabilities so they can attain their full potential as citizens and taxpayers. Investing in people with disabilities not only increases their economic productivity but also saves substantial federal funds by avoiding the high costs of institutionalization, welfare dependency, and other inappropriate expenses.

More than 500,000 Americans with CP average \$500,000 each in added lifetime medical costs, plus \$20,000 to \$30,000 annually for non-medical support services such as personal-care attendants (often paid by Medicaid and other government programs). Adults with CP are estimated to average \$300,000 in additional lifetime costs to the federal Supplemental Security Income program. Thus, CP research and prevention have the potential to return many dollars in federal savings for each federal dollar invested.

To summarize, our Fiscal 2003 recommendations (with comparisons to President Bush's Budget and actual Fiscal 2002 funding levels) are:

5	8	6

	Fiscal year		
	2002 actual	2003 President	2003 UCP recommends
Technology State Programs CDC Birth Defects & Developmental Disab. Center (including CP Cen-	60.9	30.9	60.9
ters of Excellence)	90.6	90.0	125.0
Child Care & Development Block Grant	2,090.0	2,090.0	2,190.0
Individs. w/Disabs. Ed Act (IDEA) Pt. B State Grants	7,528.5	8,528.5	9,980.0
Maternal & Child Health Block Grant (Title V)	731.5	731.5	850.0
Social Services Block Grant (Title XX)	1,700.0	1,700.0	2,800.0
Pres. Bush's Respite Care Demonstrations (NEW)		(1)	(1)
Bush's Direct Service Worker (Aide) Demo (NEW)		9.0	(2)
Parents, Inc. (Alaska) (NEW)			3.4
National Health Tracking Network (NEW)			(3)

Note.—All figures are in \$ Millions of Budget Authority. Budget Authority is used because it allows meaningful "apples to apples" multi-year comparisons. It may differ from Outlays due to factors including forward funding and advance appropriations. Sources: President's and agency budgets. <sup>1</sup>\$207 million over 5 years but fiscal year 2003 amount not specified.

<sup>2</sup>See text. <sup>3</sup>See text. <sup>3</sup>If authorizing statute is enacted in fiscal year 2003, funding should be a pro-rata partial-year amount based on a full first-year author-ization of \$127.5 million. This may require an fiscal year 2003 supplemental appropriation.

We will now detail the reasons for our recommendations.

## ASSISTIVE TECHNOLOGY

The Assistive Technology Act of 1998 (ATA) authorizes funding for state programs that make loans to people with disabilities for a variety of equipment that helps them be active, productive citizens. Such items include specialized computers that synthesize speech for people unable to talk, wheelchair lock-in security devices for motor vehicles, and special bathroom and kitchen equipment that accommodates people with disabilities of the arms and legs.

ATA phased in states' participation on a multi-year basis. Because of this phasein, nine states (Arkansas, Colorado, Illinois, Kentucky, Maine, Maryland, Min-nesota, Nebraska and Utah) were scheduled to be "phased out" in fiscal year 2002 and lose all AT funding. The Labor-HHS-Education subcommittees, in conjunction with congressional authorizing committees, continued funding for these states in fiscal year 2002. But if ATA is not re-authorized this year, no fiscal year 2003 AT funding will be provided to those nine states or to fourteen other states: Alaska, Indiana, Iowa, Massachusetts, Mississippi, Nevada, New Mexico, New York, North Carolina, Oregon, Tennessee, Vermont, Virginia, and Wisconsin. President Bush's Budget assumes ATA will not be reauthorized; hence it includes

a \$30 million reduction, which would comprise a 49 percent cut compared to fiscal year 2002. The unemployment rate is 73.9 percent for working-age people with severe disabilities, with consequently high federal costs for income-support programs. UCP believes ATA State grants support the infrastructure that brings together people with disabilities and the assistive technology they need to communicate with their families and fellow workers as well as the ability to transport themselves to work. Without this infrastructure the loans that enable people with disabilities to buy such equipment would go unpublicized. This is a small investment with a very large positive result for people with disabilities.

# CDC NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

This Center, established by the Children's Health Act of 2000, became fully operational in fiscal year 2002. It is essential that this new Center be financially stable for two reasons. First, financial stability is needed to attract highly qualified federal career staff. Second, extramural researchers must be assured that funds will be available for worthy multi-year projects, or else they will turn to non-disability topics.

President Bush's proposed Budget would cut the Center by \$557,000 (exclusive of inflation) and three full-time positions, which would be a step backward. UCP agrees with the Coalition for Children's Health recommendation that fiscal year 2003 funding be \$125.0 million in order to allow the Center to fully implement its

missions under the Children's Health Act of 2000 and other authorizing statutes. Within CDC, we are requesting \$8.5 Million for the Centers for Disease Control to establish six Cerebral Palsy Research and Prevention Centers as extramural research units. This would be a new program. The incidence of cerebral palsy (CP) is increasing, and the more than 500,000 Americans with CP average \$500,000 each in added lifetime medical costs, plus \$20,000 to \$30,000 annually for non-medical support services such as personal-care attendants (often paid by Medicaid and other government programs). Adults with CP are estimated to average \$300,000 in additional lifetime costs to the federal Supplemental Security Income program. Thus, CP research and prevention have the potential to return many dollars in federal savings for each federal dollar invested.

## CHILD CARE AND DEVELOPMENT BLOCK GRANT

For families with young children and monthly incomes under \$1,200, childcare typically consumes 25 percent of income. When children have disabilities, childcare tends to cost an even larger share of income because extra staff training, equipment, and physical accommodations are required. Families of those children need even more help to obtain quality childcare, both in affording the care and in having access to childcare centers that can appropriately serve children with disabilities. For all these reasons, UCP strongly endorses H.R. 2787 which would earmark a percentage of the total CCDBG appropriation for services to children with disabilities. Authorization for the CCDBG will expire on September 30, and is linked to re-

Authorization for the CCDBG will expire on September 30, and is linked to reauthorization of the Temporary Assistance for Needy Families (TANF) program. If Congress substantially changes TANF or CCDBG, that could affect the appropriate level of CCDBG's fiscal year 2003 appropriations. It is clear that President Bush's proposed, "level funding" of \$2.09 billion would be inadequate. It would not keep pace with inflation, let alone address any of the currently unmet need. UCP supports an fiscal year 2003 increase of \$100 million to keep pace with inflation, as proposed in S. 18, S. 1000, H.R 265 and H.R. 2097. Addressing current unmet needs may best be addressed as part of the pending reauthorization.

Childcare is an essential factor in an individual's ability to work. For some parents caring for a child with a disability it may be appropriate to exempt them from TANF work requirements. For others, however, specialized childcare may be the key to opportunities to better the family economically. Childcare is a critical part of that success and needs to be adequately supported at the federal level.

#### INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA) PART B STATE GRANTS

We are pleased that President Bush's Budget increased federal funding of Part B of IDEA to 18 percent. The President, however, has not fulfilled the promise to federally fund 40 percent of the total costs of special education.

Under IDEA local school districts are required to provide special education services to the nation's 6 million children with disabilities. Before IDEA, only 50 percent of children with disabilities received an appropriate education and 20 percent received no schooling. Now almost all children with disabilities receive an appropriate education and their high school graduation rate is steadily increasing. It is improper, however, that the federal government requirement to provide edu-

It is improper, however, that the federal government requirement to provide education for children with disabilities has been under funded by the federal government. This has forced states find billions of dollars from other educational programs. This is of particular concern this year because many state and local education agencies are facing major funding challenges due to both recessionary revenue reductions and the growth of special education costs.

UCP supports fiscal year 2003 funding of \$9.98 billion. This reflects the \$2.45 billion annual increase proposed by the Harkin-Hagel Amendment (SA 360), which passed the Senate in 2001, as well as by S. 466 (which has 30 co-sponsors) and H.R. 1330 (which has 73 co-sponsors).

#### MATERNAL AND CHILD HEALTH BLOCK GRANT

By law, 30 percent of MCHBG funds must be spent for children with disabilities and other special needs; MCHBG also funds prenatal care for many uninsured pregnant women and other services. President Bush's proposed fiscal year 2003 funding level of \$739 million, the same amount as approved for fiscal year 2002, does not keep pace with inflation or population growth.

keep pace with inflation or population growth. When children with "special health care needs," i.e. physical, developmental and behavioral disabilities, lack health insurance coverage, the Maternal and Child Health Block Grant can pay for their required services. In fiscal 2002, approximately 1 million such children are being so served, but approximately 1.6 million such children will not receive needed services for lack of funding.

In addition, MCHBG lacks funds to serve all uninsured pregnant women. Yet women who do not receive prenatal care have a rate of costly low-birthweight babies that is twice that of those who receive regular care.

UCP therefore strongly urges MCHBG be funded at the full authorization level of \$850 million.

#### SOCIAL SERVICES BLOCK GRANT

The Social Services Block Grant (Title XX of the Social Security Act) funds human services, which, in 38 states, includes services for people with disabilities. One example of how these funds are spent is in California where SSBG funds are used to provide direct care workers to support individuals with disabilities. Direct care workers provide people with disabilities assistance in routine matters of daily living, such as dressing and eating.

Since fiscal year 1996, the SSBG program has been cut from \$2.8 billion down to the current \$1.7 billion; a reduction that states have been unable to make up. President Bush's proposed fiscal year 2003 level funding of \$1.7 billion would exacerbate these problems.

Increasing SSBG by 65 percent, to its full \$2.8 billion authorized level, would mean that approximately 369,000 more adults and children with disabilities would receive services through this block grant. (This is based on the assumption that states and localities would continue to allocate their current proportions of SSBG dollars to services for people with disabilities; approximately 570,000 people with disability currently receive SSBG services, according to the HHS Administration on Children and Families.) An increase in SSBG funding is advocated by many Members of Congress, as demonstrated by relevant provisions of S. 501 (28 co-sponsors), S. 1924 (13 co-sponsors), and H.R. 1470 (72 co-sponsors). It also is supported by 80 national organizations including the National Conference of State Legislatures, the National Association of Counties, the U.S. Conference of Mayors, Catholic Charities USA, the United Jewish Communities, and Lutheran Services in America.

#### RESPITE CARE DEMONSTRATIONS

As a continuation of the President's New Freedom Initiative, HHS is proposing three new demonstrations on the mandatory side of the budget at a cost of \$207 million over 5 years (fiscal year 2003 funding level not specified). Two of the demonstrations would provide respite services, one for caregivers of adults with disabilities and the other for caregivers of children with substantial disabilities. The third demonstration would make home and community based waiver services available to children residing in psychiatric residential treatment facilities. Although details on these demonstrations have not been released publicly, we support these demonstrations in principle.

#### DIRECT SERVICE WORKER (ATTENDANT) DEMONSTRATION

Many people with severe disabilities rely on personal attendants to help them perform daily activities such as eating, getting dressed, and using the bathroom. The bulk of these attendant services are paid for by Medicaid, but Medicaid payment rates in most states are very low, typically \$6 to \$10 per hour. And these rates are supposed to pay for not only attendant compensation but also provider agency costs such as recruitment, training, liability insurance, and required paperwork.

such as recruitment, training, liability insurance, and required paperwork. It is not surprising that attendants' wages are typically \$7 to \$9 per hour and that half lack employer-sponsored health insurance. UCP-affiliated providers report attendant vacancy rates of 25 percent to 35 percent, and 100 percent annual turnover rates. UCP Affiliates often must subsidize attendants' Medicaid payments with charitable contributions, and often cannot accept new clients even though the Supreme Court's Olmstead decree requires states to provide such community-based services to people with disabilities whenever feasible.

The shortage of community attendants keeps many thousands of people with disabilities in institutions where the majority of the \$100,000-a-year per-person costs are paid by the federal share of Medicaid spending. Not only is this a costly approach but also it is not in keeping with the Olmstead Supreme Court decision.

We applaud President Bush for proposing a \$9 million demonstration program with the goal of reducing attendant vacancies and job turnover. UCP would, however, strongly urge the Committee to consider a larger demonstration currently being supported by a wide coalition of church groups, labor unions, nursing homes and disability advocates. That 3-year demonstration would provide \$500 million each year to increase wages and benefits for direct support workers and \$100 million to study and publicize best practices in the recruitment, retention and training of direct support workers. The current shortage of direct support workers will only increase as the population ages. It is essential that the workforce be stabilized so that people with disabilities and aged Americans are not vying against each other for an inadequate workforce to care for their most basic needs of daily living.

#### PARENTS, INC. ALASKA

In conjunction with West Virginia, PARENTS, Inc of Alaska is requesting for \$3 million to create a model that increases access to childhood development and early intervention information among parents who are challenged by their abilities and environments. PARENTS, Inc is also asking for:

- -\$1 million to strengthen post-confinement outcomes for Alaskan Native/Indian youth with disabilities in order to build skills in the juvenile justice system;
- \$1 million for a technology in action program which will use technology to develop and deliver customized training systems to accommodate partnerships among Alaskan parents, special education, general education personnel and related services to improve performance of students with disabilities;
- -\$1 million a parent-to-parent mentor and home visitation program expansion; and \$400,000 for capital improvement of the Anchorage Statewide Parent Resource Center.

We thank you for your consideration of our position and look forward to working with the Committee.

# NATIONAL HEALTH TRACKING NETWORK FOR DEVELOPMENTAL DISABILITIES AND BIRTH DEFECTS

Reliable, timely data on the incidence and prevalence of specific diseases and disabilities are essential to determine the extent and causes of these problems and whether preventive measures are effective. Although the government collects such epidemiological data for many infectious diseases, it lacks this information for developmental disabilities such as cerebral palsy, collects data on birth defects such as spina bifida in only a few states, and has similar data limitations for asthma, childhood cancers, neurological diseases, and endocrine disorders.

UCP supports a Nationwide Health Tracking Network to gather epidemiological data on disabilities and non-infectious diseases, as proposed in S. 2054/H.R. 4061 by Sens. Clinton, Reid and Kennedy and Reps. Pelosi and 36 co-sponsors. This legislation would provide state grants to increase tracking of on birth defects, developmental disabilities, asthma, children's cancers, neurological diseases, and endocrine disorders, as well as related financial assistance to CDC and university-based epidemiology programs. The bill would provide an annual authorization level totaling \$127.5 million and has been endorsed by more than 85 groups including Aetna USHealthcare, American Heart Association, American Lung Association, March of Dimes, Breast Cancer Fund, and the United Steelworkers of America.

Dimes, Breast Cancer Fund, and the United Steelworkers of America. Although this legislation has not yet been enacted, UCP believes that the need for it is so critical that, if it is enacted this year, the Subcommittee should consider either funding the full authorized amount as part of a supplemental appropriation or by adding an appropriations amendment to the bill itself.

enture running the full authorized amount as part of a supplemental appropriation or by adding an appropriations amendment to the bill itself. United Cerebral Palsy Associations, Inc. ("UCP") is a Washington D.C.-based notfor-profit corporation incorporated in 1948. The mission of UCP is to advance the independence, productivity and full citizenship of people with cerebral palsy and other disabilities, through its commitment to the principles of independence, inclusion and self-determination. UCP is the leading source of information on cerebral palsy and is a pivotal advocate for the rights of all people with disabilities. UCP and its nationwide network of over 100 affiliates in 40 states strive to ensure the inclusion of persons with disabilities in every facet of society.

#### PREPARED STATEMENT OF THE NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS

The National Alliance of State and Territorial AIDS Directors (NASTAD), whose members are responsible for administering state HIV/AIDS prevention and care programs nationwide, respectfully submits testimony for the record regarding federal funding for HIV/AIDS programs in the fiscal year 2003 Labor, HHS and Education Appropriations legislation. NASTAD appreciates the past support the Committee has given to these programs that are of the utmost importance to Americans living with HIV/AIDS.

NASTAD believes that if we are going to reduce the number of persons being infected with HIV in the coming years and improve access to care and treatment for those Americans suffering with HIV/AIDS, we need to employ a mutil-faceted approach which relies on increased funding for the Title II programs of the Ryan White CARE Act and HIV/AIDS prevention and surveillance programs at the Centers for Disease Control and Prevention (CDC). The deterioration of states' fiscal positions have left numerous state HIV prevention and care programs subject to state spending cuts. Currently, the cumulative state revenue shortfall is \$40 billion and growing, leaving these important programs increasingly vulnerable to significant state funding cuts. NASTAD respectfully requests that the Labor, HHS, and Education Subcommittee ensure the financial vitality of these programs that are integral to reducing the number of new HIV infections and to the provision of prevention, care and treatment for response to the growing number of people living with HIV/AIDS.

NASTAD respectfully requests an increase of \$100 million in fiscal year 2003 for HIV prevention and surveillance cooperative agreements with state and local health departments and an increase of \$212 million for state Ryan White CARE Act Title II grants for care and AIDS Drug Assistance Programs (ADAPs).

#### HIV/AIDS PREVENTION, SURVEILLANCE AND RELATED PROGRAMS

The President's goal, as articulated in his fiscal year 2003 budget, of reducing the number of new infections 50 percent by 2005, cannot be achieved without a sufficient funding commitment on the part of the federal government.meeting the growing needs of our communities to respond effectively to the increased numbers of new infections each year. State and local health departments play an integral role in not only reducing the number of new infections, but also increasing the number of people who know their HIV status and linking infected individuals to prevention, care and treatment services—all of which are goals of the CDC strategic plan. State and local health departments between the changing face of the epidemic by working closely with affected communities through the HIV prevention community planning process and by building capacity and support for community-based organizations responding to the epidemic in their communities. To build on these successes and achieve the President's and CDC's goals, state and local health departments need more resources. As it stands, state and local HIV prevention programs funded by CDC receive less than half of the funds Congress allocates for HIV prevention programs.

NASTAD respectfully requests a funding increase of \$70 million for HIV prevention cooperative agreements with state and local health departments. We strongly believe this is a sound investment for the Subcommittee, as the reduction in new infections will save lifetime treatment costs. The increased resources will allow states to strengthen their science-based programs to target prevention interventions to HIV-infected persons to promote the adoption of behavior change to avoid further transmission; to expand faith-based initiatives; to reach partners of HIV-infected individuals and refer them into care; to provide capacity building and technical assistance, especially for administrative management, to community-based organizations; and to target outreach and HIV counseling and testing efforts that focus on populations at high-risk of infection including highly-impacted racial and ethnic minority communities, young gay men of color, substance abusers, women and youth in highrisk situations.

NASTAD also respectfully requests an increase of \$30 million in fiscal year 2003 for HIV/AIDS surveillance cooperative agreements with state and local health departments to strengthen HIV and AIDS case reporting, supplemental surveillance activities, seroepidemiology, behavioral surveillance, incidence modeling, and evaluation.

NASTAD also respectfully requests an increase of \$159 million for the Minority HIV/AIDS Initiative (MHAI) in fiscal year 2003. The MHAI provides targeted resources to address the growing HIV/AIDS epidemic and its disproportionate impact upon communities of color. State and local health departments view these additional resources as essential to reducing new infections in communities of color, by building the capacity of minority community-based organizations to tailor strategies that most effectively meet the needs of their communities.

most effectively meet the needs of their communities. NASTAD respectfully requests an increase of \$64 million in fiscal year 2003 for viral hepatitis programs at CDC in order to increase the ability of state and local health departments to integrate, as appropriate, hepatitis prevention, counseling, testing and medical referral services with HIV/AIDS prevention programs and to provide vaccines hepatitis A and B to high-risk adults.

NASTAD respectfully requests an increase of \$80 million in fiscal year 2003 for STD prevention, treatment and surveillance activities undertaken by state and local health departments.

#### HIV/AIDS CARE AND TREATMENT PROGRAMS

The federal government and states have a proven track record of working in partnership to respond to the unmet needs of low-income people living with HIV/AIDS, particularly through the Ryan White CARE Act (RWCA). Although funding for the RWCA has grown substantially over the past 10 years, federal and state funding have not kept up with the growth in demand for services, including the need for HIV/AIDS treatments through the state AIDS Drug Assistance Programs (ADAPs). The RWCA Title II Core program is the only federal funding stream that provides support for comprehensive primary care and essential supportive services for uninsured and underinsured people living with HIV/AIDS whether they reside in urban, suburban or rural communities. The states' RWCA care and treatment programs are safety net programs, being the payer of last resort and providing services to those most in need. With unemployment on the rise, increasing the ranks of the uninsured, states' RWCA programs, particularly ADAPs, are experiencing an increase in those seeking treatment with no other options in health care coverage. Without an infusion of new resources, states will be unable to maintain their existing programs, much less, enroll new clients. Title II Core programs provide an array of essential services including diagnostic,

Title II Core programs provide an array of essential services including diagnostic, viral load testing and viral resistance monitoring, HIV care and treatment for vulnerable at-risk populations, and primary care networks that improve the overall HIV/AIDS care systems in states. Yet these programs continue to experience inadequate funding increases to match the pace of service demand. To sustain existing state HIV/AIDS care and treatment programs and to address the increase in demand for these services, NASTAD respectfully requests a total of \$1.2 billion in fiscal year 2003 for state Ryan White CARE Act Title II grants. This reflects a proposed increase of \$212 million over fiscal year 2002 funding, including an increase of \$50 million for Title II Core programs and a \$162 million increase for ADAPs. The federal/state partnership on ADAPs has significantly contributed to the de-

The federal/state partnership on ADAPs has significantly contributed to the decline in AIDS deaths since 1995. However, the number of people living with HIV is growing, therefore increasing the number of individuals to be served by state ADAPs. This growth is expected to continue due to states' intensive outreach and referral efforts to specifically target communities of color and the underserved. NASTAD's annual assessment of state ADAPs chart continuing growth in the number of clients served by ADAPs and the per client average costs of therapies used by ADAP clients nationwide. Specifically, as of January 2002, ADAPs are serving over 85,000 HIV infected individuals per month nationwide, with an average of 670 new clients per month. NASTAD's request of \$162 million reflects client utilization and program expenditure projections for fiscal year 2003 based on trend data collected over the past 6 years. Of the needed \$162 million increase, \$30 million is necessary just to cover the jump in drug prices due to inflation. We also note that ADAPs have been underfunded for the past two fiscal years and continue to be unable to meet the needs of all those eligible. Several states have been forced to cap or restrict access to drug treatments. In addition, ADAPs continue to use every means necessary to reduce pharmaceutical costs, including participation in the federal 340B drug discount program and the development of innovative cost-saving alternatives such as insurance purchasing programs.

ternatives such as insurace purchasing programs. Using cost estimates published in the literature, it has been projected that to turn the corner on the HIV/AIDS epidemic in this country, an additional investment of \$1.5 billion in HIV prevention funding is needed. Funding of this magnitude would enable our prevention efforts to reach the 5 million individuals in this country estimated to be at serious risk of infection and in need of proven prevention interventions. It has also been estimated that to reach the 300,000 individuals in this country who are HIV infected and unaware of their serostatus through targeted outreach, counseling and testing programs, an additional, sustained investment of \$300 million per year is needed.

As you craft the Labor, HHS, and Education Appropriations legislation for fiscal year 2003, NASTAD respectfully requests that you strongly consider all of these critical funding needs. It is essential that the United States continue to demonstrate its commitment to fighting the ongoing HIV/AIDS epidemic on the homefront and work to ensure that additional resources are available to meet the growing needs of the global HIV/AIDS pandemic. The National Alliance of State and Territorial AIDS Directors thanks the Chairman, Ranking Member and members of the Subcommittee, for their thoughtful consideration of our recommendations.

#### PREPARED STATEMENT OF GALLAUDET UNIVERSITY

Congress has played a vital role in the higher education of deaf people in the United States through 138 years of continuous support for Gallaudet University. Congressional support of Gallaudet represents a commitment to and confidence in the aspirations of individuals with disabilities that is unique in the world. Each year I am grateful to have the chance to discuss with you the opportunities that have been opened to deaf Americans because of Gallaudet University.

I would first like to express my profound appreciation to the Congress for its generous allocation of funding in fiscal year 2002 to support our efforts to upgrade security on the Gallaudet campus. As you know, during the previous year two of our students were tragically murdered and a third was arrested for these horrifying crimes. Because of these terrible events, we did a painstaking review of our campus security systems. We determined that, although our campus was very safe and our crime rate was quite low, we needed do everything in our power to ensure that events like this never happen again. If Gallaudet University is to flourish, we must be able to demonstrate to current and prospective students and their families that our campus is safe and secure, and this means that there had to be a substantial increase in the resources devoted to safety and security. Because of Congress's generosity, we have been able to implement the plans that we feel are needed to ensure the continuing safety of our students and employees. The need for continued attention to campus security has increased because of the tragic events of September 11, 2001. Paradoxically though, the negative impact of this event on the economy, including the stock market, has affected the availability of resources to support a continued commitment to security related improvements in addition to all of our other programmatic needs. Nevertheless, our campus is a much safer place today because of the generosity of Congress.

of the generosity of Congress. For the past several years, Gallaudet has been engaged in the refinement of our strategic plan and in the process of working with the Department of Education to ensure that our plan fulfills the requirements of the Government Performance and Results Act (GPRA). Assessment of progress toward our goals, as tracked by GPRA indicators, is now an explicit part of the budget process. Gallaudet has made progress in achieving all three of its strategic objectives which focus on: student academic and career achievement, setting the standard for best educational practices for individuals who are deaf or hard of hearing, and establishing a sustainable resource base.

In July of 2001, in a highly favorable report, Gallaudet University received reaffirmation of its accreditation by the Middle States Association of Colleges and Schools, Commission on Higher Education. The Middle States Association Accreditation Report recognized the successful integration of technology into instruction at Gallaudet. More than 65 percent of students and 45 percent of faculty use Gallaudet's online learning system (Gallaudet Dynamic Online Collaboration). The Middles States report concluded with this outstanding affirmation of Gallaudet's role in American higher education:

"Many American universities these days spend a great deal of time fabricating reasons to declare themselves unique. Gallaudet University, the MSA team is convinced, truly is unique. Gallaudet is unique in its student body of deaf and hardof-hearing students, unique in the daunting challenges with which those students present the administrative staff and faculty, and unique in the very real diversity those students bring to the institution. Gallaudet's achievement of a minority population of 24 percent is an extraordinary accomplishment, one your visiting colleagues, from the vantage points of our various institutions can only envy. We envy as well the very substantial contribution the University is making to improve the lives and futures of deaf and hard-of-hearing individuals in America and throughout the world. Every college these days has a mission statement; Gallaudet actually has

In order for Gallaudet to continue to serve a critical function for people who are deaf in the United States and the world, it is vital that we increase the number of students who graduate. To that end, we are using different but interrelated approaches. We have continued to upgrade our technological infrastructure and infuse the most advanced technology into all of our programs of instruction and research, as well as into our administrative and student assessment functions. As technology redefines the landscape of education and the workplace, Gallaudet is re-examining how it can ensure that our students are prepared to become effective users, consumers, and producers of technology. The University is employing technologies that support all types of learning—including traditional face-to-face instruction, selfpaced instruction, and online learning. Gallaudet students, faculty, teachers, and web-based courses, video conferencing, and real-time captioning. We are currently developing a web-based student tracking system that supports more timely intervention with students who are most at risk of leaving before graduation. During fiscal year 2001, Gallaudet committed more than \$5 million to improvements in its technological base, and during fiscal year 2002, we also anticipate spending more than \$5 million for this purpose. We project that our need will continue in fiscal year 2003, although it will be extremely difficult for us to maintain this level of commitment during a time of limited financial resources. If our University and the students who graduate from it are to continue to be competitive in the market place, we must continue to enhance our investment in this area. As important as technological expertise is to students generally, it is even more important for deaf students, as it truly has leveled the playing field for deaf people in many occupations.

We are particularly motivated to increase the graduation rate of our students, because of the excellent prospects that Gallaudet graduates enjoy. Data about our alumni, collected over the past several decades, indicate that they have a high rate of success in obtaining productive employment and in earning advanced degrees. Researchers at the University have completed a comprehensive study that provides further information about the success of our deaf graduates. In this study, information was gathered on all alumni who either graduated from or left the University prior to 1998. Consistent with information collected during the past 20 years, more than 60 percent of our former undergraduates went on to graduate school and more than 40 percent earned advanced degrees. This is about twice the rate for a comparison group of undergraduate programs for hearing students. Also consistent with previous surveys is the finding that only 4 percent of bachelor's level respondents were unemployed and looking for work—for graduate degree holders, the corresponding figure was an even more impressive 2 percent. Moreover, in a placement survey of recent graduates conducted last year, we found that 100 percent of respondents who graduated in 2000 were either employed or in graduate school.

A further indication of our long term commitment to investment in technology is the completion of our new Student Academic Center, the second building on the Gallaudet campus to be constructed without Federally appropriated funds. This state of the art high-tech facility will be completed during the summer of 2002, in time to be used by deaf people from all over the world who will be coming to Gallaudet for the second Deaf Way celebration of deaf arts and culture. We were able to construct this building because of the success of our first-ever capital campaign which just concluded after surpassing its goal of \$30 million by almost \$10 million. During fiscal year 2001 and 2002, we have focussed on meeting the need for enhancements to our security systems and personnel and have deferred development

During fiscal year 2001 and 2002, we have focussed on meeting the need for enhancements to our security systems and personnel and have deferred development of much needed programs. At the budget level we are proposing, we will again be able to focus on developing the programs that are needed by the deaf people of the nation. Program development in fiscal year 2003 will focus on the following areas: Honors programs for the most talented of our undergraduate students and developmental programs for those most at risk, interpreter training at the bachelor's level, leadership training for the next generation of deaf leaders, and increased support for undergraduate science and computer training programs.

for undergraduate science and computer training programs. Gallaudet also prides itself on the programs we provide for younger learners. The Laurent Clerc National Deaf Education Center is comprised of the Kendall Demonstration Elementary School (KDES), the Model Secondary School for the Deaf (MSSD), and related research, demonstration, and outreach activities designed to improve educational programs for deaf children throughout the United States. The Clerc Center is playing a vital role in serving the extended deaf community by continuing to implement its three priorities for research, development, and dissemination that were established through a process involving public input: 1. Literacy; 2. Family involvement; and 3. Transition to work or higher education. A new programmatic goal is to find effective ways to work with and educate children with cochlear implants, as these children represent a growing proportion of the deaf and hard of hearing school population. To this end, our new cochlear implant center is now in operation at the Kendall School.

In 2001, MSSD implemented a revised curriculum based on five major student outcomes related to: (1) essential knowledge/academics, (2) communication, (3) critical/creative thinking, (4) emotional intelligence, (5) life planning. The new graduation requirements include milestones to be achieved beyond course requirements, such as a portfolio reflecting students' work in the five outcome areas, a senior project and presentation, work experience, and community service.

In keeping with its mandate to serve the nation's deaf students, the Laurent Clerc Center has been greatly expanding its work with a variety of educational programs throughout the country. The Center is currently cooperating with programs in the following locations: Arizona—Tucson; California—Burbank, Encino, Fremont, Lakewood, Lodi, Modesto, Oakland, Rancho Cordova, Redding, Riverside, San Bernardino, San Diego, West Covina; Colorado—Colorado Springs; Connecticut— West Hartford; Florida—Miami, Port Richey, Port St. Lucie; Georgia—Clarkston; Hawaii—Honolulu; Illinois—Chicago, Jacksonville; Kentucky—Louisville; Massachusetts—Middleboro; Michigan—Bloomfield Hills; Montana—Billings; Nebraska—Lincoln; Nevada—Carson City, Reno; New Jersey—Newark; New Mexico—Santa Fe; New York—Ithaca, Jackson Heights; Ohio—Cincinnati; Oregon—Medford; Pennsyl-vania—Pittsburgh, Scranton; Tennessee—Knoxville; Texas—Kerrville; Utah— Logan, Salt Lake City; Virginia-Charlottesville, Fairfax, Yorktown; Washington-Seattle; Wisconsin-Milwaukee.

In addition to the legally mandated national mission of the Clerc Center, through which Gallaudet provided direct service to more than 150,000 individuals and distributed more than 200,000 professional publications and other products in fiscal year 2001, the University provides other services to large numbers of people in the United States. In fiscal year 2001 more than 30,000 people attended conferences and other events for professional training sponsored by Gallaudet through its University level continuing education programs. Through these activities and its many research programs, the University is able to provide information about the edu-cational and other needs of America's deaf citizens at a level that is unprecedented in our history

#### FISCAL YEAR 2003 BUDGET REQUEST

The budget request for Gallaudet University for fiscal year 2003 is \$99,700,000, \$2,762,000 more than the amount that was appropriated in fiscal year 2002, and \$5,254,000 more than the amount in the President's fiscal year 2003 request for Gallaudet.

At this level of funding, we will be able to fund needed salary increases for our dedicated faculty and staff, we will be able to support improvements in our technological infrastructure so that our students and employees can work with the latest equipment and software, and, having completed the funding for enhancements of our security systems in fiscal year 2002, we will be able to support programmatic growth in a number of areas, including: Honors programs for the most talented of our undergraduate students and developmental programs for those most at risk, in-terpreter training at the bachelor's level, leadership training for the next generation of deaf leaders, and increased support for undergraduate science and computer training programs. Finally, we will be able to continue to contribute to the Federal endowment matching program. This program has been the engine driving our extremely successful private fund raising efforts in recent years.

Thank you for the opportunity to provide you with this statement. I would be very pleased to respond to any questions you may have or provide any additional information you may need.

Thank you for your continuing support of Gallaudet University.

#### HEALTH RESOURCES AND SERVICES ADMINISTRATION/AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

#### PREPARED STATEMENT OF RTI INTERNATIONAL

#### FUNDING FOR RESEARCH ON MEDICAL QUALITY, SAFETY, AND OUTCOMES

Agencies:

Agency for Healthcare Research and Quality

-Centers for Medicare and Medicaid Systems -Centers for Disease Control and Prevention The Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Quality (AHRQ) is the lead agency for the Agency for Healthcare Research and Char (Healthcare Research agency for Healthcare research on topics such as healthcare quality, costs, patient safety, and medical errors. We are concerned not only about the cuts proposed for that agency, the principal agency established by Congress to support health services research, but also for cuts being proposed in the research budgets for the Centers for Medicare and Medicaid Systems, and the Centers for Disease Control and Prevention.

In a time of rising healthcare costs, increasing numbers of uninsured, and concern over access to treatment and prevention, we should be increasing the Federal government's investment in the research that the public and private sectors will need

 address these challenging health system problems.
 The Administration has proposed to cut AHRQ's budget by \$49 million, or 16 percent, with the cut falling entirely on research activities. RTI supports a total budget for this agency of \$390 million. AHRQ funds research that helps decision makers at all levels, from Federal and State policy makers, through those who run health care systems, to patients and doctors who use their tools every day. Examples of the benefits include definitive guidelines for clinical practice (http:/ /guideline.gov), preventive care guidelines (http://www.ahrq.gov/clinic/ uspstfix.htm), and hospital statistics that will be valuable for needs such as preparing for emergency response (http://www.ahrq.gov/data/hcup/hcupnet.htm). The Agency operates with the same rigorous peer review system as NIH to evaluate grants and contracts, it addresses critical needs in patient care, yet it has only one seventy-fifth of NIH's budget. The result of the proposed cut would be no new research projects in fiscal year 2003, a 46 percent reduction in grants related to quality and costs, and a 31 percent reduction in applied research such as evidence-based practice.

- The Centers for Medicare and Medicaid Systems (CMS) will see their research budget cut almost in half from \$55.3 million to \$28.4 million. After subtracting \$12.4 million for the Medicare Beneficiary survey, and \$6 million for CMS to meet other statutory requirements, CMS will have only \$10 million in discretionary research funding. However, their fiscal year 2003 commitments for funding projects already underway is \$17 million. This means CMS would have to cut existing research by \$7 million. RTI supports a funding level of \$60 million to ensure that CMS can meet its current obligations and expand research into areas such as quality care for those with chronic illnesses; plan and beneficiary participation in managed care; approaches to educating beneficiaries through use of the Internet (e-health); and the impact of technological changes on Medicare and Medicaid.
- —The Centers for Disease Control and Prevention (CDC) \$17 million extramural prevention research budget—the only extramural health services research program at the CDC—would be eliminated. CDC developed this program to move knowledge about effective strategies for preventing disease and disability from research to implementation in diverse community practices and programs. The program uses a model of community-based participatory prevention research, and has supported over 50 projects based in states and localities throughout the country. Cutting this program will eliminate the second round of projects designed and initiated by community-based research collaborations. RTI urges restoration of the \$17 million so that CDC can conduct the second round of projects and collaborate with others to accelerate the dissemination of research results to professionals and communities who can put the results into practice.

Thank you for your consideration of this matter, which is of critical importance to protecting the health of the public.

#### PREPARED STATEMENT OF THE AMERCIAN DENTAL EDUCATION ASSOCIATION

My name is Dr. David Johnsen. I am the Dean of the University of Iowa College of Dentistry. Today, I am pleased to represent the American Dental Education Association (ADEA) as its President and to offer recommendations for fiscal year 2003 appropriations for dental education and research.

<sup>A</sup>DÊA is the premier national organization that speaks for dental education. It is dedicated to serving the needs of all 55 U.S. dental schools, as well as hospitalbased dental and advanced dental education programs, dental research institutions, and the faculty and students in these institutions. It is within these institutions that future practitioners and researchers are educated; the majority of dental research is conducted; and significant dental care is provided to many underserved low-income populations, including individuals covered by Medicaid and the State Children's Health Insurance Program (SCHIP).

Children's Health Insurance Program (SCHIP). ADEA concurs with the Surgeon General's report, Oral Health in America, released in 2000, which alerts Congress and the nation to the full meaning of oral health and its importance to general health and well-being. It makes clear too that there are profound disparities in the oral health of Americans, amounting to a "silent epidemic" of dental and oral diseases affecting our most vulnerable populations, i.e., low-income persons of all ages, but especially low-income children and seniors. The long-term consequences of this disparity deleteriously affect the school, work, and home activities of these individuals and, ultimately, their quality of life.

In addition to these alarming disparities, other significant challenges exist with regard to the infrastructure of dental education and the oral health delivery system. For instance:

-The dentist-to-population ratio is declining, creating concern as to the capability of the dental workforce to meet emerging demands of society and provide required services efficiently. In one-third of the counties in Iowa, 20 percent of the dentists are age 60 or more. Once these dentists retire, who will take their places? The need for dentists in Iowa may soon become urgent.

One indicator to measure the potential need for dentists is an increase in the designated dental health professions shortage areas (HPSAs). The number of dental HPSA's in the United States in December 2000 was 1,233; in December

2001, there were 1,853. The population in these geographic areas is 38.5 mil-lion. In Iowa, the number of dental HPSAs jumped from 3 in December 2000 to 73 in June 2001, encompassing a population of 500,000. To meet the target ratio of dentists to patients, according to the Health Resources and Services Ad-ministration (HRSA) guidelines, Iowa would need an additional 131 dentists.

- Dental education debt has increased, affecting both career choices and practice locations. In 2000, 45 percent of individuals who had debt graduated with debt over \$100,000 and 21 percent had debt greater than \$150,000. The average debt was \$106.000.
- Current and projected demand for dental school faculty positions and research scientists is not being met. Presently, there are 400 budgeted, but vacant, fac-ulty positions in the 55 U.S. dental schools. The issue of access to care cannot be addressed successfully without first addressing (and increasing) the number of dentists entering academia and research. ADEA's survey of dental students graduating in 2000 found that only 0.5 percent plan to seek careers in academia and research.
- A crisis in the number of faculty and researchers threatens the quality of dental education, oral, dental, and craniofacial research, and, ultimately, access to nec-essary oral health care. Access to care and faculty shortages are inextricably linked. And,
- Lack of diversity and the number of under-represented minorities in the oral health professions is disproportionate to their distribution in the population at large. Their low rate of enrollment in dental schools forebodes their continued

Iarge. Incir low rate of enrollment in dental schools forebodes their continued under-representation in academia, research, and the dental workforce. Mr. Chairman, ADEA's funding requests for fiscal year 2003 take into account many of the challenges I have just mentioned. Indeed, the federal programs being considered by this Subcommittee are playing a significant role in responding posi-tively to the challenges of oral health disparities, dental education, and diversity in the workforce. Consequently, it is imperative that Congress appropriate adequate funding for the continuation and enhancement of these programs. In particular, the American Dental Education Association urges the Subcommit-tee's positive consideration for the following five programs that are of critical impor-tee's nositive consideration for the following five programs that are of critical impor-ted.

tee's positive consideration for the following five programs that are of critical importance to dental education and research:

(1) For General Dentistry and Pediatric Dentistry Residency Training programs, the American Dental Education Association recommends that the Subcommittee adequately fund the Primary Care Cluster to ensure an appropriation of \$15 million for these two primary care dental programs.

These two programs provide dentists with the skills and clinical experiences need-ed to deliver a broad array of oral health services to the full community of patients. They are highly effective in improving access and availability to primary care dental services. The Bureau of Health Professions acknowledged the value of the General bentistry Residency Training program in this way: "Considering the relatively mod-est 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."

A 2001 HRSA-funded study found that postdoctoral general dentistry training programs, because they are typically either dental school- or hospital-based, generally serve as safety net providers to underserved populations. General dentistry programs are important because they increase access to care while training dental residents to become competent in treating diverse populations, including economi-cally disadvantaged and aged patients as well as those needing specialized care, i.e., mentally disabled, heart, hypertension, cancer and diabetes patients. According to the study, the Title VII, Section 747 grant program for general dentistry has been the dominant force for the creation and expansion of new programs and training positions. Between 1995 and 1999, first-year training positions in general dentistry programs increased by 169, while first-year training positions in pediatric dentistry programs increased by 24. Pediatric dentistry is the dental counterpart to general medical pediatrics. Only recently has the program begun to expand after 20 years of little change, despite increased societal needs. Many applicants to pediatric den-tistry residency training programs are turned away due to lack of positions. In 1999–2000, there were 3,528 applications for only 205 first-year positions. In the first 2 years of funding, fiscal year 2000 and fiscal year 2001, approximately \$2.7 million was awarded to 14 dental education institutions to fund general and pediatric dental residencies. However, eight additional programs in fiscal year 2000 and three programs in fiscal year 2001 were approved, but un-funded. While preventive oral health care for children is one of the great successes in public health, there remains significant unmet need. For example, 25 percent of the pediatric population experiences 80 percent of the dental cavities, and these are concentrated in low-income and minority populations. Two-thirds of patients seen in pediatric dentistry programs are Medicaid recipients. Almost 52 million school hours, equivalent to more than 850,00 school days, are missed each year by children because of dental problems.

Residents trained in general dentistry and pediatric dentistry programs are necessary to meet the needs of Medicaid and SCHIP populations. These primary care training programs are requisite components of the Health Resources and Services Administration? (HRSA) and health initiative to improve access to oral health care

Administration's (HRSA) oral health initiative to improve access to oral health care. (2) For the Health Professions Education and Training Programs for Minority and Disadvantaged Students, the American Dental Education Association recommends \$135 million, including \$3 million for the Faculty Loan Repayment Program.

The Health Professions Education Training (Title VII) programs have been successful in creating the basic infrastructure for educating a primary care workforce to care for vulnerable populations. However, that infrastructure requires sustained and increased federal support to meet the challenges of diversifying the workforce, addressing student indebtedness, eliminating faculty shortages, and eliminating oral health care disparities in underserved communities.

Two federal programs, the Centers of Excellence (COE) and the Health Careers Opportunity Program (HCOP), play critical roles in preparing, recruiting and retaining disadvantaged students in predoctoral health professions schools. Recruiting and retaining under-represented minorities (Black/African Americans, Native Americans/Alaska Natives, and Hispanic) in dental education remains a serious challenge. As the U.S. population becomes increasingly multicultural, so must the faculties and students in academic dental institutions. The federally funded COE and HCOP programs are key in assisting health professions schools to prepare disadvantaged and minority students for entry into dental, medical, pharmacy, and other health professions. The federal government has a responsibility to help to develop a culturally competent workforce that will reduce health care disparities related to cultural factors.

Another Title VII diversity program, the Faculty Loan Repayment Program (FLRP), assists dentists and other qualified clinicians to enter academia. It is the only federal program that endeavors to increase the number of economically disadvantaged faculty members. The program takes on additional significance in light of current and predicated faculty shortages. As I have said previously, the issue of access to care cannot be addressed successfully without first addressing (and increasing) the number of dentists entering academia and research. In 2002, the Faculty Loan Repayment Program was funded at \$1.3 million. While dentistry alone could use the entire appropriation, I should note that graduates from 23 different health care disciplines competed for this limited pool.

Unless Congress and the dental education community itself take action to develop, recruit, and retain faculty, access problems will surely worsen. Congress should increase funding and broaden eligibility for the Faculty Loan Repayment Program to faculty members with qualifying student loan debt, regardless of their background. And Congress should create a separate program directed at eliminating faculty shortages in the nation's 55 dental schools. Furthermore, general and pediatric dentistry residents who are committed to academic careers should be eligible for FLRP awards.

ADEA strongly recommends that you reject the Administration's decision to zero fund all of these critical Title VII diversity programs. On the contrary, this Subcommittee should expand the programs. (3) For the Ryan White HIV/AIDS Dental Reimbursement Program of the Ryan

(3) For the Ryan White HIV/AIDS Dental Reimbursement Program of the Ryan White CARE Act, the American Dental Education Association recommends an appropriation of \$19 million, a modest increase of \$6 million over the fiscal year 2002 level.

Federal support for this program increases access to oral health services for HIV/ AIDS patients, while, at the same time, providing dental students and residents the education and training necessary to deliver oral health care to this population. Thus, two major and appropriate objectives of the federal government, that is, service to patients of limited means and education of future practitioners, are accomplished by this important, but very modest, federal program. As a result of immune system breakdown, HIV/AIDS patients are more suscep-

As a result of immune system breakdown, 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. In fact, many of the first physical manifestations of HIV infection are found in the oral cavity. A dentist is often the first health care professional to diagnose these patients.

Private insurance and Medicaid coverage for dental services is very limited or simply unavailable for adults. This lack of adequate 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 encourages treatment of patients by alleviating some of the financial burden incurred by the dental education institutions that serve them.

In 2001, the program provided retrospective reimbursement to 85 dental education programs that treated more than 66,000 patients who could not pay for services rendered. The \$10 million paid to these institutions represented approximately 64 percent of the direct costs incurred from providing dental services to low-income HIV and AIDS patients.

(4) For the National Health Service Corps (NHSC) Scholarship and Loan Repayment Programs, the American Dental Education Association supports the President's recommended funding level of \$191 million and requests that the Subcommittee encourage the Corps to increase dental participation in these programs.

ADEA strongly supports the National Health Service Corps (NHSC) Scholarship and Loan Repayment Programs that 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, particularly in the fiscal year 1999 appropriations report language, Congress instructed the Corps to increase dental participation in the loan repayment and scholarship awards programs. NHSC should open the scholarship program to dental students in all 4 years of dental school and increase the number of dental hygiene students receiving both scholarships and loan repayment. Currently, the dental scholarship program is open only to third- and 4-year dental students.

It is critical that the National Health Service Corps' commitment to dentistry be strengthened as the need for dental providers in underserved areas throughout the nation becomes more pronounced. Also, NHSC should continue to work with dental education institutions, dental organizations, and state and local public health departments to determine dental site readiness, especially in rural and border areas. (5) For the National Institute for Dental and Craniofacial Research (NIDCR), the

(5) For the National Institute for Dental and Craniofacial Research (NIDCR), the American Dental Education Association endorses the recommendations of the American Association for Dental Research (AADR) regarding research priorities and joins AADR in requesting an appropriation of \$420 million for NIDCR. Likewise, ADEA recommends that the Subcommittee encourage NIDCR to expand loan forgiveness programs for researchers and the National Institutes of Health (NIH) to collaborate with the Health Resources and Services Administration (HRSA) to integrate oral health care fully into the multidisciplinary research component of the Centers of Excellence in Women's Health.

ADEA commends the Subcommittee for its leadership in the area of biomedical research, appropriately demonstrated by significant increases in NIH funding. The National Institute for Dental and Craniofacial Research also is deserving of enhanced federal funding. Past support has yielded significant results applicable not only to oral health, but to health in general. Through collaborative efforts with NIDCR, oral health researchers in U.S. dental schools have built a base of scientific and clinical knowledge that has been widely communicated and used to improve oral health. Research is advancing investigations in bone formation and craniofacial development, treatment of facial pain, salivary gland disorders, the link between periodontal diseases and pre-term low birth weight and arteriosclerosis, to name just a few.

In conclusion, Mr. Chairman, I thank you again, on behalf of ADEA and its membership, for the opportunity to present our views and budget requests for dental education and research programs in fiscal year 2003. Continuing the federal investment in these programs is vital. So too is the development of a partnership between the federal government and dental education programs to implement a national oral health plan that guarantees access to dental care for everyone, ensures continued dental health research, eliminates disparities, and eliminates workforce shortages. In addition to being good public policy, such a plan is absolutely necessary for maintaining the oral health of our nation.

# PREPARED STATEMENT OF THE HEALTH PROFESSIONS AND NURSING EDUCATION COALITION

The members of the Health Professions and Nursing Education Coalition (HPNEC) are pleased to submit this statement for the record in support of the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act.

HPNEC is an informal alliance of over 40 organizations representing a variety of schools, programs, and individuals dedicated to ensuring that Title VII and VIII pro-

grams continue to help educate the nation's health care and public health personnel. HPNEC members are thankful for the support the Subcommittee has provided to the programs, which are essential to building a well-educated, diverse health care workforce.

The health professions and nursing education programs provide support to students, programs, departments, and institutions to improve the racial and ethnic diversity, accessibility, and quality of the health care workforce. These programs are designed to accomplish the following objectives:

- —Meet the nation's needs to increase the supply of primary medical and dental care providers, mental and behavioral health professionals, public health and allied health professionals, and nurses;
- -Educate and train more health professionals in fields experiencing shortages, such as the current shortages in nursing, pharmacy, pediatric dentistry, mental and behavioral health professionals, public health, and allied health, such as radiology and clinical laboratory;
- -Improve the geographic distribution of health professionals;
- —Increase access to health care for underserved populations; and
- -Enhance minority representation in the practicing health professional workforce.

In particular, the providers trained through these programs help meet the health care delivery needs of the over 3,800 Health Professions Shortage Areas (HPSAs) in this country, at times serving as the only source of health care in many rural and disadvantaged communities. These programs provide an essential and stable infrastructure for the training and education of health professionals, with a needed emphasis on primary care and preventive medicine across the life span, from pediatrics to geriatrics.

ncs to genatrics. A November 2001 report by the Advisory Committee on Training in Primary Care Medicine and Dentistry emphasizes the essential role of the Title VII programs in enhancing the quality and quantity of the primary care health workforce. The report quotes a study in the Journal of Rural Health: "In 1997, Title VII funded programs increased the rates of graduates entering health profession shortage areas (HPSAs), resulting in 1,357 providers... Doubling the funding of these programs . . . could decrease the time for HPSAs elimination to as little as 6 years." The Advisory Committee recommends increased budget authority for Title VII, as it supports, "innovative approaches aimed at improving quality of care and basic access to care, and has been used to great effect by programs to leverage other sources of funding." The federal investment in the health professions programs is valuable, because it fosters state-federal partnerships to enhance the nation's health

The Institute of Medicine report released March 20, 2002, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care," targets the severe health care gap between racial and ethnic groups in the United States and focuses on strategies for eliminating health care disparities in the system. It calls for increased representation of racial and ethnic diversity in the health professions, as "racial and ethnic minorities are more likely than their non-minority colleagues to serve in minority and medically underserved communities." Title VII and VIII programs, such as Centers of Excellence, Health Careers Opportunities Programs, Scholarships for Disadvantaged Students, and the Nurse Workforce Diversity programs, are designed to meet this need by bringing more underrepresented minorities into the health workforce.

Considering the life-altering and dramatic events in the country last year, an appropriate supply and distribution of health professionals has never been more essential to the public's health. During their 40-year existence, the Title VII and VIII programs have created a network of initiatives across the country that supports the training of many disciplines of health providers. These are the only federal programs designed to create infrastructures at our schools and in our communities that facilitate customized training designed to bring the latest emerging national priorities to the populations at large and meet the health care needs of special, underserved populations.

Here we do populations at large and need the needed were needed of special, energy served populations. HPNEC members recommend that the Title VII and VIII programs receive an appropriation of at least \$550 million for fiscal year 2002.—This recommendation is the second stage of a 2-year effort to increase funding by 50 percent, which HPNEC members have determined to be needed by the programs to fulfill the aforementioned missions.

HPNEC members urge the subcommittee to consider the vital need for these health professions education programs as demonstrated by the passage of the Health Professions Education Partnerships Act of 1998 (Public Law 105–392), which reauthorized these programs. The reauthorization provided additional flexibility in the administration of these programs and consolidated them into seven general categories: Minority and Disadvantaged Health Professions Training; Primary Care Training; Interdisciplinary, Community-Based Linkages; Health Professions Workforce and Analysis; Public Health Workforce Development; Nursing Workforce Development; and Student Financial Assistance.

- The purpose of the Minority and Disadvantaged Health Professionals Training programs is to improve health care access in underserved areas and the representation of minority and disadvantaged health care providers in the health professions. Minority Centers of Excellence support programs that seek to increase the number of minority health professionals through increased research on minority health issues, establishment of an educational pipeline, and the provision of clinical opportunities in community-based health facilities. The Health Career Opportunity Program seeks to improve the development of a competitive applicant pool through partnerships with local educational and community organizations. The Faculty Loan Repayment and Faculty Fellowship programs provide incentives for schools to recruit underrepresented minority faculty. The Scholarships for Disadvantaged Students (SDS) make funds available to eligible students from disadvantaged backgrounds who are enrolled as full-time health professions students Nursing students receive 16 percent of the funds appropriated for SDS.
- The Primary Care Training category, including General Pediatrics, General Internal Medicine, Family Medicine, General Dentistry, Pediatric Dentistry, and Physician Assistants, provides for the education and training of primary care physicians, dentists, and physician assistants to improve access and quality of health care in underserved areas. As noted in the November 2001 Advisory Committee report, two-thirds of all Americans interact with a primary care provider every year, and approximately one half of primary care providers trained through these programs go on to work in underserved areas, compared to 10 percent of those not trained through these programs. The General Pediatrics and General Internal Medicine programs provide critical funding for primary care training in community-based settings and have been successful in directing more primary care physicians to work in underserved areas. They support a range of initiatives, including medical student training, residency training, faculty development and the development of academic administrative units. Title VII is the only federal program that provides funding for family medicine residency training, academic departments, predoctoral programs, and faculty development. The General Dentistry and Pediatric Dentistry programs provide grants to dental schools and hospitals to create or expand primary care dental residency training programs. Recognizing that all primary care is not only provided by physicians, the primary care cluster also provides grants for physician assistant programs to encourage and prepare students for primary care practice in rural and urban Health Professional Shortage Areas. Additionally, these programs enhance the efforts of osteopathic medical schools to continue to emphasize primary care medicine, health promotion, and disease prevention, and the practice of ambulatory medicine in community-based settings.
- Because much of the nation's health care is delivered in areas far removed from health professions schools, the Interdisciplinary, Community-Based Linkages cluster provides support for community-based training of various health professionals. These programs are designed to provide greater flexibility in training and encourage collaboration between two or more disciplines. These training programs also serve to encourage health professionals to return to such settings after completing their training. The Area Health Education Centers (AHECs) provide clinical training opportunities to health professions and nursing students in rural and other underserved communities by extending the resources of academic health centers to these areas. AHECs, which have substantial state and local matching funds, form networks of health-related institutions to provide education services to students, faculty and practitioners. Health Education and Training Centers (HETCs) were created to improve the supply of health professionals along the U.S.-Mexico border. They incorporate a strong emphasis on wellness through public health education activities for disadvantaged populations. Given America's burgeoning aging population, there is a need for specialized training in the diagnosis, treatment, and prevention of disease and other health concerns of the elderly. Geriatric Health Professions programs support geriatric faculty fellowships, the Geriatric Academic Career Award, and Geriatric Education Centers, which are all designed to bolster the number and quality of health care providers caring for our older generations. The Quentin N. Burdick Program for Rural Health Interdisciplinary Training places an emphasis on long-term collaboration between academic institutions, rural health

care agencies and providers to improve the recruitment and retention of health professionals in rural areas. The Allied Health Training programs help health profession schools, state and local governments and other entities to establish or expand allied health training programs. Secretary Thompson, on a number of occasions, has expressed alarm and concern about the shortage in clinical and public health laboratory specialists, particularly given the past and anticipated bioterrorism events. In fact, studies have shown that at least 9,300 new laboratory lab practitioners are needed every year, but only 4,900 are being produced. This funding enables schools to train more needed allied health disciplines.

- The Health Professions Workforce and Analysis program provides grants to institutions to collect and analyze data on the health professions workforce to advise future decision-making on the direction of health professions and nursing programs. The Health Professions Research and Health Professions Data programs have developed a number of valuable studies on the distribution and training of health professionals, including the Seventh National Sample Nursing Survey, finalized in February 2002.
- training of health professionals, including the Seventh National Sample Nursing Survey, finalized in February 2002. —The Public Health Workforce Development programs are designed to increase the number of individuals trained in public health, to identify the causes of health problems, and respond to such issues as managed care, new disease strains, food supply, and bioterrorism. The Public Health Traineeships and Public Health Training Centers seek to alleviate the critical shortage of public health workers, particularly in underserved areas. Preventive Medicine Residencies are traditionally underfunded through Medicare GME, and this program seek to provide training to the only medical specialty that provides extensive training in both clinical medicine and community health to improve the country's prevention efforts. Dental Public Health Residency programs are vital to the nation's dental public health infrastructure. The Health Administration Traineeships and Special Projects grants are the only federal funding provided to train the managers of our health care system, with a special emphasis on those who serve in underserved areas. —The Nursing Workforce Development programs provide training for basic and
- -The Nursing Workforce Development programs provide training for basic and advanced degree nurses to improve the access to, and quality of, health care in underserved areas. Health care entities across the nation are experiencing a crisis in nurse staffing, caused in part by an aging workforce and lack of young people entering the profession. At the same time, the need for nursing services is expected to continue to increase over the next 20 years. The Advanced Nurse Education program awards grants to train a variety of advanced practice nurses, including nurse practitioners, certified nurse midwifes, nurse anesthetists, public health nurses, and nurse administrators. Workforce Diversity grants support opportunities for nursing education for disadvantaged students through scholarships, stipends, and retention activities. Basic Nurse Education and Practice grants are awarded to schools of nursing to strengthen basic nurse education Loan Repayment Program repays up to 85 percent of nursing student loans in return for at least 2 years of practice in a designated nursing shortage area. The Title VIII nursing programs also support the National Advisory Council on Nurse Education and Practice, which is charged with advising the Secretary of Health and Human Services and Congress on nursing workforce, education, and practice improvement issues.
- cation, and practice improvement issues. —The loan programs in the Student Financial Assistance assist needy and disadvantaged medical and nursing school students in covering the costs of their education. The Nursing Student Loan (NSL) program provides loans to undergraduate and graduate nursing students with a preference for those with the greatest financial need. The Primary Care Loan (PCL) program provides loans covering the cost of attendance in return for dedicated service in primary care. The Health Professional Student Loan (HPSL) program provides loans covering the cost of attendance for financially needy health professions students based on institutional determination. The NSL, PCL, and HPSL programs are funded out of each institution's revolving fund and do not receive federal appropriations. The Loans for Disadvantaged Students (LDS) program provides grants to health professions institutions to make loans to health professions students from disadvantaged backgrounds.
- -HPNEC members respectfully urge support for funding of at least \$550 million for the Title VII and VIII programs, an investment essential not only to the development and training of tomorrow's health care professions but also to our nation's efforts to provide needed health care services to underserved and minority communities. We appreciate the support of the Subcommittee and look forward

to working with members of Congress to achieve these goals in fiscal year 2003 and into the future.

## THE HEALTH PROFESSIONS AND NURSING EDUCATION COALITION (HPNEC)

Administrators of Internal Medicine; Ambulatory Pediatric Association; American Academy of Family Physicians; American Academy of Pediatric Dentistry; American Academy of Pediatrics; American Academy of Physician Assistants; American Association of Colleges of Nursing; American Association of Colleges of Osteopathic Medicine; American Association of Colleges Pharmacy; American College of Nurse-Midwives; American College of Physicians-American Society of Internal Medicine; American College of Preventive Medicine; American Dental Association; American Dental Education Association; American Geriatrics Society; American Nurses Association; American Occupational Therapy Association; American Pediatric Society; American Sychiatric Nurses Association; American Psychological Association; American Society of Clinical Laboratory Science; Association of American Medical Colleges; Association of Departments of Family Medicine; Association of Family Practice Residency Directors; Association of Medical School Pediatric Chairs; Association of Minority Health Profession Schools; Association of Schools of Public Health; Association of Subspecialty Professors; Association of Schools of Public Health; Association of Subspecialty Professors; Association of Women's Health, Obstetric, and Neonatal Nurses; California Area Health Education Center; Clerkship Directors in Internal Medicine; National Area Health Education Center Organization; National Association of Geriatric Education Centers; North American Primary Care Research Group; Society for Pediatric Research; Society of General Internal Medicine; and Society of Teachers of Family Medicine.

# PREPARED STATEMENT OF THE CITY OF NEWARK, NJ

The City of Newark, NJ hereby submits for the record, testimony regarding two innovative projects that are of great importance to the State of New Jersey's largest City. The projects described below each address an aspect of the critical health needs of Newark's low-income population. They are (1) the Emergency Medical Services Demonstration Project, and (2) the Inner City Hepatitis C Initiative. A brief summary of each proposal is presented below, followed by details of both projects.

## NEWARK COORDINATED EMERGENCY MEDICAL SERVICES DEMONSTRATION PROJECT

The objective of Newark's Coordinated EMS Demonstration Project is to develop a coordinated model for a City-wide system for efficient patient transportation and emergency services utilization, tracking and billing. Funding is requested to assist in the design and implementation of a system that will assure transportation of patients to the appropriate specialty hospital or other medical facility. The system will include a billing and service allocation component to reduce inefficiencies and deter fraud, waste and abuse. The system will be coordinated with the City's 911 integrated dispatch, to insure the timely transfer of calls and delivery of services. The City's dispatch center handles over 300,000 calls for service per year, and must efficiently channel calls for medical service to the EMS system in a manner that allows for tracking of services while transferring operational responsibility. An allocation of \$5 million is requested to establish the Newark Coordinated

An allocation of \$5 million is requested to establish the Newark Coordinated Emergency Medical Services demonstration project.

#### INNER CITY HEPATITIS C INITIATIVE

The objective of the City of Newark's Inner City Hepatitis C Initiative is to accelerate the detection, counseling, evaluation and treatment of chronic hepatitis C in inner city residents. It is estimated that more than 7,000 Newark residents have highly contagious chronic Hepatitis C (HCV), but less than 1,000 are enrolled in treatment programs. HCV is highly contagious, with approximately 40,000 new cases nationally per year, with over 85 percent developing chronic disease. Newark's program will provide education, counseling, medical evaluation and treatment, and will include testing and treatment for HIV and Hepatitis B. Program

Newark's program will provide education, counseling, medical evaluation and treatment, and will include testing and treatment for HIV and Hepatitis B. Program goals are to reduce morbidity and mortality from Hepatitis C, and at the same time decrease its transmission to others in the community. Program will provide education, counseling, medical evaluation and treatment, and will include testing and treatment for HIV and Hepatitis B. The program will greatly increase the diagnosis and treatment of both HCV and HIV.

An allocation of \$7 million is requested to establish the Inner City Hepatitis C Initiative.

## NEWARK COORDINATED EMERGENCY MEDICAL SERVICES DEMONSTRATION PROJECT

The objective of Newark's Coordinated EMS Demonstration Project is to develop a coordinated model for a City-wide system for efficient patient transportation and emergency services utilization, tracking and billing. Funding is requested to assist in the design and implementation of a system which will assure transportation of patients to the appropriate specialty hospital or other medical facility. The system will include a billing and service allocation component to reduce inefficiencies and deter fraud, waste and abuse. The system will be coordinated with the City's 911 integrated dispatch, to insure the timely transfer of calls and delivery of services. The City's dispatch center handles over 300,000 calls for service per year, and must efficiently channel calls for medical service to the EMS system in a manner that allows for tracking of services while transferring operational responsibility. Over 100,000 calls for service per year go to the Emergency Medical Services system in Newark.

Currently, the City of Newark contracts with the University of Medicine and Dentistry of New Jersey (UMDNJ), through University Hospital, to provide a complete system of dedicated 9–1–1 emergency medical services. These services include: basic life support units integrated with advanced life support services, emergency treatment and transportation to local area hospitals as defined in an Approved. Hospitals for Patient Transport policy, heavy rescue and vehicle extrication, and service as the lead agency in response to mass casualty incidents within the City. UMDNJ provides centralized medical dispatch communications per NJ State requirements, and the interface with City E911 services is crucial to both efficient and effective dispatching, as well as to securing appropriate and adequate reimbursement for services.

The combination of an increase in the number of calls for service, tremendous advances in available technology, and pressures on the billing system present both a challenge and an opportunity for a unique demonstration project. The City of Newark's Police Computer Aided Dispatch system is the central point for 911 emergency calls, and calls to it for medical assistance are transferred to UMDNJ. However, calls for assistance can also be placed directly to the emergency medical assistance provider. There is no integrated system which can track all calls, the disposition of them, and ultimately, the payment for them. The reimbursements paid by the City, Medicaid, Medicare, the State's Charity Care system, and managed care providers do not cover the cost of capital expenditure for system upgrades. Further, the integration of the City's E9–1–1 system with the UMDNJ system cannot currently be funded through municipal sources, due to other needs and demands. The City is now unable to track and verify EMS services and billing to residents and/or third parties for which it is responsible. Therefore, an fiscal year 2003 allocation of \$5 million is requested to establish a much needed demonstration project for an integrated system for coordinated delivery of emergency medical services.

#### INNER CITY HEPATITIS C INITIATIVE

The Hepatitis C virus (HCV) is currently the most common cause of hepatitis, cirrhosis and liver cancer. Highly contagious, it affects 170 million people worldwide and over 4 million residents of the United States. Over 85 percent of infected persons develop chronic disease, with progression to end-stage disease in 20 percent of them. HCV is highly contagious, with approximately 40,000 new cases nationally per year, and an increasing number of deaths per year, now at 8,000 to 10,000. It is estimated that its mortality will double or triple over the next two decades, unless there is a significant change in prevention and treatment. A higher proportion of African Americans than other populations had been affected, and there is a growing burden of chronic liver disease in this community due to HCV infection. Further, the risk factor for HIV and HCV are similar, so there is often co-infection.

The current epidemic of Hepatitis C has not been adequately addressed for residents in Newark, NJ, or the nation. It is estimated that more than 7,000 Newark residents have highly contagious chronic Hepatitis C (HCV), but well under 1,000 are enrolled in treatment programs. Many of those with end-stage disease are not eligible for medical therapy or transplantation because of their economic status.

The proposed program will provide education, counseling, medical evaluation and treatment, and will include testing and treatment for HIV, increasing recognition of both viruses. Goals are to reduce morbidity and mortality from Hepatitis C, and at the same time decrease its transmission to others in the community. The program will greatly increase the detection, diagnosis and treatment of both HCV and HIV, hopefully serving as a national model. Patient education will be emphasized and needed data collected for a computerized system on chronic HCV and its relationship to other conditions.

A first step in control of HCV is an educational program for residents who are not aware that they have the disease, and then move to screen the entire popu-lation, including inner city residents, at risk for the development of HCV. Although the local government treatment budget for HIV and STDs encompasses Hepatitis, and some services are provided by local medical facilities, there is no comprehen-sive, ongoing coordinated effort. Requested funds would be utilized to expand and coordinate detection, counseling, evaluation and treatment of Chronic Hepatitis C in inner city Newark residents. An fiscal year 2003 allocation of \$7 million is re-quested to establish this much needed demonstration project to provide vital serv-The City of Newark's most vulnerable population. The City of Newark wishes to express its deep appreciation to this Committee for

permitting the presentation of these important projects. Your positive response for Newark's request for support will have a positive impact on the health and wellbeing of Newark's citizens.

#### PREPARED STATEMENT OF THE HEART OF HOSPICE MUSIC

#### SUMMARY

Heart of Hospice Music (HHM) requests startup capital in the amount of \$469,000 to fund its first 2 years' operations. HHM has been an individual effort to gift a two-CD set of thoughtfully compiled, spirit-filled music to individuals facing end-of-life care. Our vision is to make this music available to any person who is in hospice care or otherwise experiencing the journey and challenge of terminal illness. End-of-life-care professionals and others serving in this field confirm the benefits music therapy can provide for the terminally ill and their friends, family, and caregivers. It is our hope that this music will offer comfort and solace and allow for a more calm and tranquil passage.

## WHO

Heart of Hospice Music (HHM), presently applying for 501(c)(3) status to operate

as an Iowa nonprofit corporation. *Comprised of.*—Chris Bischof, Los Gatos, California; Keith Bischof, Clarinda, Iowa; James Morrow, Kansas City, Missouri; William Davidson, Islamorada, Flor-ida; and Brian Auger, San Rafael, California.

#### WHAT

Purpose.-To gift a Heart of Hospice Music two-CD set to any person under hospice care, whether they are receiving care at home or in a healthcare institution. In the future, we plan to include a listening device with headphones for those who cannot afford one.

## BACKGROUND

#### Origin: Personal Experience with Mother's Alzheimer's

This project originated as a result of my family's heartfelt experience of caring for our mother, Marilyn Bischof, in her final years with Alzheimer's disease.

## Music Therapy Recommended

Many end-of-life care organizations suggest the use of "music therapy" as part of the caregiving effort for the dying person. Our family received this recommendation as a single sentence in an information packet. Little more was said, and as caregivers, we were left to interpret this advice and gather music selections on our own.

## Our Family Incorporates Music Therapy

Because of the length of mom's illness, our family was able to incorporate this element of music into her experience, adding to the collection over time. In the early years of Mom's Alzheimer's, she continued to enjoy her favorite music, including contemporary, popular, and classical music, operas, and musicals. As her disease progressed, and she became more and more withdrawn, I was moved to include healing and soothing music-pieces with spiritual messages and/or angelic melodies, Gregorian chants, Eastern devotional songs, Native American selections, sacred compositions from early Christian mystics, and meditative and inspirational songs.

## Results

In my personal experience, the use of carefully chosen, sacred, and spirit-filled song selections provided comfort and solace, and perhaps eased the tension and assisted in our mother's letting-go process.

## Delivery Method Is Key

Intuitively, as our mother's caregivers, we were guided over time to adjust the manner in which music was played in her presence. In the early years, we played music through an audio player on a dresser several feet away from her bed. But as she became more withdrawn and her time was ending, we perceived that she was no longer connecting with music projected from the middle of the room. We purchased a set of high-quality, lightweight headphones through which she listened to music each day for a few hours. We sensed a peacefulness in her being and an easing of her breath, which we partially attribute to the soft, gentle music she received in this manner.

WHY

## Patient Benefits

It is said that the two most important issues at the time of death are (1) how you have lived your life and (2) your state of mind. The first cannot be changed; it is complete. We can, however, have an influence on the second (state of mind) for our loved ones, through our compassionate caregiving efforts, which may include "music therapy."

We named this project "Heart of Hospice Music" out of our intention to use the universal language of music to open the hearts of dying patients as they approach the end of their lives. It is our hope that this music will allow for a more conscious, calm, and harmonious life completion, offering the patient courage, love, and a tranquil passage.

We wish to emphasize the distinction between "feel-good" music or a patient's "favorite" music and the special type of healing and comforting selections that we were moved to share with our mother during her final years. The benefits we observed in her, and that I believe in my heart of hearts the music provided, are widely confirmed by end-of-life-care professionals and others who study and care for the terminally ill.

# Others Who Benefit

In addition to nurturing the soul of the dying person, Heart of Hospice Music is designed to open a pathway of compassion in the hearts of all involved with the sacred experience of death and dying.

- -Family members, friends, and hospice/medical staff and volunteers have already expressed their heartfelt appreciation for the tranquility and comfort they receive from listening to our CDs.
- -Many people feel apprehensive, even helpless, as they consider visiting a loved one in hospice care. We foresee that Heart of Hospice CDs will provide an opportunity for such individuals to bring a meaningful gift, thus easing their fear of stepping into the room of the dying person.
- -Those who choose to contribute their time, talent, and/or treasure to this project receive the unquantifiable benefits of pure and heartfelt giving.
- Even musicians benefities below of pure their songs on Heart of Hospice Music's compilation CDs. Though they may never become personally involved with the dying, they are humbled to share their creative gifts of the heart for this worthy cause.

# Why Hospice Care?

Modern medicine tends primarily to address the physical and biological aspects of a dying patient's care. By their nature, hospice care organizations—and especially their volunteers—bring forth an element of open-hearted compassion, bridging the gap between the patient's physical and emotional/spiritual needs. Therefore, Heart of Hospice Music has chosen to focus its initial distribution efforts toward U.S. hospice facilities and their patients receiving in-home care. Over time, we intend to expand this project to include nursing homes, hospitals, assisted living facilities, and the like.

## Few Are Able to Provide This Loving Gift

Now we arrive at the core of this Heart of Hospice Music project, where we see its true merit and the beautiful need that it fulfills.

Looking back, my brother, sister, and I recognize both the profound blessing and the significant challenge that music therapy presents for a person charged with the care of a dying loved one. For the family member(s) or caregiver(s) of the terminally ill person, this suggestion generally remains little more than a sentence on a piece of paper, low on the priority list among the seemingly endless and overwhelming matters demanding daily attention. In the midst of their myriad responsibilities and heartrending feelings, little time or emotional energy are available to take on such a task.

Individuals or families tending to the needs of a loved one in their last days often experience great strain on many levels. During the course of days, weeks, and months of caregiving efforts, they can be physically burdened, emotionally taxed, and spiritually drained as they hold down jobs and juggle the affairs of their own family lives. In addition, family members are often at odds, as this time often brings up unresolved family issues.

up unresolved family issues. Unless family or friends already own CDs or tapes that can be shared with their loved one in this tender stage, caregivers are unlikely to undertake the effort to search music stores for suitable selections. After my mother's death, as I began collecting material for this project, I was often disappointed to find only one or two appropriate selections on CDs whose cover art and written descriptions appeared to be fitting for my purpose. In addition, many inspirational vocal pieces contained lifeengaging lyrics, and instrumental pieces were more uplifting or upbeat than was desired for this project.

In addition, we have learned from hospice care professionals that hospitals frequently release dying patients to hospice facilities just days before their passing, leaving relatives little time to attend to this meaningful but nonessential detail.

#### REQUEST

Heart of Hospice Music requests startup capital in the amount of \$469,000, to fund the first 2 years' operations. Projected costs are as follows:

Minimal staff salary: One full-time administrator (\$35K per year for 2 years) and two part-time assistants (\$5K each per year for 2 years)	\$90,000
Grant writing and fund-raising, public relations materials	5,000
Legal setup	2,500
Legal setup Office equipment and supplies	10,000
Web site design and content development	4,500
Cost of CDs: materials and production: \$3.75 per CD (Initially targeted	_,
toward 35,000 recipients per year for 2 years. This is a conservative	
5 percent of the estimated 700,000 patients currently in U.S. hospice	
care.)	262,500
Postage/shipping (\$1.35 per CD $\times$ 35,000 CDs per year for 2 years)	94,500
 Total	469,000

#### ON A PERSONAL NOTE

Those of us involved in Heart of Hospice Music wish no profit from this project. For us, this is a fully unconditional act of giving, with no strings attached and no reward sought.

Our desire is to make this very special hand-selected music available to all in need, regardless of their circumstances or personal background. It is truly our gift to others, a way to carry forward the spiritual rewards we received from our personal experience with the passing journey of our loving parents.

"Some things you do to feed your pocketbook; others you do to feed your soul."

## PREPARED STATEMENT OF THE NATIONAL AHEC ORGANIZATION

I am pleased to present testimony on behalf of the National AHEC Organization. I am director of the Ohio Statewide AHEC Program, director of the Medical College of Ohio AHEC program, and a member of the National AHEC Organization. We are the professional organization representing the Area Health Education Centers (AHECs) and Health Education Training Centers (HETCs). Together, we seek to enhance access to quality health care, particularly primary care and preventative care, by improving the supply and distribution of health care professionals through community—academic partnerships. HETCs have a similar mission to AHECs, but are unique in their focus on public health matters associated with extremely underserved areas within our country, especially areas found along the border with Mexico.

## PERSISTENT WORKFORCE SHORTAGES

Mr. Chairman, contrary to what may be commonly understood, persistent and severe shortages exist in a number of health professions. Chronic shortages exist for all health professions in many of our nation's underserved communities, and substantial shortages exist in all communities for some professions such as nursing, pharmacy, and certain allied health fields. While the supply of physicians in the non-primary care specialties may well be adequate, supply and distribution problems for primary care physicians, nurses, and many allied health professionals are undermining access and quality in many of our nation's communities.

Historically, the supply of and demand for health care professionals has waxed and waned in a manner that produced cycles of shortage and excess. However, it is reasonable to believe that the current shortages are of a different and more persistent nature. First, the breadth and depth of shortages are greater than at any time in the past. More disciplines are in short supply, more sites of care (hospitals, nursing homes, home care agencies, and clinics) are experiencing shortages, and the duration of vacancies is longer. Second, the demand for health care services is steadily and inexorably increasing due to the aging population and the advances in medical technology. Third, the health care provider population is aging itself. A high proportion of the current health care workforce is approaching retirement age. Fourth, the resources with which the health care industry might respond to shortages are inadequate to the challenges. Due to the squeeze of managed care, provider institutions are unable to increase salaries, and due to cuts in government funding, educational institutions are unable to expand class sizes. Finally, the career opportunities available to women, who dominate the health care professions, have expanded greatly. The well-advertised degradation in the working conditions for nurses and other health care professionals is occurring at a time when alternative career choices abound.

Health care workforce shortages are occurring in a context of an increasingly aged population with greater needs for health care services, both in terms of a greater number of patients and a higher level of acuity. In addition, health technology steadily produces advances that require a higher level of training and sophistication on the part of health care providers. These trends are occurring at time when the number and the level of academic preparedness of students entering the health professions are decreasing. It is difficult for health care professionals to keep up with rapid technological advances. Practitioners, especially older practitioners, are leaving their fields due to the increased technological demands.

#### WHAT AHECS DO

Mr. Chairman, the AHEC/HETC network is the federal government's most flexible and efficient mechanism for addressing a wide and evolving variety of health care issues on a local level. Through AHECs and HETCs, national initiatives can be targeted to the areas of greatest need and molded to the particular issues confronting individual communities. Whether the issue is the nursing shortage, bioterrorism preparedness, or access for the uninsured, AHECs and HETCs, where they exist, can assemble the appropriate local collaboration and apply federal, state, and local resources in a precise and cost-effective manner.

Since our inception almost 30 years ago, AHECs have partnered with local, state, and federal initiatives and educational institutions in providing clinical training opportunities to health professions and nursing students in rural and underserved communities. We bring the resources of academic health centers to bear in addressing the health care needs of these communities. Currently, there are 45 AHEC programs and 170 centers located in 43 states. AHEC programs are based at schools of medicine, which are the federal AHEC grant recipients, and are implemented through the regional offices (centers), each of which serves a defined geographic area.

AHEC programs perform four basic functions:

1. They develop and support the community based training of health professions students, particularly in underserved rural and urban areas. Exposing health professions students to underserved communities increases the likelihood that they will return to these communities to practice.

2. They provide continuing education and other services that improve the quality of community-based health care. Improving the quality of care also enhances the retention of providers in underserved communities, particularly community health centers.

3. They recruit under-represented minority students into the health professions through a wide variety of programs targeted at elementary through high schools. Minority students are grossly under-represented in the health professions and are more likely to practice in underserved communities.

4. They facilitate and support practitioners, facilities, and community based organizations in addressing critical local health issues in a timely and efficient manner.

#### THE ROLE OF HETCS

The HETC programs were created to address the public health needs of severely underserved populations in border and non-border areas. Currently, HETC programs exist in 9 states and are also supported by a combination of federal, state, and local funding, the majority of which comes from non-federal sources.

Because the majority of preventable health problems are due to health behaviors and the environment, HETCs focus on community health education and health provider training programs in areas with severely underserved populations. HETCs target minority groups, disadvantaged communities, and communities with diverse culture and languages. Virtually all AHEC and HETC programs are collaborative in nature. They rou-

Virtually all AHEC and HETC programs are collaborative in nature. They routinely partner with a wide variety of federal, state, and locally funded programs. Examples of these collaborations include health professions schools, primary care residency programs, community health centers, primary care associations, geriatric education centers, the National Health Service Corps, public health departments, health career opportunity programs, school districts, and foundations. Additionally, AHECs and HETCs often go beyond their core functions to under-

Additionally, AHECs and HETCs often go beyond their core functions to undertake a wide variety of innovative programs that are tailored to specific health issues affecting the communities they serve. Because health issues vary from community to community and over time, the programs of each AHEC and HETC also vary considerably. AHECs and HETCs respond to changing health and health workforce needs in a flexible and timely manner. Examples of current issues for which we are directing our resources are:

1. The nursing shortage.—Currently, AHECs and HETCs are working with schools of nursing, state nursing associations, and others to increase the number of qualified applicants to nursing schools, increase minority enrollment in nursing schools, expand the number of community-based nursing training sites, and retrain nurses who wish to re-enter the profession.

2. *Bioterrorism education.*—Currently, AHECs and HETCs are working with public health departments to educate health and public health professionals on surveillance, reporting, risk communication, treatment, and other responses to the threat of bioterrorism.

3. The National Health Service Corps (NHSC).—AHECs and HETCs undertake a variety of programs related to the placement and support of NHSC scholars and loan repayment recipients.

## JUSTIFICATION FOR FUNDING RECOMMENDATIONS:

Mr. Chairman, I respectfully ask the Subcommittee to support our recommendations to increase funding for the health professions and nursing education programs under Title VII and Title VIII of the Public Health Service Act to at least \$550 million. Our recommendations are consistent with those of the Health Professions and Nursing Education Coalition (HPNEC). The AHEC and HETC programs improve access to primary and preventative care

The AHEC and HETC programs improve access to primary and preventative care through community partnerships, linking the resources of academic health centers with local communities. AHECs and HETCs have proven to be responsive and efficient models for addressing an ever-changing variety of community health issues. However, AHECs and HETCs have not yet fully realized their potential to be a

However, AHECs and HETCs have not yet fully realized their potential to be a nationwide infrastructure for local training and information dissemination. In order to realize that potential additional federal investment is required. That is why we are requesting an increase in funding to \$40 million in fiscal year 2003 from \$33.4 million in fiscal year 2002 for AHECs and \$10 million in fiscal year 2003 from \$4.4 million in fiscal year 2002 for HETCs.

Mr. Chairman, thank you for the opportunity to present the views of the National AHEC Organization. We look forward to working with you and your staff. I would be happy to answer any questions that you or your colleagues may have.

### PREPARED STATEMENT OF THE NATIONAL RURAL HEALTH ASSOCIATION

The National Rural Health Association (NRHA) thanks Chairman Harkin, Ranking Member Specter and members of the Subcommittee for the opportunity to submit this testimony for the record regarding fiscal year 2003 appropriations for programs important to our nation's rural health care delivery system. We believe we can offer you an insightful look at the unique health care needs of rural and frontier Americans.

The NRHA and its membership are grateful for the funding provided to rural health programs in fiscal year 2002 and the support shown for rural health by Con-

gressional leaders. In fiscal year 2002 the Community Health Centers program, the National Health Service Corps, State Offices of Rural Health and Rural Health Policy Development (Research) received increased funding. In addition, \$15 million was added to the Rural Hospital Flexibility Grant Program to help small hospitals respond to the requirements of HIPAA, upgrade billing systems and implement quality improvement.

Over 22 million Americans live in rural and frontier areas. More than 8 million rural residents are uninsured and another 4.5 million are underinsured. The federal programs profiled below have a proven track record of expanding access to health care services in rural areas, thereby ensuring that the benefits of health care are available to all Americans, regardless of where they live.

The NRHA is a national nonprofit membership organization that provides leadership on rural health issues. The association's mission is to improve the health of rural Americans and to provide leadership on rural health issues through grassroots advocacy, communications, education and research. The membership of the NRHA is a diverse collection of individuals and organizations, all of whom share the common bond of an interest in rural health. Individual members come from all disciplines and include hospital and rural health clinic administrators, physicians, nurses, dentists, non-physician providers, health planners, researchers and educators, state offices of rural health and policy-makers. Organization and supporting members include hospitals, community and migrant health centers, state health departments and university programs.

members include hospitals, community and migrant health centers, state health departments and university programs. One of the NRHA's top priorities is the National Health Service Corps program. The National Health Service Corps (NHSC) is a federal program aimed at encouraging health care professionals to practice in underserved rural and urban areas. Since 1972, 20,000 NHSC clinicians have fulfilled a pledge to serve rural and urban underserved communities in exchange for scholarships or loan repayment. Today 4.6 million people who would otherwise lack access to health care are served by over 2,400 NHSC professionals. 60 percent of these provide health care services to rural and frontier Americans. The NHSC currently meets only 11.3 percent of overall need in Health Professional Shortage Areas (HPSAs). The NRHA believes that the National Health Service Corps deserves funding in fiscal year 2003 of \$250 million to allow the program to provide access to health care to many more underserved rural and frontier communities.

State offices of rural health coordinate rural activities and interests across the state, provide information and technical assistance to rural communities and help to improve recruitment and retention of health professionals. State offices of rural health also serve as coordinators for national programs such as the Rural Hospital Flexibility Program and the State Children's Health Insurance Program. State offices of rural health are funded by a 3:1 state to federal match, with states providing three times the contribution of the federal government. The NRHA is appreciative of the increase in fiscal year 2002 to \$8 million for State Offices of Rural Health, and supports level funding at \$8 million in fiscal year 2003.

The Consolidated Health Centers Program is comprised of four parts: Community Health Centers, Migrant Health Centers, Health Care for the Homeless Programs and Public Housing Primary Care Programs. Currently over 1,000 health centers serve more than 11 million patients across the nation. Community health centers are an important part of the rural safety net, providing care to the uninsured and underinsured who would otherwise lack access to health care, including 5.4 million rural residents (1 out of 10). Community health centers focus on wellness and prevention in addition to primary care services and foster community bonds through consumer boards governing each center. The Bush administration has pledged to increase the number of community health centers to 1,200 nationwide, doubling the number of people served by these facilities. To adequately meet this goal and ensure new community health centers are added in rural areas, increased funding is necessary. The NRHA supports the expansion of the community health center program and advocates fiscal year 2003 funding of \$1.544 billion.

Authorized under the Consolidated Health Centers Program, the Rural Health Outreach and Network Development Grant Program serves to support innovative health care delivery systems as well as vertically integrated health care networks in rural America. Rural Health Outreach and Network Development Grants help establish new partnerships between health organizations and other community institutions to improve the delivery of clinical care and enable health care providers to be more efficient by sharing resources. Since 1991, 3.2 million people in all but 4 states have been served by the Outreach and Network Development Grant Program through grants totaling \$228 million. The grants provide up to \$200,000 a year for 3 years to each grantee. About 60 percent of grantees have continued to provide services beyond their federal grant period. One Outreach grantee in rural eastern Iowa is the Maquoketa Community School District Health Access Project, which aims to increase access to health care for every school-aged child in their region. The project has four major goals: utilizing a community-wide planning group to determine local health care needs and strategies to meet these needs, conducting a yearly health assessment of every schoolaged child, providing accessible medical services for students, and implementing monthly training and information sessions for parents and community members.

A new Outreach grantee for fiscal year 2002 is the Pennsylvania Mountains Healthcare Alliance, a network of seven community based hospitals. The Rural Health Outreach grant funded by the federal government will allow this network of rural hospitals to install an integrated information management system, train personnel on this system, and implement a comprehensive data management program. This data management program has the potential to increase access to quality care for rural residents in underserved areas of Pennsylvania, providing a model for rural hospitals to follow in reducing costs, analyzing services provided and identifying and adopting best practices. Ultimately, the grant provided through the Rural Health Outreach Grant Program will help to improve health care for the population served by this network of health care providers. The NRHA advocates \$60 million in fiscal year 2003 for the Rural Health Out-

The NRHA advocates \$60 million in fiscal year 2003 for the Rural Health Outreach and Network Development Grant Program. In adding special project earmarks to this line item, the NRHA strongly urges Congress not to let the base funding for Outreach and Network Development Grants to fall below the fiscal year 2002 level of \$38.3 million.

Rural Health Policy Development (Research) funds health policy research focusing on the implications for rural Americans of decisions made by policymakers in Washington. The rural health research centers provide data on issues such as Medicare reimbursement, workforce and managed care in rural areas. The NRHA advocates \$20 million in fiscal year 2003 for Rural Health Policy Development (Research). In adding special project earmarks to this line item, the NRHA strongly urges the Administration not to let the base funding for Rural Health Policy Development to fall below the fiscal year 2002 level of \$10 million.

The Rural Hospital Flexibility Grant Program allows small, low-volume hospitals to convert to Critical Access Hospitals (CAHs), which provide needed emergency, outpatient and short-stay inpatient services. CAHs are encouraged to develop a network with other full-service hospitals in their region in order to provide a full range of needed services. It also helps communities to ensure that needed services, such as emergency medical services, will be available to their citizens. The Flex Program has been a lifeline to many communities, allowing them to keep their hospital open while networking different types of providers to ensure a continuum of care is available to rural residents. The NRHA advocates \$40 million in fiscal year 2003 for the Rural Hospital Flexibility Grant Program.

The NRHA is very concerned about the shortage of health professionals in rural areas and supports health professions programs that train the future workforce for the rural health care infrastructure. Many health professions grant programs funded by the Department of Health and Human Services have a rural focus or component. Graduates of training programs with a rural component are more likely to practice in rural areas, therefore funding of these programs is critical to ensuring access to health care for rural residents. Included in the Bureau of Health Professions (BHPr) are several programs that

Included in the Bureau of Health Professions (BHPr) are several programs that help to support the delivery of health care services in rural areas. The Primary Care Training cluster includes General Pediatrics, General Internal Medicine, Family Medicine, General Dentistry, Pediatric Dentistry, and Physician Assistants, provides for the education and training of primary care physicians, dentists, and physician assistants to improve access and quality of health care in underserved areas.

In the Interdisciplinary, Community-Based Linkages cluster of BHPr, the Area Health Education Centers have been a critical part of delivering the resources of academic health centers to students and clinicians in more remote rural and frontier areas. The Quentin N. Burdick Program for Rural Health Interdisciplinary Training facilitates collaboration between academic institutions and rural health care providers to improve the recruitment and retention of health professionals to serve rural areas.

The Public Health Workforce Development programs in BHPr are designed to increase the number of individuals trained in public health as well as to update the training of current public health professionals. Recent bioterrorism challenges and threats have highlighted the extent to which the public health infrastructure in the United States is uneven in its ability to respond to these challenges. Data compiled by the U.S. Department of Health and Human Services shows that less than half of the nation's public health agencies have the capacity to provide essential public health services. At this time when public health professionals are being asked to take on a critical role in surveillance and responding to bioterrorist attacks and threats, the public health workforce development deserves continued support by the federal government.

The Nursing Workforce Development programs provide training for basic and advanced degree nurses to improve the access to, and quality of, health care in underserved areas. Health care entities across the nation are experiencing a crisis in nurse staffing, caused in part by an aging workforce and lack of young people entering the profession. This crisis is felt more acutely in rural and frontier areas, which have a harder time recruiting staff and have trouble competing with the higher salaries and benefits offered in suburban areas. The Nursing Workforce Development programs are critical to making sure that health care professionals are available to provide services in underserved areas.

The NRHA is concerned that the President's proposed budget includes a drastic cut in funding for Health Professions programs and advocates funding of \$690 million (including \$250 million for National Health Service Corps) in fiscal year 2003 for these programs.

Telehealth services address essential access to health care needs for rural Americans. These innovative programs currently provide medical care, technical assistance, distance learning and training programs to rural Americans in more than 30 states. The NRHA advocates \$40 million for this program in fiscal year 2003. In adding special project earmarks to this line item, the NRHA strongly urges Congress not to let the base funding for Telehealth to fall below the fiscal year 2002 level of \$6.1 million.

The Community Access Program (CAP) provides grants to health care providers to build integrated health care networks to serve uninsured and underinsured local residents. Because rural communities have a high rate of uninsured, CAP has been an essential program in various rural communities throughout the nation. The NRHA urges Congress to continue funding for this program, and advocates funding of \$125 million in fiscal year 2003 for CAP. The NRHA thanks Chairman Harkin and the members of the subcommittee for

The NRHA thanks Chairman Harkin and the members of the subcommittee for the opportunity to submit testimony for the record on vital rural health programs supported by the federal government. We look forward to working with you as the annual appropriations process moves forward, and stand ready to help the Subcommittee and the Congress to ensure access to quality health care services for rural and frontier Americans.

#### PREPARED STATEMENT OF THE KENNEDY KRIEGER INSTITUTE

The Kennedy Krieger Institute in Baltimore, Maryland, appreciates the opportunity to present its views on a number of important fiscal year 2003 budget priorities. We seek your support for a \$1.5 million facilities construction request and we also would like to highlight the efforts of three federal agencies under your jurisdiction and the important work that they do to strengthen the capacity of programs, such as the Kennedy Krieger Institute, to make progress in the important areas of education and health.

#### THE KENNEDY KRIEGER INSTITUTE

The Kennedy Krieger Institute is an independent research institution located adjacent to Johns Hopkins University. The mission of the Institute is to focus solely on disorders related to the brain and central nervous system. Brain related disorders effect one in four adults and one in ten children at a cost to society of \$400 billion per year. The overall goal of research at the Kennedy Krieger Institute is to understand the developing central nervous system through the study of relationships between genes, the brain and human behavior. Although the Institute has special expertise with regard to children, the research scope includes studies of changes in the brain and the central nervous system across the lifespan.

The Kennedy Krieger Institute is a comprehensive resource for children with disabilities, recognized as a research facility and training center for health care professionals from around the world. The Institute treats a wide array of children with neurological diseases including, but not limited to, Down syndrome; attention deficit hyperactivity disorder; lead poisoning, autism; cerebral palsy; genetic and metabolic disorders, like fragile X syndrome, neurofibromatosis, tay sachs disease, tourette syndrome; spina bifida; degenerative brain disorders; mental retardation; and many others. The Institute is well-known for its strong interdisciplinary research and care in many fields including medicine, psychology, education, physical and occupational therapy, audiology, speech and language therapy, social work, child development, nutrition and nursing.

# THE KENNEDY KRIEGER INSTITUTE COMMUNITY BEHAVIORAL HEALTH CENTER

The Kennedy Krieger Institute's inpatient neurobehavioral unit is specifically designed to work with multi-disabled children with severe behavioral problems. Intensive, individualized programs are designed, implemented and taught to parents and other caregivers. The most rewarding aspect of this program is that it allows many children to avoid life-long institutionalization and return to their homes. The Institute integrates cutting edge neurobiological and behavioral research efforts into a comprehensive program which also includes day treatment services; outpatient services; home and community services; and school programs for children with disorders of the brain. Interdisciplinary teams at the Institute devise innovative approaches to meet the total needs of their young patients. Because pediatric brain disorders are difficult to diagnose, one of the Institute's most important services is assessment. Parents from around the country and around the world bring their children to Kennedy Krieger to obtain accurate diagnoses and comprehensive treatment, all in one place.

The Kenedy Krieger Institute is seeking federal support through the Health Resources and Services Administration (HRSA) facilities construction account to assist in the construction of a four-story, 80,000 square foot, Community Behavioral Health Center in East Baltimore. The Center will provide a comprehensive, multidimensional, interdisciplinary environment in which to evaluate, diagnose, treat, and recommend and offer behavioral management services to children and adolescents with developmental or acquired disabilities and those with severe and challenging behaviors. The Center will include new bedrooms, classrooms and living area, as well as treatment and observation rooms.

Over the past 10 years, the Kennedy Krieger Institute has grown such that it occupies space in multiple locations in Baltimore City. Behavioral management programs are currently housed at several different Kennedy Krieger sites (the Broadway facility, Fairmount School, Biddle Street Complex and Hopkins Bayview Campus) because of a lack of space to consolidate these programs at any one site. By uniting and expanding the scope of services already offered by Kennedy Krieger Institute, the Center will foster greater interdisciplinary collaboration that will ultimately benefit the patients, family and staff of KKI—as well as address the outstanding need for additional behavioral health services.

Request: The Kennedy Krieger Institute seeks \$1.5 million from the U.S. Department of Health and Human Services Health Resources and Services Administration (HRSA) facilities construction account in the fiscal year 2003 Labor-HHS-Education Appropriations bill. This funding will contribute to the support received from foundation and private sources, and federal, state, and local agencies for the construction of the Kennedy Krieger Institute Community Behavioral Health Center.

# BASIC AND CLINICAL RESEARCH

The Board of Directors, the researchers, health professionals and patients and families at the Kennedy Krieger Institute are all very grateful for the support that this Committee has provided to the National Institutes of Health (NIH) over the past several years. The resources that Congress has appropriated have enabled the research community to grasp research opportunities that a decade ago we could not even have dreamed possible. This is making an incredible difference in the lives of the children that we treat.

We are currently experiencing an unprecedented appreciation of the benefits to health and life quality that can result from biomedical and behavioral research. Of particular note is the most welcome present and predicted increase in public sector funding for basic research and the dramatic, if not explosive, private sector investment in biology. With such appreciation and tangible support comes the responsibility to organize the scientific enterprise so as to produce effective interventions. And, our challenges are many.

Many children with developmental disabilities and neurological diseases display severe behavior problems. The mission of our basic and clinical research, clinical care, and educational programs is to improve the quality of life for these children and their families through a variety of mechanisms including:

-providing advanced and comprehensive treatment services;

-promoting the widespread dissemination of effective interventions; and

—improving treatment technologies through basic and clinical research.

With that said, we support treatment and research initiatives including but not limited to behavior programs, pediatric feeding disorders, neuroimaging, basic and clinical research efforts and training.

The National Institute of Child Health and Human Development (NICHD) and the National Institute of Neurological Diseases and Stroke (NINDS) support a number of important initiatives with regard to brain biology; neurobehavioral assessment and protocol development; translation studies related to cognition pathways of learning disorders from a developmental perspective; molecular sciences to further understand the molecular basis of many developmental disabilities; brain mapping; and other basic and clinical programs which are at the core of the programs conducted at the Kennedy Krieger Institute. Further, the National Center for Research Resources (NCRR) supports important neuroimaging studies for neuroscience, metabolic, behavioral, and other research. The Kennedy Krieger Institute receives funding from the NCRR for our neurobehavior research unit through a subcontract from the Johns Hopkins University General Clinical Research Center (GCRC). The support we receive is used to conduct studies related to functional imaging. We believe it is important for the Committee to consider an NIH National Imaging Network for Clinical Research that will enable NCRR to provide the resources to create links between the GCRC to the imaging center. This sort of infrastructure would be vitally important to facilitate and integrate research networks.

Clearly, multiple programs supported by the NIH enrich our capacity to address important basic and clinical research issues in the population that we serve. The work of this Committee ensuring a sustained commitment to these programs has enabled institutions, such as ours, to move forward at unprecedented speed. To that end, we also urge the Committee to continue its efforts in support of the NIH.

Request: The Kennedy Krieger Institute endorses the recommendation of the Ad Hoc Group for Medical Research Funding calling for a \$3.7 billion increase for NIH, resulting in a total NIH budget of \$27.3 billion in fiscal year 2003. The Kennedy Krieger Institute commends the President for proposing a \$27.3 billion budget for NIH, which if approved, will complete the national bipartisan campaign to double the NIH budget over 5 years.

We thank the Committee for its past support and we greatly appreciate the opportunity for the Kennedy Krieger Institute to present it views relative to fiscal year 2003 program priorities.

PREPARED STATEMENT OF THE NATIONAL ASSEMBLY ON SCHOOL-BASED HEALTH CARE

- -Every day over 52 million of America's children go to school-many needing health care services to be successful in school.
- -But in only 1400 schools nationwide, parents have a solution: school-based health centers.
- In these centers, through community, health and school partnerships, students can get regular check ups, immunizations, asthma care, mental health counseling, and other essential services.
- -Federal support is needed so that communities and families can organize schoolbased health centers.

Federal public health and primary care appropriations play a critical role in supporting the delivery of medical and mental health services in school settings. The National Assembly on School-Based Health Care (NASBHC) urges the Committee's support for programs that emphasize the coordination of public health, primary care, mental health and pupil support services in school settings where students can access on-site services that promote good health and academic success.

access on-site services that promote good health and academic success. The Maternal and Child Health Block (Title V of the Social Security Act) is used by many state and local health departments to fund health and mental health services in schools. Despite great demand and competition from communities to create school-based health programs, these dollars are limited. As states seek to balance budgets through difficult program cuts, federal public health funding will be even more critical. We urge Congress to fully fund the authorized level of the maternal and child health block grant.

Healthy Schools, Healthy Communities is the first program in the Health Resources and Services Administration to receive funding solely for promoting and establishing school-based health centers. Created in fiscal year 1994 under Section 330 of the Public Health Service Act and administered by the Bureau of Primary Health Care, Healthy Schools, Healthy Communities provides direct service funding to community health care organizations for the purpose of delivering comprehensive interdisciplinary primary care (including nutrition, mental health, dental care, and social services) to at-risk children and adolescents where they are most accessible: in their schools. School-based health centers are considered a significant vehicle for achieving 100 percent access and zero health disparities for at-risk school-age children.

The National Assembly on School-Based Health Care seeks \$25 million to fund the existing 75 Healthy Schools Healthy Communities grantees and to add 25 additional sites to the program.

State School-Based Health Care Organizations.—An amendment to the Senate's 2001 Health Care Safety Net legislation (not yet passed out of the full Senate as of this writing) includes a \$5 million authorization for state school-based health center networks to coordinate federal, State, and local health care services that contribute to the delivery of school-based health care; provide technical support training; and conduct operational and administrative support activities for statewide SBHC networks.

Why is this important?

- With states facing revenue shortages, publicly funded school-based health centers are in great danger of being crippled by difficult budget decisions.
- -The legislation would create statewide support organizations to ensure that the centers are able to access the myriad public health, mental health, Medicaid and pupil support dollars that ensure the delivery of quality, comprehensive health and mental health services to school-aged children and youth. -It would help centers maximize operational effectiveness and efficiency by pro-

-It would help centers maximize operational effectiveness and efficiency by providing technical support training -State organizations could provide technical assistance for communities inter-

-State organizations could provide technical assistance for communities interested in planning and implementing school-based health centers. Thank you for your consideration of these critical services. With your support,

Thank you for your consideration of these critical services. With your support, more families can send their kids to school confident in the knowledge that the school and community are protecting and promoting their children's health and well-being.

#### PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PEDIATRICS

This statement is submitted on behalf of the American Academy of Pediatrics and the endorsing organizations, the Society for Adolescent Medicine and the Ambulatory Pediatric Association. The American Academy of Pediatrics of Pediatrics is an organization of 55,000 primary care pediatricians, pediatric medical subspecialists and pediatric surgical subspecialists dedicated to the health of all children. The Ambulatory Pediatric Association is an organization of over 2,000 members who are academic general pediatricians and child health professionals. The Society for Adolescent Medicine includes over 1,400 physicians, nurses, psychologists, social workers, nutritionists and others involved in service delivery, teaching or research on the health and welfare of adolescents.

America's children are generally healthier now than they were only half a generation ago. National infant mortality and child death rates have dropped significantly over the last decade, and today nearly 81 percent of 2-year-olds have received their immunizations. However, despite these significant improvements, 12.3 million children and adolescents through age 21 remain uninsured. Moreover, racial and ethnic health disparities for many children and adolescents continue to exist. Clearly, we have much work to do. As clinicians we must not only diagnosis and treat our patients but also promote strong preventive interventions to improve the overall health and well-being of all infants, children, adolescents and young adults. Likewise as policy-makers, you have an integral role to play in improving the health of the next generation through sustained and adequate funding of vital federal programs.

<sup>6</sup> Last year the American Academy of Pediatrics had identified four key priorities to improve the health and well being of America's children and adolescents: access to health care, quality of health care, immunizations and physician payment. However, recent events have identified a fifth and critical priority—terrorism and emergency preparedness. Our statement will focus on those issues that most immediately fall under the jurisdiction of this committee—access, quality, immunizations and terrorism and emergency preparedness.

# ACCESS

We believe that all children and adolescents should have full access to health care. From the ability to receive primary care from a pediatrician trained in the unique needs of children to timely access to pediatric medical subspecialists and pediatric surgical specialists, America's children deserve access to quality pediatric care.

Maternal and Child Health.—The Maternal and Child Health (MCH) Block Grant Program is the only federal program exclusively dedicated to improving the health of all mothers and children. In addition to directly providing preventive and primary care services to more than 27 million women, children and adolescents nationwide, the MCH Block Grant Program supports community programs around the country in their efforts to reduce infant mortality, prevent injury and violence, expand access to oral health care, address racial and ethnic health disparities and provide comprehensive care for children with special health care needs. The MCH Block Grant Program also plays a significant role in the implementation of the State Child Health Insurance Program (SCHIP). One of the many successful MCH Block Grant programs is the Healthy Torust

One of the many successful MCH Block Grant programs is the Healthy Tomorrows Partnership for Children Program, a public/private collaboration between the MCH Bureau and the American Academy of Pediatrics. In its 14th year, Healthy Tomorrows supports family-centered, community-based initiatives in over 120 communities, including Ohio, Wisconsin, Texas, and Maryland, that work to address such issues as access to care, preventive health care and comprehensive service coordination. To continue to foster these and other community-based solutions for local health problems, in fiscal year 2003 we strongly support an increase in funding for the MCH Block Grant Program to \$850 million, the full authorization level. *Adolescent Health.*—Many of today's adolescent health care needs are addressed through a network of public and private services. For example, the MCH Block Grant Program includes efforts dedicated to addressing interdisciplinary adolescent training and services and research for adolescents' physical and mental health care

Adolescent Health.—Many of today's adolescent health care needs are addressed through a network of public and private services. For example, the MCH Block Grant Program includes efforts dedicated to addressing interdisciplinary adolescent training and services and research for adolescents' physical and mental health care needs. HRSA's Office of Adolescent Health also supports programs for vulnerable populations, including health care initiatives for incarcerated and minority group adolescents, and violence and suicide prevention. The family planning program, Title X of the Public Health Services Act, ensures that all teens have access to valuable family planning resources. Title X does not include funding for abortion services. Continued vigilance is needed, however, if the myriad of health care needs of America's teens is to be met. In particular, the consequence of adolescent pregnancy, sexually transmitted diseases (STDs), and HIV/AIDS demands that adolescents be able to make informed, responsible sexual decisions. While a report by Child Trends suggests the percentage of teenagers having sexual experiences is declining, research also indicates that those teens who are engaging in sexual activity are inconsistently using contraception and therefore still at great risk. Responsible sexual decision-making, beginning with abstinence, is the surest way to protect against sexually transmitted diseases and pregnancy. However, for adolescent patients who are already sexually active, confidential contraceptive services, screening and prevention strategies should be available. We therefore support a funding level in fiscal year 2003 of \$325 million for Title X of the Public Health Service Act.

Mental Health.—It is estimated that 13.7 million children and adolescents have a diagnosable mental or emotional disorder and that approximately 7.5 million of those children and adolescents under the age of 18 require mental health services. Unfortunately, these numbers could increase as children and adolescents continue to adjust to the new stressors introduced in the aftermath of the events of September 11. Despite these startling statistics, the National Institute of Mental Health (NIMH) estimates that fewer than one in five of these children receive the help they need. One key point of access for helping these children receive the mental health care they need is the inclusion of mental health services—provided by qualified counselors, psychologists, and social workers—in this nation's schools. The Safe and Drug Free Schools and Communities Program recognized the importance of these services, which provide critical interventions, deter students from delinquent activity and help all children focus on learning. To ensure the continued and growing success of this program and others focusing on children and adolescents suffering from mental health problems, the American Academy of Pediatrics and the endorsing organizations recommend that \$140 million be allocated in fiscal year 2003 for the Mental Health Services for Children program.

the Mental Health Services for Children program. Health Professions Education and Training.—Critical to building a pediatric workforce to care for tomorrow's children and adolescents are the Training Grants in Primary Care Medicine and Dentistry, found in Title VII of the Public Health Service Act. These grants are the only federal support targeted to the training of primary care professionals. They provide funding for innovative pediatric residency training, faculty development and post-doctoral programs throughout the country. For example, the University of Maryland-Baltimore has used Title VII funds to establish an innovative pediatric residency training and education program that helps pediatricians provide better care to underserved communities. Located in a federally-designated "empowerment zone," the program combines workshops and clinical experiences to improve pediatric residents' understanding of the impact of cultural diversity on the practice of medicine and the primary skills needed to care for underserved patients. The program also allows residents to gain insight into the basic principles of managed care through a 1-month rotation focusing on the administrative aspects of managed care practice.

Through the enduring support of Congress, the Title VII program has continued to finance exciting educational opportunities in a variety of settings to educate and train tomorrow's generalist pediatricians to be culturally competent and to meet the health care needs of their communities. We recommend fiscal year 2003 funding of at least \$40 million for General Internal Medicine/General Pediatrics. We also join with the Health Professions and Nursing Education Coalition in supporting an appropriation of at least \$550 million in total funding for Titles VII and VIII. We further recommend an increase in funds in fiscal year 2003 for the National Health Service Corps, a key component to ensuring an adequate distribution of health care providers across the country, but emphasize the need for continued support of training and education opportunities for health care professionals who will work in these areas.

Independent Children's Teaching Hospitals.—Equally important to the future of pediatric education and research is the dilemma faced by independent children's teaching hospitals. Children's hospitals across the country are critical to the care of the nation's children and play a significant role in training tomorrow's pediatricians and pediatric subspecialists. However, these hospitals qualify for very limited Medicare support, the primary source of funding for graduate medical education in other inpatient environments. As a bipartisan Congress has recognized in the last few years, funding is needed to continue the education and research programs in these child- and adolescent-centered settings. We therefore join with the National Association of Children's Hospitals to recommend ongoing funding of this program plus an adjustment for nominal inflation as permitted under the law, for \$292 million. The support for independent children's hospitals should not come, however, at the expense of valuable Title VII and VIII programs, including grant support for primary care training.

# QUALITY

Access to health care is only the first step in protecting the health of all children and adolescents. We must ensure that the care provided is of the highest quality. Robust federal support for the wide array of quality improvement initiatives is needed if this goal is to be achieved.

Research.—Quality of care rests on quality research—for new detection methods, new treatments, new technology and new applications of science. As the lead federal agency on quality of care research, the Agency for Healthcare Research and Quality (AHRQ) provides the scientific basis to improve the quality of care, supports emerging critical issues in health care delivery and addresses the particular needs of priority populations, such as children. Substantial gaps still remain in what we know about health care needs for children and adolescents and how we can best address those needs. Children are often excluded from research that could address these issues. The AAP strongly supports AHRQ's objective to encourage researchers to include children as part of their research populations. We also support increasing AHRQ's efforts to build pediatric health services research capacity through career and faculty development awards and practice-based research networks. As AHRQ's research agenda moves forward it is important to continue to provide policymakers, health care providers, and patients with the information to continuously improve health care therefore, we join with the Friends of AHRQ to recommend funding of \$390 million for AHRQ in fiscal year 2003.

Since its inception, the National Institutes of Health (NIH) is an integral part of the public health continuum. NIH has served as a vital component in improving the nation's health through research, both on and off the NIH campus, and in the training of research investigators. Over the years, NIH has made dramatic strides that directly impact the quality of life for infants, children and adolescents through biomedical and behavioral research. For example, even with existing racial and ethnic health disparities, the overall life expectancy of a baby born today is almost 30 years greater then a child born at the beginning of the 20th century. One reason is due to the development of a substance to prevent the lungs of an infant from collapsing when he/she is born with respiratory distress syndrome, an immaturity of the lungs. Another reason is development of vaccines to protect against infectious diseases that once killed or disabled millions of children and adults. The pediatric community applauds the ongoing commitment of Congress, through the leadership of this subcommittee, to increase NIH funding. We join with the Ad Hoc Group for Medical Research Funding in recommending an appropriation of \$27.3 billion for NIH to achieve the bipartisan goal of doubling the NIH by 2003. In addition, to ensure ongoing child and adolescent focused research, such as the National Longitudinal Study of Adolescent Health and the National Children's Study conducted at the NICHD; we join with the Friends of NICHD Coalition in requesting \$1.284 billion in fiscal year 2003.

We commend this committee's ongoing efforts to make pediatric research a priority at the highest level of the NIH. We urge continued federal support of NIH efforts to increase pediatric biomedical and behavioral research, including such proven programs as targeted training and education opportunities and loan repayment. We recommend an appropriation of at least \$10 million for ongoing support for the Pediatric Research Initiative in the Office of the NIH Director and sufficient funding to continue the new pediatric training grant and pediatric loan repayment programs enacted in the Children's Health Act of 2000 to ensure that we have adequately trained pediatric researchers in multiple disciplines that will not come at the expense of other important programs.

pense of other important programs. Finally, as clinicians, we know first hand the considerable benefits for children and society in securing properly studied and dosed medications. These benefits include reduced medical errors and adverse drug effects; reduced health care costs through fewer hospitalizations and shortened hospital stays; and availability of more child-friendly formulations for infants and children. But until now there has been little incentive for drug companies to study off-patent drugs—drugs that are critically needed therapies for children. Therefore, we urge your support to provide the NIH with sufficient funding—\$200 million—to establish a fund to study generic (off-patent) and selected on-patent drugs for pediatric use.

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 continue to 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 and not weaken any other valuable component of the Public Health Service.

#### IMMUNIZATIONS

Since the advent of the polio vaccine in 1955, the United States has invested in a national immunization campaign to prevent the population from contracting devastating diseases such as smallpox, polio, diphtheria, pertussis, measles and meningitis. For example, measles, a disease so close to elimination in the western-hemisphere that today many parents as well as most of our pediatric residents in training have never seen a case of measles. In 2000, there were approximately 81 cases of measles resulting in 19 hospitalizations for a total of 77 days. Before the vaccine became available, measles killed 3,000 children a year in the United States and also caused 48,000 children to be hospitalized each year. We have to be sure to keep vaccinating our children against illnesses. The fact that we do not see those diseases anymore simply means the vaccines are working, and they will only continue to work if we continue to immunize our children.

Pediatricians, working alongside public health professionals and other partners, have brought the United States its highest immunization coverage levels in history. As a result, disease levels are at, or near, record low levels. We attribute this, in part, to the Vaccines for Children (VFC) Program and encourage Congress to maintain its commitment to ensuring the program's viability. The VFC program combines the efforts of public health 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."

The public health infrastructure that now supports our national immunization efforts must not be jeopardized with insufficient funding. One of the conclusions of the Institute of Medicine report, Calling the Shots, was that unstable funding for state immunization programs threatens coverage levels for specific populations and age-groups and vaccine safety. Here are three examples that reinforce the need for a strong and sufficient infrastructure. First, adolescents continue to be adversely affected by vaccine preventable diseases (e.g., chicken pox, hepatitis B, measles and rubella, also known as German measles). Comprehensive adolescent immunization activities at the national, state and local level are needed to achieve national disease elimination goals. Second, adequate funding is needed for the implementation of the December 2000 Executive Memorandum to improve immunization rates for children at risk, through the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). Estimates are that in 41 states, the immunization rates for children enrolled in WIC are lower than the rates for other children in their age group—in some cases by as much as 20 percent. Lastly, 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 or overdue. It also helps pediatricians and other health care professionals know the immunization status of the children they serve in general and specifically when on the very rare occasion there is an adverse event or a recall notice of a particular vaccine lot.

While the ultimate goal of immunizations clearly is eradication of disease, the immediate goal must be prevention of disease in individuals or groups. To this end, we strongly believe that continued investment in CDC efforts must be sustained. In fiscal year 2003, we recommend at least \$696 million for CDC's immunization program and sufficient funding for CDC's global immunization initiatives that includes funding for polio eradication and the elimination of measles and rubella.

#### TERRORISM AND EMERGENCY PREPAREDNESS

As with many other aspects of health care research and delivery, children's unique health and mental health needs require special consideration when it comes to terrorism and emergency preparedness. Children are not little adults—they require different equipment and supplies, as well as different drugs and drug dosages, if they are to survive a terrorist attack or other disaster.

One specific program that assists local communities in providing quality care to children in such situations is the Emergency Medical Services for Children (EMSC) grant program. While children currently account for up to 30 percent of all emergency department visits and 10 percent of ambulance runs annually, many facilities lack the specialized equipment needed to care for children. Moreover, many emergency personnel do not have the necessary education or training to provide optimal care to children. In order to assist local communities in providing the best emergency care to children, we urge that the EMSC program be funded at \$25 million in fiscal year 2003.

Beyond the EMSC program, we know that the broader public health infrastructure must be strengthened if children and their families are to receive quality care following a terrorist attack or other disaster. Local pediatricians and pediatric specialists, children's hospitals, poison control centers, schools and other child care facilities must be active partners in the public health system, working together with first responders, public health offices and public health laboratories. To that end, the Academy joins the broader public health community in recommending at least \$940 million for upgrading state and local health capacities in fiscal year 2003.

#### CONCLUSION

We appreciate the opportunity to provide our recommendations for the coming fiscal year. As this Subcommittee is once again faced with difficult choices and multiple priorities we know that as in the past years, you will not forget America's children.

#### PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF OSTEOPATHIC MEDICINE

As Vice President for Health Services and Medical Affairs of the New York Institute of Technology and Chair of the Board of Governors of the American Association of Colleges of Osteopathic Medicine (AACOM), I am pleased to present the views of our nineteen colleges on fiscal year 2003 appropriations for health professions education assistance programs under Titles VII and VIII of the Public Health Service Act. First, I would like to express AACOM's appreciation for the continued efforts of this Subcommittee to maintain a commitment to health professions education. The Subcommittee's vision has enabled colleges of osteopathic medicine in particular to address the physician workforce needs dictated by a rapidly changing health care delivery system.

However, we are not yet able to say that we are in a position to meet these workforce needs completely. *Healthy People 2010*, a document that serves as a blueprint for health care delivery, has articulated two overarching goals: Increase the Quality and Years of Healthy Life; and Eliminate Health Disparities. To achieve these goals by 2010, we must begin now to train health professionals who have the necessary skills and commitment. More than ever, institutions need the support of Title VII and Title VIII programs to develop a workforce consistent with *Healthy People 2010*.

The principal vehicle for addressing the specialty and geographic maldistribution of physicians has been through primary care education and training. The 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. Osteopathic physicians represent 5.5 percent of the U.S. physician workforce, but constitute 15 percent of the physicians practicing in communities of fewer than 2,500 in population. This commitment is reflected in our institutions' missions and in the profile of our medical students. Our latest data show that over 40 percent of our entering students come from small towns and rural areas (i.e., towns of fewer than 50.000).

In addition, the Senate Special Committee on Aging recently conducted a hearing focusing on the "crisis in the shortage of geriatric-trained health care professionals." Senator John Breaux, Chairman of the Committee stated that, "These shortages are not only a threat to an increasing number of elderly Americans, but also to the economic health of our country.

Similarly, the osteopathic medical education community is sensitive to the in-creasing gap between the number of elderly patients and the number of physicians trained specifically to serve this growing population. Several colleges of osteopathic

medicine have established geriatric centers, utilizing Title VII funding. The health professions assistance programs under Title VII of the Public Health Service Act have been valuable in our efforts to ensure these commitments. Support under these programs include: training of underrepresented minority and disadvan-taged students; general internal medicine residencies; general pediatric residencies; family medicine training; preventive medicine residencies; Area Health Education Centers; Health Education and Training Centers; Health Career Opportunities Pro-

grams; Centers of Excellence Programs; and geriatric training authority. Title VII also authorizes student assistance programs that are especially impor-tant to osteopathic medical students. Our students have the highest average debt upon graduation among the health professions (\$128,000). Congress should be con-cerned with minimizing the debt load of graduates of health professions schools, if they, in turn, can be expected to hold down medical costs, practice in primary care, and locate in underserved areas.

and locate in underserved areas. Accordingly, Mr. Chairman, AACOM recommends that the fiscal year 2003 fund-ing level for Titles VII and VIII of the Public Health Service Act be increased to \$550 million. These figures do not include funding for children's hospitals graduate medical education programs or for the National Health Service Corps which are amounts separate from Titles VII and VIII funding. This funding level would pro-vide a much needed boost toward ensuring that training of a workforce who will be delivering the types of services and providing the full access to these services identi-fied in Healthy Poenlo 2010 fied in Healthy People 2010.

Again, I appreciate the opportunity to present our views to the Subcommittee. If I can provide you with any additional information, you may contact either me at the New York Institute of Technology or Michael Dyer, Vice President for Government Relations at AACOM at (301) 968-4151.

# PREPARED STATEMENT OF THE LOVELACE RESPIRATORY RESEARCH INSTITUTE, ALBUQUERQUE, NM

It is proposed that the Department of Health and Human Services through Office of the Secretary—Minority Health Account support the development of the Minority Respiratory Health Center. This Center will address the crises affecting minority populations experiencing a much higher and more severe level of respiratory dis-ease, especially those located in major metropolitan areas. Diseases like asthma, and smoking related diseases like lung cancer and emphysema, are rising at unprec-edented rates. The Lovelace Initiative seeks a partnership with the HHS to address

the acute need to attack those most severely impacted by the respiratory epidemic. We respectfully request \$4 million. The appropriate Federal agency is the Depart-ment of Human and Health Services, Office of the Secretary—Minority Health Account.

# THE PROBLEM

Vulnerable populations in the United States, especially those located in major metropolitan areas, are experiencing a much higher and more severe level of respiratory disease. Diseases like asthma, and smoking related diseases like lung cancer and emphysema, are rising at unprecedented rates. —The number of asthma sufferers has more than doubled between 1980 and

1998.

- -Of this group, children make up more than half.
- -Asthma disproportionately affects inter-city dwellers mostly in Hispanic and African American families.
- —The rate is of asthma in these populations is  $2\frac{1}{2}$  times higher than the asthma rate in whites.
- —The hardest hit are children of Puerto Rican descent who are 2 to 3 times more likely to have asthma than any other ethnic group. 20 percent to 30 percent of these kids from 6 months to 11 years old have asthma.
- African-American children must face a death rate from asthma of 3 times that of the general population as a whole.The NY Department of Health reports that up to 30 percent of the children in
- -The NY Department of Health reports that up to 30 percent of the children in its minority populations have asthma.

# THE SOLUTION

The Minority Respiratory Health Center—attacking the disproportional impact of respiratory disease on our minority populations

The Lovelace Respiratory Research Institute founded the Minority Respiratory Health Center to address this national crisis.

- The Minority Center will provide a focused research plan that addresses the creation of treatments and preventions to address this disparate impact of respiratory disease.
   The Center is pursuing treatments that are particularly effective in addressing treatments that are particularly effective in addressing treatments.
- —The Center is pursuing treatments that are particularly effective in addressing the needs of these vulnerable populations, including: developing an aerosol vaccine for the asthma, developing preventative treatments that take advantage of the genetic tools developed in recent years, and providing more systemic and clinical treatment protocols that are more tailored to the lifestyle needs of these populations.
- -The Center will provide opportunity for the development of minority researchers and technical workers.
- —The Center will also develop a communication network for distributing, receiving and linking to these targeted populations. It will also serve as an advocacy center for gaining national support to continue the attack until this epidemic is wiped out.

# RESEARCH AGENDA

Through several key lines of research, the scientists at LRRI in conjunction with the Minority Center are evolving a comprehensive program to understand the mechanisms by which minority populations are at greater risk for respiratory disease and to try to design inexpensive, non-labor intensive new approaches to treatment and prevention. The areas of focus for these scientists will be Asthma, COPD/emphysema, lung cancer, environmental respiratory health and tobacco product use.

#### Asthma

Asthma and other allergic diseases of the respiratory system represent one of the largest public health problems in the world. It is estimated that over \$7.5 billion a year are spent for asthma treatment in the United States alone. If rhinitis and other related allergic conditions are included, this figure increases significantly. Asthma has doubled in children and increased by 50 percent in the general population of the United States within the past 10 years with no accepted explanation. Allergic diseases are caused by immune responses to allergens (e.g., pollen, cat

Allergic diseases are caused by immune responses to allergens (e.g., pollen, cat allergen, dust mites). All current treatments for these maladies involve the application of medicinal products that interfere with the production or action of mediators from immune cells stimulated by allergens. Three classes of drugs are used:

-Glucocorticoids that reduce inflammation when given systemically or by inhalation;

-Beta blockers that reduce the smooth muscle responses in the airways; and

-Mast cell function inhibitors that reduce histamine release.

None of these approaches cures allergic diseases or attacks the underlying, immunological cause of allergies. The prevention or elimination of allergic immune responses would alleviate the need for the toxic drugs presently used to treat allergic diseases.

The Minority Center through its relationship with LRRI is developing an entirely new and unique approach to cure allergic disease by preventing allergic immune responses in susceptible children and by suppressing allergic immunity in individuals who already have allergies. Data developed at LRRI and elsewhere indicate the real possibility that immunizing people with selective antigens can prevent the onset of, or reverse existing allergic immune responses.

LRRI has the staff and facilities to determine whether or not this new therapeutic approach for the treatment of allergic diseases will be effective. This therapeutic approach will be evaluated in three stages.

-Determine efficacy in animals.

-Evaluate safety in animals and humans.

—Demonstrate efficacy in humans. 1. *LRRI's Approach.*—The impetus for this approach is centered on the cost of treatment for the 44 million Americans not covered by health insurance, and the hundreds of millions of people worldwide who cannot afford life-long expensive medical treatment. This is obviously even more relevant to the many tens of millions of asthmatics in Third World countries, in Africa and Asia, and Šouth and Central America where follow-up respiratory treatment is nonexistent. A simply adminis-America where follow-up respiratory treatment is indexistent. A simply administered, inhaled asthma vaccine administered to very young children would offer a real opportunity to eliminate this grave worldwide public health crisis.
2. Who Would Pay for an Effective Preventive?—The proposed treatment would inevitably come as an inhaled nontoxic antigen. Studies will be required to determine

if a single treatment would provide permanent protection, or if repeated treatments will be required to maintain protection. Accurate data are unavailable on the num-bers of asthma sufferers in Third World countries. Using as an example the U.S. statistics such as those quoted earlier in Individuals Who Will Benefit, it seems safe to suggest that managed care delivery systems and major insurers in developed countries would demand this vaccine as being the most cost-effective way to prevent asthma. Similarly, in underdeveloped countries public health officials and govern-ment and private funding sources would see the long-term benefits of making the vaccine widely available. As many as 40 percent of children, 1 year or younger, may benefit from treatments that prevent asthma and other allergic diseases. The result-ing health care savings would dwarf the direct pharmaceutical costs.

3. Short-term Goals.—The Minority Center seeks funding for the initial research and development necessary to complete ongoing studies that prove the efficacy of the technology in animal models and then commence clinical trials. We have an international reputation in the field of extrapolation of respiratory system animal studies to humans through its former DOE laboratory, the Inhalation Toxicology Re-search Institute, now privatized by LRRI. This group of 150 internationally recognized scientists and technicians include inhalation toxicologists, veterinary pathologists, respiratory immunologists, and aerosol specialists.

# COPD / Emphysema

Hispanics in the United States represent the only major group of people for whom the use of tobacco products is on the rise. African-American populations have a disproportionately high rate of use (especially urban African-American men). In both cases, Chronic Obstructive Pulmonary Disease (COPD) and related fibrotic and inflammatory airway and lung disease are expected to rise substantially as the popu-lations' age. As in the case of asthma, the Minority Center will concentrate on low technology, cost-effective methods of mitigating the growing public health burden by identifying the genetic causes of the susceptibility to COPD among minority people at risk.

COPD, which includes chronic bronchitis and emphysema, is associated with cigarette smoking. Therefore, environmental factors are clearly very important in the development of this disease. However, COPD develops in only 20-35 percent of smokers, indicating that genetic factors are critical in determining which cigarette smokers are at risk of developing airflow obstruction. Therefore, it is likely that persmokers are at risk of developing annow obstruction. Inference, it is inkery that per-sons with COPD have polymorphisms (genetic changes or "mutations") in one or more of these genes resulting in altered gene function. In support of this hypothesis, sequence analysis of the MMP-9 gene has revealed three functional variable sites, one of which alters an amino acid encoded in the active site, and two in the pro-motor metion which methods are activity. Our preliminary methods have a given moter region, which modulate promoter activity. Our preliminary results show a sig-nificant association of the CA repeat polymorphism in the promoter region of MMP– 9 with the development of COPD. The results from a study LRRI has undertaken could lead to the identification of subjects who should receive corrective treatments proactively to delay disease development and progression.

A second approach is a new treatment paradigm. Our scientists have recently discovered some of the mechanisms that cause excess mucus production in affected individuals, and a preliminary inexpensive inhalation therapy is being developed. Excess mucus production is one of the primary symptoms of COPD and its reduction or termination by an easy-to-apply means would dramatically reduce the public health burden of inflammatory respiratory disease in general and COPD in particular.

# Lung Cancer

The disproportionate burden of this devastating usually fatal disease on African-American populations is directly related to the high rates of tobacco use in their urban populations. These rates, although stable for this group of people, continue to increase for Hispanic populations. Early inexpensive detection methodologies offer the greatest hope for a positive impact on the dismal statistics (for example, mortality in African-Americans is running 150 percent higher than the populations as a whole). LRRI has developed a rapid and potentially inexpensive detection methodology that appears to detect the presence of lung cancer up to 3 years ahead of current standard of care methods. This cancer can be cured if detected early, but it seldom is detected early enough.

LRRI scientists have developed a method of amplifying absent DNA mutational events, which when applied to smokers at high risk predicts the presence of lung cancer cells. The use of enhanced polymerase chain reaction technology is 50 times more sensitive than previous methods and detects the presence of lung cancer in 100 percent of the research subjects. This test with further work can be developed into a quick outpatient, non-invasive test that could be undertaken for a few dollars per test. Using sputum, the samples themselves can be obtained in almost any community setting.

LRRI scientists believe that it will be possible to mitigate lung cancer rates in inner city populations via a technique called chemoprevention. This is an approach designed to interrupt the cellular malignant transformation process by the injection of minute quantities of agents known to have this effect. The most likely initial candidate is dietary selenium, which appears to play a role (when present at unusually low levels in the diet) in lung cancer. A national study is now underway to prove the efficacy of adding selenium to the diets (or as a pill) to populations of smokers a highest risk in urban populations.

Education alone appears ineffective in mitigating smoking behaviors in minority populations, and some other approach must be tried. This extremely low-cost, easily applied approach could greatly improve the respiratory health of these people at risk. Details of this large, multi-center clinical trial are available on request. Administrative and facilities (equipment and technical) staff will be required to support this work.

# Environmental Respiratory Health

LRRI currently operates the EPA National Environmental Respiratory Center (NERC). The mission of this group of scientists is to define the causes of health effects from breathing the complex mixtures of air pollution. This Center will integrate its program into the Minority Center via the public policy function as individual pollutants are identified and their role in asthma, COPD, and lung cancer becomes better defined. This Center is funded via a variety of sources other than significant administrative support and would not require new incremental funding. The role of secondary environmental smoke is also being investigated by the Center, and the behavioral aspects of this increasingly recognized problem would evolve as a joint NERC-MRHC project to be funded outside the scope of this proposal.

# BOTTOM LINE

We don't exactly know why the rates of asthma and minority population tobacco use are growing, and we don't know why they are disproportionately affecting minority communities, primarily in urban centers. We do know that this epidemic is severely impacting many of our nation's citizens by bringing untold emotional stress on those who are sick and those that must take care of them. That stress is even more significantly impacting the growth of our country, by keeping these people away from school and their work. It is time to support the Minority Center that is targeting practical and real scientific solutions. The great news is the Lovelace scientists who are pioneering an asthma vaccine report that their experiments are indicating positive results. We need funding to make these human cures. There is light at the end of the tunnel.

On behalf of the Society of Teachers of Family Medicine, the Associations of Departments of Family Medicine, the Association of Family Practice Residency Directors, and the North American Primary Care Research Group, we of would like to

PREPARED STATEMENT OF THE SOCIETY OF TEACHERS OF FAMILY MEDICINE, THE ASSOCIATIONS OF DEPARTMENTS OF FAMILY MEDICINE, THE ASSOCIATION OF FAMILY PRACTICE RESIDENCY DIRECTORS, AND THE NORTH AMERICAN PRIMARY CARE RESEARCH GROUP

thank you for the opportunity to provide this statement for the record on behalf of funding for family medicine training, and the Agency for Health Care Research and Quality (AHRQ).

# HEALTH PROFESSIONS: THE PRIMARY CARE MEDICINE AND DENTISTRY CLUSTER

Mr. Chairman, the Organizations of Academic Family Medicine would like to thank you for this committee's commitment to these programs. We appreciate the increased funding included in the fiscal year 2002 appropriations funding bill. Family medicine training programs are funded under Section 747, the Primary Care Medicine and Dentistry cluster, of Title VII of the Public Health Service Act. We ask that you continue your support for family medicine training, and bring the appropriations level for section 747, the Primary Care Medicine and Dentistry Cluster, up to \$169 million for fiscal year 2003, of which \$96 million is needed for family medicine.

This statement is designed to show the committee how its investment is paying off. This statement will discuss the success of these programs and include recommendations about what still needs to be done. As you look at all the opportunities you have to fund domestic health programs you need to be able to make judgments about the value and utility of these programs. We have been asked in various venues to show proof that these funds actually do what they are designed to do. We must show that this money makes a difference. In this statement we intend to do just that. In addition, we believe Congress also needs to understand the unmet needs that exist in our nation needs Health Professions programs can successfully help address.

neip address. President's Budget Request for fiscal year 2003 Zeros Out Primary Care Funding The President's budget zeroes out funding for the Primary Care Medicine and Dentistry cluster. In addition, the proposal includes only \$94 million for all of the Health Professions programs, a sharp cut of 75 percent from the fiscal year 2002 level of \$378 million. The proposal emphasizes that the grant program was developed in response to a physician shortage, as it did last year, although the document acknowledges a geographic maldistribution of doctors. The budget also claims, "most of the health professions grants have not proven effective because they do not accurately address current health professions problems." According to several studies (see below), Title VII dollars have proven effective in addressing several major health professions problems.

# Family Medicine Training Programs Are A Success

First, let's take a look at health professions training specifically family medicine training. These programs are producing the outcomes that Congress has requested. In a current study (currently submitted for peer reviewed publication), the Robert Graham Center For Policy Studies In Family Practice and Primary Care has shown that federal funding through Title VII of family medicine departments, predoctoral programs, and faculty development has made a difference. The study shows that:

- –All three types of grants made a difference in producing more family physicians, and more primary care doctors. Predoctoral and department development grants made a difference in producing more primary care doctors serving in rural areas, and more primary care doctors serving in primary care health professional shortage areas.
- —Sustained funding during the years of medical school training had more positive impact than intermittent funding.
- -We must conclude from this data that this funding means that thousands of physicians are making different career choices, choices that positively affect millions of patients in underserved areas and in primary care. Moreover, if this money were to "go away" fewer students would be making these career choices.

# Other Indicators Of Success

The federal government's independent General Accounting Office (GAO) has also shown that this money works. The GAO, in two reports in 1994, addressed the question of how do we know Title VII money is well spent? A July 1994 report, states that "the programs were important for funding innovative projects and providing seed money' for starting new programs. For example, Title VII was considered important in the creation and maintenance [emphasis added] of family medicine departments and divisions in medical schools."

In another report, the GAO states in October 1994 that "students who attended schools with family practice departments were 57 percent more likely to pursue primary care." In addition, the report goes on to say that "students attending medical schools with more highly funded family practice departments were 18 percent more likely to pursue primary care and students attending schools requiring a third-year family practice clerkship were [also] 18 percent more likely to pursue primary care." The money spent on Section 747 of Title VII is directly targeted in these areas.

Loss of funding for family medicine training would cause tremendous impact on service to the underserved Data show that if production of family physicians was to fall, the impact on the nation's underserved would be great. The fewer the number of family physicians produced, the greater the number of new health profes-sional shortage areas, or HPSAs. This holds true even in comparison with the combined loss of internists, pediatricians and obstetrician/gynecologists. The United States relies on family physicians unlike any other specialty. Without family physicians an additional 1332 of the United States' 3082 urban and rural counties would qualify for designation as primary care HPSAs. This contrasts with an additional 176 counties that would meet the criteria if all internists, pediatricians, and ob/gyns in aggregate were withdrawn.

The bottom line is that without family physicians 1332 counties would qualify for primary care HPSA designation vs. 176 counties if other primary care specialists were withdrawn.

# What Is The Unmet Need?

Why Must We Continue To Fund And Grow These Programs? According to a study by Politzer, et al (The Journal of Rural Health, Winter, 1999) Title VII funding is key to ending HPSAs. This funding has led to the time needed for HPSA elimi-nation to decrease to 15 years. Doubling the funding for these programs would decrease the time for HPSA elimination to as little as 6 years.

According to the study, without this funding, not only would HPSAs not be elimi-nated, but the number of shortage areas would continue to grow. Moreover, success has been attained by an allocation of funds more favorable to family medicine than the other two primary care specialties. Title VII funding has indeed accomplished many of the objectives for which it was

- designed: —Funding of innovative projects Providing "seed money" for the start-up of new
  - projects; -The creation and maintenance of departments of family medicine in the nation's medical schools;
  - The development of 3rd year clerkships in family medicine The increase in students selecting primary care residencies from those schools with funded family medicine departments and 3rd year clerkships;
  - The increase in students selecting primary care residencies from those schools
  - with funded family medicine departments and 3rd year clerkships; -The increased rate of graduates from Title VII funded projects entering practice in medically underserved areas (MUAs), with a resultant reduction in the time required for Health Professions Shortage Area (HPSA) elimination.

# Section 747 Advisory Committee Recommends Higher Funding

In 1998, Congress established an Advisory Committee to review and make recommendations on Section 747. The Advisory Committee on Training in Primary Care Medicine and Dentistry (ACTPCMD) recently released its recommendations to Congress and the Secretary of the Department of Health and Human Services. The first of six recommendations urges greatly expanding federal support for Section 747 as well as the success of Title VII funded programs.

The training enterprise that does not value primary care either financially or oth-erwise is a key part of the problem. Title VII funds that support the infrastructure and stability of family medicine departments in medical schools have to be sustained in order to keep producing the current levels of primary care physicians and, more specifically, those who will practice in rural and other underserved areas. Clearly, the programs of Title VII are on the right track toward meeting the health care challenges of the 21st century. So, while we believe that current funding must be maintained, more needs to be done.

# Future Funding Priorities

ACTPCMD's report to Congress lays out priorities for training primary care providers. If additional funds are made available, Title VII dollars could enhance current training, allowing it to be even more effective at providing: high-quality health care for underserved populations culturally competent care continued demonstration authority to address emerging health initiatives additional interdisciplinary learn-ing opportunities better quality of health care, eliminating health disparities, and improving patient safety Primary Care Training Programs React Quickly to Emerg-ing Health Challenges Title VII dollars have created an infrastructure that allows educational programs to respond to contemporary health care issues. Specifically, the ACTPCMD report states that:

Investment in education to provide primary care has effects that touch the largest number of people in the country. No other group of health care providers can exert such a broad influence on the kind and quality of health care in the United States. Primary care training programs are ideally positioned to react quickly to meet everchanging health care needs and issues, whether they are related to HIV/AIDS, growing numbers of elderly with chronic illnesses, implications of the modern genetics revolution, the threat of bioterrorism, or other issues that will continue to emerge and demand rapid educational intervention. Thus, this infrastructure is uniquely able to play a pivotal role in bringing emerging issues in health care to the population at large.

Mr. Chairman, we know that this committee has to weigh the value of funding various programs against each other. We hope that the evidence we have presented here will bring the committee to the conclusion that funding spent on these programs would bring value for the money and would be money exceptionally well spent.

# FUNDING FOR THE AGENCY FOR HEALTH CARE RESEARCH AND QUALITY (AHRQ)

Mr. Chairman, once again, we thank you and this committee for increasing funding for this important agency. It is apparent that the key federal agency available to fund primary care research is the Agency for Healthcare Research and Quality (AHRQ). In it's recent reauthorization, Congress established within the Agency a Center for Primary Care Research to "serve as the principal source of funding for primary care practice research in the Department of Health and Human Services." The statute defined primary care research as research that "focuses on the first contact when illness or health concerns arise, the diagnosis, treatment or referral to specialty care, preventive care, and the relationship between the clinician and the patient in the context of the family and community.

# Funding Request For AHRQ

We recommend appropriations of \$390 million for the Agency for Healthcare Research and Quality (AHRQ) in fiscal year 2003. AHRQ conducts primary care and health services research geared to physician practices, health plans and policymakers that helps the American population as a whole.

# President's Budget Request for fiscal year 2003 Cuts AHRQ Funding

The President's budget includes \$251 million for AHRQ, a cut of \$49 million, or 16 percent, from the current funding level of \$300 million. One unfortunate consequence of earlier earmarking of funds for the agency is that a cut of \$50 million is felt disproportionately throughout the agency. A cut of this magnitude would result not only in the inability to provide new grants or contracts in fiscal year 2003, but would also mean a 46 percent cut in existing grants and a 31 percent cut in existing contracts. The budget also makes funding for the agency completely dependent on transfers from other agencies, rather than on a Congressional appropriation. This is a less secure funding method for this important agency.

# What Does AHRQ Do?

AHRQ's three goals are to:

(1) improve physician practice and Americans' health outcomes,

(2) improve the quality of health care (e.g., patient safety), and

(3) improve the health care system (e.g., increase access and reduce costs). In brief, AHRQ "helps to improve the health and health care of the American people"—(AHRQ report, March, 2001).

# How Does AHRQ Meet Its Goals?

AHRQ translates research findings from basic science entities like the National Institutes of Health into information that doctors can use every day in their practice with their patients. Another key function of the agency is to support research on the conditions that affect most Americans.

# AHRQ Translates Research into Everyday Practice

Congress has provided billions of dollars to the National Institutes of Health, which has resulted in important insights in preventing and curing major diseases. AHRQ takes this basic science and produces information that physicians can use every day in their practices. AHRQ also distributes this information throughout the health care system. In short, AHRQ is the link between research and the patient care that Americans receive. An example of this link is basic science research showing that beta blockers reduce mortality. AHRQ supported research to help physicians determine which patients with heart attacks would benefit from this medication.

# AHRQ Supports Research on Conditions Affecting Most Americans

Most Americans get their medical care in doctors' offices and clinics. However, most medical research comes from the study of extremely ill patients in hospitals. AHRQ studies and supports research on the types of illness that trouble most people. AHRQ looks at the problems that bring people to their doctors every day not the problems that send them to the hospital. For example, AHRQ supported research that found older antidepressant drugs are as effective as new antidepressant medications in treating depression, a condition that affects millions of Americans.

# Institute of Medicine Recommends \$1 Billion for AHRQ

The Institute of Medicine's report, Crossing the Quality Chasm: A New Health System for the 21st Century (2001), recommended \$1 billion a year for AHRQ to "develop strategies, goals, and actions plans for achieving substantial improvements in quality in the next 5 years." The report looked at redesigning health care delivery in the United States. AHRQ is a linchpin in retooling the American health care system.

# RECOMMENDATIONS FOR FAMILY MEDICINE TRAINING AND RESEARCH

The Organizations of Academic Family Medicine have two main recommendations

for the fiscal year 2002 Labor/HHS Appropriations hill. They are as follows: We ask that you continue your support for family medicine training, and bring the appropriations level for section 747, the Primary Care Medicine and Dentistry Cluster, up to \$169 million for fiscal year 2003, of which \$96 million is needed for family medicine.

In order to support critical practice-oriented primary care research, and to ensure that existing grants and contracts will not be cut, we are asking that the Agency for Healthcare Research and Quality be funded at \$390 million.

# PREPARED STATEMENT OF THE SOCIETY OF GENERAL INTERNAL MEDICINE

The Society of General Internal Medicine (SGIM) appreciates the opportunity to provide testimony to the Senate Labor, Health and Human Services and Education Subcommittee regarding fiscal year 2003 appropriations to key programs within the Department of Health and Human Services

SGIM is an international association of 3,000 physicians and other health professionals who combine treating patients with teaching and conducting research. SGIM is dedicated to improving patient care, medical education, and research in primary care and general internal medicine. As such, SGIM believes it is uniquely positioned to recommend appropriate funding levels to continue and expand the critical work of the Agency for Healthcare Research and Quality (AHRQ) and the Title VII and VIII Health Professions Programs.

SGIM would like to thank the subcommittee for its support of AHRQ and the Title VII and VIII programs in recent years, and encourages the subcommittee to provide a strong investment in these programs for fiscal year 2003.

#### AGENCY FOR HEALTHCARE RESEARCH AND QUALITY (AHRQ)

SGIM strongly supports AHRQ's mission and work to support, conduct, and disseminate research that improves access to and outcomes and quality of health care services. AHRQ's health services research complements the biomedical research of the NIH by helping clinicians, patients, and health care institutions make choices about what treatments work best, for whom, when, and at what costs.

AHRQ is the only federal agency performing health care related cost-effectiveness research. AHRQ's research often addresses the cost-efficiency of new modalities or interventions and the appropriateness of their application for large patient sub-pop-ulations such as those served by Medicare and Medicaid. For instance, AHRQ sup-ported research that led to the development of new technology to help emergency room doctors improve their decision making about whether to hospitalize or dis-charge patients with chest pain. It is estimated that 200,000 people a year could be spared a hospital stay they did not need, and that more than 100,000 individuals could be spared an unnecessary admission to a critical care unit. The potential savings to the health system because of this instrument is estimated to be \$700 million a year.

An AHRQ Evidence-based Practice Center found that children suffering from uncomplicated acute otitis media (AOM), a middle ear infection, and treated with amoxicillin fared just as well as those treated with more expensive antibiotics. This research represents large cost savings to the Medicaid program since pediatricians can prescribe the less expensive medication and achieve the same result.

AĤRQ often collaborates with other Department of Health and Human Services (HHS) agencies, particularly the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC).

The private sector cannot replace the work of AHRQ. The private sector puts a relatively small amount of financial resources toward initiatives similar to AHRQ research, focused primarily on products developed by the specific company. As a result, the objectivity of the research could be threatened. In comparison, AHRQ research is evidence-based and is able to withstand scientific scrutiny and has a high degree of credibility.

ŠGIM believes a fiscal year 2003 budget of \$390 million is necessary for AHRQ to fully carry out its congressional mandate to improve health care quality, including reducing errors in medicine and advancing health outcomes information. Consistent, stable funding for investigator-initiated research is essential. Investigatorinitiated research has proven to result in clinical innovations that translate into improved patient outcomes. Modest grant levels provided to clinical investigators often result in advancements with positive economic implications far outweighing the initial investment. Congress must sustain ample funding for investigator-initiated research to encourage sufficient numbers of researchers to enter and remain in this field.

SGIM is concerned with the President's proposed budget of \$251 million for AHRQ, a cut of \$48 million or 16 percent. Under this budget, AHRQ would be unable to fund any new research or training grants. Funding for current grants (except for protected areas such as patient safety research) would be reduced by 50 percent, requiring grant and contract renegotiations that will significantly reduce our knowledge and understanding of how to cost-effectively provide quality health care. Reductions in the AHRQ funding stream will result in lost opportunities for research projects currently in the middle of a two- or 3-year grant cycle. Mid-course interruptions will halt some projects just as these initiatives are about to bear fruit in the form of improved patient health outcomes and reductions in healthcare expenditures. Such reductions will also have a chilling effect on individual, investigator-initiated research, an "All-American", competitive process through which applicants that have received modest levels of grant funding have developed initiatives with financial implications far beyond the original investment.

# TITLE VII AND VIII HEALTH PROFESSIONS PROGRAMS

The health professions and nursing education programs under Title VII and VIII of the Public Health Service Act provide support to students, programs, departments, and institutions to improve the accessibility, quality, and racial and ethnic diversity of the health care workforce. In addition to providing essential training and education opportunities, these programs were designed to combat health professional shortages in rural and underserved areas by educating and training primary care providers with the goal that they return to serve in such areas. Graduates of these programs are three to ten times more likely to practice in medically underserved areas than graduates of non-funded programs. They help meet the health care delivery needs of the over 3,000 Health Professions Shortage Areas in this country, and at times, they serve as the only source of health care in many disadvantaged communities.

In November 2001, the Advisory Committee on Training in Primary Care Medicine and Dentistry released its first congressionally mandated report, which emphasizes the essential role of the Title VII programs in enhancing the quality and quantity of the primary care health workforce. The report states:

"Investment in education to provide primary care has effects that touch the largest number of people in the country. No other group of health care providers can exert such broad influences on the kind and quality of health care in the United States. Primary care training programs are ideally positioned to react quickly to meet ever-changing health care needs and issues, whether they are related to HIV/ AIDS, growing numbers of elderly with chronic illnesses, implications of the modern genetic revolution, the threat of bioterrorism, or other issues that will continue to emerge and demand educational intervention."

These funds provide training for faculty and residents in training hospitals, ensuring that there is an adequate supply of physicians and professors of primary care. One half of primary care providers trained through these programs go on to work in underserved areas, compared to 10 percent of those not training through a program funded by this cluster. Under the Title VII grants for primary care medicine and dentistry, funding for

Under the Title VII grants for primary care medicine and dentistry, funding for general internal medicine and general pediatrics training supports four initiatives: medical student training, residency training, faculty development, and development of academic administrative units. Over the past 15 years, these programs have supported the training of approximately 16,000 primary care internists. As the only federal funding dedicated to the education and training of the general internal medicine workforce, Title VII support is crucial to increasing access to health care for underserved populations. More than 69 percent of graduates from general internal medicine residencies funded by Title VII practice primary care after graduation. This rate is nearly twice that of residency programs that do not receive such support. General internal medicine Title VII residency programs that do not receive such support. SGIM believes the Title VII and VIII health professions programs should receive

SGIM believes the Title VII and VIII health professions programs should receive a fiscal year 2003 budget of \$550 million, including at least \$40 million directed to general internal medicine/general pediatrics training. By providing a targeted funding stream for primary care training in general internal medicine, Title VII continues to be essential to the education and distribution of general internists in rural medically underserved communities.

SGIM is disappointed that the President's fiscal year 2003 budget plan decreases funding for these programs by 75 percent, for a total of \$94.5 million. SGIM commends the Senate Budget Committee for including in its budget resolution a 2 percent increase for the Health Resources and Services Administration, which administers the Title VII and VIII programs, and for specifically stating that this increase will restore the President's proposed virtual elimination of the health professions programs. SGIM, however, urges Congress to significantly increase funding to these programs, not maintain the fiscal year 2002 level due to the vital need for these health professions education programs.

# PREPARED STATEMENT OF THE MARCUS INSTITUTE

The marcus institute is pleased to have the opportunity to present its request for federal funding in fiscal year 2003 to the Committee. The Marcus Institute seeks \$4.2 million from the Health Resources and Services Administration facilities construction account to assist with the construction of new, state-of-the-art facilities.

# MARCUS INSTITUTE, ATLANTA GEORGIA

The Marcus Institute, located in Atlanta, Georgia, is named after Home Depot cofounder Bernie Marcus, who provided a \$5 million grant to establish the Institute. The Institute is known as a nationally recognized center for excellence for the provision of coordinated and comprehensive services for children and adolescents with developmental disabilities and severe and challenging behaviors. Since 1993, the Marcus Institute has provided clinical services to more than 16,000 individuals, conducted research, and provided education and training programs. The foremost goal of the Marcus Institute is to improve the quality of life for its patients to facilitate the greatest participation possible in family, school, and community life. The Institute provides community-based treatment for children who display the

The Institute provides community-based treatment for children who display the most severe forms of behavior disorders, including aggression, self-injurious behavior, and pediatric feeding disorders. Without appropriate treatment, these children are at substantial risk for health problems and lifelong placement in residential programs that often costs more than \$100,000 per year and millions of dollars over the individual's lifetime. More than 80 percent of the children receiving treatment at the Marcus Institute meet their primary discharge goals, compared to 2 percent for traditional outpatient mental health services.

The Marcus Behavior Center currently provides a continuum of consultative, outpatient, educational, and day treatment services for children with severe behavior disorders. Those with the most severe problems are seen in our intensive day treatment programs. Young children (usually below age 6) are admitted to the Feeding Day Treatment Program if they display behaviors such as food refusal or food selectivity (eating one or only a few foods) that necessitate medical interventions (e.g., gastrostomy tubes) to prevent malnutrition or death. School-aged children (ages 3 to 21) are admitted to the Severe Behavior Day Treatment Program if they have developmental disabilities and display severe self-injurious behavior (SIB), aggression, or property destruction that poses a significant risk to self, others, or the environment, which cannot be safely managed or effectively treated in a less intensive program.

<sup>1</sup> Less severe cases are served through our outpatient and consultative programs, whereas the most severe cases are served through our day treatment programs. For example, SIB consists of repetitive motor responses that produce physical harm to the individual who displays the behavior. Typical forms of SIB include head banging, self-biting, head hitting, body hitting, scratching, eye poking, and ear poking. SIB is extremely rare among individuals of normal intellectual functioning. It is seen in approximately 6 percent to 16 percent of individuals with mental retardation and autism.

tion and autism. The Marcus Institute seeks federal facility construction assistance towards the construction of new, state-of-the-art facilities for the Marcus Institute. The creation of the new facilities will greatly enhance the capacity of the Marcus Institute to provide services to the community. The Institute is currently operating in 29,000 square feet of leased space in a commercial office park. The new facility will have 80,000 square feet, including 10 classrooms, a vocational life skills center, and a center for parents to practice feeding their children suffering from eating disorders. In addition, the new facility will have expanded clinical medical areas for children with Fetal Alcohol Syndrome/Effect and other neurological and genetically derived problems, medical research and training facilities that are not possible in the current leased space.

The new facilities will also include a distance learning facility, allowing families to stay closer to home for treatment and follow-up, Marcus Institute practitioners to increase their productivity and treat additional children, and an improvement to the knowledge base among local community providers who work with these children at home. Also, the Marcus Institute staff will rise from 100 to 300, providing jobs with entry salaries of \$25,000 and higher.

The services available through the Marcus Behavior Center at the Marcus Institute are the only services of their kind in the Southeastern United States. These services are so incredibly absent that the Marcus Institute has a 2-year waiting list. The completion of the Marcus facility will significantly reduce the waiting period for children and their families.

The total cost of the new project is \$25 million. In addition to the \$5 million grant from Mr. Marcus, the Woodruff Foundation has committed \$3 million, and individual donors have pledged \$2.5 million. The State of Georgia has provided \$1.5 million to date for start up costs. The Institute is seeking additional support through foundation grants, individual donors and agencies for the project. In fiscal year 2002 the Marcus Institute initiated a request for \$5 million from the HRSA construction account. The Institute is extremely grateful for the \$800,000 targeted appropriation it received from this account in fiscal year 2002. Our request for \$4.2 million in fiscal year 2003 represents the unmet need for construction of the new facilities.

Request: We respectfully request \$4.2 million in fiscal year 2003 funding through the Health Resources and Services Administration (HRSA) Construction account to provide assistance with the construction of new, state-of-the-art health facilities for the Marcus Institute. The Marcus Institute was created as a result of a generous donation by Bernie and Billie Marcus. It is known as a nationally recognized center for excellence for the provision of coordinated and comprehensive services for children and adolescents with developmental disabilities and severe and challenging behaviors.

Thank you for the opportunity to present this request and for your consideration.

#### PREPARED STATEMENT OF THE ASSOCIATION FOR PROFESSIONALS IN INFECTION CONTROL AND EPIDEMIOLOGY

Thank you for this opportunity to provide testimony to the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies. The Association for Professionals in Infection Control and Epidemiology (APIC) is a nonprofit, voluntary international organization comprised of individuals whose chief responsibility is preventing and controlling infections that occur in the health care setting. Infection control professionals come from a wide range of clinical backgrounds such as medicine, nursing, medical technology and microbiology.

# SUMMARY

Among our requests for fiscal year 2003 are (1) \$7.9 billion for the Centers for Disease Control and Prevention (CDC); (2) \$390 million for the Agency for Healthcare Research and Quality; (3) ensuring sound science in regulatory agencies, particularly within the Occupational Safety and Health Administration (OSHA); and

(4) enhancing patient safety. Most importantly, we hope to draw your attention to the issue of unnecessary regulation as it relates to a dilution of our health care resources and, by extension, the ultimate safety of our patients.

# CDC FUNDING

As you realize, a major element of CDC's mission is to protect our nation's citizens against the threat of infectious disease. Today our CDC officials face the particularly challenging issues of increasing antimicrobial resistance and threats of bioterrorist activity. As a member of the CDC Coalition, we are advocating a funding level of \$7.9 billion for CDC for fiscal year 2003. Since bioterrorism preparedness is a top priority of the Bush Administration, we have identified three areas that require immediate attention in fiscal year 2003. Providing support to these areas is crucial in order to maximize the impact of our response efforts.

(1) Providing health care facilities, physicians, first responders, laboratory technicians and others with accurate information and training on detection, treatment, management, and exposure management of biological pathogens;

(2) Supporting and providing a comprehensive uniform protocol for response, to be distributed and implemented nationwide;

(3) Facilitating better public health infrastructure, coordinating both internal and external state activities, and providing a holistic nationwide public health safety net.

# PATIENT SAFETY

The CDC, AHRQ and the public health community share responsibility for ensuring the safety of patients in health care facilities. The ever-present threat of hospital-acquired infections requires constant vigilance on the part of our health care providers, particularly infection control professionals. Policy makers are well aware that our nation's health care facilities are facing continual cost containment pressures and are expected to provide top-notch health care despite a continual dwindling of resources. What may be lesser known is the direct impact of these expectations on our ability to provide optimal patient care. We are performing a balancing act—providing acute care services, and protecting our patients and workers from adverse outcomes—all while endeavoring to comply with regulatory requirements and cost containment pressures.

Of paramount concern to us is the promulgation of unnecessary regulations, such as those put forth by the Occupational Safety and Health Administration (OSHA). We in health care know what needs to be done to protect our workers and patients. Clinical guidelines as well as Federal guidelines (such as those issued by the CDC) offer the information necessary to do this effectively.

Unless regulatory requirements are based in science and are deemed absolutely necessary, we simply cannot spare the resources required to comply. This is more than a resource management issue—it is a patient safety issue, plain and simple. We cannot be expected to provide optimal protection to our patients and health care workers when we must squander limited resources to comply with unnecessary, burdensome regulatory requirements.

We are heartened by the approach to regulation touted by Labor Secretary Elaine Chao and OSHA Administrator John Henshaw. Both individuals have advocated the notion of voluntary standards and have articulated a desire to ensure efficacy in any regulatory requirements. This is absolutely critical to the health care community. We hope you will consider inserting strong language into the fiscal year 2003 appropriations bill requiring science-based policy at OSHA. One step toward achieving this goal would be to establish an Office of Science Policy at OSHA, similar to that established within the Environmental Protection Agency (EPA).

We need strong Congressional support in order to continue providing the best quality patient care and we thank you for your attention to our concerns. If you should have any questions or require additional information, please contact Jennifer Thomas at jthomas@apic.org or Staci Dennison at dennison@hmcw.org (tel: 202– 544-7499).

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF CHILDREN'S HOSPITALS

The National Association of Children's Hospitals (N.A.C.H.) is pleased to have the opportunity to submit the following statement for the hearing record in support of the Children's Hospitals' Graduate Medical Education (CHGME) program in the Health Resources and Services Administration (HRSA).

On behalf of the nation's nearly 60 independent children's teaching hospitals, we thank the Subcommittee for the remarkable achievement that Congress made last year in providing full, equitable GME funding for these hospitals, giving them for the first time the same level of federal support for their teaching programs that all other teaching hospitals receive through Medicare. We urge the Subcommittee to continue to provide equitable funding for Children's Hospitals GME in fiscal year 2003 so that these institutions will have the resources to train and educate the nation's pediatric workforce.

N.A.C.H. is a not-for-profit trade association, representing more than 100 children's hospitals across the country. Its members include independent acute care children's hospitals, acute care children's hospitals organized within larger medical centers, and independent children's specialty and rehabilitation hospitals.

N.A.Ć.H. seeks to serve its member hospitals' ability to fulfill their four-fold missions of clinical care, education, research, and advocacy devoted to the health and well being of all of the children in their communities. Children's hospitals are regional and national centers of excellence for children with serious and complex conditions. They are centers of biomedical and health services research for children, and they serve as the major training centers for future pediatric researchers, as well as a significant number of our children's doctors. These institutions are major safety net providers, serving a disproportionate share of children of low-income families, and they are also advocates for the public health of all children.

#### BACKGROUND: THE NEED FOR CHILDREN'S HOSPITALS GME

While they account for less than 1 percent of all hospitals, the independent children's hospitals train nearly 30 percent of all pediatricians, half of all pediatric specialists, and a majority of future pediatric researchers. They also provide required pediatric rotations for many other residents. They train about 4,000 residents annually, and the need for these programs is even more heightened by the growing evidence of shortages of pediatric specialists around the country.

Prior to initial funding of the CHGME program for fiscal year 2000, these hospitals were facing enormous challenges to their ability to maintain their training programs. The increasingly price competitive medical marketplace was resulting in more and more payers not covering the costs of care, including the costs associated with teaching. The independent children's hospitals were essentially left out of what had become the one major source of GME financing for other teaching hospitals—Medicare—because they see few if any Medicare patients. They received only  $\frac{1}{200}$  (or less than 0.5 percent) of the federal support that all other teaching hospitals received under Medicare. This lack of GME financing, combined with the financial challenges stemming from their other missions, was threatening their teaching programs, as well as other important services.

In addition to their teaching missions, the independent children's hospitals are a significant part of the health care safety net for low-income children. On average, they devote nearly half of their patient care to children who are assisted by Medicaid or are uninsured. More than 40 percent of their care is for children assisted by Medicaid, and Medicaid covers only about 84 percent of the cost of that care. Without the Medicaid disproportionate share hospital (DSH) payments, Medicaid would cover less than 70 percent of children's hospitals' patient care costs. Further, these hospitals provide many important services from dental care to child abuse programs that are either uncovered or very underpaid. The independent children's hospitals also are essential to the provision of care for

The independent children's hospitals also are essential to the provision of care for seriously and chronically ill children in this country. They devote more than 75 percent of their care for children with one or more chronic or congenital conditions. They provide more than 40 percent to 75 percent of the inpatient care to children with many serious illnesses—from children with cancer or cerebral palsy, for example, to children needing heart surgery or organ transplants. In some regions, they are the only source of pediatric specialty care. The severity and complexity of illness and the services and resources that these institutions must maintain to assure access to this quality care for all children are also often inadequately reimbursed.

The CHGME program, and its relatively quick progress to full funding in fiscal year 2002, came at a critical time. Between 1997 and 2000, independent children's hospitals on average experienced declining operating margins and total margins. By fiscal year 2000 more than a quarter of the hospitals were not able to cover their operating costs with operating revenues, and nearly 20 percent were not able to cover their total costs with total revenues.

Continuing this critical CHGME funding is more important for these hospitals than ever in light of serious state budget shortfalls in many states and the resulting pressures for significant reductions in state Medicaid programs. Further, unless Congress intervenes, cuts in the Medicaid DSH program will take effect this fall,

with devastating results for these and other safety net hospitals in many states. The pediatric community, including the American Academy of Pediatrics, Association of Medical School Pediatric Department Chairs, and others, has recognized the critical importance of the GME programs of the independent children's teaching hospitals, not only to the future of the individual hospitals and their essential services but also to the future of the nation's pediatric workforce and the provision of children's health care and advancements in pediatric medicine overall.

Lastly, many of the independent children's hospitals are a vital part of the emergency and critical care services in their communities and regions. They are part of the emergency response system that must be in place for bioterrorism other public health emergencies. Expenses associated with preparedness will add to their continuing costs in meeting children's needs

#### CONGRESSIONAL RESPONSE

In the absence of any movement towards broader GME financing reform, Congress in 1999 authorized the Children's Hospitals' GME discretionary grant program to address the existing inequity in GME financing for the independent children's to address the existing inequity in GME inhancing for the independent children's hospitals and ensure that these institutions could receive equitable federal support to sustain their teaching programs. The legislation was reauthorized in 2000 through fiscal year 2005 and provided for \$285 million through fiscal year 2001 and such sums as may be necessary in the years beyond.<sup>1</sup> Congress passed both the ini-tial authorization (as part of the "Healthcare Research and Quality Act of 1999") and the reauthorization (as part of the "Children's Health Act of 2000"). With the support of this Subcommittee, Congress appropriated initial funding for the program in fiscal year 2000, before the enactment of its authorization. Following that enactment Congress moved substantially toward full funding for the program

that enactment, Congress moved substantially toward full funding for the program in fiscal year 2001 and completed that goal in fiscal year 2002, providing \$285 mil-lion for the program within the Health Resources and Services Administration (HRSA). This represents an extraordinary achievement for the future of children's health care as well as for the nation's independent children's teaching hospitals

The \$235 million appropriated in fiscal year 2001 was distributed at the end of the fiscal year through HRSA to 57 children's hospitals according to a formula based on the number and type of full-time equivalent (FTE) residents trained, in accordance with Medicare rules as well as the complexity of care and intensity of teaching the hospitals provide. Consistent with the authorizing legislation, HRSA has begun to allocate the \$285 million in fiscal year 2002 funding in bi-weekly periodic payments to eligible independent children's hospitals.

# FISCAL 2003 REQUEST

We respectfully request that the Subcommittee continue equitable GME funding for the independent children's hospitals by providing \$292 million for the program in fiscal year 2003. This would continue the fiscal year 2002 appropriation of \$285 million and provide for an adjustment for inflation by the consumer price index to recognize higher wages and costs. The authorization, providing for such sums as may be necessary in fiscal year 2002 and beyond, would allow for such an adjustment, and it would be in keeping with the provision of such adjustments in Medicare.

Adequate, equitable funding for Children's Hospitals' GME is an ongoing need. Our institutions continue to train new pediatric residents and researchers every year. We have appreciated very much the congressional support we have received and the attainment of the program's authorization in fiscal year 2002. Now, we ask Congress to maintain this progress in fiscal year 2003. Support for a strong investment in GME at independent children's teaching hos-

pitals is consistent with the repeated concern the Subcommittee has expressed for the health and well being of our nation's children—through education, health, and social welfare programs. It also is consistent with the Subcommittee's repeated emphasis on the importance of enhanced investment in the National Institutes of Health (NIH) overall, and in NIH support for pediatric research in particular, for which we are very grateful

The CHGME funding has been essential to the ability of the independent children's hospitals to sustain their GME programs. At the same time, it has enabled

<sup>&</sup>lt;sup>1</sup>The Lewin Group, an independent health policy analysis firm calculated in 1998 that independent children's teaching hospitals should receive approximately \$285 million in federal GME support for nearly 60 institutions to achieve parity with the financial compensation provided through Medicare for GME support to other teaching hospitals.

them to do so without sacrificing support for other critically important services that also rely on hospital subsidy, such as many specialty and critical care services, child abuse prevention and treatment services, poison control centers, services to low-income children who have inadequate or no coverage, mental health and dental services, and community advocacy, such as immunization and motor vehicle safety campaigns.

In conclusion, the Children's Hospitals GME program is an important investment in children's health. The future of the pediatric workforce and children's access to quality pediatric care, including specialty and critical care services, could not be assured without it. Again, N.A.C.H. thanks this Subcommittee and Congress for its continuing support.

For further information, please contact Peters D. Willson, vice president for public policy, N.A.C.H., at 703/797–6006 or pwillson@nachri.org.

#### PREPARED STATEMENT OF BABYLAND FAMILY SEVICES, INC.

We would like to take this opportunity to thank you for allowing Babyland Family Services, Inc. to submit testimony today on two extremely important projects: (1) The Babyland Peditric Health Center; and (2) an Education Technology Project.

# THE BABYLAND PEDIATRIC HEALTH CENTER: WHERE HEALTHY BEGINNINGS LEAD TO BRIGHTER FUTURES

Amount Requested.—\$1 million capital request through the Department of Health and Human Services Health Resources and Services Administration (HRSA) and/or the Department of Housing and Urban Development EDI Fund.

Background.—Babyland provides child care and early childhood education services for 750 children (0 to 5 years old) at eight child care centers and provides emergency shelter and family support services to 750 other at-risk and low-income children and families. Babyland is currently Newark's Early Head Start grantee (serving children 0 to 3 years old, pregnant teenagers, young fathers and families living with HIV/AIDS) and has a partnership with the Newark Public Schools to provide Abbott preschool services to over 250 children. The agency has an extensive partnership with the New Jersey Department of Human Services for the provision of child welfare, family violence and child care services.

Babyland is a lead agency for the United Way's Success By 6 Initiative and the State's Family and Children Early Education Services (FACES) Initiative which, combined, provides early childhood support services to 2,000 children and over 30 other child care agencies and schools. The agency provides employment training and placements in the areas of child care and medical day care for TANF recipients as well as accreditation support for local teachers and child care centers. Babyland is implementing the Open Airways Asthma Education Program at eight elementary schools through a grant from the Centers for Disease Control. Finally, the agency's newly established Technology Initiative is providing early computer education to preschool children, a Technology Center for computer-related employment skills to local residents and an agency intranet that will develop an outcome and service-based model for family support services.

## PROJECT DESCRIPTION

Babyland is in a unique position, as the lead agency for several collaborative initiatives that promote the development of young children under 6 years old, to launch a pediatric health initiative that will prevent and manage childhood illnesses in Newark. In partnership with over 20 child care agencies, elementary schools and local health care providers, Babyland will develop a coordinated community-based approach for residents to gain access to health care services. As part of the agency's new multipurpose building, this grant will enable the agency to include a pediatric and family health center that will directly provide basic health services to over 1,000 families and provide health education, assessments, screening and follow-up services to 2,000 families with children under 6 years old.

In addition to the pediatric and family health center, the new multipurpose building will include a child care center for 198 children (0 to 5 years old), a computer technology center, an employment training and placement center and family resource center. The new health center will particularly focus on increasing immunizations, screening for lead poisoning, asthma management, preventive dental care services, nutrition, prenatal care, home safety, parent education and child development, HIV/AIDS prevention and other preventive health education. Increased access to health care services will be achieved through the following methods: training and placing 45 low income residents in the medical day care/special needs field; training for over 50 Abbott Family Workers who provide case management services for 2,000 preschoolers; parent-to-parent workshops that will be part of a series of parent and health education workshops; and creative grass-roots efforts that will encourage families to utilize the health center's resources. Community outreach workers, parents, nurses and a team of other health professionals will provide health outreach, education and services. Services will be coordinated with existing partners that include the Newark Department of Health, the Newark Public Schools, child care agencies and other local health care service providers.

Matching Funds.—\$1 million capital funding from the following: The Annie E. Casey Foundation (\$166,000 unrestricted award) and \$500,000 from a lender. Operating funds will come from the United Way, Essex County and the State of New Jersey. Other potential funders could include previous health-related supporters such as the Robert Wood Johnson Foundation, the Johnson and Johnson Company and the Healthcare Foundation of New Jersey.

# THE NEWARK PROJECT: A SOLUTION TO THE DIGITAL DIVIDE AMONG URBAN FAMILIES

Request.—\$1.6 million from the Department of Education, Fund for the Improvement of Education.

The purpose of this initiative is to serve as a model educational program that closes the "digital divide" among minority inner city children and families. This technological network links center and home-based child care centers and schools; community resources and service providers; educational, economic and resource information sources; training centers and administrative offices. The establishment of this network will be a model for educating urban children and serve as a conduit for comprehensive family support services.

The focus of this initiative is to establish the telecommunications linkages necessary for the educational development of 1,000 preschool and school-age children and to provide computer and technology training for 2,000 parents, teachers, family service workers and entry-level employees. As a result, this initiative will strengthen children's educational skills; promote the self-sufficiency of and enhance the educational skills of parents; enable the agency to better track child and family needs in order to enhance client services; and link the community to local and national resource centers.

Background.—Computer technology is transforming the economic and social landscape of this country by offering information and educational opportunities for individual growth and community development. Inner-city children and residents are inadequately prepared to take advantage of these growth opportunities. If the gap in information technology—the digital divide—is not bridged, a large segment of society will be further polarized and left without the tools needed for full participation in society.

We are making substantial progress in the implementation of our Technology Initiative this year by installing computer workstations in our preschool classrooms; by developing our agency's intranet capabilities and outcomes evaluation software; and by acquiring and developing the layout of our new Computer Technology Center, which is scheduled to open in May 2002. These efforts have been made possible through our fiscal year 2001 grant. Babyland has been a major non-profit child and family service organization in

Babyland has been a major non-profit child and family service organization in Newark, New Jersey for over 33 years and currently provides comprehensive child and family development services to 1,500 at-risk children and their families each year. BFS programs provide a continuum of educational services to individual children from infancy to 18 years old (including teenage mothers and young fathers) as well as multiple support services for family members. The agency is able to build extensive relationships with families and to provide follow-up care. As a result, Babyland is in a unique position to launch and oversee a major computer and technology initiative that will provide extensive training and technology support for individual families. This technology initiative will assist clients who have no other tangible means of becoming computer literate and of acquiring the requisite skills necessary to be informed and self-sufficient.

# Specific Provisions

Technology Center, as part of a new multi-purpose community resource and education center, that will provide distance learning, online and network linkages to educational institutions and community resources, professional development and training in basic and advanced computer and technology skills for low-income parents, neighborhood residents and entry-level employees.

Technology hardware and software (technical assistance, network installation and expansion, wiring, modems, printers etc.) for children, parents and residents, and teaching/social service staff in classrooms, homes, family resource centers and safe havens.

Technology Training, Curriculum Development and Professional Development for children, parents and residents, educational and social services staff, as well as local, State, national and international community-based family service providers.

# The initiative will benefit the following

Children at nine child care centers (850 preschoolers) and support shelters (200 school-age children).

Parents and family members (2,000) at 14 Babyland sites with links to community resources

Agency Staff (350), including teachers and family service workers, for client tracking purposes; training and professional development; and access to community re-sources to be provided through workstations, wireless technology and/or palm pilots. Parents and children in the home for educational instruction and support, eco-

ratents and timuten in the nome for educational instruction and support, eco-nomic and resource information, links to other parents and teachers, parenting edu-cation (child and family health, child behavior and development, cultural sensitivity, etc) and professional education (ex. Certifications, GED, etc.). Family day care homes with links to community resources, professional education,

BFS child care centers and other child and family resource centers. Child and family service providers, throughout Newark, New Jersey, the nation

and South Africa, who will receive training in child, family and community development

#### Key Outcomes

Enhanced early childhood development and education for children (three to 13 vears old).

Enhanced ability of inner city residents, especially low-income parents and teenagers, to learn computer and technology skills.

Enhanced tracking of 1,500 children in center- and home-based child care facilities; teenage parents; victims of domestic violence; homeless families; and children in foster care.

Enhanced delivery of professional development of teaching and family service staff.

Enhance the provision and delivery of parent education programs.

Enhanced delivery of clinical and therapeutic services to parents and children. Enhanced ability to fulfill State and Federal reporting requirements and to provide community development consultation to local, State, national and international family service providers.

This project received a total of \$923,000 (fiscal year 2002—\$200,000 and fiscal year 2001—\$723,000) in federal appropriations so far. But in order for the system to be fully operational and implemented for the entire target clientele population, an additional allocation of \$1.6 million is being sought.

We hope you find these two projects worthy of your support.

Thank you for your consideration.

# PREPARED STATEMENT OF THE AMERICAN SOCIETY FOR CLINICAL PATHOLOGY

There is a serious shortage of medical laboratory personnel in the United States. This statement will attest to the shortage, provide national data on the subject as well as an explanation for this workforce shortage problem, and discuss a proven solution to the problem—the Allied Health Project Grants program, under Title VII of the Public Health Service Act. We respectfully request \$21 million to fund the

Allied Health Project Grants program for fiscal year 2003. The American Society for Clinical Pathology (ASCP) is a nonprofit medical spe-cialty society representing 151,000 board certified pathologists, other physicians, clinical scientists (PhDs), medical technologists and technicians. It is the world's largest organization representing pathology and laboratory medicine. As the leading provider of continuing education for medical laboratory personnel, the ASCP en-hances the quality of the profession through comprehensive educational programs and materials.

# THE PROBLEM

The United States has a serious shortage of laboratory medical personnel with vacancy rates for seven of ten key laboratory medicine positions at an all time high. Vacancy rates for cytotechnologists, the professionals who evaluate Pap smears and other cellular material, and histotechnologists, the individuals who prepare tissue specimens for cancer biopsies, are at an alarming high of over 20 percent.

The American Society for Clinical Pathology's Board of Registry, in conjunction with MORPACE International, Inc., Detroit, conducts a biennial wage and vacancy survey of 2,500 medical laboratory managers. The survey measures the vacancy rates for 10 medical laboratory positions, and compares and contrasts these data with that from 1988, 1990, 1992, 1994, 1996, and 1998 studies. The data for 2000 was published in March 2001; some specifics from the survey are outlined below.

Vacancy rates for cytotechnologists in the northeast average 45 percent, 16.7 percent for the east north central, and 33.3 percent for the far west. Rural areas average a 20 percent vacancy rate for cytotechnologists, and large cities a rather surprising 28.3 percent rate. Private reference laboratories have an average vacancy rate of 20 percent for

Private reference laboratories have an average vacancy rate of 20 percent for histotechnologists, and hospitals have a 37.7 percent shortage of the same profession. The west south central region of the country has a 73.7 percent vacancy rate for histotechnologists, and the south central Atlantic states have an average vacancy rate of 16.7 percent. By comparison, the vacancy rate for medical technologists will not appear to be

By comparison, the vacancy rate for medical technologists will not appear to be a problem, but it too is reason for concern. Medical technologist vacancy rate averages 11.1 percent, but rural areas show 21.1 percent vacancy and hospitals with 100–299 beds have a rate of 17.6 percent.

While the supply of laboratory personnel is dwindling, the demand for these professionals is increasing—as evidenced, in part, by the rise in wages.

Beginning wage increases from 1998 to 2000 were the largest experienced since comparisons from the 1990 to 1992 studies. Pay for nine of the 10 employee positions increased at least 6.9 percent from 1998 to 2000, with histotechnologist pay increasing 15.8 percent. Median average pay rate increases from 1998 to 2000 were larger than comparisons for any other time period. Only medical technologist supervisors (at 8.6 percent) and medical laboratory technician staff (at 8.5 percent) had wage increases of less than 10 percent. Histologic technicians (at 13.3 percent) and histotechnologists (at 15.4 percent) experienced the largest increases.

# MEDICAL LABORATORY PROGRAMS

One of the logical solutions to this vacancy rate problem is to train more students; however, the number of programs are decreasing. For example, in Michigan, we have seen the number of programs plummet from 27 to 8 in less than two decades. In California, there are no programs available for histologic technicians or specialists in blood banking. There are only two programs for cytotechnologists, one program for medical laboratory technicians, and one for phlebotomists in that entire state.

It is important to note that education programs for training medical laboratory personnel are sponsored by a variety of organizations and institutions, ranging from hospitals to degree-granting colleges and universities. According to the *Health Professions Education Directory* published by the Amer-

According to the *Health Professions Education Directory* published by the American Medical Association, the number of medical technology programs decreased from 383 in 1994 to 273 in 1999. The number of graduates in medical technology has similarly decreased from 3,563 in 1994 to 2,491 in 1999, a 30 percent decline in 5 years.

# ASSESSMENT

There are several reasons why the vacancy rate is increasing and the number of program enrollees is decreasing. A number of available positions are outside the traditional clinical laboratory. Some program directors have reported that graduates are gaining employment in laboratory information systems companies, "dot.coms," and corporations that manufacture or distribute diagnostic reagents, supplies or equipment. With limited resources, hospitals have merged, thus decreasing the availability of training sites for medical laboratory programs. Some programs have responded by increasing access to other laboratory training sites, such as forensics laboratories, blood centers, physician offices, and outpatient clinics. Yet, with these shifts, the continued demand for laboratory services is real and is expected to grow.

shifts, the continued demand for laboratory services is real and is expected to grow. In Iowa, according to the Bureau of the Census, the population is projected to grow by 4 percent by 2020, and the population over age 65 is projected to grow by 37 percent in the same time period. In Pennsylvania, the population is projected to grow by 3 percent by 2020, and the population over age 65 is projected to grow by 24 percent in the same time period. Given the country's aging population, the number and complexity of biopsy specimens and the use of molecular techniques will likely increase during the next decade. Laboratory professionals who entered the workforce in the 1960s and 1970s will be retiring soon as the average age for a medical technologist now is 45 years old. The threat of bioterrorism calls for trained laboratory professionals to respond. The laboratory-allied health workforce will need to be able to react accordingly with appropriate numbers of trained and educated personnel.

# CURRENT WORKING SOLUTIONS

There are solutions to these problems. As a professional organization, ASCP believes it holds a responsibility to address the workforce shortage. As such, ASCP offers scholarships to medical laboratory technology students each year to relieve some of the financial burden of higher education, but this does not come close to fulfilling the need. We produce career brochures and audiovisual materials for high school students and younger children to learn about opportunities in the laboratory. ASCP also exhibits and advertises at the annual conference for the National Association of Biology Teachers in an attempt to help these educators guide interested students to careers in the laboratory.

On the public side, there are grants available to help attract laboratory professionals to the field, especially minorities and individuals in rural and underserved communities. The Allied Health Project Grants program, administered by the Health Resources and Services Administration, has been successful in effectively attracting new allied health professionals into the laboratory field. For example, the University of Nebraska Medical Center established medical tech-

For example, the University of Nebraska Medical Center established medical technology education sites in four communities in rural Nebraska, including a student laboratory in central Nebraska, under an Allied Health Project Grant. As of 2001, of 89 rural program graduates, 97 percent took their first job in a rural community, and 74 percent took their first job in rural Nebraska.

and 74 percent took their first job in rural Nebraska. The grants are also designed to create successful minority recruiting and retention programs for medical technologists. This was the focus of a University of Maryland, Baltimore project initiated by allied health grant funding in 1991. Through utilizing a four phase design, which begins with career awareness activities for elementary and middle school students, this model provides a continuum of activities that progressively focuses on identifying, retaining, and advancing interested students to the completion of a baccalaureate degree. The University of Maryland, Baltimore has created a successful minority recruiting and retention program for medical technologists with Allied Health Project Grant funding with an average 89 percent student retention rate. As a direct result of this federal support, the medical technology program has, as of fall 2000, reached a 64 percent minority student enrollment at a majority institution, one of the highest in the courty.

While allied health professionals comprise more than 60 percent of the entire health care work force, and number more than 3 million individuals, the attention paid to these health professionals is rather small. Allied health professionals are involved in the prevention, identification, monitoring, and evaluation of diseases, disabilities and disorders. The Allied Health Project Grants program is a relatively small step in assuring that funding is available to attract allied health professionals to the professions and to underserved communities. Given the critical shortages mentioned, it needs to be taken quite seriously.

We respectfully request funding for the Allied Health Project Grants in the amount of \$21 million.

Thank you for the opportunity to provide this statement for the hearing record.

#### PREPARED STATEMENT OF THE COALITION FOR AMERICAN TRAUMA CARE

The Coalition for American Trauma Care is pleased to provide the Subcommittee with its recommendations for fiscal year 2003 appropriations for public health programs that support trauma care, trauma care research, and injury prevention.

grams that support trauma care, trauma care research, and injury prevention. The Coalition for American Trauma Care is a nonprofit association of national health and professional organizations that seeks to improve care for the seriously injured patient through improved delivery of trauma care services, research and rehabilitation activities. The Coalition also supports efforts to prevent injury from occurring.

Injury is one of the most important public health problems facing the United States today. It is the leading cause of death for Americans from age 1 through age 44. More than 145,000 people die each year from injury, 88,000 from unintentional injury such as car crashes, fires, and falls, and 56,000 from violence-related causes. Over 85 children and young adults die from injuries in the United States every day

translating into 30,000 deaths annually. Injury is also the most frequent cause of disability. Millions of Americans are non-fatally injured each year leaving many temporarily disabled and some permanently disabled with severe head, spinal cord, and extremity injuries. Because injury so often strikes the young, injury is also the leading cause of years of lost work productivity and, at an estimated \$224 billion in lifetime costs each year, trauma is our nation's most costly disease.

Attention to injury was never more important in the wake of the 9/11 attacks. Particularly concerning is our failure, as a nation, to fully implement organized systems of trauma care in every state and region. The Health Resources and Services Administration is completing a survey of the states that is expected to show that only half have critical elements of an organized system of trauma care.

only half have critical elements of an organized system of trauma care. Trauma Care Systems.—The Coalition supports \$6 million in fiscal year 2003 for the HRSA trauma care systems program. This is the amount Congress has authorized for the program. Last year, Congress provided \$3.5 million which permitted HRSA to conduct an assessment of each state's trauma care system and to establish a new National Trauma Systems/EMS Program within the Maternal and Child Health Bureau. As the 1999 IOM report, Reducing the Burden of Injury: Advancing Prevention and Treatment, notes, federal leadership and resources for trauma care systems is important since trauma and EMS systems provide critical life-saving services. Many studies documented in the report show that even in the first year of implementation, trauma systems reduce preventable death rates by 50 percent or more. The Coalition for American Trauma Care sincerely hopes the Subcommittee will consider providing a modest amount of funding to re-establish a critical life-saving program that also prevents costly, life-long disability.

National Center for Injury Prevention and Control.—The Coalition supports \$160 million in funding in fiscal year 2003 for the National Center for Injury Prevention and Control which is currently funded at \$150.6 million. While the Coalition remains a strong supporter of the National Center for Injury Prevention and Control, members would like to see more balance in support for unintentional injuries. Significant increases in the NCIPC in recent years have largely been earmarked for violence prevention—an important focus for NCIPC after disturbing incidents in public schools around the country. However, unintentional injury remains the leading killer of children and young adults and NCIPC's efforts to translate what works into communities should receive increased funding. These efforts help prevent, for example, the 20,000 head injuries that occur every year by encouraging the use of bicycle helmets, and reduce burn-related injuries through smoke detector implementation programs. The Coalition is also disappointed that as the funding base for the National Center for Injury Control and Prevention has grown, the relative amount of funding for acute care research and demonstration has diminished.

The Agency for Healthcare Research and Quality (AHRQ).—The Coalition supports an fiscal year 2003 funding level of \$390 million. Current funding is \$300 million for the agency. AHRQ provides the evidence-based information needed to improve health care quality, enhance access to health care services, and more efficiently utilize health care resources. AHRQ is an important source of funding to assess trauma services research so that emergency response and treatment approaches to the very costly problem of serious injury are as efficient and cost-effective as possible. Trauma clinicians are constantly challenged to find ways to cut costs in the current managed care environment, but want to do it correctly by maintaining, or improving, quality of care and patient outcomes. Accomplishing this goal requires a specific research investment that can only be undertaken by the AHRQ with an increase in funding for this essential agency.

Traumatic Brain Injury (TBI).—Traumatic brain injury is a leading cause of trauma-related disability. Brain injury is a silent epidemic that compounds every year, but about which still little is known. The Coalition urges you to provide \$36.8 million in fiscal year 2003 appropriation—\$16.3 million above the current level of \$20.5 million—to fully fund the reauthorized Traumatic Brain Injury Act as follows: \$7 million for CDC for surveillance so that we can learn the incidence and prevalence of brain injury in the U.S. population; \$9.8 million for HRSA grants to states for demonstration projects to improve access to health care and other services; \$5 million for NIH research with \$5 million for a TBI Clinical Trials Network at the National Center for Medical Rehabilitation Research (NCMRR) and \$10 million for five research centers at the National Institute for Neurological Disorders and Stroke (NINDS).

Children's Emergency Medical Services.—Injury is the leading cause of death for children in the United States. The Children's EMSC program at the Health Resources and Services Administration is designed to improve the emergency response to children who are critically injured or ill. The Coalition urges you to provide at least \$22 million in fiscal year 2003 appropriations for this vital program. Preventive Health/Health Services Block Grant (PHHS).—The Coalition supports

Preventive Health /Health Services Block Grant (PHHS).—The Coalition supports an fiscal year 2003 funding level of \$210 million, which is currently funded at \$135 million. This program provides flexible funding to states to allow them to address specific health problems identified under the Healthy People 2010 assessment process. This amount is the level that states have estimated they need to meet the minimum of what they need to address under the Block Grant. The PHHS Block Grant is the largest single source of federal funding for state Emergency Medical Services (EMS)—the first line of defense against death and disability resulting from severe injury. Every time the block grant has been reduced EMS funding has dropped precipitously. In 1981 EMS funding was \$30 million; it is now well under \$10 million for the fifty states.

The Coalition for American Trauma Care appreciates the support the Subcommittee has provided to many trauma and related programs in the past. However, much remains to be done to address this leading public health problem so that we can achieve the substantial health and social welfare cost savings addressing increased research, timely treatment and rehabilitative interventions, and prevention will provide the citizens of the United States. Much also remains to be done, specifically, to extend organized systems of trauma care to all states and regions so that the nation is prepared for terrorist attacks that could result in a multitude of seriously injured individuals. The Coalition looks forward to working with the Subcommittee to achieve these goals.

# PREPARED STATEMENT OF THE AMERICAN ACADEMY OF PHYSICIAN ASSISTANTS

On behalf of the nearly 43,000 clinically practicing physician assistants in the United States, the American Academy of Physician Assistants (AAPA) is pleased to submit comments on fiscal year 2003 appropriations for Physician Assistant (PA) education programs that are authorized through Title VII of the Public Health Service Act.

A member of the Coalition for Health Funding (CHF), the American Academy of Physician Assistants supports the CHF recommendation to appropriate \$51.8 billion for the Public Health Service in fiscal year 2003. The Academy is also a member of the Health Professions and Nursing Coalition (HPNEC) and supports the HPNEC recommendation to provide at least \$550 million to support the Titles VII and VIII programs in fiscal year 2003. The Academy believes that the recommended increase in funding for the Title VII health professions programs is well justified. The programs are essential to the development and training of primary health care professionals and contribute to the nation's overall efforts to increase access to care by promoting health care delivery in medically underserved communities.

The Academy is very concerned with the Administration's proposal to eliminate funding for most Title VII programs, including training for primary care medicine and dentistry, and cut health professions programs funding overall by 75 percent. As Members of the Subcommittee are aware, these programs are designed to help meet the health care delivery needs of the nation's Health Professional Shortage Areas (HPSAs). By definition, the nation's 3,800 HPSAs experience shortages in the primary care workforce that the market alone can't address. We wish to thank the Members of this Subcommittee for your historical role in supporting funding for the health professions programs, and we hope that we can count on your support for these important programs in fiscal year 2003.

# OVERVIEW OF PHYSICIAN ASSISTANT (PA) EDUCATION

PA programs provide students with a primary care education that prepares them to practice medicine with physician supervision. Physician assistant programs are located at schools of medicine or health sciences, universities, teaching hospitals, and the Armed Services. All PA educational programs are intensive education programs that are accredited by the Accreditation Review Commission on Education for the Physician Assistant.

The typical PA program consists of 111 weeks of instruction. The first phase of the program consists of intensive classroom and laboratory study, providing students with an in-depth understanding of the medical sciences. More than 400 hours in classroom and laboratory instruction are devoted to the basic sciences, with over 70 hours in pharmacology, more than 149 hours hours in behavioral sciences, and more than 535 hours of clinical medicine.

The second year of PA education consists of clinical rotations. On average, students devote more than 2,000 hours or 50–55 weeks to clinical education, divided between primary care medicine and various specialties, including family medicine, internal medicine, pediatrics, obstetrics and gynecology, surgery and surgical specialties, internal medicine subspecialties, emergency medicine, and psychiatry. During clinical rotations, PA students work directly under the supervision of physician preceptors, participating in the full range of patient care activities, including patient assessment and diagnosis, development of treatment plans, patient education, and counseling.

Physician assistant education is competency based. After graduation from an accredited PA program, the physician assistant must pass a national certifying examination jointly developed by the National Board of Medical Examiners and the independent National Commission on Certification of Physician Assistants. To maintain certification, PAs must log 100 continuing medical education credits over a 2-year cycle and reregister every two years. Also to maintain certification, PAs must take a recertification exam every 6 years.

# PHYSICIAN ASSISTANT PRACTICE

Physician assistants are licensed health care professionals educated to practice medicine as delegated by and with the supervision of a physician. In all states, physicians may delegate to PAs those medical duties that are within the physician's scope of practice and the PA's training and experience, and are allowed by law. Forty-seven states, the District of Columbia, and Guam authorize physicians to delegate prescriptive rivileges to the PAs they supervise.

PAs are located in almost all health care settings and in every medical and surgical specialty. Fourteen percent of all PAs practice in rural areas where they may be the only full-time providers of care (state laws stipulate the conditions for remote supervision by a physician). Approximately 20 percent of PAs work in urban and inner city areas. The majority of PAs are in primary care. Nearly one-quarter practice in surgical specialties. Seventy percent of PAs practice in outpatient settings. In 2001, an estimated 170 million patient visits were made to PAs and approximately 213 million medications were prescribed or recommended by PAs.

# CRITICAL ROLE OF THE TITLE VII, PUBLIC HEALTH SERVICE ACT, PROGRAMS

A growing number of Americans lack access to primary care, either because hey are uninsured, underinsured, or they live in a community with an inadequate supply or distribution of providers. The growth in the uninsured U.S. population increased from approximately 32 million in the early 1990s to nearly 43 million today. Simultaneously, the number of medically underserved communities continues to rise, from 1,949 in 1986 to 3,800 today.

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 geographic 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 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.

Furthermore, now that there is compelling evidence that race and ethnicity correlate with persistent, and often increasing, health disparities among U.S. populations, increasing the diversity of health care professionals is essential. Title VII programs are unique in that they seek to recruit providers from a variety of backgrounds. This is particularly important, as studies have shown that those from disadvantaged regions of the country are 3 to 5 times more likely to return to those areas to provide care.

# TITLE VII SUPPORT OF PA EDUCATION PROGRAMS

Targeted federal support for PA education programs is currently authorized through section 747 of the Public Health Service Act. The program was reauthorized in the 105th Congress through the Health Professions Education Partnerships Act of 1998, Public Law 105–392, which streamlined and consolidated the federal health professions education programs. Support for PA education is now considered within the broader context of training in primary care medicine and dentistry. Public Law 105–392 reauthorized awards and grants to schools of medicine and osteopathic medicine, as well as colleges and universities, to plan, develop, and oper-

osteopathic medicine, as well as colleges and universities, to plan, develop, and oper-ate accredited programs for the education of physician assistants and faculty, with priority given to training individuals from disadvantaged communities. The funds ensure that PA students from all backgrounds have continued access to an afford-able education and encourage PAs, upon graduation, to practice in underserved com-munities. 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 dur-ing the clinical rotation portion of their training; and (3) recruiting and retaining students who are indigenous to communities with unmet health care needs. The program works. A review of PA graduates from 1991–1999 reveals that 16.5 percent of students graduating from PA programs supported by Title VII are from underrepresented minorities, compared to 7.7 percent of graduates from programs that did not receive Title VII support. Similarly, 13.5 percent of the graduates who attended PA programs receiving Title VII support during the 8-year period practice in underserved communities, compared to 10.1 percent of graduates of programs not receiving such support during the same period.

receiving such support during the same period.

The PA programs' success in recruiting and retaining underrepresented minority and disadvantaged students is linked to their ability to creatively use Title VII funds to enhance existing educational programs. For example, a PA educational pro-gram in Iowa uses Title VII funds to target recruitment efforts to disadvantaged students, providing shadowing and mentoring opportunities for prospective stu-dents, increasing training in cultural competency, and identifying new family medi-cine preceptors in underserved areas. PA programs in Texas use Title VII funds to create new clinical rotation sites in rural and underserved areas, including new sites in border communities, and to establish non-clinical rural rotations to help students understand the challenges faced by rural communities. A PA program in Kan-sas has used Title VII funds to provide a significant portion of the training for 500 PA students in remote, medically underserved communities in the state. Several other PA programs have been able to use Title VII grants to leverage additional re-sources to assist students with the added costs of housing and travel that occur during relocation to rural areas for clinical training. 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 commu-nities 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 53 percent between 2000 and 2010.

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. Nor has the Title VII support for PA education kept pace with increases in the cost of educating PAs. A review of PA program budg-ets from 1984 through 1999 indicates an average annual increase of 7.2 percent, a total increase of 173 percent over the past 16 years; yet, federal support has remained relatively static.

#### RECOMMENDATIONS ON FISCAL YEAR 2003 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 2003. 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 or bioterrorist attack, 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 reducated 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.

Furthermore, while the Academy applauds the Administration's proposal to strengthen the safety net by increasing support for Community Health Centers, it should not do so at the expense of Title VII programs. These programs are the infrastructure that provides the pipeline of trained health professionals to these facilities. Eliminating funding for most Title VII programs will effectively destroy a network of initiatives across the country that supports the training of providers to meet the needs of special, underserved populations. Eliminating this resource would be devastating to the country's neediest communities and certainly will not improve access to health care for individuals in these areas.

Cess to health care for individuals in these areas. A recent report by the Advisory Committee on Training in Primary Care Medicine and Dentistry quotes a study in the Journal of Rural Health: "In 1997, Title VII funded programs increased the rates of graduates entering health profession shortage areas (HPSAs), resulting in 1357 providers . . . Doubling the funding of these programs . . . could decrease the time for HPSAs elimination to as little as 6 years." The Advisory Committee concluded that ". . . Title VII remains a modest investment, but, as has been demonstrated, one with substantial future payoffs in terms of system quality, access to care, and a culturally competent system of care for the entire population."

The American Academy of Physician Assistants is particularly appreciative of the increase in funding for PA education programs that was appropriated for fiscal year 2002. Yet, funding must increase further to meet the increasing demand for PA graduates in the growing number of medically underserved communities. Accordingly, the Academy respectfully requests that the Title VII and VIII health professions programs receive \$550 million in funding for fiscal year 2003, including \$18 million to support PA educational programs, as recommended by the Advisory Committee on Primary Care Medicine and Dentistry.

Thank you for the opportunity to present the American Academy of Physician Assistants' views on fiscal year 2003 appropriations.

# PREPARED STATEMENT OF THE AMERICAN ACADEMY OF FAMILY PHYSICIANS

The 93,500 member American Academy of Family Physician submits the following statement for the record on three issues of critical importance to family physicians in the United States: (1) funding for family medicine training in Section 747 of the Public Health Service Act; (2) funding for the Agency for Healthcare Research and Quality (AHRQ); and (3) funding for rural health programs.

# FAMILY MEDICINE TRAINING PROGRAMS

# Recommendation

The Academy supports appropriations of \$169 million for Section 747 of Title VII of the Public Health Service Act for fiscal year 2003.—Section 747 authorizes the Primary Care and Dentistry cluster, which includes support for family medicine, general internal medicine and general pediatrics, physician assistants and general and pediatric dentistry. This figure includes \$96 million for family medicine programs.

# Section 747 Advisory Committee Recommends Higher Funding

In 1998, Congress established an Advisory Committee to review and make recommendations on Section 747. The Advisory Committee on Training in Primary Care Medicine and Dentistry (ACTPCMD) recently released their recommendations to Congress and the Secretary of the Department of Health and Human Services. The first of six recommendations urges greatly expanding federal support for Section 747 to \$198 million. The Committee notes the growing need for primary care providers, as well as the success of Title VII funded programs.

# President's Budget Request for Fiscal Year 2003 Zeros Out Primary Care Funding

As you know, the President's budget once again zeroes out funding for the Primary Care Medicine and Dentistry cluster. In addition, the Administration includes only \$94 million for all of the Health Professions programs, a sharp cut of 75 percent from the fiscal year 2002 level of \$378 million. The proposed budget emphasizes that the grants were developed in response to a physician shortage, as it did last year, although this year the budget document acknowledges a geographic maldistribution of doctors. The budget also claims, "most of the health professions grants have not proven effective because they do not accurately address current health professions problems." In fact, according to several studies (see below), Title VII dollars have proven effective in addressing several major health professions problems.

# What Does Title VII Do?

Section 747 is the only program at the federal level that supports family medicine training programs at both the undergraduate and graduate level. It is designed to increase both the number of primary care physicians and the number of individuals who will provide health care to the underserved. The program has succeeded in achieving its goals and Congress should support it at higher funding levels.

# Title VII Meets Its Goals: Grants Increase the Number of Primary Care Physicians Due to Section 747 funding, thousands of physicians are making career choices

to go into primary care and family medicine and to serve millions of patients.

A study by the Robert Graham Center for Policy Studies showed that medical schools that received Section 747 family medicine funds produced more medical students who practiced ultimately:

—in family medicine or primary care (family physicians, general practitioners, general internists or general pediatricians);

–in a rural area; or

—in a whole county Primary Care Health Professions Shortage Area (those counties with inadequate numbers of family physicians, general pediatricians, general internists or obstetrician/gynecologists).

Sustained funding during the years of medical school training had more positive impact than intermittent funding.

# Title VII Meets Its Goals—Grants Put Physicians in the Right Places—Loss of Funding Would Hurt the Underserved

Without family physicians, counties around the United States would not receive essential primary care services.—Another study by the Robert Graham Center showed that the United States relies on family physicians more than any other physician specialty. Specifically, the study looked at counties designated as Primary Care Health Professions Shortage Areas (HPSAs). Right now, there are 3,082 counties in the United States; 784 qualify as Primary Care HPSAs. The study found that if family physicians were to be withdrawn from all 3,082 counties, an additional 1,332 counties would become Primary Care HPSAs—a 43 percent increase. In contrast, if all internists, pediatricians and obstetrician-gynecologists were to be taken out of the nation's counties, only another 176 would become shortage areas—a 6 percent increase.

Finally, a recent article in The Journal of Rural Health found that Title VII funding is key to ending HPSAs. According to the study, without this funding, not only would HPSAs not be eliminated, but the number of shortage areas would continue to grow. In addition, the article states that Title VII funding has cut to 15 years the time needed to eliminate all HPSAs. Doubling the funding for these programs would decrease the time for HPSA elimination to as little as 6 years (Robert M. Politzer, ScD, et. al. Winter, 1999) It is clear that underseved populations, particularly in rural areas, depend on the care that family physicians provide.

# Future Funding Priorities

ACTPCMD's report to Congress lays out priorities for training primary care prorent training, allowing it to be even more effective at providing:

high-quality health care for underserved populations

-culturally competent care

continued demonstration authority to address emerging health initiatives

- -additional interdisciplinary learning opportunities
- -better quality of health care, eliminating health disparities, and improving patient safety

# Primary Care Training Programs React Quickly to Emerging Health Challenges

Title VII dollars have created an infrastructure that allows educational programs to respond to contemporary health care issues. Specifically, the ACTPCMD report states that:

Investment in education to provide primary care has effects that touch the largest number of people in the country. No other group of health care providers can exert such a broad influence on the kind and quality of health care in the United States. Primary care training programs are ideally positioned to react quickly to meet everchanging health care needs and issues, whether they are related to HIV/AIDS, growing numbers of elderly with chronic illnesses, implications of the modern genetics revolution, the threat of bioterrorism, or other issues that will continue to emerge and demand rapid educational intervention. Thus, this infrastructure is uniquely able to play a pivotal role in bringing emerging issues in health care to the population at large.

# AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

# Recommendation

We recommend appropriations of \$390 million for the Agency for Healthcare, Research and Quality (AHRQ) in fiscal year 2003.—AHRQ conducts primary care and health services research geared to physician practices, health plans and policymakers that helps the American population as a whole.

# What Does AHRQ Do?

AHRQ has the following three goals:

1. Improve physician practice and Americans' health outcomes;

2. Improve the quality of health care (e.g., patient safety);

3. Improve the health care system (e.g., increase access and reduce costs). In brief, AHRQ "helps to improve the health and health care of the American cople . . . "—(AHRQ report, March, 2001). people . . . "-

# President's Budget Request for Fiscal Year 2003 Cuts AHRQ Funding

As you know, the President's budget includes \$251 million for AHRQ, a cut of \$49 million, or 16 percent, from the current funding level of \$299 million.—This would mean cuts of 46 percent from existing grants to absolutely no new grants or contracts in 2003. The budget also makes funding for the agency completely dependent on transfers from other agencies, rather than on a Congressional appropriation. This is a less secure funding method for this important agency.

# How Does AHRQ Meet Its Goals?

AHRQ translates basic science research findings like those of the National Institutes of Health into information that doctors can use every day in their practice. Another key function of the agency is to support research on the conditions that affect most Americans.

1. AHRQ Translates Research into Everyday Practice.-Congress has provided billions of dollars to the National Institutes of Health, which has resulted in important insights in preventing and curing major diseases. AHRQ takes this basic science and produces information that physicians can use every day in their practices. AHRQ also distributes this information throughout the health care system. In short, AHRQ is the link between research and the patient care that Americans receive.

For example, research shows that beta blockers reduce mortality. AHRQ supported research to help physicians determine which patients with heart attacks would benefit from this medication.

. AHRQ Supports Research on Conditions Affecting Most Americans.-Most typical Americans get their medical care in doctors' offices and clinics. However, most medical research comes from the study of extremely ill patients in hospitals. AHRQ studies and supports research on the types of illness that trouble most people. In brief, AHRQ looks at the problems that bring people to their doctors—not the problems that send them to the hospital. For example, AHRQ supported research that found older, cheaper antidepressant

For example, AHRQ supported research that found older, cheaper antidepressant drugs are as effective as new antidepressant medications in treating depression, a condition that affects millions of Americans.

#### Institute of Medicine Recommends \$1 Billion for AHRQ

The Institute of Medicine's report, Crossing the Quality Chasm: A New Health System for the 21st Century (2001) recommended \$1 billion for AHRQ to "develop strategies, goals, and actions plans for achieving substantial improvements in quality in the next 5 years. . . ." The report looked at redesigning health care delivery in the United States. AHRQ is a linchpin in retooling the American health care system.

#### RURAL HEALTH PROGRAMS

Finally, the Academy supports continued funding for several rural health programs. In particular, we support the programs of the Federal Office of Rural Health Policy; Area Health Education Centers, two programs that are equally important to health care in rural areas and in our inner cities; the Community and Migrant Health Center Program and the National Health Services Corps. State rural health offices, funded through the National Health Services Corps budget, help states implement such programs so that they benefit rural residents as much as 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

# Thank you for your consideration of these important requests.

# PREPARED STATEMENT OF THE ASSOCIATION OF WOMEN'S HEALTH, OBSTETRIC AND NEONATAL NURSES

The Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN) appreciates the opportunity to comment on the fiscal year 2003 appropriations for nursing education, research, and workforce programs, as well as programs designed to improve maternal and child health. AWHONN is a membership organization of 22,000 nurses whose mission is to promote the health of women and newborns. AWHONN members are registered nurses, nurse practitioners, certified nurse midwives, and clinical nurse specialists who work in hospitals, physicians' offices, universities and community clinics across North America as well as in the Armed Forces around the world.

AWHONN appreciates the support that this Subcommittee has provided for nursing education, research and workforce programs, as well as maternal and child health programs in the past. We realize that there are many competing priorities for the Subcommittee members, and we appreciate your consistent support.

#### IMPENDING NURSING SHORTAGE

AWHONN supports the advancement of quality care through an adequate nurse workforce. The release of data from the Bureau of Health Professions, Division of Nursing's National Sample Survey of Registered Nurses—February 2002, confirmed that of the approximate 2.7 million nurses in the nation, only about 82 percent of these nurses were working full-time or part-time in nursing. The increase in the number of licensed RNs that was reported from 1996–2000 was the lowest increase reported in previous national surveys. When other key factors are considered, such as retirements of RNs and the aging of the baby boomer population, it is clear that the demand for nursing services will dramatically increase as the supply of nurses dips greatly below previous levels.

dips greatly below previous levels. Workforce demand models are indicating that the nation will suffer a dramatic nursing shortage that peaks in 2010. This shortage is unlike any other nurse shortages in the past. In the past, it was often an issue of supply and demand. With modest federal support of programs that increased the pipeline of nursing students and employer salary increases, the nursing supply would gain momentum and close the supply-demand gap. These solutions will not alone make the difference in this nursing shortage. The predominate factor in this shortage is the impending retirement of up to 40 percent of the workforce by 2010 or soon thereafter. This will occur at the same time that demand for health care services as well as the services of registered nurses is increasing to meet the needs of the aging baby boomer population. As a result, it will take long term planning and innovative initiatives at the local, state and federal level to assure the adequate supply of a qualified nurse workforce for the nation.

# DEPARTMENT OF HEALTH AND HUMAN SERVICES

#### Health Professions Education Partnerships Act of 1998—Title VIII of the Public Health Service Act (formerly the Nurse Education Act)

AWHONN is requesting an increase by at least \$40 million over fiscal year 2001 to fund the NEA at approximately \$120 million. In addition, AWHONN is requesting at least an additional \$10 million in appropriations for fiscal year 2003 for the nursing education loan repayment program for nurses (Sec. 846 of the Public Health Service Act).

Service Act). The shortage of registered nurses and the effect of the shortage on nurse staffing and patient safety demand a significant increase in funding for these Title VIII programs. Nursing is the largest health profession with over 2.7 million nurses, yet only one-tenth of 1 percent of the federal health funding of the nation is directed to nursing education.

to nursing education. Title VIII programs provide valuable resources to support the nursing community in its efforts to provide quality patient care. A significant increase in Title VIII would lay the groundwork to expand the nursing workforce and faculty, through education and clinical training, in order to address some of the serious nursing shortage issues.

The Nurse Education Act (Public Health Service Act Title VIII), enacted in 1964, represents the only comprehensive federal legislation to provide funds for nursing education. The programs authorized in this portion of Public Law 105–392 help schools of nursing and nursing students prepare to meet patient needs in a changing health care delivery system, favoring programs in institutions that train nurses for practice in medically underserved communities and Health Professional Shortage Areas. Reauthorized as the Nursing Workforce Development section in 1998, the new NEA gives the Department of Health and Human Services more discretion over the focus of federal spending, while keeping with previous goals.

hew NEA gives the Department of Health and Human Services more discretion over the focus of federal spending, while keeping with previous goals. Minorities account for only 12 percent of the total population of nurses in the United States. Funds from the Nurse Education Act support projects that would increase the number and educational opportunities for minority nurses who would then be able to provide culturally competent, linguistically appropriate health care services to underserved communities.

Services to underserved communities. The nursing shortage is not confined solely to care providers; there is also a growing, significant shortage of nurse faculty. The American Association of Colleges of Nursing (AACN) reports that the average age of nursing professors is 52, and for associate professors the average age is 49. The impending retirement of these seasoned educators will impact the ability of our schools and universities to meet the educational health care needs of the nation. While the capacity to implement faculty development is currently available through Section 811 and Section 831, adequate funding and direction is needed to ensure that these programs are fully operational. In addition, options to provide support for full-time doctoral study are essential to rapidly prepare the nurse educators of the future. AWHONN suggests that funds be directed to faculty development and mentoring. In anticipation of the pending nursing shortage, the nursing community will continue to seek a broad range of legislative initiatives that will bolster the supply of nurses in the nation. Additional appropriations will be requested to implement these initiatives upon passage of this legislation.

# NATIONAL INSTITUTES OF HEALTH (NIH)

# AWHONN joins many others in supporting the professional judgement budget amount of \$25 million for the fiscal year 2003 appropriations. This would bring NINR to a total funding level of \$145 million

AWHONN supports continued and increased funding to the National Institute of Nursing Research to support nurse research on the cost effectiveness of different nursing practices on patient outcomes. This research will allow us to refine the practice and provide quality patient care in its current challenging environment.

NINR engages in significant research affecting areas such as: research on health disparities in ethnic groups, training opportunities in genetic research and in health disparities, and studying telehealth interventions in rural/underserved populations. These research programs directly affect patients and families and contribute to decreased medical costs and increased quality of patient care.

In addition, NINR research improves outcomes for women and children. A report by the U.S. Agency for Healthcare Research and Quality states that the most common reason for hospital admission in the United States is childbirth. This accounts for 3.8 million annual hospital admissions. This is a joyous event in most women's lives, but complications of pregnancy such as pre-term birth and low birthweight infants are some of the more expensive reasons for hospitalization. Nurse research has helped redesign care delivery models that optimize pregnancy outcomes and shorten hospital stays for vulnerable low birthweight babies.

For example, NINR-funded projects have contributed to breakthroughs in nursing that have improved infant health after hospital discharge for at-risk mothers and babies. One model utilized home follow-up assessment and care by an advanced practice nurse and showed decreased health system costs by shortening the length of stay of the infant and avoiding subsequent re-hospitalization.

Because of the emphasis on biomedical research in this country, there are few sources of funds for high-quality behavioral research for nursing other than NINR. It is critical that we increase funding in this area in an effort to improve the consumer's experience with the health care system, optimize patient outcomes and decrease the need for extended hospitalization.

#### NATIONAL INSTITUTE OF CHILD AND HUMAN DEVELOPMENT (NICHD)

# AWHONN supports the professional judgment budget, which includes an increase of \$170.4 million, bringing the appropriation for NICHD to just over \$1.284 billion

NICHD seeks to ensure that every baby is born healthy, that women suffer no adverse consequences from pregnancy, and that all children have the opportunity to fulfill their potential for a healthy and productive life unhampered by disease or disability. With increased funding NICHD could expand its use of the NICHD Maternal-Fetal Medicine Network to study ways to reduce the incidence of low birth weight. Prematurity/low birthweight is the second leading cause of infant mortality in the United States and the leading cause of death among African American infants. AWHONN, like many organizations directly involved in initiates to improve the health of women and newborns, looks to NICHD to provide national initiatives, such as the Maternal-Fetal Medicine Network to assist with the care of pregnant women and babies.

One specific example of the important research that evolves from NICHD is research that led to the finding that the hormones that control the body's response to stress are involved in the process that prevents a mother's immune system from destroying an embryo that has implanted in her uterus. This finding opens up promising new ground in the quest to treat recurrent miscarriage, preventing and treating preeclampsia, and determining the causes of unexplained infertility.

#### MATERNAL AND CHILD HEALTH BLOCK GRANT

### AWHONN recommends funding at the full authorization level of \$850 million for the Maternal Child Health Block Grant for fiscal year 2003

This program provides comprehensive, preventive care for mothers and young children, as well as an array of coordinated services for children with special needs. In fact, the Maternal Child Health Block Grant (MCH) serves over 80 percent of all infants in the United States, half of all pregnant women, and 20 percent of all children. MCH programs are facing increased demands for services due to continued growth in the Children's Health Insurance Program, which in turn identifies more children who are eligible for other MCH Services. Title V complements Medicaid and the State Children's Health Insurance Program by providing "wrap-around" services and enhanced access to care in underserved areas.

Additional funding would give states the resources they need to expand prenatal and infancy home visitation programs, an approach that has been shown, in NINR research, to improve the prenatal health-related behavior of women and reduce rates of child abuse and neglect as well as maternal welfare dependence. Postpartum home visits can also increase the percentage of mothers who choose to breastfeed. Many new mothers can get frustrated and stop breastfeeding in the first few days; a visit from a qualified health care provider can greatly encourage women to continue breastfeeding. This can also positively impact the goals of the Healthy People 2010 initiative to raise the rate of initiation of breastfeeding to 75 percent and the 6-month rate of breastfeeding to 50 percent.

The MCH funds assure that women, children and youth have access to such basic but critical services regardless of whether they have insurance or whether their insurance covers the service. Particularly in underserved areas of the country where health care providers, including community health centers, are in short supply, MCH funds can help assure that women and children get the services they need.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

# AWHONN supports the Friends of CDC's recommended fiscal year 2003 appropriation of \$7.9 billion for the Centers for Disease Control and Prevention. This figure represents a near doubling of the CDC fiscal year 2002 budget

For nearly 60 years, the Centers for Disease Control and Prevention (CDC) has evolved to assume responsibility for programs in infectious disease surveillance, control and prevention, injury control, health in the workplace, prevention of heart disease, cancer, stroke, obesity and other chronic diseases, improvements in nutrition and immunization, environmental effects on health, prevention of birth defects, laboratory analyses, outbreak investigation and epidemiology training, and data collection and analysis on a host of vital statistics and other health indicators. Now more than ever, CDC's role in protecting the nation's health through prevention has become evident as we address issues of terrorism, emergency preparedness and health system capacity and infrastructure. Increased funding for CDC is critical.

For over 30 years, CDC has been deeply involved in the prevention of birth defects through programs like the Folic Acid Education Campaign and the new National Center on Birth Defects and Developmental Disabilities (NCBDDD). The public health impact of birth defects is tremendous. Of the four million babies born each year in the United States, approximately 150,000 are born with a serious birth defect. According to CDC, the lifetime costs of caring for infants born in 1992, with at least one birth defect<sup>1</sup> or cerebral palsy was about \$8 billion. The emotional and financial burden for the families with affected children is devastating. CDC funds several programs critical to reducing the number of children born with birth defects. The fiscal year 2002 funding level of \$91 million is indequate to continue CDC's work reduce the incidence of costly birth defects. We respectfully request that you provide the NCBDDD \$115 million in funding in fiscal year 2003 to prevent these serious birth defects through programs like the Folic Acid Education Campaign.

Under the President's proposed fiscal year 2003 budget, CDC programming for chronic disease prevention would be cut by nearly \$51 million. This proposed cuts is troubling when statistics are reviewed. Heart disease and stroke are the first and third leading causes of death in the United States, causing one death every 33 seconds and \$298 billion a year in healthcare costs and lost productivity, according to CDC estimates. Women are most commonly misdiagnosed for cardiovascular disease and nearly 8 million women are currently living with cardiovascular disease. Cardiovascular disease kills nearly half of all American women.

Sixty-one percent of American adults are overweight or obese and nearly 14 percent of children and adolescents are overweight. Obesity is considered a major public health problem because it serves as the gateway disease for many other illnesses including but not limited to: depression, type 2 diabetes, hypertension, congestive heart failure, stroke, poor female reproductive health and pregnancy complications. These are but two examples of illnesses with programmatic public health funding through CDC. Cuts to these programs will potentially leave millions of Americans without primary prevention programs that ultimately save lives and money. We respectfully request that you provide CDC chronic disease prevention and health promotion programs with \$1.1 billion to ensure that these programs have the resources necessary to translate preventive health research into practice. This investment will save lives and billions in health care costs and productivity.

Thank you for the opportunity to submit testimony on these critical areas of funding.

## Administration for Children and Families

#### 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 Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies as it considers fiscal year 2003 appropriations for the Low Income Home Energy Assistance Program (LIHEAP). The CONEG Governors commend the Subcommittee for its past support of this important program; and appreciate the increased funding provided in fiscal year 2002. While we recognize the difficult decisions facing the Subcommittee this

<sup>&</sup>lt;sup>1</sup>These birth defects include: Spina bifida, truncus arteriosus, single ventricle, transposition/ double outlet right ventricle, Tetralogy of Fallot, tracheo-esophageal fistula, colorectal atresia, cleft lip or palate, atresia/stenosis of small intestine, renal agenesis, urinary obstruction, lowerlimb reduction, upper-limb reduction, omphalocele, gastroschisis, Down syndrome, and diaphragmatic hernia.

fiscal year, we request that the Subcommittee appropriate \$3 billion in regular fiscal year 2003 LIHEAP funding and provide advance appropriations for fiscal year 2004. In addition, we request that the full authorized funding authority be provided for each year to allow for the release of emergency funds for unforeseen circumstances, such as price spikes in natural gas or heating oil, severe weather and other potential emergencies.

LIHEAP plays an essential role in making home energy affordable for the region's very low-income households—the elderly and disabled on fixed incomes, families with young children, and those making the difficult transition from welfare to work. Two-thirds of the region's LIHEAP recipients have annual incomes of less than \$8,000 per year. For many of these households, annual income is not sufficient to pay winter heating bills, even in periods of economic growth or stable energy prices. Many low-income residents are forced to choose between heating their homes or purchasing food or vital medications.

Despite the increase in LIHEAP funding, a mild winter and stable energy prices, the demand for LIHEAP assistance continued to be strong this year, as many households still struggle to pay down the outstanding heating bills of the previous winter season. Regular LIHEAP program funds were rapidly obligated, and several states depleted their available LIHEAP resources, including emergency assistance—putting thousands of our most vulnerable families at risk. Even with the increased LIHEAP funding, the program currently serves less than 20 percent of the eligible families. Confronted with depleted LIHEAP program funds and pressures on state budgets, states now face the prospect of having limited resources to assist families facing the shut-off of utilities, or to take advantage of cost-efficient measures to prepare for the next heating season. In addition, some states may lack the resources to take advantage of cost-efficient measures to prepare for the next heating season.

to take advantage of cost-efficient measures to prepare for the next heating season. An increase in the regular LIHEAP appropriation to \$3 billion for fiscal years 2003 and 2004 will enable states across the nation to more fully implement costeffective measures to meet the continuing energy needs of our most vulnerable citizens. State LIHEAP programs could stabilize heating fuel prices for low-income households and expand the reach of limited program funds if an agency could achieve some form of price protection through contracting with retailers on a fixed or ceiling price basis when heating oil prices are most attractive—generally in the summer months. Today, these "prebuys" are difficult to do, since the programs face the constraints of limited or no funds to carry forward to a new heating season, and the new appropriation is not available until October 1 of each year. An increased federal appropriation, and advance funding, would allow states to manage the program resources in a manner to better take advantage of retail contracts.

Enactment of advance funding is vital to the states' program planning activities for the coming heating season. In the Northeast, where the heating season begins in early October, states generally spend up to 70 percent of the LIHEAP funds during the first two quarters of the fiscal year. States must be prepared to begin their LIHEAP program as soon as the new fiscal year starts. Advance funding permits them to do this, even when—as occurred last fall—Congress has not yet enacted the Labor, HHS and Education appropriations bill for the new fiscal year.

The current uncertainty of world energy markets underscores the importance of states being able to prepare for the potential of volatile energy prices. These preparedness activities, while critical, cannot fully shield our lowest-income citizens from the impacts of higher heating fuel prices. Your support for fiscal year 2003 LIHEAP appropriations at the \$3 billion level and the enactment of advance fiscal year 2004 appropriations is urgently needed to enable our states to help mitigate the potential life-threatening emergencies and economic hardship that confront the region's most vulnerable citizens. We thank the Subcommittee for this opportunity to share the views of the Coali-

We thank the Subcommittee for this opportunity to share the views of the Coalition of Northeastern Governors, and we stand ready to provide you with any additional information on the importance of the Low Income Home Energy Assistance Program to the Northeast.

#### PREPARED STATEMENT OF THE NATIONAL NETWORK FOR YOUTH

#### INTRODUCTION

The National Network for Youth, founded in 1975, is a membership organization of youth-serving agencies, young people, youth workers, and youth advocates who seek to ensure that all young people can be safe and lead healthy and productive lives. The National Network focuses its work with and for youth, especially those who, because of life circumstance, disadvantage, past abuse, or prejudice, need greater opportunities and supports to become contributing members of their communities.

nucles. The National Network thanks the Senate Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies for the opportunity to testify on fiscal year 2003 appropriations for the U.S. Departments of Labor, Health and Human Services, and Education. While we are supportive of the dozens of programs in each of these departments that reach young people—and seek full funding for each of them—we focus our statement on several programs that are priorities for the National Network.

# U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

# Appropriations for Runaway and Homeless Youth Act Programs

Runaway and Homeless Youth Act (RHYA) programs ensure safety and support in community-based settings to thousands of youth who would otherwise risk death, illness, sexual exploitation, educational failure, unemployment, and contact with the child welfare and juvenile systems. We can not emphasize enough how important RHYA programs are to the safety

We can not emphasize enough how important RHYA programs are to the safety and well-being of youth facing the direst circumstances imaginable—and how underresourced these programs are compared to their need. The National Network for Youth urges Congress and the Administration to appropriate \$150 million in fiscal year 2003 for RHYA programs. Of the total, \$130 million should be directed to the Runaway and Homeless Youth consolidated account, which funds the Basic Center Program (BCP), Transitional Living Program (TLP), and Runaway and Homeless Youth Act support activities. The remaining \$20 million should be directed to the Runaway Prevention account, which funds the Street Outreach Program (SOP).

Basic Center Program.—The BCP provides grants to community-based, faithbased, and local public organizations to provide emergency shelter for youth under age 18, and counseling for youth and their families to assist them in reuniting with their families or connecting to alternative guardians.

Although Congress appropriated a generous increase for the RHYA consolidated account last year, the total increase was applied to the TLP portion of the account; the BCP and support portions of the account were actually decreased by \$2.1 million. There is some danger that this reduction could result in the loss of basic centers in some of the states that have centers with grants expiring in fiscal year 2002. States that could be affected by the BCP shortfall are Alaska, Colorado, Florida, North Dakota, Oklahoma, Oregon, South Dakota, and Wisconsin. Also at risk of reductions are vital RHY support activities. We understand that the Family and Youth Services Bureau is attempting to reprogram fiscal year 2002 funds in order to prevent the loss of any services to young people. However, it is essential that Congress increase the consolidated account in fiscal year 2003 in order to reclaim ground lost in fiscal year 2002 in terms of emergency supports for our nation's runaway youth, and to ensure that this situation is not repeated in the fiscal year 2003 grant cycle.

grant cycle. Transitional Living Program.—The TLP provides grants to community-based, faith-based and local public organizations to provide longer-term residential supports as well as independent living opportunities to youth ages 16–21 who are unable to return home safely, in order to promote their successful transition to adulthood and self-sufficiency. We are grateful to Congress for providing a generous \$19 million increase to the TLP program last year, in response to the Administration's desire to increase housing opportunities for homeless parenting youth. We are also appreciative of the Administration for building on this momentum and recommending an additional \$10 million in fiscal year 2003 for residential supports for homeless young parents through a maternity group home program. Since this program has yet to be authorized, the National Network for Youth suggests that Congress consider satisfying the intent of the President's request by adding the requested additional resources to the TLP, as was done in fiscal year 2002. The TLP has an excellent track record in reaching homeless parenting youth.

has an excellent track record in reaching homeless parenting youth. Street Outreach Program.—The SOP provides grants to support street-based outreach and education to runaway, homeless, and street youth who have been sexually abused or are at-risk of sexual abuse, in order to connect these young people with services and a chance for a safe and healthy future. The SOP ensures rapid engagement with young people in an effort to prevent the most terrible situations that take place when they are subjected to life on the streets—physical and sexual abuse, assault, commercial sexual exploitation, disease, long-term homelessness, and even death. Congress has not increased SOP funding since fiscal year 1998. The runaway prevention account must be increased this year in order to reverse the funding stagnation that has beset the SOP for four years. Runaway and Homeless Youth Support Activities.—The Runaway and Homeless Youth Act authorizes a number of activities designed to support young people in high-risk situations and assist RHYA-funded service providers and prospective grant applicants. These include the National Runaway Switchboard (a toll-free telephone system that enables youth to receive crisis counseling, be referred to services, and communicate with their families), an information clearinghouse, and a network or regional training and technical assistance providers. Young people, parents and caregivers, grantees, applicants, and the public rely on these services in numerous ways. For example, public, community-based and faith-based organizations depend on T&TA providers to facilitate collaboration among youth-serving systems and programs, foster the establishment of cost-effective and comprehensive continuums of services for youth, and disseminate effective practices. Full funding of the RHYA consolidated account will enable these support entities to expand existing services and develop new programs.

#### APPROPRIATIONS FOR CHILD WELFARE PROGRAMS

John H. Chafee Foster Care Independence Program.—Young people transitioning from foster care are at great risk of homelessness, educational failure, unemployment and inability to form and sustain relationships because basic needs and emotional supports have not been arranged with them prior to the termination of state custody. The John H. Chafee Foster Care Independence program (CFCIP) provides grants to states to assist current and former foster care youth to support their successful transition to adulthood. The National Network for Youth urges Congress and the Administration to appropriate at least \$200 million in fiscal year 2003 for the CFCIP (\$140 million in guaranteed funds and \$60 million in discretionary funds for education and training vouchers). New discretionary funds for education opportunities and training vouchers through CFCIP would expand access to critical academic achievement and employment readiness opportunities to youth transitioning from foster care, who are not reached by many other educational or employment programs.

Child Abuse Prevention and Treatment Act Programs.—Nearly three million reports of suspected child abuse and neglect were filed in 1999, leading to screening of nearly 1.8 million children and services to 826,000 young victims. The Child Abuse Prevention and Treatment Act (CAPTA) provides grants to states and community-based family resource and support programs to aid in the prevention, assessment, investigation, prosecution, and treatment of child abuse and neglect. CAPTA also provides grants to state child protective service offices for program innovation and improvement. The National Network for Youth urges Congress and the Administration to appropriate at least \$166 million in fiscal year 2003 for CAPTA programs. Additional funds for CAPTA programs would enable states and community-based organizations to serve a greater number of children, youth, and families in high-risk situations. *Promoting Safe and Stable Families.*—Severe family conflict, physical and sexual

Promoting Safe and Stable Families.—Severe family conflict, physical and sexual abuse, and parental alcohol and drug addiction remain the key causal factors for runaway behavior. The Promoting Safe and Stable Families (PSSF) program provides grants to states to develop and support services for children and families, including extended or adopted families, who are in high- risk situations or in crisis. The National Network for Youth urges Congress and the Administration to appropriate at least \$505 million in fiscal year 2003 for the PSSF program (\$305 million in guaranteed funds and \$200 million in discretionary funds). Additional funds for the PSSF program would enable states, localities, and community-based organizations to support families in high-risk situations, assure families are kept intact, and facilitate family reunification.

#### APPROPRIATIONS FOR HIV/AIDS PROGRAMS

CDC HIV Prevention Program.—The National Center for HIV, STD, and TB Prevention (NCHSTP) of the Centers for Disease Control and Prevention is responsible for public health surveillance, prevention research, and programs to prevent and control human immunodeficiency virus (HIV) infection and acquired immuno-deficiency syndrome (AIDS), other sexually transmitted diseases (STDs), and tuber-culosis (TB). NCHSTP provides grants to states, local communities, and community-based organizations to support prevention efforts. Half of new HIV infections each year occur in individuals under the age of 25. Over half of adolescents who engage in sexual intercourse do so unprotected, putting them at higher risk for contracting STDs and HIV/AIDS. We urge Congress and the Administration to appropriate at least \$1.5 billion in fiscal year 2003 for NCHSTP. Additional funds for NCHSTP

would ensure that states and communities are able to provide science-based disease prevention services to a greater number of people, including youth. *Ryan White CARE Act Title IV Program.*—Title IV of the Ryan White Comprehen-

Ryan White CARE Act Title IV Program.—Title IV of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act authorizes grants to public and nonprofit agencies to develop comprehensive systems of care for children, youth, women and families with HIV disease, including medical treatment, health care, social services, and access to clinical research. Community-based entities receiving Ryan White Title IV funds are leaders in the national effort to include young people in HIV/ AIDS research and to engage and retain HIV-positive youth in care. Only a very small portion of federal HIV/AIDS treatment and care resources reach young people. We urge Congress and the Administration to appropriate at least \$81 million in fiscal year 2003 for the Ryan White Title IV program. Additional funds for the Ryan White Title IV program would ensure access to HIV/AIDS treatment and care services for a greater number of young people, while also allowing Title IV programs to fulfill their responsibilities to the other population groups (children, women, and families) who are also the focus of Title IV.

#### U.S. DEPARTMENT OF LABOR

# Appropriations for Youth Employment Programs

Youth have been hard hit by the current economic recession. Many businesses face severe skills gaps and are seeking help finding and preparing qualified workers. Many young people, even those who may be employed, do not possess the academic, work-readiness, or vocational competencies sought by employers. In October 1999, 11.2 percent of the 34.2 million 16–24 year olds in the United States were not in a high school program and had not completed high school. Further, despite a low unemployment rate of 4.2 percent, only 54 percent of young individuals who did not complete high school were employed, while nearly 90 percent of college graduates and 75 percent of high school graduates in that age range were employed. The conditions for minority youth are even less encouraging. In 1999, on average, 75 percent of white youth were employed compared to 66 percent of Hispanic youth and only 59 percent of black youth. Rates in urban and isolated rural areas are often lower.

Workforce Investment Act Youth Training.—Workforce Investment Act (WIA) youth training programs provide improved comprehensive services to eligible youth, ages 14 to 21, in local communities. WIA grantees provide assistance in achieving academic and employment success, training opportunities, mentoring opportunities, support services, and incentives for recognition and achievement. The National Network for Youth urges Congress and the Administration to appropriate at least \$1.8 billion in fiscal year 2003 for WIA youth training programs. We strongly oppose the Administration's proposed reductions to WIA youth employment programs. Youth Opportunity Grants.—The Youth Opportunity Grants (YOG) program pro-

Youth Opportunity Grants.—The Youth Opportunity Grants (YOG) program provides grants to local workforce boards for programs aiming to increase the long-term employment of youth, ages 14–21, living in high-poverty areas. The grants respond to community-wide issues including dropout rates, skills development, and unemployment. The National Network for Youth urges Congress and the Administration to appropriate at least \$275 million in fiscal year 2003 for the YOG program. We strongly oppose the Administration's proposal to essentially eliminate this effective program.

Job Corps Program.—The Job Corps program provides grants to states and communities to develop comprehensive residential education and job training program for youth in high-risk situations, ages 16–24. Job Corps programs provide youth with the academic, vocational and social skills training they need to gain independence and get quality, long-term jobs or further their education. We urge Congress and the Administration to appropriate at least \$1.5 billion in fiscal year 2003 for the Job Corps Program. We welcome the Administration's proposal to substantially increase funding for the Job Corps program.

# U.S. DEPARTMENT OF EDUCATION

# Appropriations for Education for Homeless Children and Youth Program

The Education for Homeless Children and Youth program provides grants to states to assist them in assuring that homeless children and youth enroll, attend, and succeed in school. State educational agencies (SEAs) use EHCY funds to review and revise laws, regulations, practices, and policies that may act as a barrier to enrollment, attendance, and success. The program also supports a Coordinator of Education for Homeless Children and Youth in each state who gathers comprehensive information about homeless children and youth and barriers to their regular attendance at school. States also make subgrants to selected local educational agencies (LEAs) to addressing enrollment, attendance, and achievement problems caused by transportation issues, immunization and residency requirements, lack of birth certificates and school records, and guardianship issues.

Vigorous implementation of the educational rights and protections for homeless youth and children is largely dependent on resources to SEAs and LEAs to implement federal mandates. States are able to ensure direct services to only 28 percent of the children and youth that they identify being in homeless situations. As a result, many school districts have difficulty implementing EHCY provisions. The National Network for Youth urges Congress and the Administration to appropriate at least \$70 million in fiscal year 2003 for the EHCY program.

# Appropriations for 21st Century Community Learning Centers Program

The 21st Century Community Learning Centers (21st CCLC) program provides grants to states, local educational agencies, and nonprofit organizations to develop and expand opportunities for children and youth and their families to continue to learn new skills and discover new abilities after the school day has ended.

The number of youth who are unsupervised by an adult during the after-school hours is increasing. The demand for afterschool activities for young people far outpaces the availability of positive programming for them. The National Network for Youth urges Congress and the Administration to appropriate at least \$1.5 billion in fiscal year 2003 for the 21st CCLC program. Additional funds for the 21st CCLC program would ensure access to supervised and productive afterschool activities for a greater number of children and youth.

#### PREPARED STATEMENT OF THE NATIONAL YOUTH SPORTS PROGRAM FUND, INC.

Mr. Chairman and Members of the Subcommittee, my name is Edward Thiebe and I am president of the National Youth Sports Program Fund, Inc. (NYSPF). I appreciate this opportunity to testify on behalf of the National Youth Sports Program Fund, Inc. Board of Directors in support of the fiscal year 2003 national youth sports program appropriation, which falls under the office of community services at the Department of Heath and Human Services (HHS).

The NYSPF has been competitively awarded a grant under Section 682 of the Community Services Block Grant Act, as amended 42 U.S.C. 9923. As the Labor, Health and Human Services and Education Subcommittee reviews

As the Labor, Health and Human Services and Education Subcommittee reviews the hundreds of programs under its jurisdiction this funding cycle, it is my hope that you will give careful consideration to the merits of the national youth sports program. The Subcommittee generously funded the program at \$17 million last year. We are grateful for your continued support for this program that provides so many youth from disadvantaged backgrounds with a positive and enriching summer experience. The NYSPF is a successful public/private partnership that leverages community

The NYSPF is a successful public/private partnership that leverages community and private resources to support 203 campus-based youth programs. The resources provided by the federal government are matched by the participating colleges and universities, local public and private businesses, the National Collegiate Athletic Association (NCAA), the NYSPF and other National Governing Bodies of amateur sport. These partners match every federal dollar two to one.

The mission of each of the 203 National Youth Sports Program (NYSP) sites is to provide young people from disadvantaged backgrounds with a wholesome summer experience that combines sport and physical fitness with academic enrichment and character development on a college campus. An average of 375 boys and girls participate at each NYSP site and are served at a daily cost of \$8.60 per student. The NYSPF utilizes the best resources our nation's colleges and universities have to offer and the participating youth are made to feel that they belong in that setting. In addition, students receive health education, a medical screening at no cost to the student or their family and a hot, well-balanced USDA approved meal each day.

# PUBLIC/PRIVATE PARTNERSHIP RESULTS IN SHARED RESOURCES AND HIGH QUALITY PROGRAMS

The NYSPF, in collaboration with the Department of Health and Human Services, develops rigid criteria for participation, carefully selects and evaluates sites, and distributes the funds to NYSP sites to operate programs. Colleges and universities host the programs, provide staff and facilities in addition to cash and other in-kind services. The NYSPF provides administrative support and through NCAA licensee agreements obtains sports equipment and apparel to ensure that federal dollars can be applied to direct expenses to support the community-based programs. Through this team effort, the NYSP has developed into a program that serves 73,204 youth in high quality summer programs and has grown from two institutions in its first year to 203 in the summer of 2002.

The effectiveness of each NYSP site is further ensured by the hands-on leadership of local community leaders through an advisory committee and the involvement of the mayor or city manager. Each NYSP site and participating institution coordinate the program through the NYSP advisory committee, comprised of representatives from local agencies (such as the housing authority and mayor's office), private industry and state government. Each NYSP advisory committee reviews program components, plans curricula, develops recruitment strategies and identifies resources to support the program.

To ensure that every program site strives to attain the highest level of services to its participants and that federal dollars are used appropriately to achieve maximum benefit, an annual evaluation of each program site is conducted by the NYSPF. The evaluation reviews compliance with the criteria established by HHS and the NYSPF and determines if each program meets or exceeds the high expectations required of an NYSP site. Programs found to be in noncompliance are provided technical assistance and professional development.

To enhance the quality of instruction, the NYSPF also has developed a partnership with many of sports' National Governing Bodies, such as U.S. Tennis Association (USTA) and Professional Golfers Association (PGA). These governing bodies provide highly qualified instructors who administer innovative developmental programming that encourages children of sport to engage in non-traditional activities.

BUILDING HEALTHY BODIES AND MINDS—NYSP OFFERS DISADVANTAGED YOUTH PHYSICAL EDUCATION AND ACADEMIC ENRICHMENT ON A COLLEGE CAMPUS

Young people from economically disadvantaged homes face many obstacles that sometimes prevent them from cracking the lines of poverty. Today 1 in 5 children lives in poverty and 1 in 6 has no health insurance. These children are surrounded by risk factors of broken families, domestic violence and substance abuse. They are searching for a sense of family and a sense of community. These children are also in search of an experience that includes adults who serve as mentors and role models. Attaining a higher education is the solution but it is one of the most difficult for some of these youngsters to attain or even dream about.

In addition to health and economic factors, children are facing over-whelming obstacles in reaching basic education achievement levels. As reported in the Children's Defense Fund, *Yearbook 2001*, 2,911 students drop out of high school each day. Our country's economy demands post-secondary degrees, but of every five children only two go on to complete 4-year degree programs. Offering enrichment opportunities, providing encouragement and exposing youth to the possibilities of higher education are ways that we can break down educational barriers for today's children, especially those also struggling with poverty.

In the Surgeon General's Report to the President, *Promoting Better Health for Young People through Physical Activity and Sports*, in Fall 2000, he reported that the percentage of young people who are overweight has doubled in the last 20 years. This increase has led to more risk factors for cardiovascular disease and increased cases of type 2 diabetes (commonly know as "adult-onset diabetes") among adolescents. The impact of obesity in adolescence is not limited to the physical and emotional well being of teenagers, but the national health care budget. The Surgeon General reported that \$100 billion, 8 percent of the total health care budget, is spent on diseases associated with obesity.

In his report, the Surgeon General listed several strategies to combat physical inactivity in America's youth. One of the strategies includes supporting communitybased youth sports and recreation programs. NYSP is one solution to this strategy.

NYSP has also evaluated the special needs of its older participants, those from ages 13–16 years old. The senior program began in 1997 at four locations. The senior component places an emphasis on character development, higher education achievement and test taking skills. Each senior program incorporates the theme "Focus on Respect" in their program. In recent remarks to a Joint Session of Congress, President Bush stressed the importance of teaching "our children not only reading and writing, but right from wrong." Through the senior program, NYSP can help prepare students for the rigors of standardized testing (including ACT or SAT preparation), reinforce reading and writing skills for future use and enhance computer skills, and offer mentoring opportunities to younger participants. Senior programming for 25 sites is scheduled for 2001.

#### NYSP CREED

#### [Practiced daily]

I am a good sport at all times and conduct myself with decency and honesty. I do my best to get along with others and have pride in myself.

I put forth my best effort in all competition and always compete fairly.

Furthering the educational commitment of the NYSP, selected programs across the country have been enhanced to include special emphasis on math and science skills. The reinforcement of classroom learning with hands-on experiments and creative teaching methods challenge students to raise their expectation for academic success. This component was offered in 125 sites in 2001.

A sense of urgency is needed to face the challenge of preparing a new generation of children for the future. The NYSP agenda puts children first in education by insisting that programs invest in quality teaching; provide access to facilities that support learning; to make sure that every child gets a healthy start in life. Secretary of State Colin Powell addressing the Republican National Convention in July 2000, stated, "we are obligated to involve the entire community and use resources efficiently."

The NYSP program teaches its students the value of an active lifestyle by offering innovative and age appropriate teaching methods in sport specific areas. Every NYSP program offers at least three of the following sports: badminton, basketball, dance, football, gymnastics, physical fitness, soccer, softball, swimming, tennis, track and field, volleyball and wrestling. Other sports of local interest may also be included. This variety of sport activity allows participants to be exposed to non-competitive fitness activities that they can participate in their entire life. NYSP targets areas where the local communities alone could not support this

NYSP targets areas where the local communities alone could not support this level of youth sports programming. Rural areas, public housing and inner city neighborhoods are prime locations to reach these at-risk youth. NYSP is pleased to be working in collaboration with the Surgeon General and HHS to improve the physical well being of youth.

Healthy individuals contribute to healthy communities. Both are essential to a healthy and productive economy and to the pursuit of individual happiness and independence. An essential component of the NYSP is to ensure that the students who participate receive appropriate medical services. With the help of the local medical community, each of the programs' participants receives a free medical screening before the program session begins. In 2001, over 76,917 medical examinations were administered. If a health problem is found, the child is referred for adequate follow-up treatment. During the summer session, children who are injured or become ill during NYSP activities are covered by health insurance and treated by a certified medical professional.

NYSP students are also taught about nutrition and the value of eating healthy, well-balanced meals. Each NYSP provides at least one hot U.S. Department of Agriculture approved meal each day of the program.

Perhaps the most distinguishing feature of NYSP is its location on college and university campuses. Using the personnel and facilities of higher education, NYSP introduces students to a different environment, one comprised of high quality resources and apart from the threats and dangers of the street. Participants have the opportunity to see the institution from the inside, to walk the halls and engage in activities in the classrooms. They also interact with college students and faculty who work with the program and value college life. This experience in the world of post secondary education is part of the NYSP strategy to encourage youth to aspire beyond their current school life.

Each NYSP program is led by a full time employee of the university, who supervises the administrative, instructional, and support staff. The program employs a local staff of instructors and support personnel to maintain an instructional participant-to-staff ratio between 15 and 20 to 1. NYSP puts thousands of people in positions to help themselves and the community. These worthwhile summer jobs offer training to local community members. The staff includes physical education teachers, coaches, elementary and secondary educators, college students and administrators who make up an administrative, instructional and support staff. In 2001, this national program created over 5,370 summer jobs.

## FISCAL YEAR 2003 APPROPRIATION REQUEST TO EXPAND PROGRAM

The demand for NYSP programs in both rural and urban settings has never been greater. The NYSP is under constant demand to expand its programs. We are aware of the priority the Administration and Congress are placing on cost-effective programs that serve disadvantaged youth during the summer and after school. President Bush in his inaugural address stated that, "persistent poverty is unworthy of our nation's promise, and whatever our views of its cause, we can agree that children at risk are not at fault."

This year the National Youth Sports Program is requesting a \$3 million increase in the appropriation. This increase will allow 3,375 participants to be added to the rosters nine new program sites to have an impact in communities where young children need athletic, health and educational programming. In addition, additional funds may be applied to expand the math/science component to 81 new sites and increase the senior leadership component to all 203 programs.

#### CONCLUSION

NYSP keeps children and their achievement at the center of each education goal and maintains a sense of urgency, believing in children and expecting every child to learn. The fundamentals of education, sport and community participation stand as true today as they did when the program began in 1969. Legendary basketball coach, John Wooden embodies the balance between excelling in athletics and developing good character. One of his maxims goes straight to the heart of what NYSP is working to accomplish: "Ability may get you to the top, but it takes character to keep you there." We remain convinced that the fundamental values of honesty, trust, respect, fairness and responsibility offer an important foundation and model for the over 1.6 million participants that have passed through the program and for the thousands of children who will be served by the NYSP in the 21st century.

This year you will be faced with many choices about how to allocate federal dollars. NYSP continues to provide positive opportunities for children during the hours when they are not in school and their parents/guardians are at work. We believe that the National Youth Sports Program is one of those better choices for America's children and we ask for your favorable consideration for increased funding for this program to enable more children to participate.

# NYSP Facts At A Glance

#### [Program year 2001]

Number of participants ages 10–16	73,204
Number of institutions	196
Number of states, including the District of Columbia and Puerto Rico	48
Number of communities	177
Number of medical examinations administered	77,106
Number of jobs created	5,370
Number of volunteers	1,326
Federal grant cost per child/day	\$8.60
Federal cost per participant per child for a 5-week program	\$215.00

#### PREPARED STATEMENT OF THE BLUE CROSS BLUE SHIELD ASSOCIATION

The Blue Cross and Blue Shield Association (BCBSA), which represents 43 independent, locally operated Blue Cross and Blue Shield Plans throughout the nation, is pleased to submit written testimony to the subcommittee on fiscal year 2003 funding for Medicare contractors.

Blue Cross and Blue Shield Plans play a leading role in administering the Medicare program. Many Plans contract with the federal government to handle much of the day-to-day work of paying Medicare claims accurately and in a timely manner. Blue Cross and Blue Shield Plans serve as Part A Fiscal Intermediaries (FIs) and/ or Part B carriers and collectively process most Medicare claims.

This testimony focuses on three areas:

-Background, including a description of Medicare contractor functions;

-Current financial challenges facing Medicare contractors; and

-BCBSA recommendations for Medicare contractor fiscal year 2003 funding.

# BACKGROUND

Blue Cross and Blue Shield Medicare contractors are proud of their role as Medicare administrators. While workloads have soared, operating costs—on a unit cost basis—have declined about two-thirds from 1975 to 2001. In fact, contractors' administrative costs represent less than 1 percent of total Medicare benefits.

Medicare contractors have four major areas of responsibility:

1. Paying Claims.—Medicare contractors process all the bills for the traditional Medicare fee-for-service program. In fiscal year 2003, it is estimated that contractors will process over one billion claims, more than 3.8 million every working day.

2. Providing Beneficiary and Provider Customer Services.—Contractors are the main points of routine contact with Medicare for both beneficiaries and providers. Contractors educate beneficiaries and providers about Medicare and respond to over 40 million inquiries annually.

3. *Handling Hearings and Appeals.*—Beneficiaries and providers are entitled by law to appeal the initial payment determination made by carriers and FIs. These contractors handle over 7.4 million annual hearings and appeals.

4. Special Initiatives to Fight Medicare Fraud, Waste, and Abuse.—All contractors have separate fraud and abuse departments dedicated to assuring that Medicare payments are made properly. Few government expenditures produce the documented, tangible savings of taxpayers' dollars generated by Medicare anti-fraud and abuse activities. For every \$1 spent fighting fraud and abuse, Medicare contractors save the government \$16.

#### CURRENT FINANCIAL CHALLENGES

Of utmost importance to attaining outstanding performance is an adequate budget. However, Medicare contractors have been severely underfunded since the early 1990's. Reductions in funding concurrent with increases in workload have seriously eroded contractors' ability to fight fraud and abuse. Between 1989 and 2000, the number of Medicare claims climbed almost 70 percent to over 800 million, while payment review resources grew less than 11 percent. As a result, the amount allocated to contractors to review claims shrank from 74 cents to 48 cents per claim. Because of the significant cost of reviewing claims, this decline in funding resulted in CMS directing contractors to reduce the percentage of claims that were scrutinized and investigated. Similarly, the percentage of cost reports audited declined between 1991 and 1996, the chances that any institutional provider's cost report would be reviewed in detail fell from about 1 in 6 to about 1 in 13.

The Medicare Integrity Program (MIP) created by Congress in 1996 as part of the Health Insurance Portability and Accountability Act (HIPAA) provided a permanent, stable funding authority for the portion of the Medicare contractor budget that is explicitly designated as fraud and abuse detection activities. MIP funding was set at \$500 million in 1998 and is authorized to rise to \$720 million in fiscal year 2003. After fiscal year 2003, the permanent authorization is capped at \$720 million despite continuing projected increases in claims volume.

<sup>1</sup>BCBSA supports the authorized funding level of \$720 million for MIP in fiscal year 2003 and urges Congress to consider extending funding increases beyond fiscal year 2003 so that Medicare contractors can continue important activities to reduce the amount of fraud, waste, and abuse in the Medicare program.

Contractors' enhanced anti-fraud and abuse efforts due to MIP funding contributed to the significant decline in improper claims and documentation submitted by providers. The OIG audit of fiscal year 2001 claims estimated that improper Medicare payments had dropped to \$12.1 billion, or about 6.3 percent of the \$191.8 billion in Medicare payments. The fiscal year 2001 improper payment rate is the lowest to date and less than half of the 13.8 percent reported in fiscal year 1996.

est to date and less than half of the 13.8 percent reported in fiscal year 1996. But, the creation of MIP did not solve the budget problems for the remainder of the contractor budget. The largest portion of the contractor budget—program management—continues to face severe funding pressures. Program management activities include claims processing, beneficiary and provider education and communications, and hearings and appeals of claims initially denied. Between 1989 and 1998, funding for program management activities (adjusted for inflation) declined by 18 percent. During this period, the volume of Medicare claims increased by 84 percent; Medicare outlays (in real dollars), by 65 percent. Whenever possible contractors responded to reduced funding by achieving significant effi-

Between 1989 and 1998, funding for program management activities (adjusted for inflation) declined by 18 percent. During this period, the volume of Medicare claims increased by 84 percent; Medicare outlays (in real dollars), by 65 percent. Whenever possible, contractors responded to reduced funding by achieving significant efficiencies in claims processing, lowering program management costs per claim by 56 percent in real dollars over this period. But even these efficiencies have not been enough to keep pace with rising Medicare claims volume and diminishing funding levels. For example, this year, contractors have been instructed to cut back on customer service plans, responding to inquiries, Medicare secondary payer activities, provider training and other provider services in order to live within the fiscal year 2002 budget. It should be noted that Medicare contractors have had to cut back on important provider and beneficiary services in past years as well due to funding shortfalls, even though these services were critically important and contractors had wanted to enhance these programs.

Inadequate budgets for program management also impact Medicare's fight against fraud and abuse. While many think of program management activities as simply paying claims, these activities are Medicare's first line of defense against fraud and abuse and are critically linked to MIP activities. As an example, many of the frontend computer edits (e.g., preventing duplicate payments and detecting suspicious claims) are funded through program management. Inadequate funding impacts different functions at different times, but always disrupts the integration of all the functional components needed to "get things right the first time." It thus results in inefficiency and higher costs.

#### BCBSA FISCAL YEAR 2003 FUNDING RECOMMENDATIONS FOR MEDICARE CONTRACTORS

BCBSA is pleased that Secretary Thompson and many Members of this subcommittee have recognized the need for additional administrative resources at CMS. However, we are concerned the Administration's fiscal year 2003 budget relies on a proposal for \$130 million in new user fees from providers and it does not appropriately reflect the expected increase in claims volume.

BCBSA urges Congress to take the following steps to allow Medicare Contractors to meet increased workloads as well as beneficiary and provider needs:

#### Increase Medicare Contractor Program Management Funding to \$1.72 Billion for Fiscal Year 2003

Medicare contractors are facing significant increases in Medicare claims volume. Blue Cross and Blue Shield Medicare contractor data for the first quarter of fiscal year 2002 shows an approximate 11 percent increase in both Part A and B claims over the fiscal year 2001 level. While this rise is not expected to continue at this level, current projections suggest Medicare fee-for-service claims volume in fiscal year 2003 will be 6 percent higher than the fiscal year 2002 level. However, the President's budget only assumes an unrealistic 2 percent increase in claims volume.

- -Additional funding is necessary to ensure that contractors have the resources needed to fulfill important responsibilities to beneficiaries, providers, and the government and to keep up with expected increases in claims volume, inquiries and appeals.
- The President's budget for fiscal year 2003 requests a total funding level of \$1.67 billion for Medicare contractors, an increase of \$141 million over fiscal year 2002 appropriations (however, this amount proposes using \$130 million in new user fees).
- -BCBSA recommends an additional \$47 million over the President's budget request to address the expected 6 percent rise in both Part A and B claims volume, for a total of \$1.72 billion in fiscal year 2003.

#### Reject New User Fees Financing Mechanism

While BCBSA appreciates the President's willingness to increase overall funding levels for Medicare contractors, the Association is very concerned that CMS recommends a new financing mechanism be adopted to collect \$130 million in new user fees from doctors, hospitals and other providers by charging a \$1.50 fee per claim fee for paper or duplicate claims.

- -History has shown user fees to be an unpredictable stream of funding. In order
- for contractors to maintain performance, funds must be consistent and reliable. —Congress has consistently rejected user fees similar to those recommended in the Administration's budget. Congress should reject them again and provide
- \$1.72 billion in appropriated funds for Medicare contractors.

# Address Rising Workloads so Beneficiaries and Providers Receive the Best Services

BSBSA strongly believes that the first priority in Medicare should be the beneficiaries and the providers who care for them. Therefore, adequate funding is needed to address contractor workloads. CMS estimates that Medicare contractors will pay 987 million claims in fiscal year 2003—a 2 percent increase over the fiscal year 2002 level. However, actual Medicare contractor data suggests claims will rise to over 1 billion in fiscal year 2003. Claims volume is increasing for several reasons:

-More beneficiaries are enrolling in traditional Medicare fee-for-service as private plans exit the M+C program;

- —Beneficiaries have more covered services than in past years—recent legislation has provided coverage for prostate/colorectal cancer screening, clinical trial services, glaucoma screening, nutrition therapy, more frequent pap and pelvic exams, to name a few; and
- -There are simply more eligible Medicare beneficiaries.

It is important to note that neither the Administration's budget nor the BCBSA request account for two critical issues that could require additional funding: implementation of the coverage and appeals reform provisions of the Benefits Improvement and Protection Act of 2000, if it is not delayed; and an approximate 8 percent postal increase expected June 30, 2002. Additional funding will be necessary to account for these changes.

BCBSA would also like to point out that the President's budget only provides for an inflation rate increase of 1 percent. While BCBSA believes a Cost of Living Ad-justment (COLA) is necessary, we are concerned that a 1 percent increase underestimates the level of actual increase contractors expect to incur. However, BCBSA un-derstands the tight budget constraints the Committee faces. Therefore, we have not recommended an additional increase in the COLA. As the fiscal year 2003 Labor/HHS/Education appropriations process begins, we

urge Congress to fund Medicare contractor program management at \$1.72 billion.

# MEDICARE CONTRACTOR BUDGET

[In millions of dollars]

	Fiscal year 2002	Administration fiscal year 2003 rec- ommendation	BCBSA fiscal year 2003 recommenda- tion
Program Management	1,534 (1,081) 700	1,675 (1,128) 720	1,722 (1,175) 720
Total Contractor Budget	2,234	2,395	2,442

# DEPARTMENT OF EDUCATION

# PREPARED STATEMENT OF THE CLOSE UP FOUNDATION

My name is Stephen A. Janger, and I am president of the Close Up Foundation. I appreciate the opportunity to submit testimony in support of the Close Up Fellow-ship Program administered by the Close Up Foundation. These fellowships, as you know Mr. Chairman, support the participation of low-income students and their par-ticipating teachers in our Close Up Washington civic education program. Before be-ginning, I want to express, on behalf of everyone at the Foundation, our deep appre-ciation for the Subcommittee's past support when these fellowships were known as the Allen J. Ellowships the Allen J. Ellender Fellowships.

Who could have imagined the travail this country has suffered since Close Up was last before you to request fellowship funding? The tragic events of September 11 and their aftermath have affected the American psyche and society in ways we don't yet fully understand. We do know about many of the economic repercussions that con-tinue to be felt across a wide spectrum of businesses and industry. The Close Up

Foundation has been among those organizations most profoundly affected. Out of an understandable concern for the safety of students, many school districts across the country imposed immediate travel bans for school-sanctioned activities. These travel bans, coupled with parental concerns in districts that did not embargo travel have cut Close Up's enrollments by about 40 percent for the current academic year. Unfortunately, as is most often the case, students from low-income families lost more opportunities than did their peers of more affluent families. With travel bans easing a bit recently, it is much more difficult for students of need, who often require community support beyond the Close Up Fellowships to generate that support for this academic year. The abrupt curtailment of our enrollments during this academic year has caused

Close Up to focus on survival and maintaining a quality program. Feedback about our Washington program from our participating students and teachers has been steadily positive, so we know we have succeeded in maintaining quality program-ming. To survive, we have undergone significant staff and budget reductions.

But we are pushing ahead vigorously, believing that our work is more important than ever. Teachers across the country share our belief that this is the time to expand civic learning opportunities for students of every background—so that young people from every walk of life, irrespective of family affluence, can understand better and appreciate more their legacies as Americans. Our mission at Close Up is to teach the legacies of this great nation and to help young people understand the responsibilities necessary to sustain the blessings of those legacies.

Just as athletes need opportunities to participate in sports to hone their skills, young people learning citizenship skills need similar opportunities to acquire and practice the skills of citizenship. Mastering French comes through opportunity to practice, learning to cook comes about in a kitchen, athletic provess is acquired on the athletic field. Skills of democratic citizenship similarly need encouragement and honing in appropriate arenas and venues. There is no substitute for the excitement

generated and the learning acquired by using the nation's capital as a "living classroom." Our mission brings every kind of player, every kind of student into our classroom.

American democracy has always been dependent upon an informed and involved citizenry. Throughout the past several decades, numerous studies have documented an alarming decrease in civic participation among young people, accompanied by an increasing distrust of public officials. It is still too soon to tell how such attitudes and behaviors will be affected by the events of September 11. While surveys show that Americans are demonstrating unprecedented support for our government leaders, including record-high levels of trust, this may change depending on the shortand long-term outcome of the nation's military and political responses to the attacks.

What we do know, Mr. Chairman, is that America will always need citizens who understand the crucial role they play in our democracy. National education goals call for all young people to be prepared for responsible citizenship, yet nearly threequarters of high school seniors are not proficient in civics (National Assessment of Educational Progress, United States Department of Education, 1999). In American democracy, responsible citizenship requires both knowledge and action. Civic education can address this need by giving young people an understanding of how government works, the skills to get involved, the confidence that their voice counts, and that they can make a difference.

Close Up's work was launched more than three decades ago in another era of conflict to help address the disaffection and disillusionment so many young Americans felt during the Vietnam War. Our work has remained relevant and effective, and is needed now more than ever. By bringing young people "close up" to government and public officials, the Washington program demonstrates how each individual can be part of the development of public policy in America. We give young people a chance to interact with leaders, opinion makers, and peers from across the nation. They share opinions and ideas. They learn to speak out, and they learn to listen to other thoughts and ideas. Of paramount importance is that our young people who listen, absorb, and share ideas are a mirror reflection of the rich diversity of our country. Your support of the Close Up Fellowships makes this diversity possible. A key component of the Close Up week in Washington is Capitol Hill day. Close

A key component of the Close Up week in Washington is Capitol Hill day. Close Up participants have an opportunity to view Congressional committees at work, to watch House and Senate floor action, and, most importantly, to meet when possible with their elected representatives or their staffs. Again and again, participants tell us what a profound change in attitude they experience after meeting with their Representative or Senator or their staffs. Our students and teachers relish face-to-face meetings with questions and answers. These "simple" meetings do more than any textbook, lecture, or news report could ever hope to accomplish in connecting students to their elected representatives and instilling a feeling of belonging to the system and a receptivity to the whole idea of civic responsibility. The axiom of "one person can make a difference" is significantly reinforced in these Capitol Hill meetings.

ings. Since 1971, Close Up has brought nearly 600,000 students, teachers, and other Americans to the nation's capital for in-depth experiences with government in action. We could not be more proud that some 140,000 of these participants have come through fellowship support provided by the Congress in conjunction with Close Up generated support from the private and philanthropic sectors. Beyond our Washington Program, many thousands more take part each year in Close Up community and state-level civic education programs. Additionally, textbooks and national television programming on *Close Up on C-SPAN* expand Close Up's outreach into thousands of classrooms and millions of living rooms nationwide. These local and state Close Up programs, this textbook distribution, and our television programming are a "no cost" multiplier to the federal government. They are made possible by the widespread success of the Washington Program and the important seed role of the Close Up Fellowships.

Close Up differs from other government studies programs in its commitment to providing civic education opportunities to interested young people from every background. There is no national academic requirement for participation in our Washington Program; fellowship recipients are selected by each individual school based upon need and program interest. Outreach to disadvantaged young people is at the core of our work, and the Close Up fellowships support students who are recent immigrants, migrants, American Indians, Native Alaskans, and students who are hearing and visually impaired and physically challenged. We have a significant outreach to young people in Puerto Rico, and for the second year in a row, have had a group of students who are long-term cancer and leukemia survivors. Outreach to public, private, and parochial schools in urban, rural, and suburban areas has helped Close Up achieve this broad range of participation that reflects America's diversity. This diversity would not be possible were it not for the seed funding provided by the U.S. Congress as part of the Close Up Fellowship Program.

Close Up is also distinct from other civic education organizations in that teachers accompany their students to Washington and participate in a teacher program conducted concurrently with, but apart from, the student program. This special program presents educators with new ideas and teaching methodologies and promotes interaction with their peers. These educators swap teaching strategies and ideas that have worked in their own classrooms. This inspiring exchange of ideas and teaching methods, this experiential "civic education teaching laboratory," simply cannot be equaled by the textbook alone. It is food for renewal, and our teachers tell us that they return to their schools reinvigorated. This reinvigoration goes back to the classroom as a great multiplier for all their students—far beyond those who come to Washington.

Additionally, a good portion of these teachers is from schools that are considered "at-risk," with large pockets of students most in need of assistance and/or motivation.

Thus, Close Up Fellowships create an impressive multiplier of federal funds. The fellowships are utilized by teachers as "seed" funding to stimulate local interest and participation in the Close Up Washington program. For example, teachers often divide a full fellowship among several deserving students who meet the income eligibility requirement. These students, in turn, demonstrate their desire to participate in the program through local fundraising activities—often taking an entire year— and creating broad community support to supplement the Close Up Fellowships. The Close Up Fellowship recipients are most often the core around which teachers build the Washington high school program and the local and state Close Up government study programs.

The impact that the Close Up program makes on students is always more powerfully stated through the words of participants themselves. Five of the quotes below are from students who received fellowships to attend Close Up. All quotes are used with permission but, to protect privacy, we have not identified which students participated using fellowships, unless mentioned by the individual in the quote. The quotes are presented chronologically by year of participation, starting with the oldest. These alumni, however, have made these statements in the recent past (since October 2001) as they registered as Close Up alumni on our web site.

"Tm a veteran actor with leading roles in over 20 films and I'm also a national spokesperson for the National Network To End Domestic Violence, which is based in DC. I came to Close Up in 1972 with a few students from my high school. We were chaperoned by my homeroom teacher, Susi Baldwin. . . . I was a runaway who had endured years of abuse at the hands of my father. My high school took me in like a foster child and Miss Baldwin watched over me like an angel. She had to convince the administration at our school to give me one of the scholarships to attend Close Up. I was a former gang member and very angry young man, but my high school, Miss Baldwin and your program gave my life new meaning and direction. I ended up becoming senior class president and going on to college on a full scholarship. I just wanted to let you know that your program not only gave my life new direction, but probably helped to save it . . ."—Victor Rivers, student, 1972 Miami Coral Park High School, Miami, Florida

"I am a mechanical designer in the automotive business. While my experience with Close Up did not lead to a career in government or politics, it made Washington real. It was a fantastic opportunity for me. I went on a fellowship. I never would have had the opportunity otherwise. Probably the biggest thing I took away from my experience is a lifelong love of politics, history, and the desire to stay involved."—Rod Clouse, student, 1978 Riverdale Senior High School, Port Byron, Illinois

"I am currently in my 13th year of public service as a Deputy Sheriff. I was promoted in 1995 to the rank of Sergeant and am currently working in the Administrative Offices of the Sheriff. I was surfing the net to find that Close Up is still a viable program after all of these years . . . "My Close Up experience, in March 1981, was very fulfilling. It was the first time

"My Close Up experience, in March 1981, was very fulfilling. It was the first time that I ever traveled away from home. In the week that I spent in D.C., I learned so much about our government. I would recommend the experience to any student."—Arlene Brooks, student, 1981 Sylvan Hills High School, Georgia

"I am serving in the U.S. Navy, and planning on going into politics once I retire from the service. I enjoyed my experience with the Close Up Foundation. Discussing the different political issues of the time with students from different parts of the United States was enlightening. I also enjoyed the opportunity to visit the Embassy of the former Soviet Union. The biggest thing that I got from my experience with the Foundation was a greater respect for our political institutions in this country, as well as becoming more interested in how they work."—James Floyd, Sr., student, 1989 Jasper County High School, Ridgeland, South Carolina "I have just recently graduated from The Ohio State University, where I received

"I have just recently graduated from The Ohio State University, where I received a BA in Political Science. Close Up was an amazing experience that I will never forget. It let me see the exciting world of politics and in a way opened up my eyes to my future. Thank You!!!!"——Megan McFadden, student, 1993 Chagrin Falls High School, Chagrin Falls, Ohio

"I loved my experience with the Close Up Program!! It continues to be one of the most vivid memories I have and has IMMENSELY influenced my life. I am graduating next year from the University of Arizona with a Bachelor's degree in Political Science (thanks to my great Close Up experience!). Currently, I am in London, doing a semester-long political internship with a lobbying company associated with the Conservative Party. My intense interest in Politics is without a doubt linked to my amazing trip with your Foundation. Even in light of the many career paths that lie ahead of me, my first choice will always be to work with Close Up. I developed such an excellent rapport with my group leaders, and their influence helped to shape my future. I should only hope to make such a difference in others' lives! Thank you!!!!!!!!!

"I am currently a student at the University of Michigan. Close Up was the greatest experience of my life—I think about it daily. It was a turning point for me. Since then, I have become a better, more intelligent citizen, as well as a better person."—Adam Burns, student, 2000 Grosse Pointe North, Grosse Point Woods, Michigan

Michigan "Close Up was a life-changing experience for me. Although I didn't actually think that rural eastern Kentucky was all that existed, I didn't grasp the concept until meeting all those wonderful people nationwide at Close Up. When we all met, I got the feeling that we had known each other our whole lives, and I felt an immediate bond. I learned to respect differing views because people actually ARE coming from different places with different priorities. The bond was amazing among us . . . Close Up was great, and is something I will never forget."—Rachael Whitley, student, 2002 Boyd County High School, Ashland, Kentucky

Mr. Chairman, every generation faces a different challenge, and in the wake of September 11, Close Up has had to confront a devastating reduction in enrollments for this academic year. Our operating loss will be severe, but through substantial staff and budget reductions, we have moved ahead with our mission with enthusiasm and determination. As we rebuild our work, the Close Up Fellowships are even more crucial than in years past. Certainly, the need to understand the world around us and the political forces that shape our lives is more critical than ever before. Only through the commitment of informed and involved individual citizens can the dream of self-government survive and thrive in this country and elsewhere. And every student, regardless of economic status, must have the opportunity to develop as an informed and active citizen.

We are proud of our role in civic education in this country, and we are very grateful for the support of this Subcommittee through the years. That support, combined with support from parents, schools, small community businesses, national corporations and foundations, and the dedication of the participating students and teachers makes the Close Up program into an activity of broad-based community participation. The key to this positive chain of activity is the Close Up Fellowships. We respectfully request that this Subcommittee increase the Close Up Fellowships to a level of \$6.0 million so that we may build the increase into an even more effective multiplier, serving and inspiring thousands of additional students who would never otherwise have the opportunity to participate.

Mr. Chairman, thank you for your consideration of our request.

#### PREPARED STATEMENT OF THE AMERICAN GEOPHYSICAL UNION

Mathematics and science are constantly growing and changing. In order to teach these subjects effectively teachers, themselves, must constantly grow and change. Public Law 107–110 recognizes the need for on-going professional development programs for teachers. At the American Geophysical Union we are especially determined to provide opportunities for science teachers to participate regularly in scientific research. The Mathematics and Science Partnerships provision of Public Law 107–110 (Part B) establishes a national program to provide such opportunities. If adequate funding is provided to support Mathematics and Science Partnerships throughout the United States the quality of K-12 mathematics and science education will improve. If adequate funding is not provided the inspired language of Public law 107-110 will mock us all as this and subsequent generations of American children are left behind.

# PREPARED STATEMENT OF THE NATIONAL SOCIETY OF PROFESSIONAL ENGINEERS

As part of the No Child Left Behind Act, Congress established Math and Science Partnerships to improve math and science education. The Partnerships initiative provides funds for local school districts to join with university mathematics, science and engineering departments, the business community and educational organizations, to improve teacher quality and student achievement. The partnerships can address a variety of issues, including teacher training and professional development, curriculum development, distance learning and exchange programs. Congress authorized \$450 million for the program. Unfortunately, it received only \$12.5 million in fiscal year 2002 and the proposed budget requests the same. The National Society of Professional Engineers (NSPE) urges Congress to fund

The National Society of Professional Engineers (NSPE) urges Congress to fund the Math and Science Partnerships at the level authorized—\$450 million.

According to the 2000 National Assessment of Educational Progress, student science scores for grades 4 and 8 are flat and there has been a slight decline in scores for grade 12 since the assessment was last administered in 1996. This further underscores the need for reform and investment in math and science education, particularly at a time when our economy, national security and technological advances are heavily dependent upon the quality of our future workforce. NSPE has long been concerned about the state of K-12 science, math, engineering

NSPE has long been concerned about the state of K-12 science, math, engineering and technology education. To increase student learning in these areas and ensure that the United States remains competitive globally, we need to commit a significant amount of resources now.

Full funding for the Math and Science Partnerships will better prepare our students—America's future scientists and engineers—to meet the challenges of the 21st century.

### PREPARED STATEMENT OF THE PENNSYLVANIA EDUCATIONAL TELECOMMUNICATIONS EXCHANGE NETWORK AND THE COMMUNITY OF AGILE PARTNERS IN EDUCATION

# PREPARING THE NEW AMERICAN WORKFORCE THROUGH DISTANCE LEARNING

It is my privilege to submit testimony for inclusion into the hearing record on behalf of the Pennsylvania Educational Telecommunications Exchange Network (PETE Net), and its allied non-profit organization, a Community of Agile Partners in Education (CAPE). Created in 1994, these organizations represent a consortium membership of 116 educational institutions. We would like to first thank the Committee for providing approximately \$3½ million between 1996 and the current year from the Education account to support the development of CAPE/PETE Net. These funds have enabled us to make tremendous progress in expanding our capabilities as institutions and in enhancing the quality of education in the Commonwealth of Pennsylvania. Allow me to describe PETE Net's ambitious federal/state/local partnership to promote economic and community development by using technology to prepare the new American workforce. CAPE's vision, mission, and services will play a key role in improving the ability of our institutions to thrive in the globalizing environment of the 21st century.

a key for an improved the 21st century. CAPE/PETE Net is a state-wide educational telecommunications network: it currently is comprised of 116 educational institutions, that serve approximately onehalf million students. Members include: community colleges; public and private colleges and universities; K-12 school districts and intermediate units; medical schools and hospitals; public libraries and cultural organizations; and community-based training organizations. We are pursuing a state-of-the-art model project to demonstrate the power of interactive resource-sharing networks to help our member institutions prepare "global-ready" graduates and to strengthen the workplace skills of economically-displaced and other workers. CAPE/PETE Net is expanding its membership to include public libraries and cultural institutions. Each of these collegiate and cultural institutions brings its own group of K-12 school districts with which they collaborate in a variety of ways, e.g., Drexel University works with the financially and academically distressed Chester Uplands School District, as well as an innovative charter school in Philadelphia.

CAPE/PETE Net is designed to aid the educational institutions of our state by reducing duplication, sharing academic resources, containing costs, and facilitating the

systemic changes in vision, mission, market, structure, strategy, pedagogy, and programs necessary for our schools and colleges to thrive in the emerging globalized educational environment. It helps the students of our state by making intellectual resources accessible to them regardless of geography. In addition to linking member institutions to one another, this network connects its members to foreign educational institutions.

CAPE/PETE Net plays an important role in enhancing the competitiveness of our members, our state, and our nation by integrating new technology into the edu-cational system, and by helping members use that technology to prepare global-ready graduates. The fate of states and countries is increasingly a function of their human and relationship capital; therefore, the technological and human infrastructure that CAPE provides is a powerful, long-term economic benefit to the Commonwealth and to the nation.

CAPE/PETE Net is demonstrating how educators and students can effectively eliminate the geographic constraints and sectoral and institutional boundaries which historically have prevented massive resource sharing in education: the day of the stand-alone organization is over, given technology's capacity to help learners and institutions increase their geographical reach, educational quality, and competitiveness through cooperation.

CAPE has accomplished much in the past 8 years:

built a highly-diverse, educationally-versatile membership of over one hundred K-12, postsecondary, and cultural institutions; -raised approximately \$20M from private and public sources to financially seed

- and help create an informal distance-learning network of approximately 200 classrooms:
- -helped members design their distance-learning classrooms and trained technical staff:
- secured advantageous pricing agreements for relevant hardware, software, and telecommunications rates;
- -organized numerous faculty colloquia via multi-point videoconference;
- promoted the use of technology for the delivery of college courses to high school students:
- -created an on-line, searchable registry of approximately 2,100 faculty who are willing to share their expertise via technology; -trained approximately 2,000 K-12 and postsecondary faculty in the educational
- implications and applications of the web and videoconference technologies; -trained hundreds of non-member professionals from the U.S. Navy, U.S. Census
- Bureau, Ohio Corrections Department, public utilities, a major subcontractor to the U.S. Department of Energy, et al; -orchestrated approximately 25 major collaborative faculty projects, several of which were inter-sectoral, and many of which involved multiple technologies;
- facilitated entirely on-line successful grant proposals involving multiple institutions:
- initiated a series of workshops on organizational agility and systemic change in a globalizing world to show the wider, strategic implications of technology;
- supported the development of survey instruments to determine the relative agil-ity of schools and colleges and their readiness for change; and
- -assisted member colleges in planning and delivering courses and certificate degree programs on-line.

We now seek funds to complete the task of building resource-sharing networks to create a virtual organization, serving both rural and urban communities throughout the Commonwealth, while providing a model for workforce development and institutional change to capitalize on the educational and market opportunities of a globalizing world. With the requested \$2.0M federal funds, CAPE/PETE Net will strengthen the technological infrastructure of new members, especially public libraries, and assist in the upgrading of in-place infrastructure at other CAPE institu-tions. Further, CAPE/PETE Net will train K-12 and postsecondary teachers and other workforce trainers how to teach in a distance-learning environment.

Third, CAPE/PETE Net will work with local governments, businesses, and educational institutions to identify the educational and training needs of regional workforces, and coordinate the educational resources of member institutions to meet those needs. Finally, CAPE/PETE Net will promote the rapid dissemination of the highly effective Integrated Product Development (IPD) team approach to building creativity and entrepreneurship-essential elements of a 21st century workforcethroughout American K-12 and post-secondary education.

The latter part of the 20th century saw the emergence and acceleration of global strategies for economic production and commercial activity. Work is increasingly:

(1) geographically-distributed;

(2) technologically-mediated;

(3) inter-organizational and collaborative;
 (4) team-based, with decentralized decision-making;

(5) problem/product/project-focused; and

(6) multi-cultural/international.

This paradigm applies to the work of non-profit and governmental sectors as well as manufacturing and commerce. The end of the Cold War, radical improvements and cost-decreases in technology, and changes in governmental policies to permit the rapid movement of ideas, capital, and people were critical to the creation of what Tom Friedman, author of *The Lexus and the Olive Tree*, has termed "the globalization system." According to Jean Lipman-Blumen in *The Connective Edge*, the future success of organizations will depend upon their capacity to make the two major world trends—interdependence and diversity—work for them, not against them.

Two of CAPE/PETE Net's fundamental assumptions are:

(1) despite the "clash of civilizations" described in Samuel Huntington's book of that title, globalization, as the operating environment for organizations, in the non-profit as well as the for-profit sector, will grow stronger and more pervasive in the future, and

(2) over time, all sectors of society—including education—will be profoundly influ-enced by this system, and its implicit demand for life-long learning and the continuous upgrading of the workforce.

To function successfully in a globalizing world, organizations need to increase their agility. Agile organizations are fast, flexible, collaborative, and customizing; they have moved beyond stand-alone models of staff behavior and organizational relationships to technologically-mediated collaboration as a first-choice strategy. Achieving agility will require systemic, as opposed to incremental, change for most organizations.

A further fundamental assumption of CAPE/PETE Net's is that the processes by which people are educated need to be broadly consistent with the way in which organizations operate in a globalizing environment. It is not enough for schools and colleges to deliver content aimed at preparing students for global involvement; stu-dents and faculty must learn and work in ways that model the globalizing reality of organizational behavior. Education must now be restructured and reanimated for a world of mass customization, agility, and routine international interaction, wheth-

er the interaction serves cultural, intellectual, or commercial goals. As educational missions, markets, and programs globalize, CAPE's membership of small-and medium-sized organizations face special challenges that will require highly agile responses.

The importance of K-12 education becomes critical as competition and work extrapolates globally, and the relationship between K-12 and postsecondary education becomes more important as well. We need to use technology to integrate the cultural and intellectual resources of colleges and universities into a "K–16" system.

CAPE's higher education members face important challenges, too. Regarding the export of education and training via technology and other means, there is little question that large public and private research universities can expand their roles nationally and overseas. There is, however, a question as to whether, and if so, how,

nationally and overseas. There is, nowever, a question as to whether, and it so, now, small-and medium-sized institutions, acting alone, can be effective in such an arena. K-12 and postsecondary institutions, and their allies in cultural institutions dedi-cated to informal learning, must reflect the requirements of globalization and agility in their strategic and developmental behavior. They need the capacity to build quality and scale rapidly through collaboration in order to nourish each other's edu-cational programs and develop business opportunities by serving corporate, governmental, and non-governmental organization (NGO) clients. They need each other's help to customize teaching and learning experiences to young residential students, corporate employees, and those transitioning from welfare or incarceration to work. CAPE's raison d'etre is to create the human infrastructure and trust essential for effective collaboration in the emerging integrated world.

By establishing a truly interactive, agile communications network, CAPE/PETE Net consortium members are expanding resources and capabilities greatly while containing costs. CAPE/PETE Net is a viable initiative to help members generate revenue and manage the cost of innovation, while extending quality education to more citizens. It is ideally suited to play a key role in worker-retention activities associated with changes in America's defense industrial base, information tech-The building blocks for CAPE/PETE Net are in place and a strong foundation has

been laid. One hundred sixteen CAPE/PETE Net members have committed their resources to building an interactive network by which we create an educational model of agile organization. These institutions pay annual dues ranging from \$500 to \$5,000 depending on size and type of membership. Please see our website (www.acape.org) for a list of members and other information. However, a further federal role is indispensable. We therefore respectfully request, with the strong support of our Pennsylvania delegation, that the Labor, HHS, and Education Subcommittee set aside \$2.0 million for fiscal year 2003 to assist in the continued development and expansion of CAPE/PETE Net. Our national demonstration of organizational agility in education permits not only resource sharing among K-12, 2-year colleges, 4-year colleges and graduate institutions, medical, and cultural organizations, but the effective orchestration of workforce development programs. CAPE/PETE Net will become even more valuable to both the citizens of the Commonwealth, and all Americans as we strive to enhance our competitiveness for the challenges and opportunities of the 21st century.

Thank you very much for the opportunity to submit this testimony on behalf of CAPE/PETE Net's 116 member institutions, and for considering our request for continued investment in our mission.

#### PREPARED STATEMENT OF THE MATH/SCIENCE PARTNERSHIP COALITION

We, the undersigned groups, urge you to fulfill our nation's commitment to math and science education in H.R. 1, the No Child Left Behind Act, and fully fund the Department of Education's Math and Science Partnership Initiative at \$450 million for fiscal year 2003.

During the next decade, the United States demand for scientists and engineers is expected to increase at more than double the rate for all other occupations, according to the National Science Board. The need for a scientifically literate population is essential for our economy and our national security. Moreover, technology and the innovations it has spawned drive productivity gains and economic growth.

But today's high school students are not performing well in math and science overall, and a decreasing number of American students are pursuing degrees in technical fields. America's K-12 students score far below the best in the world on domestic and international tests.

We applaud Congress for tackling this problem head-on by establishing the Math and Science Partnerships as part of the No Child Left Behind Act. These meritbased partnerships between school districts, university science, engineering, and math departments, businesses, and educational organizations seek to improve teacher quality and student achievement in K-12 math and science.

H.R. 1 contains an authorization of \$450 million for the partnerships. Unfortunately, the funding for fiscal year 2002 was a mere \$12.5 million, amounting, in effect, to a 95 percent cut of dedicated funding for math and science education at the Department of Education. This decrease leaves most states and school districts without dedicated funding to improve education in math and science. Providing strong funding for these key areas through the Department of Education is critical, because the department is the only federal agency charged with improving teacher quality and student achievement across all states and school districts.

We urge Congress to fulfill its commitment to math and science education by supporting a \$450 million appropriation in fiscal year 2003 for the Math and Science Partnerships in the Labor-HHS-Education bill. If you have any questions, please feel free to contact Laura Geer Kolton at (202) 872–4384.

American Association of Physics Teachers; American Association of Engineering Societies; American Astronomical Society; American Chemical Society American Geological Institute; American Geophysical Union; American Institute of Physics; American Physical Society; ASEE Engineering Deans Council; ASME International, Council on Education; Citizens for the Advancement of Science Education; Council of State Science Supervisors; International Technology Education Association; Institute of Electrical and Electronics Engineers, USA; JETS, The Junior Engineering Technical Society; National Alliance of State Science and Mathematics Coalitions; National Council of Teachers of Mathematics; National Science Teachers Association; National Society of Professional Engineers; Society of Women Engineers; and Triangle Coalition for Science and Technology Education.

## PREPARED STATEMENT OF THE ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITY

Mr. Chairman, on behalf of the Association of University Centers on Disability (AUCD), formerly the American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP), I am pleased to submit this written testimony for the record as a way of sharing with you information on the cur-

rent status of the network of University Centers for Excellence in Developmental Disabilities, Education, Research, and Services (UCEs). I am Robert Stodden, Director of the Center on Disability Studies at the University of Hawaii at Manoa, Hawaii's UCE, and President of the Association of University Centers on Disabilities.

The UCEs comprise an etwork of interdisciplinary Centers on Disabilities. The UCEs comprise a network of interdisciplinary Centers, which advance policy and practice, for and with people with developmental and other disabilities, their families, and communities. Authorized by the Developmental Disabilities (DD) Assistance and Bill of Rights Act (Public Law 106–402), UCEs are established in every State and Territory of the United States as part of major research universities. Nationwide, UCEs are working together to accomplish a shared vision where all people, including people with disabilities, participate fully in their communities.

As the national network of 61 Centers has grown, so have the expectations of what it means to be a national resource. Over the years, each University Center has developed its own areas of expertise, based on the needs of their local community, state, and the evolving expectations of people with disabilities nationwide to be more included in community life. Since the reauthorization of the DD Act in 2000, the goal for the network of UCEs has been to pool together the individual expertise of each University Center to be a national resource to all people. One example is the network's involvement in the Children's Supplemental Secu-

One example is the network's involvement in the Children's Supplemental Security Income (SSI) Project, a collaborative effort between the UCEs/Leadership Education in Neurodevelopmental Disabilities (LEND) Programs and the Social Security Administration. In the project's first 3 years, 28 UCE/LEND programs conducted interdisciplinary assessment on over 500 children in 23 States. The children seen by the University Centers were applying for benefits, had their continuing eligibility called into question, or at age 18, were undergoing review for continuing eligibility. While many of these children retain SSI benefits as a result of the Centers' work, more importantly, SSA has used the findings from the project to make policy and procedural changes at a national level. Adjudication processes have been improved, individuals who were still denied eligibility received services, and new resources and information on systems were identified for local Social Security offices, as a direct result of the Centers' work.

Background.—The DD Act was originally passed by the 88th Congress to establish, a three-pronged federal system of supports, services and rights protections for people with disabilities, many of whom were warehoused in large institutions and subject to inhumane conditions. UCEs have played a critical role over the years in building the capacity of states and communities to include all their citizens. Since inception, the network has been successfully training professionals for leadership positions and direct care workers for community services; working to provide people with developmental disabilities access to needed services and supports; conducting research and validating emerging state of the art practices; providing technical assistance; and disseminating information to individuals with disabilities, families, public and private agencies, and policy makers. UCEs work in concert with their sister systems, the Developmental Disabilities Councils and the Protection and Advocacy Systems.

The DD Act continues to meet a significant societal need in the beginning of the twenty-first century as new science, policies and attitudes evolve for including and supporting individuals with disabilities in the main stream of American Society. In addition, the recent Olmstead decision of the U.S. Supreme Court has reaffirmed the right of individuals with disabilities to live in their communities. The Bush Administration has actively mobilized federal agencies to implement this decree through Executive Order 13217, "Community-Based Alternatives for Individuals with Disabilities." The Bush Administration's New Freedom initiative further promotes this goal. The country has come a long way in building community systems, but we are far from done. The UCE network can play a pivotal role in the implementation of the Olmstead decision, but adequate resources are needed to do so.

Each University Center competes for funding from the Administration on Developmental Disabilities (ADD) every 5 years. In fiscal year 2002 we received an increase of \$2.2 million for the network. We are extremely grateful for the fiscal year 2002 increase, which raised funding for each Center by about \$36,000 to approximately \$382,000. In passing Public Law 106–402, Congress recognized that in order to fulfill our mission, greater resources are needed and so the authorization level for Centers was raised to \$500,000 (a total of \$31.0 million network-wide). As you see, we still have a ways to go.

State and Local Impact.—University Centers are true examples of state-federal partnerships that work. More than one-quarter of their funds come from the states and local communities. Additional resources are leveraged from other grants and contracts, private foundations, fees for services and the host university. The federal funds provide a stable base for the Centers, but more is needed so that UCEs can

respond to local and national needs such as developing cutting edge approaches in welfare-to-work, promoting children's health, state of the art interventions for disabilities such as autism and providing services and support to assist individuals in being safe from abuse and neglect. The significance of the University Centers in every state will continue to increase as federal policies need to be translated into local goals and procedures, trained personnel, and service systems designed to efficiently and safely meet the needs of individuals with developmental disabilities and their families.

According to the DD Act, UCEs must adhere to four core functions: preparation of personnel through preservice and continuing education, provision of community services and technical assistance, conduct of research, and dissemination of information. Following are examples of how UCEs work to accomplish these goals.

services and technical assistance, conduct of research, and dissemination of information. Following are examples of how UCEs work to accomplish these goals. *Preparing Personnel for the Future: Preservice Training*.—A successful quality of life in the community for individuals with developmental disabilities begins with well-trained professionals. Centers have the unique ability to deliver high quality local and statewide personnel training in a collaborative, coordinated, interdisciplinary fashion and to address issues that are lifespan appropriate from infants to the elderly, and across health, education, and social service systems.

elderly, and across health, education, and social service systems. UCEs are preparing teachers to teach all children, including those with disabilities or diverse learning needs. UCEs work with education professionals providing them research-based instructional strategies and model approaches to effective teaching.

teaching. The Center on Human Development at the University of Oregon, has developed a Center on Positive Behavioral Interventions and Support. The Center assists local schools in identifying, adapting, and sustaining effective behavioral practices, including school-wide discipline programs. Results from their replication efforts in over 400 schools nationwide indicate that this technical assistance and research has enhanced schools' capacity to address behavioral challenges, diminish disruptions, reclaim instructional time, and enhance quality and effectiveness of instruction.

over 400 schools nationwide indicate that this technical assistance and research has enhanced schools' capacity to address behavioral challenges, diminish disruptions, reclaim instructional time, and enhance quality and effectiveness of instruction. *Direct Services and Supports Using Community Training and Technical Assistance.*—Centers provide quality services directly to families and individuals. These services include clinical, health, prevention, educational, vocational, and, diagnostic services, as well as supported employment, and person centered planning. In Ohio, the Nisonger Center of the Ohio State University, is working with families living in rural counties of Ohio who encounter many barriers to accessing quality care for their children. Because most services for children with disabilities are

In Ohio, the Nisonger Center of the Ohio State University, is working with families living in rural counties of Ohio who encounter many barriers to accessing quality care for their children. Because most services for children with disabilities are in urban areas, families in Appalachia were traveling 50–100 miles to the city for multiple evaluations by individual disciplines. This resulted in a fractured process as well as a great expense in time and money for the family. The Nisonger Center now sends teams of providers to rural areas to provide interdisciplinary care to families. They provide evaluations of children, training for local healthcare providers, and support for the families through a system of 38 rural clinics. These clinics are improving access of needed services to families and providers and help local providers to better diagnose developmental disabilities such as cerebral palsy, fetal alcohol syndrome, autism and other genetic disorders.

For many University Centers, it is the community training and technical assistance, as opposed to direct services, that has had the greatest impact on the ability of state and local service delivery systems to adequately meet the needs of people with developmental disabilities. Much of the training material for such new initiatives has been developed in the Centers and becomes available to service agencies nationwide.

The Mailman Center for Child Development in Florida is providing such assistance by developing model curricula for training programs. They have developed a 60-hour on-line course, which provides training for professionals and students in the use of assistive technology to aid individuals with developmental disabilities to achieve maximum independence in functioning.

One unique feature of the UCEs is the synergistic affect of combining research, training, AND direct services, providing the opportunity for invaluable interactions between those who investigate effectiveness, those who train service providers and those who actually put the strategies and practices into use.

An intensive Early Intervention Program at the Alaska Center provides a nationally recognized, intensive, in-home program for pre-school children with autism. The program focuses on training volunteers who provide daily intervention services for families. Results show that upon completion of the program, most of the children begin functioning in typical settings such as schools and playgroups.

Research and Dissemination of Information.—Findings from University Centers' research is used to better understand and guide policy and practice at the local, state, and federal agency level and results in increased effectiveness and speeds the

conversion of research to best practices implementation. UCEs are collecting information and measuring outcomes relative to our Nation's success at providing care for its citizens with developmental disabilities. Governors and State Legislators use

the data collected as a guide to evaluate plans and implement policy. The State of the States in Developmental Disabilities, authored by the UCE in Chicago, provides information to governors and state legislators on how state dollars are spent for care and services for persons with developmental disabilities and provides historical trends on those expenditures.

University Centers also use cutting edge technology, such as the Internet, webcasting, and distance learning to provide individuals with disabilities, their families, and professionals access to new information and networking opportunities with other families.

The Family Village project at the Wisconsin Center is an Internet system de-signed to help families with disabilities network with other families around the world. In addition, the system provides families validated disability specific informa-tion and organized listings of exiting health and community services. *Leading Through Collaboration*.—Collaboration occurs at many levels. Centers

Leading Through Collaboration.—Collaboration occurs at many levels. Centers work locally and nationally with other programs to ensure that people have access to a full spectrum of legal rights and quality care. UCEs also collaborate with fed-eral agencies to bring developmental disabilities expertise to their ongoing work. In Pennsylvania, the Equal Justice project is working extensively with the crimi-nal justice system to see that professionals in the criminal justice field are trained in developmental disabilities and are working together with the disability commu-

nity

UCEs are constantly seeking creative solutions to emerging issues and to respond to national needs. This year, the tragedy of September 11 brought forward a new need. In addition to the outpouring of concern for victims, their families, rescue workers, and others who were affected, there was also a concerted effort by parents, educators, and mental health professionals to assist children to cope with and recover from the trauma. The Westchester Institute on Health and Development, one of New York's UCEs developed Project Cope, a national clearinghouse for resources, services and supports in the aftermath of disaster. Their coping guides focused on the needs of both children and adults with disabilities were disseminated nationally via the World Wide Web and excerpted in dozens of newspapers, magazines, and newsletters.

*Fiscal year 2002 funding request.*—Again, Mr. Chairman, we believe that Congress was right in authorizing the UCEs at \$500,000 per Center, or a total of \$31.0 million. While the network of University Centers recognizes that budgets are tight, we believe that the legislation takes into careful account the appropriate amount of funding it takes to get the job done right. Without an infusion of additional fund-ing, the Center network is in danger of deteriorating at a time when it is sorely needed to continue the drive of people with disabilities toward increased independence, productivity and integration into American society. The benefit of having a na-

ence, productivity and integration into American society. The benefit of having a na-tional network is that it can be used to help implement priorities nation-wide. As resources become even more precious in light of September 11, it is a waste not to fully tap the potential of the UCE network. Additionally, the DD Act of 2000 contains a program of Family Support and other Projects of National Significance (PNS) that provide opportunities for UCEs and oth-ers to develop models of empowerment and responsibility for individuals with devel-opmental disabilities. Projects of National Significance aid state governors and law-makers as well as Congress in responding to urgent needs and collecting valuable makers as well as Congress in responding to urgent needs and collecting valuable data to make informed policy decisions. Projects like the Home of Your Own (HOYO) project, established in New Hampshire, helps individuals with developmental disabilities buy and maintain their own homes, and the Transcen, Inc. program, established in Maryland, assists youth with developmental disabilities to move successfully from school to the workplace. With additional funding, more creative programs like these can be developed, established, and duplicated in cities and states across the country.

Finally, the AUCD network also supports a unique network of 35 Leadership Education in Neurodevelopmental Disabilities (LEND) programs. These programs, fund-ed through the Maternal and Child Health Block Grant (Title V), do a remarkable job in preparing highly skilled professional leaders to both provide care to individuals with special health care needs/severe disabilities and improve the systems of care needed by these individuals and their families. While authorized at \$850 million, the Title V Block grant is funded at only \$732 million. Without additional funding, the impact of the existing LEND network is reduced and there is no possibility for expansion to meet the needs of unserved areas.

We conclude with respectfully requesting the following funding allocations:

-For the University Centers for Excellence in Developmental Disabilities Education, \$31.0 million

-For the Projects of National Significance, part of the DD Act, we recommend funding at \$22 million which includes \$15 million for Family Support

funding at \$22 million which includes \$15 million for Family Support, and —For the Maternal and Child Health Block Grant we ask that it be funded at \$850 million.

Thank you for the opportunity to share this information about the UCEs. Your careful consideration of our appropriations requests are appreciated and we are happy to share more detailed information with you at your request.

#### PREPARED STATEMENT OF THE AMERICAN NURSES ASSOCIATION

The American Nurses Association (ANA) appreciates this opportunity to comment on fiscal year 2003 appropriations for nursing education, nursing research and workforce programs. ANA is the only full-service professional organization representing the nation's 2.7 million registered nurses, including staff nurses, nurse practitioners, clinical nurse specialists, certified nurse midwives and certified registered nurse anesthetists through its 54 state and territorial nurses associations. ANA gratefully acknowledges this Subcommittee's support for nursing education and research. We appreciate your continued recognition of the important role nurses play in the delivery of health care services and the increased need to fund nursing education programs and inporting practice medias. Today, the changing demo-

ANA gratefully acknowledges this Subcommittee's support for nursing education and research. We appreciate your continued recognition of the important role nurses play in the delivery of health care services and the increased need to fund nursing education programs and innovative practice models. Today, the changing demographics of American society and the health care delivery system demand a nursing workforce that has a sound foundation in a broad range of basic sciences, as well as a unique set of critical thinking and problem solving skills.

Unfortunately, the nursing community at large is starting to observe a shortage of nurses with competence, skills and experience to meet the current demand for more complex patient care. New admissions into nursing schools have been dropping. This lack of young people entering the profession has caused the average age of resident nurses to rise to 43 years. This disturbing trend will continue to increase: The average is projected to continue to increase to 46 years old in 2010. And, as the average age of nurses increases, America's demand for nursing care is expected to balloon over the next 20 years due to the aging population. A study published in the *Journal of the American Medical Association* projects that by 2020, the demand for nurses will exceed supply by 20 percent. Therefore, 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 increased funding of these programs. Today, ANA offers our professional recommendations for federal funding of nursing education, research and workforce programs.

# DEPARTMENT OF HEALTH AND HUMAN SERVICES PROGRAMS

#### Nurse Education Act

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. When Congress reauthorized these programs by enacting the Health Professions Partnership Act of 1998 (Public Law 105-392), it provided the Secretary of Health and Human Services (HHS) 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. Under the improved Nurse Education Act (NEA) included in Public Law 105–392, the Division of Nurs-ing, the agency that administers the NEA at HHS, has the needed flexibility to focus on curriculum development and other programs to address the changing health care environment and assist in the preparation of more nurses who are able to function where there is a greater demand. The NEA is able to better address the need for increasing the numbers of minority nurses available to provide culturally competent, linguistically appropriate health care services to underserved communities by providing funding to support projects that would increase nursing edu-cation opportunities for individuals from disadvantaged backgrounds. These nurses would then 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.

For fiscal year 2002, due to the work of this Subcommittee, the Nurse Education Act was funded at \$82.5 million. For fiscal year 2003, we propose to increase fund-

ing for the activities of the NEA by at least \$40 million to \$122.5 million. Although this recommended increase is substantial, the ANA believes this additional funding is needed to help alleviate the nursing shortage, because NEA programs provide incentives for people to enter the nursing profession.

The NEA authorities are as follows:

Programs to provide advanced education to nurses.—Advanced education nurses are registered nurses trained in advanced degree programs, generally at a master's degree level. They provide primary care in lieu of physicians or provide an expanded type of primary care. This category includes nurse practitioners, nurse midwives, nurse anesthetists, clinical nurse specialists, nurse administrators, public health nurses and other nurses as determined by the Secretary of the Department of Health and Human Services. Traineeships for advanced nursing education is provided under this category. Title VIII funds have supported the development of virtually all initial state and regional outreach models which first demonstrated the delivery of part or all of a graduate program to students at sites using distance learning methodologies from university settings thereby providing advanced study opportunities for nurses in rural and remote areas.

<sup>1</sup>Due to the continued 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.

Programs to increase workforce diversity.—Both overutilization of costly emergency services and decreased access to primary care have been associated with a low representation of minority health care providers. This legislation provides for increased flexibility in the use of funds to enhance diversity in nursing education and practice. It supports projects to increase nursing education opportunities for individuals from disadvantaged backgrounds—including racial and ethnic minorities. Some support will be provided through student scholarships or stipends and can be used for pre-entry preparation and retention activities. Continued funding for programs that access this type of funding is dependent on demonstrated outcomes. *Projects to strengthen the capacity of basic nursing education.*—Funding under this category assists toward expanding basic nurse education, thereby enhancing the basic nursing workforce. Priority areas identified include: skills development for practice in organized health care systems: nursing practice arrangements care for

Projects to strengthen the capacity of basic nursing education.—Funding under this category assists toward expanding basic nurse education, thereby enhancing the basic nursing workforce. Priority areas identified include: skills development for practice in organized health care systems; nursing practice arrangements, care for underserved populations and other high risk groups; cultural competency; baccalaureate enrollment; career mobility; informatics education, including distance learning methodologies and other areas as needed. Nurse managed clinics are included under this category. During the past several years, data show that nursemanaged centers provide an average of 130,000 primary care encounters per year to individuals from vulnerable and underserved populations.

# Nurse Education Loan Repayment Program

The Nurse Education Loan Repayment Program (NELRP) repays up to 85 percent of nursing student loans in return for at least 2 years of practice in a designated nursing shortage area. For the first 2 years of service, the NELRP will pay 60 percent of the RN's student loan balance, up to \$30,000. If the participant elects to stay for another year, an additional 25 percent of the loan will be repaid, up to an additional \$7,500. Within 3 years, a nurse can pay off approximately 85 percent of his/ her student loans. More than 400 awards were distributed last year.

Due to the determined efforts of this subcommittee last year. Due to the determined efforts of this subcommittee, the Nurse Education Loan Repayment Program enjoyed record increases last year. This program was funded at \$10 million for fiscal year 2002. The President's budget recommends \$15 million in funding for the program, a 50 percent increase above last year's allocation. Although the ANA appreciates the strong support for this program from the Bush Administration, we believe that \$20 million in funding is necessary to help address the nation's growing need for nursing professionals.

#### Nurse Reinvestment Act

On December 20, 2001 both the House of Representatives and the Senate passed the Nurse Reinvestment Act (H.R. 3487, S. 1864, respectively). Although the bills differ in some respects, both would expand and issue new authority for loan repayment programs and scholarships for nursing students, in addition to providing new public service announcements to encourage more people to enter the nursing profession. ANA asks that the Subcommittee include the amount recommended in the Senate bill of \$136 million to fund programs included in this legislation. Although

the bill is still in conference, progress is advancing and a conference report is likely to be submitted soon.

# National Institute of Nursing Research (NINR)

The second funding priority for nursing is funding for the NINR, one of the institutes at the National Institutes of Health (NIH). Again we applaud this Subcommittee's commitment to advancing behavioral science research. Nursing research is an integral part of the effectiveness of nursing care. 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. Research programs supported by the NINR address a number of critical public health and patient care questions. The research is driven by real and immediate problems encountered by patients and families. Study results offer the clear prospect of improving health, reducing morbidity and mortality, and lowering costs and demand for health care.

Recent studies have included looking at the effects of hospital restructuring, such as changes in nurse staffing, on patient care; looking at the success of early intervention programs in helping young disadvantaged mothers care for themselves and their infants; and examining training programs that assist nurse aides in detecting agitation and aggression in patients with dementia. The NINR is the second-lowest funded institute at NIH and provides vital health care research for the nursing community. The Bush Administration recommends funding the NINR at \$128 million. ANA, however, recommends increasing funding for the NINR by \$25 million—from \$120 million for fiscal year 2002 to \$145 million for fiscal year 2003.

# 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 it is a source of funding for ANA's Ethnic Minority Fellowship Project (EMFP). The funding is allocated through SAMHSA to the minority mental health training programs in nursing, psychology, social work and psychiatry. The EMFP graduates have an outstanding record of public service to minority and indigent communities.

EMFP graduates receive doctoral degrees and, as clinicians, 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. These 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, EMFP graduates 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. These graduates also work as teachers in schools of nursing that serve minority students, serving as role models and providing leadership to future nurses. We believe this program is a good investment in reducing mental health care costs and recommend funding of \$5 million for fiscal year 2003 for the SAMHSA Clinical Training program.

## 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 blood borne pathogens standard which provides significant protection to front-line health care providers from possible exposure to blood borne 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 are the primary vehicle for the development and training of a corps of trained occupational health nurses and other safety professionals. Fiscal year 2002 funding was \$276 million, but the President's budget recommends a decrease in funding to \$258 million. ANA recommends an increase to \$304 million in program for fiscal year 2003.

# 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

ANA is concerned about the ability of the National Labor Relations Board (NLRB) to meet its statutory responsibility of enforcing and interpreting the National Labor Relations Act (NLRA). Potential delays in the processing of complaints and holding representation elections may jeopardize the progress in employee and employer relations. ANA considers this a core independent agency function that must be preserved. The President recommends a funding level of \$246 million—a \$20 million increase in funding from fiscal year 2002. ANA supports his request.

# 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 to 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 the increased occupational risks in nursing and their negative effect on nurses today and the future of this profession.

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 work sites. 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. Unfortunately, the Bush Administration recommends only \$437 million for OSHA a decrease from fiscal year 2002 funding. We recommend fiscal year 2003 funding of \$488 million for OSHA—an increase of \$44 million more than the previous allocation.

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 FLORIDA STATE UNIVERSITY

#### SUMMARY

Florida State University is pursuing one project this year through this subcommittee. A multi-university K-16 Reading, Math, Science Initiative through the Fund for the Improvement of Education—request total is \$6M.

Mr. Chairman, I would like to thank you and the Members of the Subcommittee for this opportunity to present testimony before this Committee. I would like to take a moment to briefly acquaint you with Florida State University.

Located in Tallahassee, Florida's capitol, FSU is a comprehensive Research I university with a rapidly growing research base. The University serves as a center for advanced graduate and professional studies, exemplary research and top quality undergraduate programs. Faculty members at FSU maintain a strong commitment to quality in teaching, to performance of research and creative activities and have a strong commitment to public service. Among the faculty are numerous recipients of national and international honors, including Nobel laureates, Pulitzer Prize winners as well as several members of the National Academy of Sciences. Our scientists and engineers do excellent research, have strong interdisciplinary interests, and often work closely with industrial partners in the commercialization of the results of their research. Having been designated as a Carnegie Research I University several years ago, Florida State University will approach \$150 million this year in research awards.

FSU has initiated a new medical school, the first in the United States in over two decades. Our emphasis is on training students to become primary care physicians, with a particular focus on geriatric medicine—consistent with the demographics of our state.

Florida State attracts students from every county in Florida, every state in the nation, and more than 100 foreign countries. The University is committed to high admission standards that ensure quality in its student body, which currently includes some 345 National Merit and National Achievement Scholars, as well as students with superior creative talent. We consistently rank in the top 25 among U.S. colleges and universities in attracting National Merit Scholars to our campus.

At Florida State University, we are very proud of our successes as well as our emerging reputation as one of the nation's top public universities.

Mr. Chairman, let me tell you about a project we are pursuing this year through the Department of Education. One of the greatest problems facing the State of Florida and the Nation as a whole is how to improve the quality of K-16 education in our public schools. Governor Jeb Bush has put education improvement as his Administration's top priority. Florida State University (FSU), with support from the State of Florida and the Governor, have strong support to initiate a state-wide partnership effort between the state's universities, local schools, teachers, principals, and other educational leaders to address this important issue. This effort is designed to improve student performance across the state of Florida as assessed by the Florida Comprehensive Assessment Test (FCAT) and other accountability measures.

In the last 2 years, FSU has engaged in a number of new initiatives designed to strengthen the ties between the public school system and the university with a renewed focus on improved student performance. FCAT and other test scores, as well as school grades based on Florida's A+ Plan, provide outcome measures of success. Other institutions among the state's universities have also undertaken efforts with local schools, boards of education, teachers, administrators, and other groups. At FSU, the various partnerships that came out of these efforts have enjoyed success as demonstrated by these results:

- —Improved FCAT scores over the past 2 years moved six of the twelve local schools served from an overall state ranking of "D" to "C". Two of Tallahassee's southside schools showed an even greater improvement in FCAT scores and a concomitant increase from a "C" to an "A". This places them among a very small percentage of Title I schools (schools with more than half the students living in poverty based on free and reduced lunch data) earning the state's top grade.
- -First grade students' scores on three reading measures indicate the Leon County FLARE Reading Grant project and the supporting mentor project are successful in "catching up" students who enter school with gaps in reading readiness skills. Both are demonstration projects that are currently supported by the National Institute of Child Health and Human Development. The projects are being led by Professor Joe Torgesen and others in the FSU's Department of Psychology.
- -Collaborative relationships have been established with the Florida Association of District School Superintendents and the North East Florida Education Consortium to provide statewide opportunities for the application of research findings and professional development for practicing teachers, principals and other educators.

Properly crafted research on priority issues can have an immense impact on future educational achievements. To serve this highly critical K-16 knowledge management function, FSU proposes coordinating these and additional efforts among a number of the state universities who wish to be involved in such K-16 efforts. By coordinating priorities, each university can focus on its areas of expertise to accomplish the research, development, evaluation, and dissemination functions essential to support improved student performance in reading, mathematics and science. This work would include:

1. Assisting educational leaders and decision-makers in developing a strategicallyplanned research agenda targeting high-priority problems in reading, mathematics, and science achievement;

2. Initiating, conducting and completing priority research projects (collaboratively and within each university) clearly responsive to critical national education needs using a data based, systems oriented model. These projects include Reading First; Early Reading First; TRIO; NICHHD Literacy and Preventive Interventions; Mathematics Skills Improvement; Reading Development; Healthy Start Initiative; and NSFs Math and Science Partnership Initiative;

3. Evaluating the impact of K-16 initiatives designed to improve student performance and disseminating results;

4. Designing and recommending specific applications in school districts; and

5. Providing teacher professional development, especially in the content areas, as teachers broaden and deepen their knowledge in response to changing educational and/or technological needs.

The proposed activities require new collaborative relationships among researchers, educators, and legislators that will connect research to practice. It is making the critical connections among research, preparation and practice that will dramatically improve teaching and learning.

improve teaching and learning. We are aware of substantial and complementary activities at USF, UCF, UNF, and UF; we are confident that other institutions will become involved in this initiative. For example, a major proposal is being jointly developed with faculty at FSU and USF that focuses on math/science teacher training activities and will be submitted to the National Science Foundation. Substantial federal support for research in learning and cognition is now provided to Professors Torgesen, Wagner and Lonigan, all in FSU's Department of Psychology, from the Institute for Child Health and Human Development (NICHHD) and that support will continue to be the foundation for this state-wide effort. We expect that additional State of Florida funding will be made available to match the federal funding sought.

FSU, as project coordinator, is seeking \$6 million, available for implementing a well-developed and coordinated plan for research and training among the participating institutions. These funds would be required in the first year of this effort. As these improvements require a multi-year effort, additional funding would be sought in the out-years, based on specific proposals developed by the participating FL institutions.

Mr. Chairman, this is just one of the many exciting activities going on at Florida State University that will make important contributions to solving some key problems and concerns our Nation faces today. Your support would be appreciated, and, again, thank you for an opportunity to present these views for your consideration.

#### PREPARED STATEMENT OF THE AMERICAN MUSEUM OF NATURAL HISTORY

# ABOUT THE AMERICAN MUSEUM OF NATURAL HISTORY

The American Museum of Natural History [AMNH] is one of the nation's preeminent institutions for scientific research and public education. Since its founding in 1869, the Museum has pursued its mission to "discover, interpret, and disseminate—through scientific research and education—knowledge about human cultures, the natural world, and the universe." It is renowned for its exhibitions and collections of more than 32 million specimens and cultural artifacts. With nearly five million annual visitors—approximately half of them children—its audience is one of the largest, fastest growing, and most diverse of any museum in the country. Museum scientists conduct groundbreaking research in fields ranging from all branches of zoology, comparative genomics, and informatics to earth, space, and environmental sciences and biodiversity conservation. Their work forms the basis for all the Museum's activities that seek to explain complex issues and help people to understand the events and processes that created and continue to shape the Earth, life and civilization on this planet, and the universe beyond. Today more than 200 Museum scientists with internationally recognized exper-

Today more than 200 Museum scientists with internationally recognized expertise, led by 47 curators, conduct laboratory and collections-based research programs as well as fieldwork and training. Scientists in five divisions (Anthropology; Earth, Planetary, and Space Sciences; Invertebrate Zoology; Paleontology; and Vertebrate Zoology) are documenting changes in the environment, making new discoveries in the fossil record, and describing human culture in all its variety. Researchers in the Museum's Institute for Comparative Genomics, established in 2001, are mapping the genomes of non-human organisms as well as creating new computational tools to retrace the evolutionary tree. The Museum also conducts graduate training programs in conjunction with a host of distinguished universities, supports doctoral and postdoctoral scientists with highly competitive research fellowships, and offers talented undergraduates an opportunity to work with Museum scientists.

The AMNH collections of some 32 million natural specimens and cultural artifacts are a major scientific resource, providing the foundation for the Museum's interrelated research, education, and exhibition missions. They often include endangered and extinct species as well as many of the only known "type specimens," or examples of species by which all other finds are compared. Within the collections are many spectacular individual collections, including the world's most comprehensive collections of dinosaurs, fossil mammals, Northwest Coast and Siberian cultural artifacts, North American butterflies, spiders, Australian and Chinese amphibians, reptiles, fishes, and one of the world's most important bird collections. The Museum has also established a super-cold storage facility, described below, for collection of tissue samples with preserved DNA for genomics research on the Earth's biodiversity. Collections such as these are historical libraries of expertly identified and documented examples of species and artifacts, providing an irreplaceable record of life on earth. They provide vital data for Museum scientists as well as for more than 250 national and international visiting scientists each year.

Permanent and temporary exhibits—from the Rose Center for Earth and Space to The Genomic Revolution, discussed below—are among the Museum's most potent educational tools, interpreting the work of Museum scientists, highlighting its collections, addressing relevant scientific and cultural issues, and presenting cutting edge content in a way that is accessible to all ages, learning levels, and backgrounds. Science Bulletins—high definition video wall displays—present breaking science news, images, and data in the Museum's new Halls of Biodiversity, Planet Earth, and the Universe. The Education Department builds these exhibitions, as well as the Museum's unique resources, to offer rich programming dedicated to increasing scientific literacy, to encouraging students to pursue science and museum careers, and to providing a forum for exploring the world's cultures. These programs attract more than 500,000 students and teachers on school visits and nearly 5,000 teachers for special professional development opportunities. The Museum is also reaching beyond its walls: through its National Center for Science Literacy, Education, and Technology, launched in 1997 in partnership with NASA, it is exploiting new technologies to bring materials and programs into homes, schools, museums, and community organizations around the nation.

# A MUSEUM PARTNERSHIP WITH DEPARTMENTS OF HEALTH AND HUMAN SERVICES AND EDUCATION

The American Museum shares with DHHS and the Department of Education a fundamental commitment to improving the nation's health and education and advancing the research, training, facilities, and technology that support them. The Museum seeks to partner with these agencies in order to leverage our complementary resources and advance critical shared goals. In partnership with DHHS and the Department of Education, the Museum will be poised to contribute its unique resources to the nation's health research and education missions: to advancing basic research in genomics and its potential applications in medicine, biomedical research, and clinical treatment; to education, and to promoting science education and science literacy in this, the era of genomics.

#### Genomic Science and Education

The U.S. Department of Education, in order to promote educational excellence for all Americans, is committed to assuring equal access to quality education opportunity and improving student achievement through scientifically-based teaching methods, professional development for teachers, academic enrichment opportunities for students, and integration of technology into classroom instruction. As both a science and a public education institution, the American Museum shares the Department of Education's commitment to national educational excellence, to improving the nation's education through quality teaching, educational opportunities outside of the classroom, and new educational technologies.

The Museum seeks to bring its extensive educational, as well as scientific, resources to bear in promoting the nation's teaching and learning about genome sciences: The Museum's website (www.amnh.org) serves as a vehicle for taking the institution's resources to millions beyond its walls. It offers in-depth virtual "tours" of exhibitions; features on curators, expeditions, and current research; access to collections; and links to the AMNH digital library. The site also features webcasts from Museum conferences and offers award-winning interactive materials for children, teachers, and families developed by its National Center for Science Literacy, Education, and Technology. The Museum's professional development program serves thousands of certified teachers and teachers-in-training each year, providing customized programs focused both on science content and ways to incorporate Museum resources into classroom curricula. The Museum has also developed an award-winning online professional development program called Seminars on Science, which allows hundreds of teachers across the country to work with Museum scientists on individual research projects and to discuss results and classroom applications with other participants.

DHHS leads the nation's health-related research and genome science, advanced sequencing technologies, instrumentation, and facilities. The American Museum, in turn, is home to a preeminent molecular research effort and a leading science education and outreach program. Indeed, natural history and genomic science are intricately related. The AMNH molecular systematics program is at the forefront of comparative genomics and the analysis of DNA sequences for evolutionary research that are of critical importance to biomedical research and the application of genome science to health treatments. In the Museum's molecular laboratories, in operation

now for 10 years, more than 40 researchers in molecular systematics, conservation genetics, and developmental biology conduct genetic research on a variety of study organisms. Their work contributes to understanding the rate and extent of evolution, which is essential for using genomic research to improve medical treatment and predictive capabilities.

# Frozen Tissue Collection

The Museum is also expanding its collections to include preserved biological tissues and isolated DNA in its new super-cold storage facility. This collection is an invaluable resource for research in many fields including genetics, comparative genomics, and biomedicine because it preserves genetic material and gene products from rare and endangered organisms that may become extinct before science fully exploits their potential. Capable of housing one million specimens, it will be the largest super-cold tissue collection of its kind. Already, more than 5,500 specimens have been accessioned. To maximize use and utility of the facility for researchers worldwide, the Museum is developing a sophisticated website and online database that includes collection information and digitized images.

## Bioinformatics Capability and Cluster Computing

The Museum has exceptional capacity in parallel computing—an essential enabling technology for phylogenetic (evolutionary) analysis and intensive, efficient sampling of a wide array of study organisms. A 560-processor cluster, constructed in-house from scratch by Museum scientists, is the fastest parallel computing cluster in an evolutionary biology laboratory and one of the fastest installed in a nondefense environment.

Over the past 8 years, Museum scientists have taken a leadership role in developing and applying new computational approaches to deciphering evolutionary relationships through time and across species; their pioneering efforts in cluster computing, algorithm development, and evolutionary theory have been widely recognized and commended for their broad applicability for biology as a whole. Indeed, the bioinformatics tools Museum scientists are creating will not only help to generate evolutionary scenarios, but also will inform and make more efficient large genome sequencing efforts. Many of the parallel algorithms and implementations (especially cluster-based) will be applicable in other informatics contexts such as annotation and assembly, breakpoint analysis, and non-genomic areas of evolutionary biology, with invaluable biomedical applications possible in the identification and treatment of disease.

#### INSTITUTE OF COMPARATIVE GENOMICS

#### Research

Building on its strengths in comparative genomics, and in concert with the health and education goals of DHHS and the Department of Education, the Museum established in 2001 an Institute for Comparative Genomics so as to contribute its unique resources and expertise to the nation's genomic research and education enterprises. The importance of comparative genomics to the nation's overall genomics research undertakings cannot be overstated. Conducting this type of research with a natural history perspective greatly enhances our understanding of the impacts of the knowledge we have gained from genomics and molecular biology.

edge we have gained from genomics and molecular biology. With the advent of DNA sequencing, museum collections have become critical baseline resources for the assessment of the genetic diversity of natural populations as well as for the pursuit of research questions pertinent to DHHS interests. Genomes, especially those of the simplest organisms, provide a window into the fundamental mechanics of life. One of the goals of the nation's genomic science research programs is to learn about the relevance to humans of nonhuman organisms' DNA sequences. This research can yield information that can be applied in solving critical challenges in health care. In short, work in comparative genomics will enrich our knowledge not only of biodiversity, but also of humans, medicine, and life itself. The AMNH comparative genomics program expects to provide vital contributions in these endeavors.

Equipped with the parallel computing facility, molecular labs with DNA sequencers, ultra-cold storage units, vast biological collections, and researchers with expertise in the methods of comparative biology, the Institute is positioned to be one of the world's premier research facilities for mapping the genome across a comprehensive spectrum of life forms. Complemented by the Museum's extraordinary education and outreach capacity, the Institute will constitute a national resource of unique scope and range.

Working cooperatively with New York's outstanding biomedical research and educational institutions, the Institute will focus on molecular and microbial systematics, expanding our understanding of the evolution of life on earth through analysis of the genomes of selected microbes and other non-human organisms, and constructing large genomic databases for a range of applications, including conservation biology. Research programs may include the evolution of critical organismal form and function based on genomic information, microbial systematics, and the use of broad scale comparative genomic studies to understand the function of important biomolecules.

The Institute's scope of activities will include: an expansion of the molecular laboratory program that now trains dozens of graduate students every year; the utilization of the latest sequencing technologies; employment of parallel computing applications that allow scientists to solve combinatorially complex problems involving large real world datasets; and development of technology-based K-12 curriculum materials, scientific conferences, and public exhibits.

In developing the Institute, the Museum plans to expand its curatorial range in microbial work; grow the super-cold tissue collection; and draw on our exhibition and educational expertise to offer enhanced public education and outreach. Plans entail expanding and renovating lab space and facilities to accommodate additional curators and students. By renovating an area adjacent to one of the existing molecular labs and possibly building new space, the Museum will add lab and associated office and maintenance space to accommodate the growing Institute's needs.

# Education Technology and Distance Education

The Museum is committed to using its unique education and technology resources in innovative ways that help to promote the nation's education and understanding of genomics. It has already launched an ambitious agenda of genomics-related exhibition, conference, and public education programming, including the landmark exhibition, The Genomic Revolution, open from June through December 2001. The exhibition, attended by approximately 500,000 visitors, examined the revolution taking place in molecular biology and its impact on modern science and technology, natural history, biodiversity, and our everyday lives. The exhibition will travel to several other venues throughout the United States. We have also hosted several conferences on important topics related to genomics: Sequencing the Human Genome: New Frontiers in Science and Technology, an international conference featuring leading scientists and policymakers in Fall 2000; Conservation Genetics in the Age of Genomics in Spring 2001; and New Directions in Cluster Computing in June 2001, which explored how parallel computing enables genomic science and other fields.

Through cutting-edge education and exhibition technologies and distance learning applications, we propose to expand and diversify the reach of our genomics related professional development, educational materials, and exhibition-related programming throughout New York City, the region, and the country. Specifically, we plan to develop a suite of standards-based curricular materials and programs related to genome science for online distribution to educators nationwide; to adapt and extend our successful Seminars on Science model of online professional development courses for K-12 teachers nationwide in subjects related to genomics; to enhance exhibition technologies and include a focus on genomics in our Science Bulletins; and to pilot a distance education initiative live from the Museum's halls and classrooms that will include a selection of regular interactive classes, professional development mini-series, and special live events, all designed to promote genomics teaching and learning in New York City, the region, and the country.

We seek \$7 million in fiscal year 2003 to partner with DHHS and the Department of Education in furthering this important genomics research and education initiative—the Museum's Institute for Comparative Genomics.—In so doing, the Museum will contribute its participatory share with funds from nonfederal as well as federal sources, including funds raised through the Museum's own efforts from the City and State of New York as well as private contributions and foundations. As a federal partnership, we propose two interrelated approaches:

- -\$5 million as a facilities/instrumentation and bioinformatics program, building on our already extensive investments
- -\$2 million as an education technology initiative to expand professional development, create K-12 curriculum materials, and launch online learning resources to promote teaching and learning nationwide about genomic science.

In partnership, the American Museum of Natural History and the Departments of Health and Human Services and Education will be positioned to leverage their unparalleled resources to advance shared goals for improving the nation's health and welfare and promoting its research and education in the genomics era. PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABIL-ITIES COUNCILS (NADDC), CONSORTIUM OF DEVELOPMENTAL DISABILITIES COUN-CILS (CDDC), AND THE COUNCIL ON DEVELOPMENTAL DISABILITIES

When the 106th Congress reauthorized the Developmental Disabilities Assistance and Bill of Rights Act (Public Law 106–402), the authority for State Councils on Developmental Disabilities was increased to \$76 million in recognition of the significance of the work of these entities in each State and Territory. While Congress slightly increased the DD Council funding for fiscal year 2002, the current level of \$69.8 still falls far short of the needs. NADDC and CDDC urge the Congress to recognize the importance of this change with a commensurate increase in the fiscal year 2003 to \$76 million for the State Councils on Developmental Disabilities.

## BACKGROUND

There are an estimated 4.5 million people with developmental disabilities in the United States, compared with the 1993 figure of more than 3 million individuals. These individuals are expected to need a combination and sequence of individually planned, special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration. By definition, the age of onset for a developmental disability is before the individual attains age twenty-two. The Developmental Disabilities Assistance and Bill of Rights Act was first enacted

The Developmental Disabilities Assistance and Bill of Rights Act was first enacted in 1963 as the Mental Retardation Facilities and Construction Act in response to the need for alternatives to large institutions. It has been expanded to meet the growing needs for community supports with each subsequent reauthorization. The Act provides the authority for funding in each State and Territory for a Council on Developmental Disabilities, a statewide Protection and Advocacy System and a University Center for Excellence in Developmental Disabilities Education, Research and Service (formerly the University Affiliated Programs).

The Councils on Developmental Disabilities (Part B of the Act) are advocacy, capacity building, and systems change entities appointed by the Governor in each State and Territory. The Councils are charged with the responsibility of promoting the development of a comprehensive system of services and supports in each State and Territory, with the goal of increasing the independence, productivity, inclusion, integration and self-determination for individuals with developmental disabilities. The Act lists a number of optional areas of emphasis for Council activities. Councils can choose to work on issues related to quality assurance, child care, housing, transportation, recreation, education, employment, and health. They are required to strengthen, support and expand opportunities for individuals with developmental disabilities to receive and provide leadership training and to work in coalitions. They are also free to establish priorities outside of those prescribed in the Act to meet the unique needs of individuals with developmental disabilities in their own State or Territory.

There are fifty-five Councils on Developmental Disabilities are not direct service providers. Rather, their charge is to encourage the creation of (1) a system of providers that deliver quality services and supports and (2) communities that are welcoming of individuals with disabilities throughout the State. Federal funding for these activities is administered by an agency also designated by the Governor. Sixty percent of the Council must be people with significant disabilities and their family members. The rest are state agency administrators, private providers, and members of the community. Together, this group develops and implements a statewide plan which lays out activities to enhance the lives of people with developmental disabilities through a variety of systemic change, capacity building and advocacy activities.

# COUNCIL ACTIVITIES

The Councils are viewed as invaluable change agents in the States and have made a significant difference in the lives of individuals and their families across the nation. Best practices promoted by Councils have resulted in, among other accomplishments, strong early childhood programs; improvements in school services; access to real, inclusive jobs through supported employment; small business ownership; training and empowerment of self-advocates; addressing the crisis in the shortage of qualified direct care professionals; home ownership; accessible transportation systems; appropriate community activities for individuals with developmental disabilities as they become older; and tremendously important supports for families so they can remain healthy and intact.

Councils must always remain abreast of changing times. Most recently, Councils across the country have been called on to address burgeoning community waiting lists; to plan for the huge demands that will be placed on the services by the aging

baby boom generation-including the loss of a large percentage of the service provider population as they reach retirement; and to face the challenges of abuse and neglect in a wide range of settings. In addition, Councils are attempting to assist States in their response to the Supreme Court's *Olmstead* decision, which mandates a substantial increase in community-based services and supports.

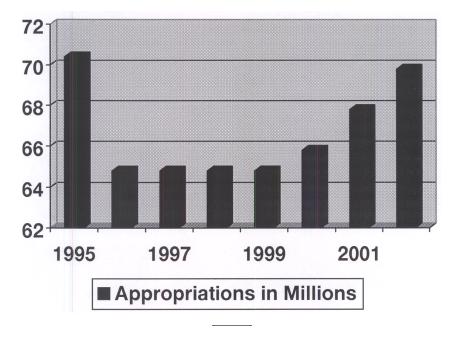
# FUNDING

Table 1 reflects a 7-year funding history for the DD Councils. It is notable that this funding level has yet to return to the fiscal year 1995 level, which was even then insufficient. Missing from this history are increases to keep pace with the growing needs in every State. With the fiscal year 2002 Federal investment in Council activities of \$69.8 million, the smallest 13 states receive just under \$450,000 and the largest States receive \$4 to \$6 million, far less than needed to fulfill the promises of the DD Act. While Councils make impressive in-roads with the small amount of funding they receive, there are many more critically-needed activities to advance the independence and inclusion of individuals with significant disabilities in every State.

#### RECOMMENDATION

In order to deliver these and the other activities that make such a difference in the lives of individuals with disabilities and their families, funding at \$76 million for fiscal year 2003 is recommended.

For additional information, contact: Mary Kelley (NADDC) 202–347–1234; mkelley@naddc.org; Ed Burke (CDDC) 540– 428–1096; epbcddc@aol.com



# TABLE 1.--8-YEAR FUNDING HISTORY FOR STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

# PREPARED STATEMENT OF THE IOWA TALENTED AND GIFTED ASSOCIATION

Thank you for providing an opportunity for us to communicate to members of the Senate on the issues facing gifted students in the United States. The Iowa Talented and Gifted Association (ITAG) represents more than 10,000 students, their families, and teachers in the state of Iowa. As the Legislative Chair for ITAG and the Super-visor for the Des Moines Public Schools Gifted and Talented Education, (which in cludes half of the gifted students in the state of Iowa), I urge you as the Chairman of the Senate Appropriations Subcommittee on Labor, Health and Human Services, and Education to appropriate \$25 million for the Javits Gifted and Talented Students Education Act in fiscal year 2003. The increase in funds would go directly to the new grants for statewide activities, allowing additional states, such as Iowa, to receive desperately needed federal funds for teacher preparation, pre-service education, programs specifically designed for under served populations and at risk youth, and other programs that the support the educational and social and emotional needs of gifted and talented students.

Iowa has a history of excellence in education. We routinely produce top scholars in the nation. We also have a strong reputation as a state that welcomes refugees when they settle in the United States. The Iowa economy has not recovered from the recession; we have more students living in poverty in both rural and urban areas. The achievement gap that exists in Iowa is undeniable; the face of Iowa continues to change. All of these factors complicate gifted education except for the common denominator: we have a responsibility to meet the needs of the learners. As educators, we recognize the need for special funding for special programs for students with special needs. Students with unique and compelling circumstances cannot have their educational needs met without appropriately trained teachers and without opportunities to excel. There is a clear need for gifted education and talent development.

An area in gifted education that is receiving attention pertains to the twice exceptional child. Gifted students who also have a learning disability or who are faced with other challenges equally deserve to have appropriate educational opportunities. Most teachers are required to take one class in special education before they become professionals. Gifted students and especially the twice exceptional children are often relegated to one chapter in a book. The very unique learning needs that this special population has demands that we offer better teacher preparation programs. In addition, the learning experiences of twice exceptional children must be very carefully tailored. A curriculum that allows high potential to develop is different for each gifted child.

Increasing the funding for Javits will make a difference in the lives of children. Thank you for your strong support of gifted students.

#### PREPARED STATEMENT OF THE NATIONAL HEAD START ASSOCIATION

On behalf of the National Head Start Association, I am pleased to testify in support of fiscal year 2003 appropriations for the Head Start program, administered by the Department of Health and Human Services under the Subcommittee's jurisdiction.

At the outset, let me share with you my concern over the recent action in Congress which threatens to allot to the annual appropriations process resources far short of those appropriate to expand our investment in answers to some of the nation's most critical needs—or to even maintain vital existing services at current levels.

The National Head Start Association is a private nonprofit membership organization representing over 900,000 children and their families, 168,000 staff, in nearly 2,400 Head Start programs across the country, including over 550 Early Head Start programs and the more than 40,000 children and families they currently serve. In this, the 37th year of Head Start, NHSA stands by the goal established by the

In this, the 37th year of Head Start, NHSA stands by the goal established by the Congress several years ago to enroll one million children in the Head Start program by the end of the coming fiscal year and doubling the number of infants and toddlers and their families enrolled in the Early Head Start initiative within that same time frame. At the same time, NHSA remains committed to keeping the promise made to low-income children and families by Presidents George H.W. Bush and Bill Clinton and by both Democratic- and Republican-controlled Congresses—namely, full funding of Head Start. Accordingly, NHSA requests the Subcommittee's favorable action on a fiscal year 2003 appropriation for Head Start of \$7.6 billion—an increase of \$1.0 billion over the fiscal year 2002 program funding level.

This moment in our nation's history presents unique opportunities. Although our country is fighting a war against terrorism on foreign lands, we may be stronger at home than at any point in recent history. On September 11, Americans came to together as firemen, police officers, and rescue workers rushed to the scene to aid people trapped in the debris. In the following months, citizens from across the country volunteered their time and resources to help those in need. Head Start was borne from these same ideals—that the government working in partnership with citizens and their local communities could improve the quality of life for children and families. If there was ever a time in which the need for Head Start and for what it represents should be supported it is now. Now is the time to invest in our future. Now is the time to answer a need that has been long placed on hold. Now is the time to fill the gap for low-income children and families. No longer should we tolerate waiting lists for Head Start and quality early care and education programs. No longer need we put on hold the delivery of the American dream to infants and toddlers born to poverty.

The 1998 reauthorization of Head Start called for marked improvements in the quality of professional development for the Head Start teaching staff, the quality of services provided to children and families, and working toward quantifiable goals—goals which recognized the primary importance of education at the forefront of the Head Start mission.

We have improved the quality of our programs, assisting those local projects in need of guidance and training and defunding those that could not meet our high standards. We have moved toward improving the training and professional competency of our classroom and program staff. We have secured, improved, and built facilities appropriate for young children and families. And we have increased the educational attainment of Head Start graduates.

This is not the time to retreat from our commitment to the full funding of Head Start—from the goal of providing every eligible low-income child access to the type of services which will give them the opportunity to gain access to the American dream. And, this is not a time to be treading water. If the nation cannot rise to the occasion, investing our resources in our children, we will have failed ourselves as well as future generations. Our richness lies in our people. It always has.

An increase of only a \$130 million over the fiscal year 2001 funding level, would force the abandonment of a number of important plans in Head Start—including the scheduled expansion of the Early Head Start program; training of teachers toward the goal of increasing credentials and college degrees such that at least one-half of all Head Start classrooms have a teacher with an Associate's, Bachelor's, or Master's degree by 2003; and bolstering our commitment to achieving education outcomes through the institution of research-based early childhood educational interventions.

The funding levels NHSA endorses will ensure that services to infants and toddlers might expand without jeopardizing scheduled increases in Head Start preschool enrollment. In fact, we support efforts to permit current Head Start grantees to expand to serve the needs of infants and toddlers so long as such expansion does not deny services to qualifying preschoolers.

Consistent with changes in public policy and growing needs in communities across the country, members of the National Head Start Association have expressed an interest in expanding services within their communities, when funds become available through annual appropriations, to serve infants and toddlers within the context of authority under the Head Start Act (other than the Early Head Start program authorized separately in the law).

For many years, we have supported a seamless program of services to low-income families with children from birth through compulsory school age. This has become increasingly important with the advent of specific funding set-aside for Early Head Start, the move toward state-funded preschool, and recent publicity over the importance of earlier intervention in order to improve the lives of younger children and their low-income families.

It is our belief that no legal impediment exists to permitting the program expansion we envision. Rather, we contend the only thing missing to permit this policy direction is the political will to make it happen. The expanded services we urge you to embrace presume compliance with program performance standards specific to the service of infants and toddlers, established local community needs, and approval by the Secretary.

When combined with the new grant authority incorporated in the 1998 reauthorization of Head Start for Early Head Start, expansion of existing Head Start programs to serve the needs of younger children is responsive to recent research emphasizing the developmental needs of younger children—and the needs of parents with infants and toddlers who are working part-and full-time in accordance with welfare reform. Needs that can be ably addressed through the Head Start model of comprehensive services.

Another issue of concern to Head Start programs across the country is the need to extend services full day, full-year in response to the needs of parents who are working full-time as well as unconventional hours because of welfare reform. For example, many centers are currently open from 8:30 a.m to 2:30 p.m. Ideally, in order to respond to their working parents, they would like to expand hours from 7 a.m. to 7 p.m.

Finally, the National Head Start Association urges the committee and your colleagues to help us to further respond to a changing world in light of welfare reform by working with us to encourage the Secretary of Health and Human Services to exercise his discretionary powers to relax limitations on the enrollment of over-income families in Head Start.

Current law defines as eligible a family whose income is at or below the national poverty level, or who is receiving public assistance defined as regular support services provided under Temporary Assistance for Needy Families. Again, while NHSA is appreciative of the effort to clearly define public assistance, NHSA would like to see a uniform, nationwide approach to enrolling families and children who are in critical need of comprehensive services but whose state or county's criteria set for TANF eligibility still renders them ineligible for Head Start. These families' incomes may only be \$500 over income guidelines but they have at-risk factors for remaining in poverty such as illiteracy, no job skills, little to no parenting skills, drug and/ or spousal abuse, and high-risk factors.

The law permits the enrollment of a "reasonable number" of over-income families to accommodate the working poor and near poor who desperately need Head Start services to maintain employability and self-sufficiency. During the last administration, Secretary Shalala interpreted "reasonable number" to permit over-income enrollment of up to 10 percent of total program enrollment. NHSA would like to see this flexibility expanded to as much as 25 percent of enrollment. This would solve a major problem as it relates to welfare reform. Under this arrangement, the working poor would still be eligible for Head Start and would have more time to become self-sufficient.

The National Head Start Association appreciates this opportunity to reinforce the critical national interest served by supporting expanded Head Start funding. With your assistance, we can continue to make a difference in the lives of our most vulnerable children, families, and communities.

In summary, we request:

- -Fiscal year 2003 appropriation of \$7.6 billion—an increase of \$1 billion over the fiscal year 2002 appropriation level;
- -Permitting the use of grant dollars for preschool grantees to expand to meet the needs of families with infants and toddlers, so long as qualified preschools are not denied services;
- —Supporting the use of grant dollars for full-day, full-year services for currently enrolled children; and
- Enhanced flexibility to allow for the participation of a larger proportion of overincome children and families where needs exist and extending services to these families in a community would not deny services to income-qualified children and families.

Thank you for allowing NHSA to present issues of importance to the Head Start community before the committee.

## PREPARED STATEMENT OF THE NATIONAL SCIENCE TEACHERS ASSOCIATION

On behalf of the National Science Teachers Association (NSTA) and the Triangle Coalition for Science and Technology Education, we urge you to support full funding of \$450 million for the Title II, Part B, Mathematics and Science Partnerships Program in the fiscal year 2003 appropriations bill for the Department of Education. The new Mathematics and Science Partnerships program created in the No Child

The new Mathematics and Science Partnerships program created in the No Child Left Behind Act will allow higher education institutions and K-12 school districts to create programs targeted specifically to address the needs of local science and mathematics educators. These merit-based partnerships among school districts; university science, engineering, and math departments; businesses; and educational organizations seek to improve teacher quality and student achievement. The partnerships will provide an opportunity to significantly improve the content knowledge and teaching skills of the nation's K-12 mathematics and science teachers.

This past year, Congress appropriated \$12.5 million to begin the new Math and Science Partnerships program. However, H.R. 1 contains an authorization of \$450 million for the partnerships. Until the program reaches a \$100 million appropriation, it will continue to be a national grant program, which means that many states and local districts will never receive any funds. When the \$100 million funding level is reached, the program becomes a formula grant program, and every state will receive Math and Science Partnership funds.

Math and science education is in crisis and in critical need of improvements and continued reforms. If we do not invest heavily and wisely in rebuilding these two core strengths, America will be incapable of maintaining its global position long into the 21st century. Providing strong funding for math and science education through the Department of Education is critical because the department is the only federal agency charged with improving teacher quality and student achievement across all states and school districts. We urge Congress to fulfill its commitment to math and science education by sup-

We urge Congress to fulfill its commitment to math and science education by supporting a \$450 million appropriation in fiscal year 2003 for the Math and Science Partnerships program (Title II, Part B) in the Labor-HHS-Education bill. Thank you for your consideration of our request and for your past support.

for your consideration of our request and for your past support. Founded in 1944, the National Science Teachers Association is the largest organization in the world committed to promoting excellence and innovation in science teaching and learning for all. NSTA's current membership of more than 53,000 includes science teachers, science supervisors, administrators, scientists, business and industry representatives, and others involved in and committed to science education.

The Triangle Coalition for Science and Technology Education represents more than 100 member organizations from three key stakeholders: business, education, and scientific and engineering societies. The Coalition provides a forum for these three sectors to work together to promote the improvement of science, mathematics, and technology education.

#### PREPARED STATEMENT OF THE QUINAULT INDIAN NATION

On behalf of the Quinaullt Indian Nation, we seek funding for a school construction project in the fiscal year 2003 Appropriations Bill for the Department of Education, Office of Impact Aid School Construction Account in the amount of \$14.2 million.

The Quinault Reservation, home of the Quinault Indian Nation (QIN), is located in Grays Harbor County in Washington State; a rural, isolated and economically deprived area. This is an area that shows persistently low-income levels and the demographics for the QIN are staggering. In 1999, 25 percent of the population was unemployed and 57 percent of those working had incomes less that \$25,000 per the Housing Needs Study for the Quinault Indian Nation conducted by Tom Phillips and Associates.

Housing on our reservation is described as unhealthy and unsafe and is attributable to deteriorating conditions. In addition, many of the homes are too small for the size of the families. This coupled with high unemployment and low wages, translates into a very low tax base for federal dollars because of the tax-free status on most of the land in the Taholah District.

In 1920 the Quinault Indian Nation decided to make a difference in the lives of our members for generations to come. That decision was to build and operate a public school on the Quinault Indian Reservation. In our vision, this school would provide quality, culturally relevant educational programs, services, resources and opportunities to members of our Nation.

Today, the Taholah School District #77 symbolizes the legacy of that vision. The current enrollment at the Taholah School is 224 students in grades K–12, as reported by the Grays Harbor Council of Governments 2000 Census Data. The village of Taholah lies in a tsunami danger zone. A "tsunami" is an unusually

The village of Taholah lies in a tsunami danger zone. A "tsunami" is an unusually large sea wave produced by a seaquake or undersea volcanic eruption, generally referred to as a "seismic sea wave". The site of the village is barely above sea level. Experts have determined that sea level is rising because of global warming patterns. For the village of Taholah, tsunami is a health and safety risk factor that we must live with everyday.

In 2001, the School building sustained structural damage from the February 28, 2001 Western Washington earthquake. The Taholah School Board of Education commissioned an assessment of the damages, which documented that the impact attributable to the earthquake included everything from damaged ceiling beams to cracks in the walls and floor surfaces.

Latent construction defects in the 1991 addition have also been identified. The overall condition of the main building is poor and the other two connecting facilities are rated as fair to poor. While none of the damage warrants restrictions in building use at the present time, there are imminent health and safety concerns overshad-owing the continued use of these structures.

The locker/shower rooms, in the gymnasium, are unsatisfactory and fail to meet the State of Washington Health and Safety standards. The boiler has recently been repaired but is in need of being replaced. The K-8 section of the school has inadequate heating and cooling systems to allow

The K-8 section of the school has inadequate heating and cooling systems to allow for fresh air and adequate ventilation throughout the building. Again, the ventilation in this area does not meet State of Washington Health and Safety Standards. Flat roofing has failed and is in need of immediate replacement. Sloped, metal roofing is severely damaged due to leakage and has been a constant drain on maintenance staff and budget resources.

This building poses a threat of endangerment to our students, faculty and our general tribal population. It has served as a multi-functional facility spanning over several decades. And, as with any checkerboard, piece-meal structure, each time an addition has been made, the original structure has weakened with the construction of the add-ons.

# THE RESERVATION IS IN NEED OF A NEW SCHOOL: \$14.2 MILLION

A long-term solution to the facility needs of this school district is what the Taholah School District is requesting from Congress.

The Taholah School District is an impacted area and would normally be able to apply for federal impact aid funds from the Department of Education. Unfortu-nately, because of budgetary restraints, there have not been any additions to the list of priority sites for the past 7 years. The existing list consists of some 200 appli-cations that have been in abeyance during this period of time. According to staff at the impact aid office, they are in the process of developing a new application pack-age that is not expected to be available until mid-summer of 2002. In the State of Washington, a school district must be able to raise a predeter-mined amount of local funds to qualify for construction funding. It has been deter-mined that the Taholah School District lacks the legal bonding capacity. The ability of the Taholah School District to provide capital funds from local efforts is hindered The Taholah School District is an impacted area and would normally be able to

due to the limited assessed valuation. The assessed valuation is significantly low within the Quinault Indian Reservation because a very large portion of the land is in federal trust status and therefore not taxable. As you can see in Exhibit A, the Taholah School District is legally limited to raising only \$1,444,802 via bonded in debtedness. And, as shown in Exhibit B, the legal bonding capacity of the Taholah School District is insufficient to meet the costs of the two main alternatives explored.

It is important to note that should the patrons of the community approve a bond indebtedness at this level, such a burden will cost in excess of \$11 per \$1,000 as-sessed valuation over 30 years. Considering the economic status of this community, that burden is excessive and unfair.

The Taholah School District is located on a site where the soil is unstable and not conducive to long-term structural support. Without outside financial assistance, the District lacks the legal financing capacity to build a new school at a new location.

The Quinault Indian Nation is prepared to assist the Taholah School District by designating land on which a new school can be built.

The health and safety of the Quinault children cannot be compromised. To abide time and to continue to put bandages where new brick and mortar should be is doing just that. The Taholah School District is dependent upon State and Federal Support to operate our school and to maintain the quality of these facilities. We have no place to turn to but to turn the quality of these facilities.

We have no place to turn to but to you. Please help us to empower the current and future generations of young Quinaults with the knowledge they will need in order to be responsible adults. Help us to provide them with the tools they will need to get good jobs wherever they may choose. We would like to take this opportunity to thank you for considering this request.

# Exhibit A.—The following is an analysis of the Taholah School District bonding capacity

Current Assessed Valuation of District	\$28,896,032
Five Percent Maximum Bonded Indebtedness	1,444,802
Current Indebtedness	

Total bonding capacity (2001) ..... 1,444,802

# EXHIBIT B.—BONDING CAPACITY IS INSUFFICIENT TO MEET THE COSTS OF THE ALTERNATIVES EXPLORED

	Total cost	State match	Local cost (Total-State)	Bond capacity	Difference
Renovation	\$5,432,584	\$1,351,563	\$4,081,071	\$1,444,802	<\$2,636,269>

# EXHIBIT B.—BONDING CAPACITY IS INSUFFICIENT TO MEET THE COSTS OF THE ALTERNATIVES EXPLORED—Continued

	Total cost	State match	Local cost (Total-State)	Bond capacity	Difference
Replacement	14,148,193	2,056,092	12,092,101	1,444,802	<10,647,299>

## PREPARED STATEMENT OF THE AMERICAN INDIAN HIGHER EDUCATION CONSORTIUM

## SUMMARY OF REQUESTS

Summarized below are the fiscal year 2003 (fiscal year 2003) requests for the nation's 32 Tribal Colleges and Universities, which encompass three areas within the Department of Education and one in the Department of Health and Human Services, Administration for Children and Families' Head Start Program.

## HIGHER EDUCATION ACT PROGRAMS

Strengthening Developing Institutions.—Section 316 under Title III, Part A, specifically supports Tribal Colleges and Universities. Within Section 316 there are two separate competitive grants programs: a) the basic program, and b) a program designed specifically to address the critical facilities and infrastructure needs at tribal colleges. We request that the section 316 programs be funded at \$24 million, with \$12 million designated for the facilities grants program.

Additionally, under Title IV, we urge Congress to fund the Pell Grant Program at the highest possible level.

## PERKINS VOCATIONAL EDUCATION ACT

We support \$7 million for the Tribally-Controlled Postsecondary Vocational Institutions under Section 117 and request report language reaffirming that this funding remain specific to the two Tribally Controlled Postsecondary Vocational Institutions: United Tribes Technical College and Crownpoint Institute of Technology. We also request that the language included in fiscal year 2002 be repeated, which states that Section 117 Perkins Grantees need not utilize restricted indirect cost rate.

## RELEVANT TITLE IX ELEMENTARY AND SECONDARY EDUCATION ACT (ESEA) PROGRAMS

American Indian Adult and Basic Education.—This title includes funding for much-needed adult education for American Indians, offered by tribal colleges, Indian tribes, institutions, state and local education agencies, and other agencies. We request the Subcommittee fund this program for Indian Adult and Basic Education at a minimum of \$5 million.

American Indian Teacher and Administrator Corps.—American Indian Teacher Corps and the American Indian Administrator Corps offer professional development grants designed to improve the quality of teachers and administrators serving American Indian communities. We request Congress support these programs at \$10 and \$5 million, respectively.

Tribal Colleges and Universities Head Start Partnership Program (DHHS-ACF).— Tribal Colleges and Universities (TCUs) are an ideal partner to help Head Start achieve its goals in Indian Country. The TCUs are working hard to meet the Congressional mandate that 50 percent of Head Start teachers earn an associate degree in Early Childhood Development or a related discipline. We request \$5 million be designated for the TCU-Head Start partnership program, to ensure the continuation of current programs and the resources necessary to fund additional tribal colleges partnership programs.

Mr. Chairman and Members of the Subcommittee, on behalf of this nation's 32 Tribal Colleges and Universities, which comprise the American Indian Higher Education Consortium (AIHEC), we thank you for the opportunity to share our fiscal year 2003 (fiscal year 2003) funding requests for programs within the Department of Education, and The Department of Health and Human Services Head Start program.

This statement will cover two areas (a) background on the tribal colleges, and (b) justifications for our funding requests.

## BACKGROUND ON TRIBAL COLLEGES

The Tribal College Movement began in 1968 with the establishment of Navajo Community College, now Diné College, in Tsaile, Arizona. A succession of tribal colleges soon followed, primarily in the Northern Plains region. In 1972, the first six tribally controlled colleges established AIHEC to provide a support network for member institutions. Today, AIHEC represents 32 Tribal Colleges and Universities located in 12 states, begun specifically to serve the higher education needs of American Indian students. Collectively, these institutions of higher education serve approximately 30,000 full-and part-time students from over 250 Federally recognized tribes.

All tribal colleges offer 2-year degrees, and several institutions offer baccalaureate and graduate-level degrees. The majority of the tribal colleges are fully accredited by independent, regional accreditation agencies.<sup>1</sup> In addition to college level programming, TCUs provide much needed high school completion (GED), basic remediation, job training, college preparatory courses, and adult education. Tribal colleges fulfill additional roles within their respective communities functioning as community centers, libraries, tribal archives, career and business centers, economic development centers, public-meeting places, and child care centers. Each TCU is committed to improving the lives of students through higher education and to moving American Indians toward self-sufficiency.

Tribal colleges provide needed access to higher education for American Indians and others living in some of this nation's most rural and economically depressed areas. These institutions, chartered by their respective tribal governments, were established in response to the recognition by tribal leaders that local, culturally-based education institutions are best suited to help American Indians succeed in higher education. TCUs combine traditional teachings with conventional postsecondary courses and curricula. They have developed innovative means to address the needs of tribal populations and are successful in overcoming long-standing barriers to higher education for American Indians. Since the first tribal college was established on the Navajo reservation, these vital institutions have come to represent the most significant development in the history of American Indian higher education, providing access to under-represented students and promoting achievement among students who may otherwise never have known postsecondary education success.

Despite their remarkable accomplishments, tribal colleges are the most poorly funded institutions of higher education in the country. Grossly inadequate funding levels remain the most significant barrier to their success. Funding for basic institutional operations for 25 reservation-based colleges is provided through the Tribally Controlled College or University Assistance Act (TCCUAA), Public Law 95–471. Funding was first appropriated through the Act in 1981, and is still less than twothirds of its authorized level of \$6,000 per full-time Indian student. In fiscal year 2002, these colleges receive \$3,916 per full-time Indian student. While mainstream institutions have a foundation of stable state tax support, TCUs must rely on annual appropriations from the Federal government for their institutional operating funds. Because tribal colleges are located on federal trust territories, states have no obligation to fund them. In fact, most states do not even pay our colleges for the non-Indian state-resident students who account for approximately 20 percent of TCU enrollments.

Inadequate funding has left many of our colleges with no choice but to operate under severely distressed conditions. Many colleges operate in surplus trailers; castoff buildings; and facilities with crumbling foundations, faulty wiring, and leaking roofs. Sustaining quality academic programs is a challenge without a reliable source of facilities maintenance and construction funding.

Today, one in five American Indians live on reservations. As a result of more than 200 years of Federal Indian policy—including policies of termination, assimilation and relocation—many reservation residents live in abject poverty comparable to that found in Third World nations. Through the efforts of tribal colleges, American Indian communities receive services they need to reestablish themselves as responsible, productive, and self-reliant.

<sup>&</sup>lt;sup>1</sup>The Tribal Colleges and Universities are accredited by regional accreditation agencies and must undergo stringent performance review on a periodic basis. The higher education division of the respective regional accreditation agency accredits twenty-seven of the TCUs. Two TCUs are at the Pre-candidate status are as they complete work to attain Candidate status; one TCU is at Candidate status. Two TCUs are accredited as "Vocational/Adult Schools" by the "schools" division of the respective regional accreditation agency.

## JUSTIFICATIONS

Higher Education Act requests.—The Higher Education Act Amendments of 1998 created a separate section within Title III, Part A, specifically for the nation's tribal colleges (Section 316). The Aid for Institutional Development programs, commonly known as the Title III programs, support minority institutions and other institutions that enroll large proportions of financially disadvantaged students and have low per-student expenditures. Tribal colleges clearly fit this definition. Tribal colleges are among the most poorly funded institutions in America, yet they serve some of the most impoverished areas of the country. They fulfill a vital role providing access to quality higher education programs, which are specifically designed to focus on the critical, unmet needs of their American Indian students and communities. This funding will help the tribal colleges effectively prepare their students for the workforce of the 21st Century in a safe environment. We strongly urge the Subcommittee to correct this oversight and fund section 316—which is critical to the tribal colleges—at \$24 million. We ask that \$12 million of these funds be specifically designated for the competitive facilities and infrastructure improvement program, also administered under this section.

The importance of Pell grants to our students cannot be overstated. Department of Education figures show that at least half of all Tribal College students receive Pell grants, primarily because student income levels are so low and our students have far less access to other sources of aid than students at mainstream institutions. 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 fund this critical program at the highest possible level.

Perkins Vocational Education Act.—Section 117 (addressing Tribally-Controlled Postsecondary Vocational Institutions) of the Carl D. Perkins Vocational and Applied Technology Education Act provides core funding for two of our member institutions: United Tribes Technical College in Bismarck, North Dakota, and Crownpoint Institute of Technology in Crownpoint, New Mexico. We support our member institutions' request of \$7 million for the Tribally-Controlled Postsecondary Vocational Institutions under Section 117 and that the language included in fiscal year 2002 be repeated, stating that Section 117 Perkins Grantees need not utilize restricted indirect cost rate.

## GREATER SUPPORT OF INDIAN EDUCATION PROGRAMS UNDER ESEA

American Indian Adult and Basic Education.—This section supports adult education programs for American Indians that are offered by tribal colleges, state and local education agencies, Indian tribes, institutions, and agencies. The Tribal College Act only supports Indian students enrolled in postsecondary programs and therefore does not include funding for remediation and adult basic education. Yet, the tribal colleges must continue to provide basic adult education classes for their communities. Before many individuals can even begin the course work needed to learn a productive skill, they first must earn a GED or, in some cases, learn to read. According to a 1995 survey conducted by the Carnegie Foundation for the Advancement of Teaching, 20 percent of the participating students had completed a tribal college GED program before beginning higher education classes at the tribal college. At some schools, the percentage is even higher. Lac Courte Oreilles Ojibwa Community College in Hayward, Wisconsin, for example, reports that nearly one-third of its students earned a GED through its tutoring and testing center. Clearly, the need for basic educational programs is tremendous, and tribal colleges need funding to support these crucial activities. Tribal colleges respectfully request that Congress appropriate \$5 million in fiscal year 2003 to meet the ever-increasing demand for basic adult education services.

American Indian Teacher Corps.—American Indians are severely under-represented in the teaching and school administrator ranks nationally. These programs, aimed at producing new teachers and school administrators for schools serving American Indian students, support the recruitment, training, and in-service professional development programs of American Indians to become effective teachers and school administrators. We believe that the tribal colleges are the ideal catalysts for these initiatives because of our current work in this area and the existing articulation agreements TCUs hold with 4-year degree awarding institutions. We request Congress support these programs at \$10 million and \$5 million, respectively, to increase the number of qualified American Indian teachers and school administrators in Indian Country.

# DEPARTMENT OF HEALTH AND HUMAN SERVICES/ADMINISTRATION FOR CHILD, YOUTH AND FAMILIES/HEAD START

Tribal Colleges and Universities (TCU) Head Start Partnership Program.—The TCU/Head Start partnership has made a lasting investment in our Indian communities by creating associate degree programs in Early Childhood Development and related fields. New graduates of these programs can help meet the Congressional mandate that 50 percent of all program teachers earn an Associate Degree in Early Childhood Development or a related discipline, by 2003. One clear impediment to the on-going success of this partnership program is the decrease in discretionary funding being targeted for the TCU/Head Start partnership. In fiscal year 1999, the first year of the program six TCUs received awards; in fiscal year 2000, \$1 million was designated annually for each of the 3-years of the seven grants awarded (the total amount requested from 14 TCUs equaled \$2,080,827). In fiscal year 2001, the duration of new grants was extended to 5-years but only \$500,000 was made available for the program. Only three additional TCUs were able to receive grants. The extension of the duration for new grants was a welcome change. We are hopeful that the current (1999 and 2000 grantees) will be able to extend their existing grants to a total of 60 months. The President's budget includes a request of \$6,667,553,000 for Head Start Programs. We request Congress direct the Head Start Bureau to designate a minimum of \$5 million for the TCU/Head Start Partnership program, to allow current grantees to extend their programs for 2 additional years and to ensure that this vital program can continue and be expanded to serve all of our tribal college communities.

## CONCLUSION

Fulfillment of AIHEC's fiscal year 2003 request will strengthen the mission of the Tribal Colleges and Universities, and contribute to the enormous, positive impact they have on their respective communities. Tribal colleges have been extremely responsible with the Federal support they have received over the last 21 years, and have proven themselves to be a sound Federal investment.

Thank you again for this opportunity to present our funding requests. We respectfully ask the Members of this Subcommittee for their continued support and full consideration of our fiscal year 2003 appropriations request.

# PREPARED STATEMENT OF THE NATIONAL INDIAN EDUCATION ASSOCIATION

The National Indian Education Association (NIEA) is the oldest and largest national organization representing the education concerns of over 3,000 American Indian, Alaska Native and Native Hawaiian educators, tribal leaders, school administrators, teachers, parents, and student members. NIEA would like to submit this statement on the President's fiscal year 2003 budget as it affects American Indian, Alaska Native and Native Hawaiian education.

The federal government is responsible for only two school systems in this country—the schools of the Department of Defense (DOD) and those operated by the Department of Interior's Bureau of Indian Affairs (BIA). Ideally, these schools should be the state of the art' when it comes to education as federal policy, especially when major educational mandates are approved by Congress and the Administration. In terms of funding, DOD schools compare with BIA schools on a per pupil basis. In terms of academic success, however, BIA schools lag behind their counterpart. If you were to look at the education levels of American Indians thirty to 50 years earlier, you would find dropout rates approaching 100 percent in some areas and few graduates exiting high school. Even fewer still were attending college. The legacy of the boarding school era was still a factor and children who were removed from their parents were becoming parents themselves. All of these factors and the insistence of Indian people to retain their culture effectively countered termination and assimilation efforts, including those carried out by the Bureau of Indian Affairs.

When you look at what has been the history of Indian education, Indian people have indeed come a long way over the last half century. All of the impediments that are now affecting academic achievement among American Indian students all have their history in the inconsistency of Indian education policy. Today is no different as in the signing of the recently passed No Child Left Behind Act (NCLB) which promises to up the ante and require higher levels of academic achievement among all students. How will Indian students fare under this scenario? For starters, Indian students are already being identified as being the lowest performers among all students. The Administration has made plans to privatize the lowest performing schools which equates to one third of the schools in the BIA system. How this initiative was conceived, the cost, and how Indian country was involved in the planning, are all factors into whether this plan will get off the ground. The legality of such a proposal is also in question. Indeed, in the long term, the administration is trying to help Indian communities, but is removing school governance the best way?

to help Indian communities, but is removing school governance the best way? According to the 1990 Census, there are 600,000 American Indian students in grades K through 12. Approximately eight percent (50,000) are educated through BIA schools on primarily Indian reservations. The majority of Indian students, however, attend public schools and are eligible for a number of education programs that are funded by the Department of Education. Specific programs for Indian students include those administered the department's Office of Indian Education. In terms of funding priorities, NIEA recommends targeted increases to the following programs with summaries on all programs benefitting Indian students.

## DEPARTMENT OF EDUCATION, OFFICE OF INDIAN EDUCATION

	President's request	NIEA request
Subpart 1, Grants to Local Education Agencies: LEAs Subpart 2, Special Programs for Indian Children:	\$97,133,000	\$97,133,000
Educational Services for Indian Children Indian Fellowships <sup>1</sup>	12,320,000	12,320,000 5,000,000
Professional Development Gifted and Talented Programs <sup>1</sup> Grants for Tribes for Education Admin/Plan/Dev <sup>1</sup> American Indian Teacher Training American Indian Administrator Initiative <sup>1</sup> Peer Review	7,220,000 360,000 100,000	3,000,000 3,000,000 7,220,000 3,000,000 100,000
Subpart 2, Subtotal	20,000,000	33,640,000
Subpart 2, Special Programs for Indian Adults: Adult Education <sup>1</sup> National Activities: Statistics and Assessment		5,000,000 5,200,000
Office of Indian Education National Advisory Council on Indian Education (Est) <sup>1</sup>	(²) 50,000	( <sup>2</sup> ) 600,000
Office of Indian Education Total	122,333,000	141,573,000

<sup>1</sup> Programs NIEA is requesting increases for. <sup>2</sup> General Administration.

## DEPARTMENT OF EDUCATION, OFFICE OF INDIAN EDUCATION (OIE) PROGRAMS

Formula Grants to LEAs. \$97.1 million.—The Department estimates that this funding assists 421,000 Indian students attending public and 42,000 students attending Bureau of Indian Affairs (BIA) schools for a total of 463,000.

Special Programs for Indian Children. Increase from \$20 million to \$33.6 million.—The Special Programs category includes the following authorizations:

Improvement of Educational Opportunities for Indian Children—\$12.3 million;
 Professional Development;

(3) Fellowships for Indian Students (not currently funded)—NIEA recommends \$5 million;

(4) Gifted and Talented Education (not currently funded)—NIEA recommends \$3 million;

(5) Grants to Tribes for Education Administration Planning and Development (not currently funded)—NIEA recommends \$3 million;

(6) American Indian Teacher Training—\$7,220,000; and

(7) American Indian Administrator Initiative—Increase from \$360,000 to \$3,000,000.

Special Programs for Indian Adults (Section 9131). Fund at \$5 million.—This program was last funded in 1995 when it received \$5.4 million for 30 projects to carry out educational programs specifically for Indian adults. National Activities. \$5.2 million.— This request would provide for research to aug-

National Activities. \$5.2 million.— This request would provide for research to augment the Year 2000 National Center for Education Statistics (NCES) Schools and Staffing Survey (SASS) and other data collection efforts. NIEA supports funding this activity through the Department's statistical agency, the National Center for Educational Statistics.

National Advisory Council on Indian Education (NACIE). Increase from \$50,000 to \$600,000.—NACIE has been without an office since 1996. The fifteen-member

Presidential council is authorized under the 1972 Indian Education Act to advise the Congress and the Secretary of Education on the needs in Indian education. Given the recently approved consultation policy approved by Secretary Paige, reinstating the NACIE office would be appropriate.

#### OTHER DEPARTMENT OF EDUCATION PROGRAMS BENEFITTING AMERICAN INDIANS, ALASKA NATIVES AND NATIVE HAWAIIANS

Amounts listed next to program are amounts expected to be received by BIA or non-BIA schools serving Indian students.

## Title I Grants to LEAs

*Title I.* \$76 million.—The Title I program is designed with the recently passed No Child Left Behind Act in mind. Higher accountability standards are an integral part of the new law and will include Indian students attending BIA Schools. BIA and outlying regions receive one percent of the Title I grants to LEAs. Approximately all 50,000 Indian students in the Bureau system will benefit from Title I services. The administration is requesting \$11.4 billion for Title I. *Reading First State Grants.* \$5 million.—The Reading First State Grants Program

Reading First State Grants. \$5 million.—The Reading First State Grants Program is new under the No Child Left Behind Act. BIA receives 0.5 percent of the State Grants funding. The Administration request for Reading First State Grants is \$1 billion.

*Comprehensive School Reform.* \$1.6 *million.*—The Comprehensive School Reform programs funding for scientifically based research to help schools meet challenging State standards. One percent of the Department's \$235 million request will assist BIA schools with school reform activities.

Event Start. \$3 million.—The Department is requesting \$200 million for the Even Start program. The program incorporates early childhood education, adult literacy, parenting education, and parent/child literacy activities. Literacy Through School Libraries. \$62,500.—This is a new program under the No

*Literacy Through School Libraries.* \$62,500.—This is a new program under the No Child Left Behind Act and is being requested at \$12.5 million. The program will help high-poverty school districts provide students with high-quality library services.

Improving Teacher Quality State Grants. \$14.2 million.—Funds are sued to strengthen the skills and knowledge of teachers and administrators to enable them to improve student achievement, development, and retention. The program consolidates the former Eisenhower Professional Development and Class-Size Reduction programs. The BIA will receive 0.5 percent of the \$2.85 billion request. Safe and Drug-Free School and Communities. \$4.75 million.—BIA schools will re-

Safe and Drug-Free School and Communities. \$4.75 million.—BIA schools will receive 1 percent of the State grants funding under this program to create and maintain drug-free, safe, and orderly environments to drug and violence prevention. The 2003 request is \$4.75 million. Native Hawaiians receive 0.2 percent of the program dollars for an approximate total of \$994,000. Impact Aid. \$519 million.—The Impact Aid program provides funding to LEAs

Impact Aid. \$519 million.—The Impact Aid program provides funding to LEAs under three separate categories including Basic Support, Payments for Children with Disabilities, and Construction. Fund are intended to help LEAs educate American Indian students attending their schools. Guidelines for parental involvement are an integral part of the program. Indian children generate 46 percent of the \$1.140 billion Impact Aid request for fiscal year 2003. —Basic Support Payments (\$462 million).—Basic Support Payment provide the

- -Basic Support Payment's (\$462 million).—Basic Support Payment provide the payments to LEAs in lieu of taxes for Indian children residing on Indian lands or other federally- connected lands which can't be taxed. Approximately 128,000 Indian children living on Indian lands generate 40 percent of the total Impact Aid allocation.
- -Payments for Children with Disabilities (\$21 million).-Impact Aid provides funding for special education-related services for approximately 18,700 Indian children living on Indian lands attending public schools. The Administration is requesting \$50 million under this program.
- -Construction (\$36 million).-Construction funds are included under Impact Aid and provide \$9 million in formula funds to districts on behalf on students residing on Indian lands. An additional \$27 million is provided for competitive construction grants. The administration request for construction is \$45 million.

English Language Acquisition \$55 million.—This program is the same at the former Bilingual Education program and supports the education of limited English proficient students. A 0.5 percent set-aside is allowed for American Indian and Alaska Native children and equals approximately \$5 million. An additional \$50 million is estimated to serve Indian students enrolled in public schools.

21st Century Community Learning Centers \$7 million.—The No Child Left Behind Act converted this program from a national competition to a State formula grant program with State educational agencies. One percent is reserved for the BIA and outlying areas. The fiscal year 2003 request of \$1 billion would provide \$7 million to the BIA.

*Education Technology State Grants \$5.1 million.*—The Education Technology State Grants program supports efforts to integrate technology into curricula to improve teaching and learning. One percent is available for the BIA and would equal approximately \$5.1 million for BIA schools. The fiscal year 2003 request is \$700 million.

Grants for State Assessments \$1.85 million.—The grants for State Assessments program helps states develop and implement the additional assessments required by the No Child Left Behind Act. With a 0.5 percent set-aside, the BIA would receive approximately \$1.85 million of the \$387 million request. Education for Native Hawaiians \$18.3 million NIEA recommends the fiscal year 2009 percent of \$20.5 million.

2002 amount of \$30.5 million).-Programs under this authority include curriculum development, teacher training and recruitment, higher education, special education, community-based learning centers, family-based education and gifted and talented programs

Alaska Native Education Equity \$14.2 million NIEA recommends the fiscal year 2002 amount of \$24 million).-Funding under this authority provide for student enrichment, preschool programs, teacher training and recruitment, and curriculum development.

Education for Homeless Children and Youth \$500,000.-The BIA received 1 percent of the \$50 million request for educational services for homeless youth.

Vocational Education \$14.75 million for Indian And Alaska Native tribes and organizations, \$2.95 million for Native Hawaiian organizations.—The BIA receives 1.25 percent of the State Grants under the Vocational Education program. The program supports academic, vocational, and technical skills of students in high schools and community colleges

Tribally Controlled Postsecondary Vocational and Technical Institutions \$6.5 million.—Provides competitive grants for the operation and improvement of tribally Controlled postsecondary vocational and technical institutions. Higher Education Aid for Institutional Development \$24.7 million: —Strengthening Tribally Controlled Colleges and Universities (\$18.1 million).—

- Authorized under this program are 1-year planning and 5-year development grants that enable institutions to improve and expand their capacity to serve American Indians students.
- Strengthening Alaska Native and Native Hawaiian-Serving Institutions (\$6.7 million).-Authorized under this program are 1-year planning and 5-year development grants that enable institutions to improve and expand their capacity to serve Alaska Native and Native Hawaiian students.

- Special Education \$86.6 million: —Grants to States (\$81.2 million).—The BIA is expected to receive 1.226 percent of the \$8.5 billion Special Education Grants to States appropriation. Approximately 8,500 Indian students in the BIA system would be served with disability education services.
- Grants for Infants and Families (\$5.4 million).-The BIA will receive funding under the Grants for Infants and Families authorization under the Special Education program.

Vocational Rehabilitation (\$26.8 million).—The Rehabilitation Act requires that between 1.0 percent and 1.5 percent of the funds appropriated under the State Grants program be set-aside for Indian tribes to provide vocational rehabilitation services to American Indians with disabilities living on reservations. The fiscal year 2003 request for this program is \$2.6 billion.

#### 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 Community Services Block Grant (CSBG) and seeks an appropriation of \$650 million for the state grant portion of the CSBG. The amount appropriated for the state grant portion in fiscal year 2002 was \$650 million. We are requesting flat funding this year in order to continue the efforts of the Community Services Network in assisting those families remaining on welfare with the intensive services they need to transition to work and to assist low-income workers in remaining at work through supportive services such as transportation and child care. These funds will continue to assist states in developing services in the 4 percent of counties that are not currently served by the CSBG. The fiscal year 2002 appropriation of CSBG included language regarding the distribution of the block grant at the state level. Each state had already employed an equitable funding formula that addressed the unique circumstances of the particular state. Many of the state funding formulas were state legislated. Passing national legislation regarding the distributions of the block grant at the state level preempts the prerogative of states to distribute the funds. NASCSP urges the committee to discourage the incorporation of authorization language in the appropriations act.

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 states believe the Community Services Block Grant (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 1,120 agencies which coordinate over \$7 billion in federal, state, local and private resources each year. Operating in more than 96 percent of counties in the nation and serving over 9 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 providing job placement and retention services, for another developing affordable housing. 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 partnerships between states and local agencies benefit citizens in each state. We believe it should be looked to as a model of how the federal government can best promote self-sufficiency for low-income persons in a flexible, 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

Locally directed.—Tri-partite boards of directors guide CAAs. 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 crosssection of the local community, they guarantee that CAAs will be responsive to the needs of their community.

Adaptability.—CAAs have demonstrated success in moving persons from welfare to work and in assisting low-income families in achieving self-sufficiency. CAAs provide a flexible local presence that governors have mobilized to deal with emerging poverty issues.

*Leveraging capacity.*—For every CSBG dollar they receive, CAAs leverage \$4.32 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.

Volunteer mobilization.—CAAs mobilize volunteers in large numbers. In fiscal year 1999, the most recent year for which data are available, the CAAs elicited more than 27 million hours of volunteer efforts, the equivalent of almost 13,000 full-time employees. Using the minimum wage, these volunteer hours are valued at more than \$141 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 also relied on by citizens in their community to deal with individual family hardships, such as house fires or other emergencies. *Accountable.*—The federal Office of Community Services, state CSBG offices and

Accountable.—The federal Office of Community Services, state CSBG offices and CAAs have worked closely to develop a results-oriented management and accountability (ROMA) system. Through this system, individual agencies determine local priorities within six common national goals for CSBG and report on the outcomes that they achieved in their communities.

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. Helping families become self-sufficient is a long-term process 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.

## WHO DOES THE CSBG SERVE?

National data compiled by NASCSP show that the CSBG serves a broad segment of low-income persons, particularly those who are not being reached by other programs and are not being served by welfare programs. Based on the most recently reported data, from fiscal year 1999:

- -70 percent have incomes at or below the poverty level; 47 percent have incomes below 75 percent of the poverty guidelines. In 1999, the poverty level for a family of three was \$13,880.
- Only 48 percent of adults have a high school diploma. -31 percent of all client families are "working poor" and have wages or unemployment benefits as income. 23 percent depend on pensions and Social Security and are therefore poor,
- former workers.
- Fewer than 15 percent receive cash assistance from TANF.
- -59 percent of families assisted have children under 18 years of age.

# WHAT DO LOCAL CSBG AGENCIES DO?

Since Community Action Agencies operate in rural areas as well as in urban areas, it is difficult to describe a typical Community Action Agency. However, one thing that is common to all is the goal of self-sufficiency for all of their clients. Reaching this goal may mean providing daycare for a struggling single mother as she completes her General Educational Development (GED) certificate, moves through a community college course and finally is on her own supporting her family without federal assistance. It may mean assisting a recovering 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 brought about 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 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
- -transportation and child care for low-income workers
- -individual development accounts
- -micro business development help for low-income entrepreneurs
- -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 other federal, state and local programs which makes it possible to provide a one-stop location for persons whose problems are usually multifaceted, 60 percent of the CAAs manage the Head Start program in their commu-nity. Using their unique position in the community, CAAs recruit additional volun-teers, bring in local school department personnel, tap into religious groups for addi-tional help, coordinate child care and bring needed health care services to Head Start centers. In many states they also manage the Low Income Home Energy Assistance Program (LIHEAP), raising additional funds from utilities for this vital pro-gram. CAAs often administer the Weatherization Assistance Program and are able to mobilize funds for additional work on residences not directly related to energy savings that may keep a low-income elderly couple in their home. CAAs also coordinate the Weatherization Assistance Program with the Community Development Block Grant program to stretch federal dollars and provide a greater return for tax dollars invested. They also administer the Women, Infants and Children (WIC) nutrition program as well as job training programs, substance abuse programs, transportation programs, domestic violence and homeless shelters, food pantries, as well as gardening and canning programs.

## EXAMPLES OF CSBG AT WORK

CAAs and state CSBG offices work diligently to support families transitioning off of the Temporary Assistance for Needy Families (TANF) block grant. Since 1994 CSBG has implemented Results Oriented Management and Accountability practices whereby the effectiveness of programs is captured through the use of goals and outcomes measures. Below you will find positive outcomes achieved by individuals, families and communities as a result of their participation in innovative CSBG programs.

- -Of the 442 homeless households served at a community action agency in Oregon, 80 received temporary housing to meet their immediate needs and 212 obtained permanent housing in fiscal year 2000.
- -98 percent of all individuals participating in a community action income management program in Montana obtained and maintained employment for 90 days in fiscal year 2000.
- —In Tulsa, Oklahoma the Individual Development Account (IDA) Matched Savings Program at Community Action Project of Tulsa County helped low-income people become more self-sufficient by providing over 150 clients with the knowledge and means to begin to accrue assets such as homes, small businesses or capitalization, education or retirement.
- As a response to the community's need the Fayette County Community Action Agency in Pennsylvania established the Community Medical Services clinic in 1997. This primary care center improves the conditions in which low-income people live by providing a full range of medical services including immunization, regular exams, treatment of chronic conditions, and blood tests to patients without health insurance.
- A community action agency in Nebraska helped low-income families maintain stable housing by improving the physical condition of housing through the weatherization of 168 units in fiscal year 2000. —Since 1988 CAP Services, Inc. has helped over 130 low-income clients own a stable in their own community and work toward master all sufficiency by an
- -Since 1988 CAP Services, Inc. has helped over 130 low-income clients own a stake in their own community and work toward greater self-sufficiency by providing services which allow them to start up and maintain micro-enterprises through the use of a Virtual Business Incubator in the counties of Marquette, Outagamie, Portage, Waupaca, and Waushara in Wisconsin.
- -Low-income clients in over 114 counties in Missouri received free Earned Income Tax Credit (EITC) assistance through local community action agencies. This resulted in over 1,500 low-income families with children receiving over \$2.5 million in refunds last year alone.

NASCSP therefore urges this committee to maintain funding the CSBG grant to the states at \$650 million.

## PREPARED STATEMENT OF FIGHT CRIME: INVEST IN KIDS

My name is Miriam Rollin, and I am the Federal Policy Director for the anticrime group Fight Crime: Invest in Kids, which is made up of more than 1,500 police chiefs, sheriffs, prosecutors and victims of violence from across the country who have come together to take a hard-nosed look at the research about what really works to keep kids from becoming criminals. I am also a former prosecutor.

Government's most fundamental responsibility is to protect the public safety. In many cases, this requires capturing, trying and imprisoning those who have committed a crime. There is no substitute for tough law enforcement. But once a crime has been committed, lives have already been shattered. Those on the front lines in the fight against crime understand that we'll never be able to just arrest, try and imprison our way out of the crime problem. We can save lives, hardship and money by investing in programs that can keep children from growing up to become criminals in the first place.

The members of Fight Crime: Invest in Kids have come together to issue a "School and Youth Violence Prevention Plan" that lays out four types of programs that research proves and law enforcement knows can greatly reduce crime. The plan calls for more investments in after- school programs, quality educational child care programs, services that can treat and prevent child abuse and neglect, and activities that get troubled kids back on track before it's too late.

These investments are overwhelmingly supported by law enforcement. A poll of police chiefs nationwide conducted by George Mason University professors showed that 86 percent of chiefs believed that expanding after-school programs and educational child care would greatly reduce youth crime and violence. When asked to rate the value on a scale of 1 to 5 of parent coaching programs for high-risk families, which are proven to reduce child abuse and neglect, 79 percent gave such programs a 1 or a 2 (with 1 being "very valuable" and 3 being "valuable").

The chiefs were also asked which of the following strategies they thought was most effective in reducing youth violence: (1) providing more after-school programs and educational child care; (2) prosecuting more juveniles as adults; (3) hiring more police officers to investigate juvenile crime; or (4) installing more metal detectors and surveillance cameras in schools.

Expanding after-school and educational child care was picked as the top choice by more than four to one over any other option. In fact, more chiefs chose "expanding after-school programs and educational child care" as "most effective" in reducing crime than chose the other three strategies combined. These chiefs are not alone. Dozens of state and national law enforcement associations have adopted resolutions highlighting the crime-fighting importance of quality child care, after-school programs, and programs that prevent abuse and neglect, including the Fraternal Order of Police, the Major Cities Chiefs organization, the National District Attorneys Association, the National Sheriffs Association, the Police Executive Research Forum, and in my own state, the Ohio Prosecuting Attorneys Association.

Now I'd like to share with you specifically how this subcommittee can help prevent crime and violence.

## EXPAND AFTER-SCHOOL PROGRAMS

In the hour after the school bell rings, violent juvenile crime soars and the prime time for juvenile crime begins. The peak hours for such crime are from 3:00 to 6:00 PM. These are also the hours when children are most likely to become victims of crime, be in an automobile accident, have sex, smoke, drink alcohol, or use drugs.

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In addition to saving lives, after-school programs save money. The Quantum Opportunities Program produced benefits to the public of more than \$3 for every \$1 spent on it, without even counting the savings from reductions in crime. Unfortunately, many communities do not have the resources to offer after-school programs. More than 10 million children lack adult supervision after-school. Our choice is simple: we can either send our children to after-school programs that will teach them good values and skills, or we can entrust them to the after-school teachings of Jerry Springer, violent video games or the streets.

The 21st Century Community Learning Centers program (21st CCLC) awards grants to communities to establish and run after-school programs that provide educational enrichment opportunities for children and their families. This committee has recognized the importance of this program, and increased funding significantly in recent years. But demand for 21st CCLC is so great that thousands of quality grant applications have been turned down over the last few years due to a lack of funding. Congress and President Bush recently increased the authorization of 21st CCLC to \$1.5 billion, and I hope you can fully-fund that level for fiscal year 2003.

## EXPAND AND IMPROVE QUALITY EDUCATIONAL CHILD CARE PROGRAMS

According to figures from the President's Administration, 62 percent of young children are in the care of someone other than their parents during the workday. The question is: will it be stimulating, nurturing care that helps kids develop, or "child storage" with too few adults who have too little training and too many kids? To quote President Bush's new early childhood initiative, "early childhood is a critical time for children to develop the physical, emotional, social, and cognitive skills they will need for the rest of their lives." The good news is that numerous studies of quality early childhood programs have shown that participants have better self-esteem, achievement motivation, social behavior, academic achievements, cognitive development, and grade retention than similar children who did not participate in such programs. What is equally important but less well-known is that quality educational child care programs can also significantly reduce the chances of a child growing up to become a criminal. A study published in the Journal of the American Medical Association last year demonstrated this. Over the last 30 years, Child-Parent Centers have provided school readiness child care to 100,000 3- and 4-year-olds in Chicago's toughest neighborhoods. The study examined outcomes at age 18 for 1,000 of these children, and a matched group of 500 similar children who had not been enrolled in the Child-Parent Centers' quality child care were 70 percent more likely to have been arrested for a violent crime by the time they reached adulthood. Kids left out of the program were also more likely to be held back in school, more likely to drop out, and less likely to graduate which are risk factors for later violence.

The researchers estimated that the program will have prevented 33,000 crimes including 13,000 violent crimes by the time all 100,000 participants reach age 18. Clearly hundreds of thousands of crimes would be prevented each year if all families nationwide had access to programs like this. When our fight against crime starts in the high chair, it won't end in the electric chair. In addition to saving lives, these programs also save money. Counting only savings to government, the Chicago Child-Parent Centers returned almost \$3 for every \$1 invested. Counting those government savings, savings to crime victims, and benefits to the participants in the program, the results are \$7 saved for every \$1 invested.

Unfortunately, millions of children are being left out of these types of programs. Without government help, such programs are just too expensive for low- and moderate-income families. In every state, the cost for an infant to attend a good child care center is higher than the cost of tuition at a public university. Adequate care for two children in a child care center can easily cost over \$12,000 a year about \$2,000 more than a full-time minimum-wage worker earns.

Many working parents can't possibly pay these costs, any more than they could pay private school tuition if public schools were eliminated. Unfortunately, the crime-reduction and other benefits I described earlier only occur when children are able to participate in quality programs not programs that are simply "child storage." We can no more afford to accept child care that is merely "custodial" than we could accept assigning some children to public schools that are "custodial" rather than "instructional." Clearly that is not what Congress or the President desires, given the recent enactment of the No Child Left Behind Act. This committee can make sure our children get a good start in life by increasing funding for the following programs.

Head Start and Early Head Start provide comprehensive services to infants and young children from poor families. Head Start is so underfunded that it cannot serve more than 40 percent of the 3- and 4-year-olds eligible for the program, while Early Head Start can serve less than 2 percent of those eligible. In addition, four in ten Head Start families need full-day, full-year services, but less than one in ten attend year-round programs, and only one in eight centers run full-day programs. Few centers even operate after 5 p.m., which is problematic because about 25 percent of low-income workers have evening or over-night jobs. An increase of \$1.0 billion in fiscal year 2003 funding for this critical program is necessary to help send more children to school ready to learn. The Child Care and Development Block Grant (CCDBG) provides states with

The Child Care and Development Block Grant (CCDBG) provides states with funds to help low-income working families afford child care. This program allows parents the flexibility to arrange child care that fits the needs of the family and can also be used for after-school activities. Unfortunately, this program is so underfunded that, according to estimates from the President's Administration, 70 percent of children eligible for child care benefits do not receive them. More funds are also needed to help increase the quality of child care programs in order to achieve crimeprevention results comparable to the ones I discussed earlier. An increase in funding of at least \$1 billion for fiscal year 2003 is badly needed for this program. The Early Reading First program helps communities support preschool literacy

The Early Reading First program helps communities support preschool literacy activities and related professional development instructional materials and assessments. I'd like to commend President Bush for his leadership in creating this program last year, and I urge the committee to approve the President's request of \$75 million for fiscal year 2003.

The Early Learning Opportunities Act (ELOA) helps communities fund parentingeducation programs and quality child development services to children under five. A fiscal year 2003 funding level of \$125 million would help this young program grow, and bring its funding to a level that is still only a fraction of its authorization level. Child abuse and neglect is a crime that keeps on hurting. It hurts innocent kids immediately. And too often, it starts a cycle of violence that leads to more crime, and sometimes more child abuse. Most kids who are abused or neglected grow up to become law-abiding citizens despite what they have gone through. But too many don't. Being abused or neglected multiplies the risk that a child will grow up to become a criminal a tragedy for the child, and also a tragedy for us all. The abuse inflicted in 1 year alone will ultimately result in tens of thousands of extra arrests for violence and hundreds of future homicides. The good news is that equality programs really work to provent abuse and perfect

The good news is that quality programs really work to prevent abuse and neglect. For example, the Nurse Family Partnership program randomly assigned half a group of at-risk mothers to receive visits by specially-trained nurses who provided coaching in parenting skills and other advice. Rigorous studies published in the Journal of the American Medical Association show the program cut abuse and neglect by 80 percent in the first 2 years. Fifteen years after services ended, the mothers had only one-third as many arrests, and their children were only half as likely to be delinquent (compared to those who got no services).

In nearly every state, child protective, foster care and adoption services lack adequate staff and training to prevent abuse, protect children and help those who have been maltreated get the nurturing care and treatment needed to help them heal. Agencies are so under-funded that many abuse and neglect reports can't even be investigated. Congress has the opportunity to help communities with these efforts through a number of different programs this committee oversees.

The Social Services Block Grant (SSBG) is the federal government's single largest support for child abuse and neglect-related services. Its helps states fund a variety of activities including foster care, adoption and child protective services. Unfortunately, funding for this program has been cut by almost 40 percent from what was promised in 1996. Bipartisan legislation in the Senate, endorsed by President Bush, would restore SSBG to its previously-authorized level of \$2.8 billion. I hope this committee will support this level for fiscal year 2003.

would restore SSBG to its previously-authorized level of \$2.8 billion. I hope this committee will support this level for fiscal year 2003. The Promoting Safe and Stable Families program (PSSF) funds community-based services that prevent child abuse and neglect through parenting-education activities, family strengthening services for troubled families, adoption services, and other preventive programs. Just this winter, Congress approved a new authorization for this program of \$200 million in discretionary spending, and President Bush has requested this amount in his budget. I hope you can make good on that promise and appropriate the fully authorized amount for fiscal year 2003.

<sup>1</sup>The Chafee Independent Living program was amended with the reauthorization of PSSF to create a new education and training voucher program for youth aging out of foster care, at a level of \$60 million a year. President Bush has requested full funding of this program for fiscal year 2003, and I hope you will support that amount.

The Child Abuse Prevention and Treatment Act provides funds to states to support prevention, assessment, investigation, prosecution, and treatment. Unfortunately, it is currently funded at only half of its authorized level. That doesn't even take into account the authorization increases recently passed by the House. Please fully fund this program at \$166 million for fiscal year 2003.

#### HELP TROUBLED KIDS GET BACK ON TRACK

When children are disruptive or troubled, it is a warning signal that it is time to start looking for causes, and to provide the proven social skills training, counseling or other services that can lead the children back to a healthier path. One of the best ways to reach troubled kids before its too late is through drop-out prevention programs. Research demonstrates that drop-outs are more likely to commit crimes than high school graduates. In one study, males who dropped out before age 15 had their odds of becoming involved in violence more than triple. This is not surprising, since dropping out has the short-term effect of leaving youngsters unsupervised on the streets, and the long-term impact of leaving teens and adults without the skills they need to make an honest living. In fact, drop-outs comprise a disproportionate percentage of the nation's prison and death row inmates.

The Drop-out Prevention program recently created by Congress as part of the new education law supports effective, sustainable and coordinated drop-out prevention and reentry programs that include remedial education, counseling and mentoring for at-risk students. This program is authorized to receive \$125 million in fiscal year 2003. I hope you can appropriate this full amount.

In conclusion: every day that we fail to invest adequately in quality early childhood education and care, after-school activities, programs that prevent child abuse and neglect, and efforts to get troubled kids back on track, we increase the risk that you or someone you love will fall victim to violence. I'm here to ask you to pay attention to this plea from the people on the front lines

I'm here to ask you to pay attention to this plea from the people on the front lines in the fight against crime: Invest in America's most vulnerable kids now, so they won't become America's Most Wanted adults later.

Thank you for this opportunity to provide written testimony to your Subcommittee.

## PREPARED STATEMENT OF THE NATIONAL CONGRESS OF AMERICAN INDIANS

On behalf of the National Congress of American Indians (NCAI) and its more than 200 member tribal nations, we are pleased to have the opportunity to present written testimony on fiscal year 2003 appropriations for the Departments of Labor, Health and Human Services, and Education.

The tragic events of September 11 brought forth the strength and the determination of our nation to survive in the face of adversity. It is this same spirit that has carried Indian Country through years of annihilation and termination. It is this same spirit that has propelled Indian Nations forward into an era of self-determination. And it is in this same spirit of resolve that Indian Nations come before Congress to talk about honoring the federal government's treaty obligations and trust responsibilities throughout the fiscal year 2003 budget process.

The federal trust responsibility represents the legal obligation made by the U.S. government to Indian tribes when their lands were ceded to the United States. This obligation is codified in numerous treaties, statutes, Presidential directives, judicial opinions, and international doctrines. It can be divided into three general areas—protection of Indian trust lands; protection of tribal self-governance; and provision of basic social, medical, and educational services for tribal members.

NCAI realizes that Congress must make difficult budget choices this year. As elected officials, tribal leaders certainly understand the competing priorities that members of Congress must weigh over the coming months. However, the fact that the federal government has a solemn responsibility to address the serious needs facing Indian Country remains unchanged, whatever the economic or political climate may be. We at NCAI urge you to make a strong commitment to meeting the federal trust obligation by fully funding those programs that are vital to the creation of vibrant Indian Nations. Such a commitment, coupled with continued efforts to strengthen tribal governments and to uphold the government-to-government relationship, will truly make a difference in helping us to create stable, diversified, and healthy economies in Indian Country.

NCAI's statement focuses on our key areas of concern surrounding the President's budget request. Of course, there are numerous other programs and initiatives within the Labor-HHS-Education appropriations bill that are important to American Indians and Alaska Natives. Attached to this testimony is a breakdown of key programs for which we urge your support at the highest possible funding level as the appropriations process moves forward.

## DEPARTMENT OF LABOR

The Census Bureau's Poverty in the United States for 2000 showed that American Indians and Alaska Natives remain at the bottom of the economic ladder—with 25.9 percent of our population falling below the poverty line. This compares to an 11.9 percent poverty rate for all races combined. Today, unemployment rates in Indian Country are the highest in the nation, sometimes topping 50 percent.

In the face of the demonstrated need to support effective employment and training programs in Indian Country, NCAI is extremely concerned about the effects of the proposed \$1.1 billion cut to discretionary programs within the Department of Labor. Specifically, we call upon Congress to reject the following programmatic reductions: *—Workforce Investment Act (WIA).*—The WIA was signed into law in August 1998,

- -Workforce Investment Act (WIA).—The WIA was signed into law in August 1998, replacing the former Job Training Partnership Act (JTPA). The President has proposed a \$2 million cut to the \$57 million currently provided for the Indian comprehensive services program, which funds tribes and off-reservation organizations to provide services to Native American youth and adults.
- zations to provide services to Native American youth and adults. —Youth Opportunity Grants.—The budget would slash funding for the Youth Opportunity Grant (YOG) program from \$225 million to \$44 million. Native American grantees serving reservation areas and Alaska Natives are eligible to apply for funding under this competitive program. The YOG program brings together the knowledge and resources of government, community and faith-based organizations to solve the problems of some of the nation's most deeply disadvantaged communities, helping them to build a more promising future for their young

people. Thirty-six communities across the county received YOG awards in February 2000, including six Native American communities.

## DEPARTMENT OF HEALTH AND HUMAN SERVICES

# Administration for Native Americans

The ANA is playing a key role in helping to move numerous tribal programs from federal dependency to developing and implementing their own locally-driven 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.

ANA administers its basic grant program in four distinct categories—social and economic development strategies (SEDS), Alaska-Specific SEDS, environmental regulatory enhancement, and Native language preservation and revitalization.

The SEDS program includes a wide range of governance projects allowing for tribal constitution revisions and codes/ordinance development, social projects that are based on maintaining and fostering cultural traditions, and economic development projects covering a wide range of areas. These economic development projects include not only the development of new enterprises but also the expansion of existing successful businesses. The majority of economic development projects are planning grants for architectural and engineering costs or grants that provide for economic development infrastructure.

The President's budget has proposed a \$1 million cut to the ANA, from \$46 million to \$45 million. We urge you to reject this cut and to increase funding to the ANA so that it may assist even more tribal governments in building their administrative capacities and infrastructures.

## Administration on Aging

Without exception, our tribal cultures teach us to honor and respect Indian elders so that our elders—the living expression of our heritage and highest values—can be teachers to us and to our children.

Aging Grants for Native Americans promote the delivery of supportive services, including nutrition services, to older American Indians, Alaska Natives, and Native Hawaiians. Funding for this program provides key "front-line" services for over 200 programs serving reservation elders, including congregate and home-delivered meals, transportation, and a wide variety of other services. In recognition of the fact that grantees report significant increases in the number of elders eligible for the service, the Administration has proposed a \$2 million increase for this program, to \$27.7 million. We are in strong support of this request, which is long overdue in light of the growing population of Native elders, and further urge that at least \$30 million be appropriated for fiscal year 2003.

We also are pleased that the Administration has proposed continuation of the current \$5.5 million for Native Americans under the Family Caregivers program, which will provide information, respite care, and other support services to 250,000 families caring for loved ones who are ill or disabled.

## Homeland Security

Tribes are very concerned about their exclusion from homeland security planning and appropriations. Tribal lands are adjacent to hundreds of miles of international border, and many reservations are home to energy generation plants and other sensitive areas that require special protection. Tribal sovereignty requires that issues of mutual security between the federal government and tribes be handled directly between these two levels of government. We support a direct appropriation to tribes of homeland security resources funded through the Department of Health and Human Services, including those provided to HRSA, CDC, and SAMHSA.

## DEPARTMENT OF EDUCATION

Most Indian students attend public schools and are eligible for a number of education programs that are funded by the Department of Education, including those administered the Department's Office of Indian Education. In light of the Administration's pledge to "Leave No Child Behind," NCAI is disappointed that the Administration has level-funded most of the programs within the Office of Indian Education, and joins the National Indian Education Association in recommending the following funding levels for Office of Indian Education programs:

<sup>-</sup>Formula Grants to LEAs (\$97.1 million).—The Department estimates that this funding assists 421,000 Indian students attending public and 42,000 students attending Bureau of Indian Affairs (BIA) schools for a total of 463,000.

- --Special Programs for Indian Children (\$33.6 million).--Funds should be allocated as follows: Improvement of Educational Opportunities for Indian Children/Professional Development (\$12.3 million); Fellowships for Indian Students (\$5 million); Gifted and Talented Education (\$3 million); Grants to Tribes for Education Administration Planning and Development (\$3 million); American Indian Teacher Training (\$7.2 million); American Indian Administrator Initiative (\$3 million).
- Special Programs for Indian Adults (\$5 million).—This program was last funded in 1995 when it received \$5.4 million for 30 projects to carry out educational programs specifically for Indian adults.
- *In 1995 which is received within the programs specifically for Indian adults. —National Activities (\$5.2 million).*—This request would provide for research to augment the Year 2000 National Center for Education Statistics (NCES) Schools and Staffing Survey (SASS) and other data collection efforts. NCAI supports funding this activity through the Department's statistical agency, the National Center for Educational Statistics.
- -National Advisory Council on Indian Education (\$600,000).—NACIE has been without an office since 1996 and is currently funded at \$50,000. The fifteenmember Presidential council is authorized under the 1972 Indian Education Act to advise the Congress and the Secretary of Education on the needs in Indian education. Given the recently approved consultation policy approved by Secretary Paige, reinstating the NACIE office would be appropriate.

#### CONCLUSION

Thank you for this opportunity to present written testimony regarding Labor-HHS-Education programs that benefit Indian Country. The National Congress of American Indians calls upon Congress to fulfill the federal government's fiduciary duty to American Indians and Alaska Native people. This responsibility should never be compromised or diminished because of any political agenda or budget cut scenario. Tribes throughout the nation relinquished their lands and in return received a trust obligation, and we ask that Congress maintain this solemn obligation to Indian Country and continue to assist tribal governments as we build strong, diverse, and healthy nations for our people.

# PREPARED STATEMENT OF THE CITY OF MIAMI BEACH, FL

On behalf of the City of Miami Beach, FL, I appreciate the opportunity to submit this written testimony to you today on two extremely important initiatives, currently underway within our city. We respectfully request your consideration of these projects for funding from your fiscal year 2003 appropriations legislation. *—Miami Beach Cultural Arts Initiative.*—The City of Miami Beach is requesting

-Miami Beach Cultural Arts Initiative.—The City of Miami Beach is requesting assistance in the amount of \$1 million from the IMLS program to continue the City's efforts to support programming and training opportunities for performing and visual arts organizations in Miami Beach, and to support local museum and educational initiatives.

educational initiatives. The City Miami Beach is the region's most powerful generator of tourism, culture, and recreation, and internationally regarded as Florida's preeminent cultural city. The arts in Miami-Dade County have an estimated annual impact of \$538 million. In 2000, Miami Beach became a self-designated arts city; sign at major City entrances welcome visitors to our "ArtsBeach." Perhaps only Rio de Janeiro surpasses Miami Beach as a culturally sophisticated, tropical seaside resort. The arts are thriving in Miami Beach and are generating significant benefits in economic development, cultural tourism, and quality-of-life for the community. Many of Florida's major cultural institutions are based in Miami Beach, among

Many of Florida's major cultural institutions are based in Miami Beach, among them the Wolfsonian-FIU (recently cited as one of the world's ten best small museums), New World Symphony (America's orchestral academy directed by Michael Tilson Thomas, conductor of the San Francisco Symphony), Miami City Ballet, ArtCenter/South Florida, Jewish Museum of Florida, and Bass Museum of Art. The City owns several performance venues, including the Jackie Gleason Theater of the Performing Arts, and Colony Theater, the latter of which was recognized by Congress as one of America's Treasures. Major performances are mounted in these venues and on the beach itself by cultural groups supported by the City of Miami Beach, including Miami Light Project, Concert Association of Florida, Rhythm Foundation, Tigertail Productions, Florida Grand Opera, and six annual film festivals. In the historic district of South Beach, the City is developing the Collins Park Cultural Center, home to the Miami City Ballet, Bass Museum of Art (with its recent \$8 million expansion), and the future Miami Beach Regional Library. Art Basel, the Swiss-based "Superbowl of contemporary art shows" (New York Times), has selected Miami Beach for its first annual fair outside Switzerland. Art Basel Miami Beach is expected to become the dominant contemporary art fair of North and South America when it debuts in December 2002.

The Miami Beach Cultural Arts Council was created in 1997 to develop, coordinate, and promote the performing and visual arts groups. It accomplishes this mission by serving as arts advocates before governmental bodies, by coordinating marketing programs, by funding not-for-profit arts organizations, by promoting international cultural tourism to the City, and more. Since 1997, the Council has awarded nearly \$3 million to some eighty not-for-profit arts groups, and joined economic forces with the Miami Beach Visitor and Convention Authority (VCA) and the Miami-Dade Department of Cultural Affairs to award grants for Beach-based cultural events and to help promising local arts groups develop. The Council is comprised of eleven spirited and knowledgeable Beach residents who express their commitment to the community through their involvement with the Council. All are volunteers appointed though a highly competitive process by the Mayor and City Commission for 3-year terms with limits of 6 consecutive years. Its two full-time staff are City employees. The Council regularly meets with hundreds of community advisers and grants panelists who serve on its various committees, as well as with its constituents.

Cultural arts grants are awarded through an annual competitive process involving peer review to eligible organizations, i.e., local, not-for-profit corporations producing or presenting visual or performing arts in the City of Miami Beach. Since its inception, the Miami Beach Cultural Arts Council has awarded the following grants:

1998–1999—awarded to 55 groups	. \$509,000
1999-2000-awarded to 56 groups	. 585,000
2000-2001-awarded to 58 groups	. 958,000
2002–2003—awarded to 71 groups	. 672,000

Another key component of the Miami Beach cultural scene is the Miami Beach Arts Trust, a not-for-profit corporation created by the Miami Beach Cultural Arts Council in 1999. The Arts Trust supports the work of the Arts Council by working to build a financial endowment for the arts in Miami Beach. The City recently purchased vacant movie theater in North Beach for a multi-million dollar renovation project that will transform it into the Byron-Carlyle Arts Center/North Beach Cultural Facility. Four not-for-profit groups recently relocated to the reconfigured lobby, as work continues in the remainder of the facility.

In 2000, the Cultural Arts Council launched a free, monthly citywide cultural arts night called "ArtsBeach Second Thursdays." This is a free celebration of the arts on the second Thursday of every month from 6 to 9 p.m. in many different locations throughout Miami Beach. All cultural groups supported by the City participate throughout the year. The series attracts thousands of participants, with the first hour featuring events for children. Because of the high demand for information about cultural activities in Miami

Because of the high demand for information about cultural activities in Miami Beach, the City created two popular non-commercial websites under the aegis of the Arts Council: ArtsBeach.com and 2ndThursdays.com. These sites have global reach and response, with tens of thousands of hits a month. Educational institutions are also an important part of the City's cultural scene,

Educational institutions are also an important part of the City's cultural scene, as illustrated by Florida International University's partnership with the Wolfsonian Museum. The City of Miami Beach has placed high priority on development of the arts through educational institutions, not only at the university level, but in primary and secondary education as well.

The cultural arts played a key role in the development of Miami Beach's South Beach area into an international economic phenomenon. The creative atmosphere the arts established in the City made Miami Beach the ideal location for film and fashion production which ultimately brought multi-national entertainment companies to Miami Beach when they looked to expand their operations into the Americas. The City is now houses over 135 entertainment industry firms, including the Latin American headquarters of companies such as Sony, MCA, MTV, Nickelodeon, Elite Models, ASCAP, and LARAS, the Latin American operations of the NARAS, the National Academy of Recording Arts and Sciences. Along with the renourishment of the City's beaches and the redevelopment of the Art Deco Historic District, the development of the arts remains one of the most important ingredients behind South Beach's re-emergence as one of the world's most important tourist destinations.

A recent study conducted by the Economics Department of Florida International University established that the performing arts provide Miami Beach with the highest economic impact multiplier of all sectors studied, meaning that dollar for dollar, more impact is generated in the local economy per dollar invested in performing arts than any other sector. The challenge for cities such as Miami Beach is providing a large enough investment from which the local economy can receive the biggest "bang for the buck."

Miami Beach is a leader in the continued role that the State of Florida plays to ensure that the United States remains competitive in the international economy, not only in the arts and tourism, but in all sectors, especially as South Florida, with Miami Beach at its epicenter, emerges as the Capital of the Americas. In order to help maintain Miami Beach's role in the 21st Century, the continued investment in quality cultural activities is necessary. To this end, the City of Miami Beach is requesting a commitment of \$1 million to the City's efforts to support programming and training opportunities for performing and visual arts organizations in Miami Beach, and to support local museum and educational initiatives.

# PREPARED STATEMENT OF CROWNPOINT INSTITUTE OF TECHNOLOGY, CROWNPOINT, NM

This testimony addresses appropriations under The Carl D. Perkins Vocational Education Act, Section 117 "Tribally Controlled Vocational and Technical Institutions."

On behalf of the Crownpoint Institute of Technology, (CIT), I thank this Subcommittee for appropriating operational funds to Section 117 on the amount of \$6.5 Million for fiscal year 2002, which is forward funded and will be awarded among eligible institutions by the Department of Education for the upcoming academic year (2002–2003). Most importantly, on behalf of all of CIT's current and future students, I thank the Subcommittee for its technical amendments in 2001 through the Emergency Supplemental Appropriations process. These critical Subcommittee interventions clarified the intent of the Congress to the Department, and in so doing, enabled CIT to remain in operation. It has been CIT understands from the Congress that this amendment provided a solution that would be effective for the duration of the Carl Perkins authorization. However, the Department advises CIT that the Department interprets this amendment to be for the current year only. We ask this Subcommittee's assistance in providing the necessary clarification to the Department.

Because the division within the Department of Education that administers Section 117 primarily administers competitive supplemental grants, such as Section 116 for tribes and tribal colleges, we believe that the Department does not fully understand the intent of the Congress in creating Section 117. This provision, Tribally Controlled Postsecondary Vocational Institutions, was crafted by the Congress to provide operational support for all tribal colleges which are not eligible for the "Tribally-Controlled Community Colleges and Universities Assistance Act," Public Law 95–471. Because the Tribal Colleges Act is funded by Interior Appropriations through U.S. Department of Interior, the Department of Education does not see the Tribal Colleges Act limits funding to only one college per tribe. During the original 1990 enactment of what is now Section 117 of the Carl Perkins Vocational Education Act; there were only two tribal colleges in the nation which were not eligible under Public Law 95–471. Although the Department does not disclose additional eligible institutions in advance of awards, to the best of our knowledge there are still only two tribal colleges in the nation that do not qualify under Public Law 95-471 and are therefore eligible for Section 117. More than two decades after their found-ing, there remain only two tribal vocational colleges in the nation, although during these same years several new tribal community colleges have been added under the Tribal Colleges Act. Each of those colleges is the only college that the sponsoring tribe has chartered. The vast majority of Indian tribes have never founded a first tribal college. Due to the small populations of most tribes, it is highly unlikely that tribes other than the Navajo will need to found second tribal colleges.

Section 117 was intentionally patterned after Public Law 95–471. The most consequential provision replicated by Section 117 from the Tribal Colleges Act is the Indian Student Count funding formula, which provides for equitable funding at each eligible institution based on full-time equivalency enrollment. This enrollment-driven, legislative safeguard intends to guarantee an equitable distribution of any appropriation on an equal level per student regardless of which eligible institution they attend, just as the Tribal Colleges Act does for the nation's other tribal colleges.

leges. The average population of tribes chartering tribal colleges ranges between 3,000 and 10,000 members. The Navajo tribe is a population anomaly among Indian tribes with 225,298 members living on and near the reservation (U.S. Census). Dine College, Tsaile, Arizona, is the Navajo Tribal College funded under Interior's Tribal Colleges Act. Founded in 1968, Dine is the first of the nation's tribal colleges. CIT was founded in 1979 as a job-skills training center. Over the first 7 years of operation, CIT evolved from a job-training center to a full-fledged vocational technical college. Skilled employment opportunities expanded for students graduating with credentialed degrees or certificates, and CIT earned full institutional accreditation from North Central Association of Colleges and Schools in 1986. CIT's outstanding success at providing its students with highly marketable career skills has enabled graduates to enter high-demand employment fields with lifelong marketable job skills.

The size of the Navajo population warrants a second college. Geographic access to postsecondary education is another reason tribal colleges were founded. These factors are even more compelling for the Navajo Nation which is comprised of a vast and remote 26,897 square mile reservation extending into three States: Arizona, New Mexico and Utah. The Navajo Nation reservation is 2,810 square miles larger than the State of West Virginia and only slightly smaller than the five New England States of Vermont, New Hampshire, Massachusetts, Connecticut and Rhode Island combined. The driving distance across this reservation is approximately nine hours. In the situation of the Navajo people, geography, isolation and population uniquely combine to predicate this unusual need for a second college. In hindsight, the Tribal Colleges Act should have allowed for this unusual situation. CIT was founded a year after the Tribal Colleges Act was passed. However, tribal colleges remained unapproved net surprisingly unwilling to dilute their

In hindsight, the Tribal Colleges Act should have allowed for this unusual situation. CIT was founded a year after the Tribal Colleges Act was passed. However, tribal colleges remained unanimously and, not surprisingly, unwilling to dilute their enrollment-driven Act to allow a second college in a situation where an unusually large tribal population existed. There are sixteen Indian tribes in the three States of Montana, North Dakota and South Dakota. Each of these tribes has a tribal college supported by the Tribal College Act. Yet the combined population of on-reservation, all-ages of these sixteen tribes is 72,835. The Navajo's one tribe population of over 225,000 exceeds this by more than three-fold.

bit an ages of these stateen these is 12,635. The taylors one three population of over 225,000 exceeds this by more than three-fold.
Enactment of Section 117, "Tribally Controlled Vocational Postsecondary Educational Institutions," was Congress's solution to this gross inequity. Section 117 would be a fair and effective solution if the Department would adhere to the student funding formula in the law. However, the Department continues to override adherence to this provision of the law with their regulations. Section 117 remains the only legislation for tribal educational institutions in existence that is not administered on a per student basis. Nearly three decades ago, Congress began equalizing funding to all tribal educational institutions, from K-12 through postsecondary levels. This policy has been largely successful and was achieved by enacting laws that require funding to be based on enrollment in instances where more than one institution is funded under any law. However, because Section 117 is administered within the Department where its other programs are supplemental to the institutions basic operational funding from another source, it seems difficult for the Department to find alternate interpretations that reduce the awards to competitions. From any perspective, this is unfair to the students. It is CIT's observation that in implementation of Section 117, the Department's regulations supercede the requirements of the law. The Department's imposition of regulations that disallow costs that are allowed in the law eliminates many necessary activities from CIT's applications for funding. This results in CIT not being able to conduct activities that are specified in the law. It also results in CIT with the largest enrollment receiving the smallest allocation. This is the exact opposite of both the intent of the Congress as well as the letter of the law.

of the law. CIT experiences particular hardship under the Department's method of interpreting Section 117 because CIT is experiencing a steadily increasing enrollment. The decennial tribal population increase is 14 percent, as compared to only 8 percent for mainstream America. Median Native American population age is now 27.4 years, 8 years younger than the median age for mainstream America. Over 10,000 students graduate from Navajo area high schools every year. Less than 6 percent of these high school graduates are bound for off reservation colleges. To accommodate the increasing demand from applicants, CIT has continued to increase its student housing capacity with assistance from the Navajo Nation and HUD funding. This year, another 16 married student units toward a 3 year total of 32. This year's residential additions will be completed by fall 2002 for students with dependant children. Students with dependant families are among those most in need of employment skills. Each year, CIT has averaged a waiting list of approximately 200 otherwise qualified students due to residential housing limitations. The town of Crownpoint offers little in the way of available rental housing and the majority students must rely on CIT's residential offerings. Daily commuting from most parts of the reservation is out of the question due to poor roads, harsh winters and incredible distances. With the ability to accommodate additional students, CIT relies even more on the Department of Education to adhere to per student funding allocation mandated by Section 117.

CIT believes it has established its merit as a tribal institution worthy of federal assistance. CIT has an 8-year average student retention rate of 95 percent, and an average job placement rate of 86 percent over the same period. CIT's current enrollment is 526 Full Time Equivalency/Indian Student Count.

CIT offers fully-accredited 2 year Associate of Applied Science degrees and/or 1 year certificates in high employment demand fields including: Accounting, Administrative Assistant, Applied Computer Technology, Automotive Technology, Building Maintenance, Carpentry, Culinary Arts, Electrical Trades, Environmental Technology and Natural Resources, Law Advocate, Legal Assistant, Nursing Assistant and Veterinary Assistant. CIT plans to offer Dental Assistant and Health Technician in response to high employment opportunities in the area and shortages of skilled workers in these fields. CIT has already secured donated and federal surplus property dental training equipment, minimizing its reliance on federal resources to achieve successful programs. If the Department does not make awards based on student count, CIT will be hampered in its ability to offer these programs. While the high demand for employees in these skilled fields will still exist, employers will recruit from outside the area, while Navajo people who could have been trained to fill these positions will remain jobless.

CIT's average student age is 26, although the actual range has been 18–64. CIT is open to and welcomes all qualified Indian and non-Indian applicants, and as just one example has retrained displaced non-Indian uranium workers from neighboring towns. However, the primary mission for this institution is to rectify the joblessness and hopelessness so prevalent among too many of the more than 200,000 reservation people. CIT graduates earn an average \$17,160 entry-level annual wage, although some fields pay as high as \$23,920 at entry level (Veterinary Assistant). CIT's lucrative but limited Commercial Drivers License graduates pays \$16 to \$18 an hour at entry level. Each employed graduate pays an average of \$2,576 of their earnings to federal taxes in the first year of employment alone. While taxes vary according to number of dependants and other factors, wage earnings and tax contributions will generally continue over an at least 30 years of employment. CIT lacks institutional resources to track all of its graduates over the past two decades, but of those tracked, 61 percent are employed in private industry and do not rely directly or indirectly on federal appropriations for jobs. In an average lifetime of employment, CIT graduates will return to the federal government the cost of its investment many times over.

Section 117 is authorized through 2003. It must be corrected before that date. We urge this Subcommittee to intervene in rectifying the misinterpretations of the law, and the misallocation of its generous appropriations at the Department level.

# PREPARED STATEMENT OF THE ASSOCIATION OF PUBLIC TELEVISION STATIONS

This testimony is submitted to the Labor, Health and Human Services, Education and Related Agencies Appropriations Subcommittee on behalf of the Association of Public Television Stations (APTS) and its members, who are the nation's local public television stations, and the Public Broadcasting Service (PBS) in support of funding for the Ready to Learn and Ready to Teach Programs at the U.S. Department of Education.

Public television requests that the Subcommittee provide funding for the Ready To Learn program at \$24 million and the Ready to Teach program at \$15 million. Both of these programs are administered through the Department of Education. The Ready To Learn program provides funding for the development and production of the highest quality children's educational television programming. It also assists local stations in their outreach efforts to provide family literacy training to teachers, parents and child care providers to effectively use these programs to prepare young children for academic success when they enter school. Ready to Teach continues the Ready To Learn theme by focusing on educational excellence throughout a child's life. The Ready to Teach program is premised upon three core objectives: teacher quality, student achievement, and innovative classroom materials and teaching tools.

Public television's Ready To Learn and Ready To Teach programs are authorized and in-place resources to ensure effective nationwide implementation of the "No Child Left Behind Act of 2001."

## READY TO LEARN FOR ALL CHILDREN

Ready To Learn is public television's contribution toward our nation's most urgent goal for our children—ensuring that they begin school Ready To Learn. In essence, the Ready To Learn service is the nation's largest classroom. Through the use of the nation's public television stations, 99 percent of the nation's population can be reached with free, over-the-air children's educational programming. The President's Budget requested \$22 million for the program for fiscal year 2003, the same amount provided by Congress in fiscal year 2002.

Ready To Learn provides the seed money for the production of award-winning, educational, and commercial-free children's programs, which actively foster literacy, math and other cognitive skills. To extend the educational impact of Ready To Learn's programs "beyond the screen," local public television stations put additional Ready To Learn funds to work by providing community-based outreach services. This national-local approach is one of the keys to the program's effectiveness. The local outreach component helps to ensure that the special needs of each community are addressed, one of the tenets of the "No Child Left Behind Act." Ready To Learn services are targeted to families with low literacy and English proficiency, children with disabilities, and other disadvantaged populations such as those in rural areas.

With disabilities, and other disadvantaged populations such as these in rula areas. To be a qualified Ready to Learn member, a local public television station must broadcast at least 6.5 hours of educational children's programming each weekday; conduct at least 20 workshops annually for parents and early childhood professionals; distribute at least 300 free books to children every month; widely distribute the PBS Families publication in English and Spanish and other bilingual and free resources on encouraging children to read and learn. Ready To Learn stations must also partner with local Head Start centers, Even Start programs, 21st Century Community Learning Centers, libraries, childcare providers, schools and other children and family oriented organizations.

Ready To Learn programs are always customized to address local needs. For example, in Carbondale, Illinois, public television station WSIU, Even Start, and a local public school joined forces to bring Ready To Learn resources to children and parents. The children's program Between the Lions is the centerpiece of this school project where 70 percent of the second grade students are reading below grade level. The students watch the series regularly, and older students read with them. Based on student evaluations, many of the students demonstrated an average increase of 1.5 grade levels in their reading scores in just 10 weeks. In Mississippi, Ready To Learn is being used in every Head Start center, child

In Mississippi, Ready To Learn is being used in every Head Start center, child care program, and K-1 classroom in two communities, involving 1,000 children overall. The two communities are Pearl River on the Choctaw Indian Reservation, and Indianola, located in the Delta region, whose population is primarily low-income, African-American (nearly all students qualify for free or reduced lunch). Key partners are PBS stations WGBH (producer of Between the Lions), Mississippi ETV and Mississippi State University, which is conducting a year-long research project funded by Ready To Learn to assess the impact of this targeted literacy outreach effort.

## THE IMPACT OF READY TO LEARN

Ready To Learn gets results. Close to 7 million children have been impacted by Ready To Learn, with nearly 650,000 parents and early childhood educators participating in more than 20,000 workshops held across the country. Based on a national evaluation conducted by the University of Alabama, findings indicated that parents who attend Ready To Learn workshops read aloud to their preschool children more often and for longer periods, and visit libraries and bookstores more often. Moreover, their children watch less television, and what they do watch is more educational.

## READY TO TEACH THROUGH TECHNOLOGY

The nation has come to recognize how technology is touching lives at the very early stages, both with learners and teachers. Computers and the Internet afford learners of all ages the chance to find information, resources, and learning tools anytime, anywhere. Public television offers these resources to teachers and parents as well. The U.S. Department of Education has called upon public television to implement Ready to Teach, a national telecommunications-based initiative that sets out to level the playing field in education by meeting three core objectives through the use of state-of-the-art technology: teacher quality, student achievement, and the development of innovative content.

The Ready to Teach program takes a two-pronged through two technology-based projects—Teacherline and Digital Educational Programming grants. Public tele-

vision is seeking \$15 million for this initiative, the same as the Senate recommendation last year. The funds will be divided so that \$9 million would be used to support the expansion of Teacherline and the remaining \$6 would be used to launch the digital programming grants.

## IMPROVING TEACHER QUALITY

The key finding of the Glenn Commission (established by the U.S. Department of Education to consider ways to improving the quality of math and science teachers) was that nearly one in four of our high school math teachers and one in five high school science teachers lack even a minor in their main teaching field. Many teachers are doing their jobs without the support they need, and students are not learning what they need to know to compete in this global economy. Teacherline has responded to this crisis. A major component of Teacherline is an on-line service that affords teachers, especially those in disadvantaged communities, professional development tools to improve their teaching skills in the subject of mathematics. Increased funds for this account would expand this project to include the teaching of science and other core educational content areas.

Currently, 29 local public television stations participate in the Teacherline program. Each participating station partners with a local school district to tailor the core curriculum to local and state standards. For example, KLVX in Las Vegas, Nevada, and the entire Clark County school system, which is one of the country's fastest growing school districts, have partnered to provide professional development and in-service support for their teachers. Teacherline is helping Clark County ensure that their rapidly increasing teacher force is fully qualified to meet state and local standards. Teachers can earn graduate credit, professional development points, and continuing education credit through Teacherline's certification series.

Many teachers struggle with methods to present specific math concepts. Teacherline provides not only a virtual academy of model lesson plans, but also provides a mentor at each participating station who is available for mentoring as well. The program also provides interactive models and internet support. Teachers have 24-hour access to free resources such as local standards-based materials. Educators also can tap into a rich source of professional support and development by communicating with teachers in their fields about effective and innovative teaching techniques. Increased funding for Teacherline will allow the project to be present in all 50 states within the next year.

# EDUCATION IN A DIGITAL WORLD

The Digital Educational Programming Grants are a newly authorized activity under the "No Child Left Behind Act." These U.S. Department of Education grants are intended for local public television stations in partnerships with school, or other learning institutions, to develop digital content for classroom instruction. The use of digital technology in the classroom is imperative for the future of our children in the new millennium. In fact, the Web-Based Education Commission's main recommendation is to enhance broadband access as a way to improve academic achievement in our country.

Public broadcasters have been aggressively raising the needed funds for the federally mandated digital transition because we enthusiastically embrace the promise of digital technology. When not broadcasting a high definition signal (HDTV) the digital broadcasting signal is able to transmit several content streams simultaneously, known within the industry as "multicasting." With our deepest roots in education, public television stations have committed the equivalent of at least one multicast channel—or 4.5 megabits per second—for formal education, pre school through post secondary and workforce training. In addition, public stations are planning a variety of other multicast services including separate channels devoted to children, public affairs, the adult learner and multicultural audiences.

Digital technology allows broadcasters to transmit not only multiple audio and video signals commonly associated with television, and additionally large streams of data. The combination of the two into a single program is known as "enhanced television." Using enhanced television signals, viewers can explore content addressed in the program in greater detail, providing for a more meaningful viewing experience. Data accompanying enhanced television programs is likely to include Web links, bibliographies, transcripts, and detailed background on a show's subject.

In an educational setting these enhancements can be directly tied to a specific lesson. Using our digital signal, these services can be delivered to schools 80 times faster than a 56K dial up modem and 15 times faster than a DSL connection. Today, schools and homes only need a simple antenna and a DTV tuner card installed in a computer to access these signals. Tomorrow, this capability will be installed in cable boxes and digital television receivers. The value of this technology is conservatively valued at \$2.4 billion per year.

The Digital Education Programming grants will provide local stations and their partners with the seed money needed to develop enhanced digital classroom materials. Grantees will be required to match funding with non-federal sources. The integration of this technology will help to engage students of the 21st century, and leverage their ability to gain and retain knowledge through various and fast-paced mediums. Public television will compete for this newly available funding source this year.

# PREPARED STATEMENT OF UNITED TRIBES TECHNICAL COLLEGE

## SUMMARY OF REQUEST

For 33 years United Tribes Technical College (UTTC) has been providing postsecondary vocational education, job training and family services to Indian students from throughout the nation. Our request for fiscal year 2003 funding for tribally Vocational and Applied Technology Act is:
 \$7 million under Section 117 of the Perkins Act, which is \$500,000 over the fiscal year 2002 enacted level. This funding is essential to our survival, as we re-

- ceive no state-appropriated vocational education monies.
- Ensure that the provision in the Fiscal Year 2002 Labor-HHS-Education Appropriations Act that waived the regulatory requirement that we utilize a restricted indirect cost rate is considered a continuing directive
- -Funding for renovation of our facilities, many of which are original to the Fort Abraham Lincoln army installation. A recent study commissioned by the De-partment of Education shows a facility need for UTTC of \$49 million.

Restricted Indirect Cost Issue.-The Fiscal Year 2002 Labor-HHS-Education Appropriations Act (PL 107-116) provides that notwithstanding any law or regulation, that Section 117 Perkins grantees are not required to utilize a restricted indirect cost rate. We thank you for taking this action. Unfortunately, the Department has interpreted this provision to apply only to our fiscal year 2002 Perkins funds. While we believe that the provision should be considered permanent law, it appears we need to fix the problem again and ask your assistance. The provision in the fiscal year 2002 Act reads:

"Provided further, That notwithstanding any other provision of law or any regulation, the Secretary of Education shall not require the use of a restricted indirect cost rate for grants issued pursuant to section 117 of the Carl D. Perkins Vocational and Applied Technology Education Act.

There is no mention of limiting this provision to fiscal year 2002 only. Nor does the conference report language (H. Rpt. 107–342) mention restricting the bill language. It reads:

"The conference agreement includes bill language allowing grantees under section 117 of the Perkins Act to be exempt from indirect cost rate requirements imposed by this program. The conferees have included this bill language because they recognize there are certain circumstances in which grantees might require additional flexibility not provided under current law or regulation. However, the conferees remain committed to maximizing federal resources for direct educational services, as opposed to paying for administrative and other indirect costs that do not increase access to high quality vocational and technical post secondary education programs for students served through this program. Therefore, the conferees urge the Secretary to report to the Committees on Appropriations and Education and the Workforce of the House and the Committees on Appropriations and Health, Education, Labor and Pensions of the Senate on the indirect cost rates of grantees participating in this program, including a justification for any grantee that has an indirect cost rate considerably greater than those allowed under current law and regulation."

In 2001, the Department of Education, for the first time, directed Indian grantees (both Sec. 116 and 117 grantees) to apply a "restricted indirect cost rate" to their grants. This means each tribal grantee must obtain another indirect cost rate-exclusively for its Perkins Act grant-from its cognizant federal agency (which in most cases is the Inspector General for the Department of the Interior.)

The Department gave two reasons for applying a restricted rate to these Perkins Act Indian programs: (1) The 1998 Amendments to the Perkins Act (Sec. 311(a)) prohibits the use of Perkins Act grant funds to supplant non-federal funds expended for vocational/technical programs. This "supplement, not supplant" limitation previously applied to State grants, only; and (2) A long-standing DoEd regulation (promulgated years before the 1998 Perkins Amendments) automatically applies the restricted indirect cost rate requirement to any DoEd grant program with a "supplement, not supplant" provision.

UTTC has no quarrel with the bases and objectives of the "supplement, not supplant" rule and seeks no change to this statutory provision. The primary targets of this rule are States and possibly local government entities that run vocational education programs with State or local funds.

By contrast, however, UTTC has little or no ability to violate this rule, as we have no source of non-federal funds to operate vocational education programs. Unlike States, we have no tax base and no source of non-federal funds to maintain a vocational education program. We depend on federal funding for our vocational/technical education program operations. Despite our inability to violate the supplanting prohibition, we are, nonetheless, being disadvantaged by a DoEd regulation intended to enforce the prohibition against States who do have the ability to supplant.

-Impact of new requirement on grantees.—Under DoEd regulations, a "restricted indirect cost rate" makes unallowable certain indirect costs that are considered allowable by other federal programs. Primarily, these are costs that DoEd believes the grantee would otherwise incur if it did not receive a Perkins grant, such as the cost of the grantee's chief officer and heads of departments who report to the CEO, as well as the costs of maintaining offices for these personnel.

Prohibiting the Perkins grant from contributing its appropriate share to the grantee's indirect cost pool will most likely mean that other federal programs operated by the grantee would be expected to pick up a great share of the indirect cost pool. This outcome may well result in objections from the other program agencies that do not want to bear costs properly attributable to the Perkins grant.

that do not want to bear costs properly attributable to the Perkins grant. We are caught between conflicting federal agency requirements and will find ourselves unable to recover the necessary share of indirect cost attributable to each of the federal programs we operate. *UTTC's Funding Authority.*—Section 117 of the Perkins Act authorizes funding

UTTC's Funding Authority.—Section 117 of the Perkins Act authorizes funding for tribally controlled postsecondary vocational technical institutions. Under this authority funding is provided to UTTC and one other tribally controlled postsecondary vocational institution, the Crownpoint Institute of Technology. We do not receive funding through the Tribally Controlled Community Colleges Act.

United Tribes Technical College: Unique Inter-tribal Educational Organization.— Incorporated in 1969, United Tribes Technical College is the only inter-tribally controlled campus-based, postsecondary vocational institution for Indian people. We are chartered by the five tribes in North Dakota and operate under an Indian Self-Determination contract with the BIA. Last year we enrolled 490 students from 44 tribes and 17 states.

The majority of our students are from the Great Plains states that, according to the 1999 BIA Labor Force Report, has an Indian reservation jobless rate of 71 percent. UTTC is proud that we have an annual placement rate (placement in jobs or in higher education) between 85–90 percent. In addition, we serve 155 children in our pre-school programs and 175 children in our Theodore Jamerson elementary school, bringing the population for whom we provide direct services to 820.

school, bringing the population for whom we provide direct services to 820. UTTC Course Offerings.—We offer 14 vocational/technical programs and award a total of 24 two-year degree and one-year certificates. We are accredited by the North Central Association of Colleges and Schools and we were re-accredited in 2001 for the longest time—10 years— and with no major stipulations.

We are very excited about the recent additions to our course offerings, and the relevance they hold for Indian communities. These new programs are: Injury Prevention; Technology Distance Learning; Nutrition and Dietary Management; Tribal Government Management, and Tourism.

- —*Injury Prevention.*—Through our Injury Prevention Program we are addressing the injury death rate among Indians, which is 2.8 times that of the total U.S. population. We received assistance through the IHS to establish the only degree granting Injury Prevention program in the nation.
- -Technology and Distance Learning.-We are bridging the "digital divide" by providing web-based education and Interactive Video Network courses from our North Dakota campus to American Indians residing at other remote sites, including the Denver Indian community. Training is currently provided in the areas of Early Childhood Education and Computer Literacy. By the year 2005, students will be able to access full degree programs in Computer Technology, Injury Prevention, Health Information Technology, Early Childhood Education, and Office Technology, and others from these remote sites.

High demand exists for computer technicians. In the first year of implementation, the Computer Support Technician program is at maximum student capacity. In order to keep up with student demand, UTTC will need more classroom space, computers and associated equipment, and instructors. Our program includes all of the Microsoft Systems certifications which translates into high income potential.

-Nutrition and Dietary Management.--UTTC will meet the challenge of fighting diabetes in Indian Country through education. As this Subcommittee knows, the rate of diabetes is very high in Indian country, with some tribal areas experiencing the highest incidence of diabetes in the world. About half of Indian adults have diabetes (Diabetes in American Indians and Alaska Natives, NIH Publication 99-4567, October, 1999).

We offer a Nutrition and Dietary Management Associate of Applied Science degree to increase the number of American Indians with expertise in human nutrition and dietetics. Currently, there are only a handful of Indian professionals in the country with training in these areas. Future improvement plans include offering a Nutrition and Dietary Management degree with a strong emphasis on diabetes education and traditional food preparation.

cation and traditional food preparation. We have also established the United Tribes Diabetes Education Center to assist local Tribal communities and UTTC students and staff in decreasing the prevalence of diabetes by providing educational programs, materials, and training.

-Tribal Government Management/Tourism.—Another of our new program is tribal government management designed to help tribal leaders be more effective administrators. We continue to refine our curricula for this program.

A newly established education program is tribal tourism management. UTTC has researched and developed core curricula for the tourism program, and five other tribal colleges will begin using our curricula (with modifications to suit their specific needs) this fall. The development of the tribal tourism program is well timed to coincide with the national Lewis and Clark Bicentennial in 2003. As you may know, Lewis and Clark and their party spent one quarter of their journey in North Dakota. Last year, UTTC art students were commissioned by the Thomas Jefferson Foundation to create historically accurate reproductions of Lewis and Clark-era Indian objects using traditional methods and natural materials. Our students had partners in this project including the National Park Service and the Peabody Museum at Harvard University. The objects will be part of a major exhibition about the Lewis and Clark expedition.

-Job Training and Economic Development.--UTTC is a designated Minority Business Center serving Montana and the Dakotas. We also administer a Workforce Investment Act program and an internship program with private employers.

We are excited by the recent receipt of an Economic Development Administration grant that will allow UTTC to develop a Center for Economic Excellence. The UTTC Center for Economic Excellence is expected to evolve into a regional "University Center" for Economic Development. Most states have such centers, and ours would be the first such tribal center.

Department of Education Study Documents our Facility/Housing Needs.—The 1998 Vocational Education and Applied Technology Act required the U.S. Department of Education to study the facilities, housing and training needs of our institution. That report, conducted for the Department by the American Institutes for Research, was published in November 2000 ("Assessment of Training and Housing needs within Tribally Controlled Postsecondary Vocational Institutions, November 2000, American Institue of Research"). The report identified the need for \$16,575,300 for the renovation of existing housing and instructional buildings (\$8 million if some existing facilities are converted to student housing) and \$30,475,000 for the construction of housing and instructional facilities.

UTTC continues to identify housing as its greatest need. We have a huge waiting list of students some who wait from 1 to 3 years for admittance. New housing must be built to accommodate those on the waiting list as well as to increase enrollment. Existing housing must be renovated to meet local, state, and federal safety codes. In the very near future, some homes will have to be condemned which will mean lower enrollments and fewer opportunities for those seeking a quality education. Single student housing must also be built and expanded to meet the College's needs.

Single student housing must also be built and expanded to meet the College's needs. Classroom and office space is at a premium. The College has literally run out of space. This means that the UTTC cannot expand its course offerings to keep up with job market demands. Most offices and classrooms that are being used are quite old and are not adequate for student learning and success. We were able to piece together three sources of funds to raise \$1 million to renovate a building to create a new student life and technology center. Funds came from the Economic Development Administration, and the USDA's Rural Development and the Department of Education's Title III programs.

Thank you for your consideration of our request. We cannot survive without he basic vocational education funds that come through the Department of Education.

## PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF COLLEGES OF NURSING

The American Association of Colleges of Nursing (AACN) respectfully submits this testimony to the Subcommittee with our requested funding priorities for nursing research and education programs. This federal support will play a critical role in the nation's effort to overcome the nursing shortage. AACN represents over 560 baccalaureate and graduate nursing education programs in senior colleges and universities across the United States.

The country is in the midst of an emerging nursing shortage unlike any that the nation has experienced over the past 30 years. Since 1995, AACN noted declining enrollments in baccalaureate nursing programs that reached a low point of 21.1 percent in 2000. In the fall of 2001 enrollments increased by 3.7 percent. This slight increase is attributed to intensive marketing by health care facilities in high schools and colleges, public-private partnerships creating additional faculty positions to expand capacity of nursing programs, and state legislation targeting funds to scholarships and nursing loan repayment programs. Potentially the start of a hopeful trend, this increase is inadequate to provide over one million new and replacement nurses that will be needed by 2010, according to the Bureau of Labor Statistics. Still, employers are reporting crisis level shortages of nurses in all health care settings including long-term care, home care, and public health. An aging workforce,

Still, employers are reporting crisis level shortages of nurses in all health care settings including long-term care, home care, and public health. An aging workforce, with the average age of RNs up to 45.2 years, compounds the shortage. Clearly the lack of appropriately educated and skilled registered nurses (RNs) is adversely changing the face of the health care delivery system.

Despite the need to expand the nursing workforce, a lack of nursing faculty has had an impact on the shortage. The majority of AACN member schools report great difficulty filling budgeted faculty positions. The small percentage of doctorally prepared nurses in this country and the lengthy completion time of a doctoral degree have limited the availability of nurses prepared to function in a faculty role. Doctoral nursing students usually attend classes while maintaining a full-time clinical position. Expanding the number of full-time doctoral students would greatly facilitate the production of available faculty. AACN members also report difficulty recruiting master's prepared nursing personnel for faculty roles because of the great disparity between clinical and faculty salaries. Schools would benefit from initiatives that provide resources to augment salaries for specialized faculty needed to support the entire program.

AACN recognizes that strategies to meet the growing nursing shortage must encompass state legislation, increased federal support, and private and public sector initiatives. We are asking the Subcommittee to graciously consider these requests and the effect that an unresolved RN shortage of this magnitude will have on the future of health care in America.

## NATIONAL INSTITUTE OF NURSING RESEARCH (NINR)

We thank you for your support of the National Institute for Nursing Research (NINR). AACN respectfully request a fiscal year 2003 funding level of \$145.45 million, which reflects an increase of \$24 million for NINR. At this funding level, NINR will support significant new research findings for the nation's largest profession of health care providers—registered nurses. This new funding will support the following new research:

- -Enhance adolescent health promotion by addressing risk behaviors such as smoking, substance abuse, unsafe sexual activity, and nutrition. Culturally appropriate interventions for ethnic minorities are needed for this population.
- -Improve the care of more than 1.6 million residents of nursing homes and many others in assisted living facilities and board-and-care homes. NINR hopes to fund studies that focus on residents' functional mobility, their adjustment to loss of independent living, and prevention of falls and depression.
- -Partner with communities to design ways to eliminate health disparities in those communities.
- -Focus on end-of-life care and research to address the public's concern with issues at the end-of-life, including symptom management, family burden, and decision-making. Directions for this research include palliative care models and, timed to the release of an upcoming Institute of Medicine report, pediatric endof-life care.

—Increase the pool of investigators to conduct nursing research and direct special emphasis toward facilitating early entry into doctoral and career development programs.

As the primary sponsor of nursing research in the country, NINR attracts new students to the profession by providing opportunities for nurse-researchers to solve important clinical problems and make a difference in patients' lives. The Institute initiates studies on the relationship between staffing mix and patient outcomes, which is vital to understanding patient safety and the skill set required of health care providers to reach optimal patient outcomes. Nursing research makes a difference in quality of life and patient outcomes. Nurs-

Nursing research makes a difference in quality of life and patient outcomes. Nursing research helps people make wise health choices that prevent disease and promote health, and provides the scientific base for the nation's 2.7 million registered nurses and others who provide patient care. The NINR supports investigators who are conducting a broad range of clinical research, developing and testing interventions to improve patient care, treating disease, managing chronic conditions, and addressing the physical and emotional concerns that are important to a diverse American public.

Nursing research increases the numbers of nursing faculty and researchers. In an effort to develop the pool of nurse faculty and researchers, NINR directs 9 percent of its budget to research training. Research training dollars will support approximately 280 pre-doctoral nurse researchers and 103 post-doctoral researchers this year and the same number under the Administration's proposed budget for fiscal year 2003. These numbers must be increased in the future to meet recent recommendations of the National Research Council to recruit nurses into the research track early in their careers. Additionally, AACN's 2001–2002 Report on Enrollments and Graduations shows that 3,312 nurses are enrolled in doctoral programs. Through the NINR, the National Institutes of Health will continue to expand its emphasis in fiscal year 2003 on clinical research, the means by which basic findings relating to behavior, molecules, and genes can be tested and translated into medical practice and improvements in public health. NINR will extend its clinical trial networks nationwide in an effort to evaluate new prevention strategies, drugs, and vaccines in large numbers of patients.

The Subcommittee investment in NINR is well justified as nursing research contributes extensively to wellness and health choices that prevent disease. There is growing evidence of advances made possible by NINR research, but we will highlight just four recent success stories. AACN believes that based on these and numerous other examples, it is clear that nursing research is making a difference in health outcomes. For example, NINR research has made a difference by identifying interventions or other studies to:

Cesarean deliveries increase the risk of uterine rupture in future pregnancies. Labor and delivery records of nearly 20,000 women who gave birth to a second single child after an earlier cesarean delivery were analyzed to assess the risk of uterine rupture. Compared to the very low risk of rupture during a scheduled repeat c-section, the risk during uninduced labor increased three-fold, and the risk during labor induced using prostaglandins increased fifteen-fold. Though more research is needed to establish cause-and-effect, since 60 percent of women with prior cesarean deliveries attempt labor with the next pregnancy, these women need to be aware of the risk of uterine rupture.

Childrens' learning deficits after aggressive treatment for acute lymphoblastic leukemia. Today many more children survive after treatment for acute lymphobolastic leukemia and are declared disease free. However, long-term consequences of the aggressive treatments (whole brain irradiation and high dose chemotherapy) used to treat the disease include learning difficulties that impair academic performance. Diminished arithmetic skills, verbal fluency, and visual and motor-related skills are observed for up to 4 years after treatment is ended. An early intervention with remedial math has shown positive results, and a larger study to test the intervention is now in progress.

Reducing risk of a second cardiac arrest. Nursing research also examines ways to lower the risks that may precede disease. Preliminary results of a biobehavioral intervention on patients who had cardiac arrest showed that there was an 86 percent reduction of risk of mortality from subsequent cardiac arrest in these patients for up to 2 years. The intervention consisted of training in physiological relaxation using biofeedback; coping skills for depression, anxiety, and anger; and health education about cardiovascular risks. Further study is needed to affirm that decreases in psychological distress subsequently improve the prognosis of those with cardiac disease. The study underscores the importance of biobehavioral approaches for survivors of cardiac arrest. Hospital restructuring makes a difference. Hospital restructuring has taken place across the nation, typically concurrent with reduced numbers of nurses providing care for patients. Within 29 academic health centers, patient outcomes were measured before and after restructuring. Many health outcomes were affected by the reduction in registered nurse hours: more RNs lead to diminished numbers of patient falls and urinary tract infections and higher satisfaction with pain control. Research such as this helps validate the concerns expressed by nurses across the country and helps the health care system measure its effectiveness in terms of patient safety and health promotion.

## THE NURSE EDUCATION ACT (NEA)

AACN recommends an increase in the NEA for fiscal year 2003 to \$122 million. This increase is \$40 million over current funding. NEA appropriations for fiscal year 2002 were \$82.05 million. Central to increasing the availability of a well-trained nursing workforce is the availability of educational grants and scholarships. Current demand for nursing student loan support significantly exceeds the resources available. In addition, scholarship support is a major incentive to enter the profession and facilitates full-time study. Title VIII of the Public Health Service Act (PHSA), the NEA, is the major federal

Title VIII of the Public Health Service Act (PHSA), the NEA, is the major federal statute providing authority for the Department of Health and Human Services to fund initiatives to expand or improve nursing education. Authorities under Title VIII provide for support of advanced practice nursing education, special initiatives for nursing clinics, support of innovations in the delivery of nursing care, expansion of enrollments in baccalaureate nursing programs, and development of initiatives to expand minority nursing enrollments. Several of the programs assist schools with their efforts to bring more students into baccalaureate nursing programs. In addition, the program for loans to nursing students allows students to acquire low interest loans that can be repaid through service in high need areas.

Advanced Education Nursing Grants (Sec. 811).—The initiative provides grants to schools to train advanced practice primary care nurse practitioners and nurse midwives. It also provides grants to educate master's and doctoral students as clinical nurse specialists, public health nurses, nurse administrators, faculty, nurse anesthetists, and non-primary care nurse practitioners. It includes traineeships for master's and doctoral students with a limit of 10 percent of appropriations for doctoral traineeships.

Nursing Workforce Diversity Grants (Sec. 821).—To increase opportunities for nursing education for disadvantaged students, including underrepresented minorities, this initiative furnishes scholarships, stipends, pre-entry preparation, and retention activities. Grantees are responsible for accomplishing the objectives of their grants.

Basic Nurse Education and Practice Grants (Sec. 831).—This initiative disseminates grants to schools of nursing to strengthen basic nurse education and practice with seven priority areas. The areas are: expanding nursing practice in non-institutional settings to increase access to primary health care, training for care of underserved and high risk populations, education for managed care, developing cultural competency, expanding baccalaureate enrollments, increasing nursing career mobility, and nursing education in informatics and use of distance learning. Nursing Student Loan Program (NSLP) (Sec. 836).—AACN recommends an appropriation of \$10.24 million for the NSLP for fiscal year 2003. Administered by the Division of Student Assistance, this program was created to address nursing workforce cheaterage. Academic institutions calent atudants approached in program was created to address nursing work-

Nursing Student Loan Program (NSLP) (Sec. 836).—AACN recommends an appropriation of \$10.24 million for the NSLP for fiscal year 2003. Administered by the Division of Student Assistance, this program was created to address nursing workforce shortages. Academic institutions select students enrolled in nursing programs for participation in the program based on financial need. The program operates on revolving funds received through student loan paybacks and returned funding received from nursing schools that close down. In fiscal year 2001, only 291 out of 1,500 eligible collegiate schools of nursing participate in the program because of reluctance to compete for the limited funding. This loan program has received no new funding since 1983.

Nursing Education Loan Repayment Program (NELRP) (Sec. 846).—AACN requests an additional \$10 million for this program in fiscal year 2003. The NELRP, administered by the Bureau of Primary Health Care, provides loans to registered nurses, nurse anesthetists, and nurse practitioners in exchange for practicing in designated Health Profession Shortage Areas. The NELRP has \$10.24 million in fiscal year 2002 funding and on July 2001, Secretary Thompson allocated an additional \$5 million that was part of a "tap." Scholarships for Disadvantaged Students (SDS).—AACN recommends that SDS

Scholarships for Disadvantaged Students (SDS).—AACN recommends that SDS be funded at \$52 million for fiscal year 2003, a \$6 million increase. Current fiscal year 2002 funding is at \$46.20 million. Scholarships for Disadvantaged Students is

a PHSA Title VII Program (Sec. 737) that provides funds to disadvantaged and mi-nority health professions students. The statute directs 16 percent of the funds ap-propriated to nursing students. This program is the major federal scholarship source for undergraduate nursing students and eliminates or reduces the financial barriers that may prevent these students from enrolling. The majority of SDS recipients are minority students

National Health Service Corps (NHSC).—AACN recommends increasing funds for the NHSC to \$203.5 million for fiscal year 2003. The National Health Service Corps Scholarship and Loan Repayment programs (PHSA Title III) seek to attract health professionals to practice in Health Professional Shortage Areas that lack such pro-viders. Many of those areas are rural, and have difficulty attracting and retaining caregivers. Nursing has a 10 percent set aside that provides funding for certified nurse midwives, nurse practitioners, and psychiatric clinical nurses specialists. In summary, AACN respectfully recommends the following appropriations for fis-cal year 2003:

## [In millions of dollars]

National Institute of Nursing Research Nurse Education Act	$145.45 \\ 122.00$
Nursing Student Loan Program Nursing Education Loan Repayment Program Scholarships for Disadvantaged Students	$     \begin{array}{r}       10.24 \\       20.24 \\       52.00     \end{array} $
National Health Service Corps Scholarship/Loan	203.50

## PREPARED STATEMENT OF THE AMERICAN SOCIETY OF MECHANICAL ENGINEERS' (ASME INTERNATIONAL) COUNCIL ON EDUCATION

The American Society of Mechanical Engineers' Council on Education strongly urges you to fully funding the Math and Science Partnerships at the Department of Education at the \$450 authorized level. These programs will draw relevant stakeholders together to better prepare our teachers and students to meet the challenges of the 21st century.

The engineering community has long been concerned with the state of K-12 science, math, engineering, and technology (SMET) education. To increase student learning in these areas, and enable the United States to compete globally with a strong, technologically literate workforce, we need to commit a significant amount of resources for SMET education now.

of resources for SMET education now. The U.S. Commission on National Security for the 21st Century warns, "The harsh fact is that the United States need for the highest quality human capital in science, mathematics, and engineering is not being met. . . . We lack not only the homegrown science, technology, and engineering professionals necessary to ensure national prosperity and security, but also the next generation of teachers of science and math at the K-12 level. . . . The nation is on the verge of a downward spiral in which current shortages will beget even more acute future shortages of high-qual-ity professionals and compatent teachers " ity professionals and competent teachers." According to the 2000 National Assessment of Educational Progress (NAEP), stu-

dent science scores for grades 4 and 8 are flat and there has been a slight decline in scores for grade 12 since the assessment was last administered in 1996. Further-more, 84 percent of science teachers and 86 percent of mathematics teachers in grades 5–8 did not major in science or mathematics. This report further underscores the need for reform and investment in math and science education, particularly at a time when our economy, national security and technological advances are heavily dependent on the quality of our future workforce.

The Math and Science Partnerships are consistent with ASME's pre-college science, math, engineering and technology (SMET) education policy, which seeks to increase greater numbers of qualified SMET workers. Specifically, ASME supports programs that:

- -Increase federally-funded research focused on SMET teaching and learning to cultivate the most effective teaching methods. Recruit, train, and retain qualified SMET teachers to meet demand.
- -Foster partnerships among educational institutions, industry, and non-profit organizations.
- Encourage the adoption of curriculum standards that cultivate high student performance; the development of curricula that foster creativity, experiential problem-solving and critical thinking; and, the development of assessments aligned with these standards and curricula.
- -Encourage women and minorities to pursue SMET coursework and careers.

For these, and many other reasons, we strongly urge you to fully fund the Math and Science Partnerships in Title II, Part B of the "No Child Left Behind Act" at the \$450 million authorization.

Thank you for considering our recommendations.

# RELATED AGENCIES

## U.S. INSTITUTE OF PEACE

## PREPARED STATEMENT OF HOWARD K. AMMERMAN, PH.D.

I am submitting this testimony as one who has observed and supported the actions of the Congressionally-created United States Institute of Peace since its inception. Furthermore, with a background in Economics, I find the relative expenditures for measures of violence for dealing with matters of conflict, as contrasted with efforts to get at and to remedy underlying causes, to be absurd. One element providing some credibility to this extreme imbalance in expenditures, in my opinion, is the role as characterized by President Eisenhower, of the "Military-Industrial Complex".

On September 12, 2001 the United States Institute of Peace issued a press release offering the advisory services for dealing with terrorism of three individuals competent to analyze aspects of this problem. The Institute, in cooperation with the British-based Airey Neave Trust, had done a study of terrorism which lead to publication of the Special Report "How Terrorism Ends" in May 1999.

Another Institute report concerning terrorism was in a draft stage on September 11 and has now been revised and completed. An International Research Group on Political Violence, convened at the Institute, produced this report issued on January 14, 2002 and entitled "The Diplomacy of Counterterrorism: Lessons Learned, Ignored, and Disputed"

A few days after the horrible events of September 11, the President of the Institute, at a meeting of the Institute Board, cited the many messages of condolence received by the Institute directly from abroad. And then he added that the Institute was being looked to from abroad for leadership and for information. "A time of great danger and of great opportunity" was his characterization of the situation.

The Institute was anxious to intensify its actions. The working group with the Airey Neave Trust was reactivated. Budget-wise, the Institute wished to get a supplemental appropriation of \$4 million for the current fiscal year. This would have made its total appropriation for fiscal year 2002 about \$19 million. When this idea was broached to Congressional committees, suggestions were made that the Institute make changes within its current budget allocations instead. In the end the Institute is slated to get an additional \$10,000.

To me this makes no sense. If one were to try to depict graphically the relative expenditures for armaments and other preparations for war as compared to alternative approaches, including those for the Department of State, it would be difficult to make the latter appear as numerically significant. Somehow the characterization as "grossly underrated" seems an unavoidable conclusion.

as "grossly underrated seems an unavoidable conclusion." The Institute, after Sept. 11, initially was directing its efforts to mobilize resources for support of humanitarian assistance and reconstruction efforts in Afghanistan. The Institute "Rule of Law Program" and its "Initiative on Religion and Peacemaking" are being brought to bear on the situation. This is being done by working with the Agency for International Development and the State Department. The objectives are to support the Afghanistan Government in reestablishing law and order, accounting for human rights violators, and promoting dialogue with Muslim clerics.

These activities are now being done in addition to, if not at the expense of, an already full program which has included the Institute's Korea Working Group now in its 8th year, workshops in Kosovo on multiethnic coexistence for Albanian and Serb communities, and an annual peace essay contest for high school students to make them more aware of the problems of international relations which they must face some day. These are just a few of the many programs of the Institute of which your Committee must have been made aware.

Actually the Institute has for years made studies of "hot spots" all over the world and has published special reports concerning them. Or through fellowships authors have been able to complete books and have them published on these areas of special political and diplomatic concern. Either way, when an international crisis develops, the Institute is in a good position to provide useful information and analyses for the benefit of the policy-determining group. When the tragic events of September 11 occurred, immediate general reactions seemed to be who promoted these acts, where can we find these promoters, and violence should be met with violence—hardly a new approach but shall we say the pattern of centuries? To what degree did the question as to why these horrible acts were committed arise? Granted that "extremists" and "fanatics" may be applicable terms, there are genuine grievances that warrant our attention. Or do we choose to ignore such? And doesn't the situation become more complicated when those who would never resort to such extreme measures nevertheless sense a degree of validity in the grievances of those who do? Furthermore, can it be said that hatred, no matter by whom against whom, is not conducive to good judgment? At best violent reactions are negative and, even if generally accepted as necessary,

At best violent reactions are negative and, even if generally accepted as necessary, alone would hardly seem to provide solutions to the underlying problems. But emphasis on the positive has all too often been neglected—the "triumph" of violence over the initial outbreak has been treated as if it were the end of the matter. True, the announced intention of remaining in Afghanistan to help in its reconstruction is a hopeful sign, even if the problem is an awesome one. But by and large to my way of thinking, there has been over the decades if not centuries an overall lack of adequate attention to the positive approach to international, as well as intranational, problems of human behavior.

But it seems to me that the United States as the global preeminent power is in a good position to enlist many of the generally sympathetic nations of the world in an accentuated emphasis on the positive. And isn't it possible that the "fallout" from such a program to get at and remedy underlying causes of world problems could overwhelm the terrorist elements in the appeal of a positive approach to the dissatisfied? Presumably a climate of hope could be generated. At least as the world's only superpower with the vulnerability this brings can we afford to pass up such an opportunities?

Within this framework I wish to return to the matter of the United States Institute of Peace. For fiscal year 2003 the Institute is requesting an appropriation of \$16.2 million after being chastised, in my opinion, for its temerity in requesting an addition to its fiscal year 2002 budget subsequent to the events of September 11. What I am pleading for is an increase of its appropriation to at least \$20 million. I don't know specifically what the Institute has in mind, but having followed its progress since its beginning, I am convinced that its emphasis on the positive offers results that violence can never bring.

It is with a background in economics that I approach this problem. As you must well know, the amount of \$20 million is trivial in comparison to the expenditures for armaments, yet the possibilities for favorable results are great. These are an alternative to what strikes me as a rather blind faith in technology. On the other hand I think the word "technology" is too narrowly defined but won't pursue the matter any further here. Actually the "weapons" used on September 11 can be considered rather crude. I shudder to think what the fatalities could have been had weapons of mass destruction been used.

I have returned to what has been said in previous communications to your Committee about appropriations over the years for the United States Institute of Peace. Thus far there has been little, if any, direct acknowledgement of the receipt of such. But back to what I think are misplaced emphases in our society. The combined intellectual capacities of the inhabitants of this planet must be awesome and of which the United States has its share. And beginning with our own country as the leader we have mobilized some of this capacity with remarkable results. At the moment examples of such are the development of nuclear weapons and sending a man to the moon. Both of these accomplishments required intensive efforts directed from the national level.

A basic element of the entire field of Economics is "the allocation of scarce resources among alternative ends". Here we have examples of an unusual degree of governmental allocation of the resources for these two projects. And yet, irrespective of the merits of either project, we can raise the question of what seems to me to have been a serious imbalance of allocations over many years if not centuries. In a nutshell while we have pursued a weapons route as an assumed path to national security we have been extremely reluctant to develop methods of conflict resolution by nonviolent means. Yet the great benefits from all the other technological developments that have bettered the lot of humanity could be nullified by violence among and within nations.

The question has been raised as to why we don't apply our strongest method, science, to our greatest problem, the achievement of peace? And I would include in this peace designation the attainment of more harmonious relations both within and among nations. It must be said that, in a sense, science has been applied to these problems in human relations. However, to reiterate, the extent of such application

has been grossly inadequate. And the proposal for application of "science" in a rigorous fashion would include many more academic disciplines than the usual Polit-ical Science, History, International Relations, Military Science, Economics and pos-sibly another or two. Certainly the increasing role of Nongovernmental Organizations (NGO's) should not be overlooked for their contributions in many cases have been very significant. And the Institute can and does work with them at times. In the area of Economics there is the ever-present problem as to the role of government versus the role of free enterprise. But in the matter of international relations, as well as matters of domestic crime and punishment, there is little argument about the necessity of governmental action. Furthermore, from the standpoint of economics, it is encouraging that costs for positive approaches to terrorism tend to be much less than that for the instruments of war. However, my concern here is with what I see as unrealistic imbalances between the two.

Were these imbalances to be more seriously addressed, the results have great potential and a greater movement in this direction in view of the violence throughout history seems long overdue. Apparently wars have in some cases brought what was widely accepted as better conditions and which have endured over considerable periods of time. Yet if during these periods of peace intense efforts have been directed toward preparation for the next war, it would seem that over the long run war itself has been a failure. Yet resource-wise the underlying causes of resort to violence have competed unfavorably with preparations for further efforts to counter violence with violence. Don't we human beings have the potential for doing much better than this? And if so, are we not gravely remiss in not having done so?

#### CORPORATION FOR PUBLIC BROADCASTING

### PREPARED STATEMENT OF THE NATIONAL FEDERATION OF COMMUNITY BROADCASTERS

Thank you for the opportunity to submit testimony to this Subcommittee regarding the appropriation for the Corporation for Public Broadcasting (CPB). As the President and CEO of the National Federation of Community Broadcasters, I speak on behalf of 200 community radio stations and related organizations across the country. NFCB is the sole national organization representing this group of stations which provide service in the smallest communities of this country as well as the largest metropolitan areas. Nearly half of our members are rural stations and half are minority controlled stations.

- In summary, the points we wish to make to this Subcommittee are that NFCB: —Requests \$395 million CPB for fiscal year 2005, a \$15 million increase over fis-
- cal year 2004 advance appropriation; Requests \$137 million in fiscal year 2003 for conversion of public radio and television to digital broadcasting.
- Requests that advance funding for CPB is maintained to preserve journalistic integrity and facilitate planning and local fundraising by public broadcasters; Requests report language to ensure that CPB utilizes digital funds it receives
- Supports CPB activities in facilitating programming services to Latino and Na-
- tive American radio stations;
- Supports CPB's efforts to help public radio stations utilize new distribution technologies and requests that the Subcommittee ensure that these technologies are available to all public radio services and not just the ones with the greatest resources

Community radio fully supports \$395 million for the Corporation for Public Broad-casting in fiscal year 2005.—Federal support distributed through the CPB is an es-sential resource for rural stations and for those stations serving minority communities. These stations provide critical, life-saving information to their listeners. Yet they are often in communities with very small populations and limited economic bases so that the ability of the community to financially support the station is insufficient without federal funds.

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 is dominated by national program services and concentrated ownership of the media.

For the past 25 years, CPB appropriations have been enacted 2 years in advance. This insulation has allowed pubic broadcasting to grow into a respected, independent, national resource that leverages its federal support with significant local funds. Knowing what funding will be available in advance has allowed local stations to plan for programming and community service and to explore additional non-governmental support to augment the federal funds. Most importantly, the insulation that forward-funding provides "go[es] a long way toward eliminating both the risk of and the appearance of undue interference with and control of public broadcasting." — House Report 94–245.

casting."—House Report 94–245. In the last 2 years, CPB has increased support to rural stations and committed resources to helping public radio take advantage of new technologies such as the internet and satellite radio. We commend these activities which we feel provide better service to the American people, but want to be sure that the smaller stations with more limited resources are not left out of this technological transition. We ask that the Subcommittee include language in the appropriation that will ensure that funds are available to help the entire public radio system utilize the new technologies, particularly rural and minority stations.

NFCB commends CPB for the leadership it has shown in supporting and fostering the programming services to Latino stations and to Native American stations. Satélite Radio Bilingüe provides 24 hours of programming to stations across the United States and Puerto Rico addressing issues of particular interest to the Latino population. In the same way, American Indian Radio on Satellite (AIROS) is distributing programming for the Native American stations, arguably the fastest growing groups of stations. There are now over 30 stations controlled by and serving Native Americans, primarily on Indian reservations. This past June CPB funded an historic Summit of Native American Radio in

This past June CPB funded an historic Summit of Native American Radio in Warm Springs, Oregon. It was an extremely important opportunity for Native American stations and producers to strategize with each other and colleagues from Public Radio and Native America on ways to improve the radio service to all Native Americans. CPB has funded a similar Summit for Latino Public Radio which will take place this coming September in Rohnert Park, California, home of the first Latino Public Radio station.

CPB plays a very important role for the public and community radio system. They are the convener of discussions on critical issues facing us as a system. They support research so that we have a better understanding of how we are serving listeners. And they provide funding to programming, new ventures, expansion to new listeners, and projects that improve the efficiency of the system. This is particularly important at a time when there are so many changes in the radio and media environment with new distribution technologies and media consolidation. An example of this support is the grant that NFCB received to update and put our Public Radio Legal Handbook online. This provides easy to read information to stations about complying with governmental regulations so that stations can function legally and use their precious resources for programming instead of legal fees.

Finally, community radio supports \$137 million in fiscal year 2003 for conversion to digital broadcasting by public radio and television.—While public television's needs are more immediate, the Federal Communications Commission is now in the process of identifying a standard for digital radio transmission. We expect that there will be funds available for radio conversion as well as television conversion. More immediately, the television conversion process is already having an impact on public radio stations. As television stations increase the space they need on their towers to accommodate both analog and digital signals, radio stations that rent space on TV towers are losing their leases and being forced to move to other towers—sometimes with very short notice. This situation will only get worse over the next year as we approach the FCC deadline for television conversion. We would like to see emergency funding to help public radio stations who lose their tower space do the necessary engineering studies and move to new tower locations.

Federal funds distributed by the CPB should be available to 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 has been distributed through the PTFP grant program. The PTFP criteria for funding are exacting, but allow for wider participation among public stations. Stations eligible for PTFP funding and not for CPB funding include small-budget, rural and minority controlled stations. We appreciate Congress' direction to CPB that it utilize its digital conversion fund

We appreciate Congress' direction to CPB that it utilize its digital conversion fund for both radio and television and ask that you ensure that the funds are used for both media. Congress stated, with regard to fiscal year 2000 digital conversion funds:

"The required (digital) conversion will impose enormous costs on both individual stations and the public broadcasting system as a whole. Because television and radio infrastructures are closely linked, the conversion of television to digital will create immediate costs not only for television, but also for public radio stations (emphasis added). Therefore, the Committee has included \$15,000,000 to assist radio stations and television stations in the conversion to digitalization. . . ."--(S. Rpt. 105 - 300

This is a period of tremendous change. Digital is transforming the way we do things; new distribution avenues like digital satellite broadcasting and the Internet are changing how we define the business we are in; the concentration of ownership in commercial radio makes public radio in general and community radio in par-During this time, the role of CPB as a convener of the system becomes even more important. And the funding that it provides will allow the smaller stations to participate along with the larger stations which have more resources, as we move into a new era of communications.

Thank you for your consideration of our testimony. If the Subcommittee has any questions or needs to follow-up on any of the points expressed above, please contact: Carol Pierson, President and CEO, National Federation of Community Broadcasters, Telephone: 415 771–1160, Fax: 415–771–4343, E-mail: cpnfcb@aol.com

The NFCB is a 27 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, community participation and support. NFCB's 100 Participant mem-bers and 100 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 provide alternative programming to 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: 41 percent of the members serve rural communities and 46 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 language; throughout the California farming areas around Fresno, Radio Bilingüe programs five stations targeting low-income farm workers; in Barrow, Alaska, 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 and night.

In 1949 the first community radio station went on the air. From that day forward, community radio stations have been 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 under 10 percent of the larger stations' budgets, but can represent up to 50 percent of the budget of the smallest rural stations.

#### PREPARED STATEMENT OF THE NATIONAL MINORITY PUBLIC BROADCASTING CONSORTIA

The National Minority Public Broadcasting Consortia (Minority Consortia) sub-mits this statement on the fiscal year 2005 appropriation for the Corporation for Public Broadcasting (CPB). Our primary missions are to bring a significant amount of programming from our communities into the mainstream of PBS and public broadcasting. In summary, we ask the Committee to:

-Reject the Administration's proposal to end forward funding of the Corporation for Public Broadcasting -Recommend at least \$395 million for CPB for fiscal year 2005, a \$15 million

increase over fiscal year 2004

Encourage CPB to increase its efforts for diverse programming with commensu-

rate increases for minority programming and the Minority Consortia Support CPB's request of \$137 million for digital conversion, but require that

some of it be made available to independent producers, not only to stations The National Minority Public Broadcasting Consortia consists of the National Asian American Telecommunications Association, the National Black Programming Consortium, Native American Public Telecommunications, Pacific Islanders in Com-munications and the Latino Public Broadcasting Project. Forward Funding.—We strongly oppose the Administration's proposal that the ad-vance funding for CPB be eliminated, a proposal that would stop CPB funding for 2 years. We appreciate that Congress rejected this proposal last year and are hopeful that you will do the same this year. Reasons to continue forward funding for CPB include:

- -The production of programming for public broadcasting usually takes several years and substantial lead time is needed for planning. -Public broadcasting programs are supported by multiple funding sources, and 2 years advance knowledge of the amount of federal funding allows CPB to better leverage its federal funds to bring in other sources of revenue. -The Minority Consortia administers a significant amount of CPB programming

—The Minority Consortia administers a significant amount of CPB programming monies, and elimination of forward funding would negatively affect our organi-zations' planning and fundraising activities. *CPB Appropriation.*—We support a fiscal year 2005 federal appropriation for CPB of at least \$395 million. This would be a reasonable, albeit modest, contribution to-ward our national treasure of public broadcasting. The debate of the past several years regarding public television and public radio has highlighted the great esteem in which they are hold.

in which they are held. Public broadcasting, including PBS and NPR, is particularly important for our na-tion's growing 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 quality programming for national audiences. Additionally, public television and radio is universally available.

Digital Conversion Assistance.—We support the Administration's request for \$137 million for digital conversion funding for CPB.

With stations able to broadcast on multiple channels, there will be a need for a tremendous amount of new, quality public broadcasting programming. There are costs involved in the conversion which go beyond the significant equipment and hardware needs of stations. It will also take additional money to produce programming for digital broadcast. All producers will face these new, higher costs.

Part of the equation in bringing more high quality diverse programming to public broadcasting is that independent producers be able to transition to digital produc-tion. Federal funding for digital conversion should include assistance for independent producers.

The Minority Consortia works closely with CPB. We value our relationship with President Coonrod and the CPB staff and appreciate the financial and technical assistance provided to us by that organization. We do not doubt CPB's commitment to increasing the diversity of programming on public television and radio but also believe they can do more with the resources at hand. The oft-stated commitment of CPB and Congress for increased multicultural programming combined with 5 years of funding increases make this an ideal time for significant progress.

Thank you for your consideration of our recommendations. We see new opportunities to increase diversity in programming, production, audience, and employment in the new media environment, and thank you for your long time support of our work on behalf of our communities.

#### PREPARED STATEMENT OF NATIONAL PUBLIC RADIO

#### INTRODUCTION

Thank you, Chairman Harkin and Senator Specter, for providing National Public Radio and its hundreds of member stations with the opportunity to submit written testimony for the record in support of the Corporation for Public Broadcasting (CPB) and its fiscal year 2005 appropriation. This year, public broadcasting is requesting that \$395 million be allocated to CPB and \$137 million be allocated for the digital conversion. These levels of funding will ensure that there is sufficient money available to help public broadcasters in their conversion to digital audio broadcasting and to produce and acquire quality educational and cultural programming. In addition, public broadcasters urge the Subcommittee to maintain advance appropriations for CPB. This long-standing practice preserves freedom of expression, affords program managers more lead time to plan and organize activities, and provides seed money for raising non-federal money

#### CORPORATION FOR PUBLIC BROADCASTING

CPB helps public broadcast stations produce, purchase, and improve programming. Local public radio stations nationwide receive the majority of federal funds allocated for radio (93 percent). This money is combined with the financial support of listeners, businesses, and foundations. The remaining 7 percent of the federal radio funds remain at CPB to support national radio programming, which is awarded on a competitive basis.

In the terms of stations, federal money accounts for roughly 13 percent of public radio station funding on average, and less than 2 percent of NPRs budget. The money allows stations to air and produce programming which attracts other private funding sources. CPB grants also encourage high standards of program quality while decision-making and accountability are maintained at the local level. The result of this public-private partnership is unrivaled programming that serves the public interest.

#### CPB FUNDED PROGRAMS

The vast majority of federal radio dollars go to local stations to help sponsor community outreach activities, create local programming, and purchase national pro-gramming from a diverse set of content providers. The following are a few of the

- many examples of the programming supported in part by federal funding:
   —The WOI Radio Iowa St. University in Ames, IA—Talk of Iowa.—A daily one-hour audience participation program which features regular and special guests who discuss and field questions on a wide variety of topics, such as horticulture, politics, and health and family matters. WDUQ in Pittsburgh, PA—The Anderson Little Report.—A weekly program that

  - WUWM in Milwaukee, WI—At Ten This Week.—An award-winning daily news interview program that airs at 10:00 a.m. and 10:00 p.m., which focuses on the issues affecting the greater Milwaukee area. The program presents in-depth exploration and detailed discussion of issues and concerns within such areas as the arts, government and politics, the economy, money and investing, education,
  - WKSU in Kent, OH.—In February of this year WKSU launched the Stark/ Wayne Bureau to provide additional public service to the residents of Stark and Wayne counties in northeast Ohio. The bureau, located at the Canton Cultural Center, covers local news on a wide range of issues such as the environment and cultural affairs. Recently, the bureau produced a three-part series on the controversy surrounding the possible development of the Industrial Excess landfill in Unionville.
  - -KQED in San Francisco, CA-Pacific Time.-A weekly half-hour program that covers ideas, trends, events, and cultural patterns for Asian Americans interested in learning more about current affairs in their countries of origin and for general audiences who wish to be better informed about daily life in Asia.
  - WCLK-FM in Atlanta, GA-Powerpoint.-A weekly two-hour national call-in and interview program produced at Clark Atlanta University featuring news and cultural discussion topics that are of special interest to the growing African-American public radio audience.
  - -KUOW in Seattle, WA—Rewind.—A nationally distributed weekly half-hour pro-gram that examines current news and events through humorous and/or satirical sketches. Rewind's elements are pulled from themes embedded in the producing station's daily local and national programs and are given a new, lighthearted and whimsical perspective.
  - -NPR in partnership with six African-American public radio stations (WBGO in Newark, NJ; WCLK in Atlanta, GA; WJSU in Jackson, MS; WNCU in Durham, NC; WEAA in Baltimore, MD; and KTSU in Houston, TX)—The Tavis Smiley Show.—A daily newsmagazine hosted by Tavis Smiley to report news and information from and about African-American experiences.

#### ADVANCE APPROPRIATIONS

The President's Office of Management and Budget has targeted for elimination the practice of advance funding. For the past 25 years, CPB appropriations have been enacted 2 years in advance, mainly to preserve freedom of expression by insulating public broadcasting from reactions to programming decisions and the uncer-tainties surrounding the annual appropriations process, such as delays in enacting appropriations.

Advance funding is extremely important to public broadcasters for other reasons as well. It provides seed money for raising non-federal funding and enhances a tremendously effective public-private partnership for public broadcasting. Since public broadcasting matches federal appropriations with private contributions, stations are able to attract the additional money that is needed so developing projects are assured of completion. Advance funding also provides the necessary lead-time to produce large scale, high quality programming. Uncertainty as to funding levels precludes long-term commitments to quality projects.

Fortunately, the House of Representatives rejected the policy of eliminating advance funding for CPB in its fiscal year 2003 budget resolution, which was passed on March 20, 2002. Section 301(b)(2) of H. Con. Res. 353 explicitly states that CPB may be provided an advance appropriation. NPR and its member stations strongly support this language and respectfully request that the Senate incorporate it into its budget resolution.

#### DIGITAL RADIO CONVERSION

Public radio will soon begin the process of converting to digital audio broadcasting. Stations are preparing to upgrade their equipment and digitize their programming in anticipation of the Federal Communication Commission's impending decision on the creation of a digital FM radio standard.<sup>1</sup> Once the Commission issues its final rule later this summer, public radio broadcasters will begin the expensive process of converting to a digital format, which is currently estimated to cost about \$116 million. That amount is solely for the cost of transmission and does not include the cost of digitizing production.

Digital radio is expected to transform the radio industry and allow it to compete on equal footing with other digitized media. Digital technology will allow stations to broadcast near CD quality sound free of interference to listeners, as well as help utilize spectrum more efficiently. Developed by the industry, In-Band, On-Channel (IBOC) technology will allow stations to simultaneously broadcast their analog and digital signals using their existing analog AM and FM frequency. Unlike television stations, radio stations will not require additional spectrum to convert to a digital format.

In addition to providing near CD quality sound and the efficient use of spectrum, digital radio will afford new service opportunities. IBOC technology has the potential to provide important new public interest programming such as:

-Assisted-living services, such as radio reading services for the print-impaired and radio captioning;

-Public safety services such as weather alerts, traffic safety, and national security notifications;

—Foreign language programming; and

-Audio-on-demand

Digital radio will also enable new functions such as the ability to search program formats, scan selective programming, and read music lyrics and song titles. CPB digital funds will play an important role in the public radio system's conver-

CPB digital funds will play an important role in the public radio system's conversion to digital radio technology. Once a FM IBOC standard is adopted, many stations will quickly begin the process of converting, which will involve high capital costs. This funding will help public radio stations finance their projects as well as leverage vital funding from other sources.

#### CONCLUSION

Through the assistance federal grants provide, public radio has grown considerably. The small, but vital funding CPB allocates to stations provides Americans with high quality, low cost community oriented educational and cultural programming. An appropriation of \$395 million for CPB in fiscal year 2005 and \$137 for the digital conversion in fiscal year 2003 will ensure that public broadcasters can continue to serve their communities with high quality programming as well as help them begin the expensive conversion to digital audio broadcasting.

NPR thanks the Subcommittee for allowing written statements to be submitted for the record, and for its long-standing support of public broadcasting.

NPR is a private, nonprofit corporation that produces and distributes award-winning programming such as *Morning Edition*, *All Things Considered*, *Performance Today*, and *Car Talk*. NPR is also a membership organization. NPR member stations are independent entities licensed to a variety of nonprofit organizations, local communities, colleges, universities, and other institutions. Public radio stations independently select and produce community appropriate programming that best serve their listening areas.

<sup>&</sup>lt;sup>1</sup>Industry testing is currently occurring on AM–IBOC technology.

#### PREPARED STATEMENT OF THE ASSOCIATION OF PUBLIC TELEVISION STATIONS

This testimony is submitted to the Labor, Health and Human Service, Education and Related Agencies Appropriations Subcommittee on behalf of the Association of Public Television Stations and its members, who are the nation's local public tele-vision stations, in support of funding for the Corporation for Public Broadcasting (CPB) in fiscal year 2005 and for the digital account at CPB in fiscal year 2003.

#### DIGITAL MANDATE

In this next fiscal year—May 2003—public television stations must be on the air with a digital signal that is mandated by law. For the past four funding cycles, we have sought supplementary funding through CPB to assist public television stations in their transition to digital facilities. APTS thanks the subcommittee for their gen-erosity in that regard. The President's budget request seeks level funding for digital funds at CPB in fiscal year 2003. While last year's appropriation of \$25 million was generous, it will not be adequate for fiscal year 2003. Public broadcasters have carefully researched digital conversion costs and have estimated the total digital conversion cost to the system to be \$1.7 million. Over the

estimated the total digital conversion cost to the system to be \$1.7 billion. Over the last 4 years, the industry has sought a federal contribution of \$699 million, or 40 First 4 years, the industry has sought a federal contribution of \$699 million, or 40 percent of the total estimated cost. To date, public television stations have raised \$748 million, or 44 percent, through state appropriations and private funding sources. However, much of the state funds are contingent upon a federal match. While the federal contribution of \$158 million through fiscal year 2002 has been appropriate the state funds are contingent upon a federal match.

while the federal contribution of \$158 million through fiscal year 2002 has been significant, it has also been inadequate. Public television stations are very grateful to this subcommittee for the \$45 million that has been appropriated for the digital fund at the Corporation for Public Broadcasting. The remaining \$113 million has been in the form of digital grants through the PTFP (the Public Telecommunication Facilities Program) within NTIA at the Department of Commerce. In order to meet the by FCC mandate to be on the air by May 2003, public television still needs \$247 million in federal funding. Public television urges the subcommittee to fund the digital account at CPB in fiscal year 2003 at \$137 million. Public television stations are also seeking \$110 mil-

fiscal year 2003 at \$137 million. Public television stations are also seeking \$110 million in fiscal year 2003 through the Public Telecommunications Program to assist in the transition to digital broadcast. Digital funds made available through the PTFP would be made available for station matching grants for the purchase of equipment that would enable stations to broadcast a basic pass-through digital signal and meet the federal mandate. Digital funds at CPB will be used for necessary investments in digital transmission and production facilities that PTFP cannot cover and for essential digital program development. It is critical to a successful transition of digital broadcasting that those funds be made available now. There is no leeway left on in the conversion schedule, although the FCC may provide 6 month extensions in limited cases.

#### ONGOING SUPPORT

The President's budget did not include a request for CPB in fiscal year 2005 as The President's budget did not include a request for Cr D in fiscal year 2009 as the administration has sought to eliminate the practice of advanced appropriations for most programs. (The President's budget does support the already appropriated funding level for fiscal year 2003.) Public television stations are grateful that both the House and Senate Budget Resolutions included language that specifically excludes CPB from the prohibition for advance appropriations. APTS urges the sub-committee to fund the general account at CPB in fiscal year 2005 at \$395 million.

Most of the funds made available to the general account at CPB go to public broadcasting stations in the form of Community Service Grants. Stations use their CSGs for general support. By fiscal year 2005, public television stations will be in the midst of a dual operations period where they must broadcasting in both analog and digital formats. This modest increase in funding from the fiscal year 2004 level of \$380 million to the requested \$395 million will help stations with the increased operating expenses associated with dual transmission.

#### THE VISION

Public broadcasters have been aggressively raising the needed funds for the digital transition because we enthusiastically embrace the promise of digital tech-nology. When not broadcasting a high definition signal (HDTV) the digital broadis able to transmit several content streams simultaneously, known within the industry as "multicasting." With our deepest roots in education, public television stations have committed the equivalent of at least one multicast chan-nel—or 4.5 megabits per second for formal education—pre school through post secondary and workforce training. In addition, public stations are planning a variety of other multicast services including separate channels devoted to children, public affairs, the adult learner and multicultural audiences.

Digital technology allows broadcasters to transmit not only multiple audio and video signals commonly associated with television, and additionally large streams of data. The combination of the two into a single program is known as "enhanced tele-vision." Using enhanced television signals, viewers can explore content addressed in the program in greater detail, providing for a more meaningful viewing experience. Data accompanying enhanced television programs is likely to include Web links, bib-liographies, transcripts, and detailed background on a show's subject.

In an educational setting these enhancements can be directly tied to a specific lesson. Using our digital signal, these services can be delivered to schools 80 times faster than a 56K dial up modem and 15 times faster than a DSL connection. Today, faster than a 56K dial up modem and 15 times faster than a DSL connection. Today, schools and homes only need a simple antenna and a DTV tuner card installed in a computer to access these signals. Tomorrow, this capability will be installed in cable boxes and digital television receivers. The value of this technology is conservatively valued at \$2.4 billion per year. Public stations have also developed the software to use a small portion of their digital capacity to delivery critical weather and public safety information in a fraction of the time it currently takes. In Iowa, there are currently over 550 schools without Internet or high-speed access. Iowa's public television stations can send broadband-like rich media educational content to these rural schools that is roughly valued at \$13.9 million per year. In Pennsylvania, the number of schools without Internet or high-speed access is over \$67

is over 2,500. The value of public digital television services to that state is over \$67 million per year.

Even in the digital age, however, public televison will not rely just on technology to serve our viewers. Local public television stations will continue to meet the needs of their communities through partnerships and outreach efforts that extend the use of our quality programming.

#### PRESCHOOL AND EARLY CHILDHOOD

Public television remains committed to bringing the highest quality children's educational programs to our nation's preschool audience. The industry has received strong federal support in this area through the Department of Education's Ready to Learn grant (which is addressed in separate testimony.) Earlier this month public television was recognized by the President and First Lady at a White House event as an important contributor to early childhood literacy. In the digital age, stations will be able to dedicate one of their multi-channels to preschool and early childhood programs such as Between the Lions and Sesame Street. This means that parents and caregivers will always be able to find a safe harbor on televison for their children.

With current technology, parents and caregivers can access supplementary information for our children's programs on the Internet. In the digital age, the amount of information will dramatically increase and this information will be immediately available through a television set with only a simple antenna to access the signal.

#### K-12 SERVICES

PBS programs remain the number one choice of teachers for classroom use. As mentioned above, in the digital age, teachers will be able to immediately access sup-port and supplementary materials over the air. This enhanced technology will be of enormous benefit to all schools, teachers and parents, but especially those without access to high-speed Internet connections.

West Virginia Public Broadcasting is one of many stations broadcasting a live program with a web component to serve students. Homework Hotline is broadcast during the school year and focuses on science and math. Public digital television's ability to deliver enhanced educational materials, such as problems from a workbook or textbook, will dramatically increase the educational value of this program. Allowing students to choose among the data and text streams for additional information will tailor the experience to their individual needs.

#### DIVERSE AUDIENCES

A major part of public television's mission is to serve those whose needs, for a variety of reasons, are not adequately addressed by commercial televison

In culturally diverse northern Virginia, MhzNetwork (WNVC and WNVT) offers programming from over 20 countries each week and appeals to the areas more than 250,000 Hispanics, 43,000 French speaking and 26,000 German speaking residents, and to the nearly 100,000 Southeast Asian residents. Public digital television's technology would allow for greater diversity of this programming. Looking to use the increased capacity inherent with digital broadcasting, WNVC World View TV—the country's only noncommercial, independent television station with an international format—plans to reach the Washington, DC area globally minded audience through foreign language, yet English accessible programming. Every year, WHUT in Washington, DC, broadcasts over 2000 hours of public af-

Every year, WHUT in Washington, DC, broadcasts over 2000 hours of public affairs and educational programming targeting ethnic minorities. The station also produces a nationally syndicated series, The Reading Club, a roundtable talk show focused exclusively on books. In a digital environment, this program would be available at various times throughout the day.

#### ADULT EDUCATION AND LIFELONG LEARNING

Public television is extremely proud of its leadership and accomplishments in the areas of adult education and lifelong learning. Many public televison stations licenses are held by higher education institutions, and have pioneered the practice of telecourses and distance learning. Every year distance-learning telecourses are broadcast by public TV stations for two-thirds of the colleges and universities in the United States. Over 500,000 adult degree candidates participate in those courses, a valuable use of technology on a scale unimaginable only a few years ago. Since 1981 more than five million adults have earned college credit using public television's Adult Learning Service telecourses. With digital television, entire channels can be devoted to adult learning.

vision's Adult Learning Service telecourses. With digital television, entire channels can be devoted to adult learning. The New Jersey Workplace Literacy Program was created in partnership with the New Jersey Department of Labor and the New Jersey Network (NJN) to deliver workforce training programs and series directly to welfare registrants, dislocated workers and other job seekers. Using digital television technology, the Internet and print materials, NJN provides interactive training services that allow participants to address individual employment-related issues at their own pace.

In West Virginia, 1,500 students receive college credit at home through West Virginia Public Broadcasting. Telecourse instruction is so successful that demand is increasing, yet the distribution system remains the same. There are not enough analog channels, nor enough airtime, to schedule all the desired courses. With digital technology, West Virginia Public Broadcasting can offer multiple college telecourses, from remediation to college level.

Kentucky Educational Television produces a variety of adult education programs that are used throughout the public television system. Two flagship literacy programs for adults produced by KET are Learn to Read, and GED on TV. GED on TV has helped over 1.2 million adults successfully obtain their GED certificate with an estimated economic impact of \$2.9 billion.

In Tacoma, Washington, KBTC works with many community and technical colleges to offer credit for televised college courses. This year's enrollment is 2,500. To further the program, KBTC is coordinating the launch of an educational access channel for four colleges in the area to provide more resources.

In Iowa, to help teachers and parents who are unaware of the state's career opportunities, Iowa Public Television created the School to Career Project. IPTV identifies career professional and videos them at work. Later, the professionals participate in videoconferences with schools.

#### PUBLIC SAFETY

Public televisions stations, with their universal reach, are perfect partners for state and federal public safety and homeland security efforts. WNYE in New York City worked with the Federal Emergency Management Agen-

WNYE in New York City worked with the Federal Emergency Management Agency (FEMA) and Skystream Networks, Sinclair Broadcast Group, Hicks & Associates, Acrodyne Industries, Inc. to develop and successfully test a new digital emergency broadcast data system in October 2001. The system could enable the fast, efficient and reliable delivery of critical information over the digital TV airwaves in a time of crisis when other communication systems may be disabled.

of crisis when other communication systems may be disabled. Last fall, KET (Kentucky Educational Television) demonstrated a new "datacasting" technology to leaders from across the commonwealth of Kentucky. This new technology uses a fraction of the digital channel to deliver weather and public safety information that can be targeted to the community at large or designated public safety officials. This technology has the ability to "push" severe weather alerts, complete with high-end weather imagery, to desktop PCs. The demonstration documented a potentially life saving reduction in response time.

onstration documented a potentially life saving reduction in response time. Using this technology, KET can pick up weather alerts distributed by satellite by the National Weather Service and then rebroadcast this data in seconds through its 15 statewide digital transmitters to homes, schools and public safety officials. Equally important, this information, through a TV broadcast signal, can be encrypted and targeted for a chosen audience. While this security feature is particularly important for law enforcement, it holds tremendous promise for a wide variety of applications for state agencies and other government organizations (e.g. training, videoconferences, computer file and software transfers, videostreaming, etc.)

#### CONCLUSION

Public broadcasting is composed of local boards of trustees, hundreds of thousands of local volunteers, local staffs and local nonprofit and business partners, and local members, all of whom ensure that public television programs and services reflect diverse local needs and interests. The digital transition will only enhance public television's role as the "town square" in the digital age, with local public television stations serving as the increasingly essential link in connecting homes, offices, workplaces, libraries, schools, colleges and local civic entities.

Public broadcasters do not create television programming and multimedia content in order to make money for shareholders. We do it to improve the quality of life for all Americans. We set out to use satellites, video and computer technology, and now digital television, to enhance primary, secondary and higher education; to broaden access to lifelong learning; to provide a safe harbor for children, free from violence; and to bring the best of arts and culture into American homes. As modernday broadcasters over the air with digital television and as "narrow-casters" over the web, we are can use the influence and power of the media: to sow seeds that will help people of all ages and backgrounds lead better, fuller, more productive lives. Funding through the Corporation for Public Broadcasting's general account and the digital fund will ensure that public digital television will achieve these public service goals in a digital age.

APTS is a nonprofit corporation whose members are the nation's public television stations.

#### CORPORATION FOR NATIONAL AND COMMUNITY SERVICE

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF SENIOR COMPANION PROJECT DIRECTORS AND THE NATIONAL ASSOCIATION OF RETIRED AND SENIOR VOLUNTEER PROGRAM DIRECTORS

#### CORPORATION FOR NATIONAL AND COMMUNITY SERVICE

We are pleased to testify in support of fiscal year 2003 appropriations for the Senior Companion Program (SCP), and Retired and Senior Volunteer Program (RSVP), both part of 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 1,000 directors who administer Senior Companion and RSVP projects across the nation, as well as local sponsoring agencies and others who value and support the work of NSSC programs. We laud President Bush on his proposal to expand volunteer opportunities for all

We laud President Bush on his proposal to expand volunteer opportunities for all Americans, and particularly for the nation's senior population. Consistent with his proposal, we support a fiscal year 2003 funding level consistent with the goal of eventually enrolling one million older Americans in the Senior Corps. In pursuit of this goal, we rise in support of increasing funding for the Retired and Senior Volunteer Program (RSVP) by \$6 million and the Senior Companion Program (SCP) by \$5 million.

For the Senior Companion Program, the National Association of Senior Companion Project Directors supports a \$5 million increase in the program's funding level to be allocated as follows: a 4 percent administrative cost increase to support program infrastructure to meet the new grant requirements of Programming for Impact (roughly \$2 million); one-third of the increase (\$1.7 million) dedicated to Programs of National Significance as required by law to expand the capacity of existing grantees and enroll more seniors wishing to volunteer; and \$1.3 million for new programs at least one in each geographic cluster administered by the Corporation for National and Community Service.

For the Retired and Senior Volunteer Program, the National Association of RSVP Directors supports a \$6 million increase in the program's fiscal year 2002 funding level to be allocated as follow: one-third of the increase (\$2 million) dedicated to Programs of National Significance as required by law as augmentations to existing grants to enroll a cadre of new volunteers and \$4 million for existing CNCS-funded projects for staffing and other infrastructure support required to continue the shift to outcome-based programming and reporting, and technology needs. In each instance, infrastructure funding will also go far toward supporting the na-

In each instance, infrastructure funding will also go far toward supporting the national goal of making it easier for more Americans to service. As one example, the advent of a new web-based recruitment system for senior service and participation by every grantee in making that system work has the potential for generating service opportunities in ways never before available. At this unique time in our nation's history with the rebirth of patriotism and rekindling of the national spirit of citizen responsibility, we know the desire is there and must rise to tap those critical resources for the nation.

In addition, the National Association of RSVP Directors and the National Association of Senior Companion Project Directors supports providing \$20 million for a new Silver Scholarship Program to award seniors with a \$1,000 transferable education award which could be used by their children and grandchildren in exchange for a significant contribution of time—at least 500 hours per year in volunteer activity. While we appreciate the President's proposal to increase funding for "Special Volunteer Programs" under DVSA by \$50 million, we feel a more appropriate allocation

While we appreciate the President's proposal to increase funding for "Special Volunteer Programs" under DVSA by \$50 million, we feel a more appropriate allocation of resources would place these funds in the existing and established framework of the Senior Corps program structure, with modifications and improvements that will likely be enacted before the conclusion of this year's appropriations cycle. In our considered opinion, use of an open-ended authority like Special Volunteer Programs ignores the strengths, needs, and innovative potential for our existing programs to meet homeland security, public safety, and other still unmet community needs. We are concerned that allocating funds under the Special Volunteer Programs authority at this time prejudges the outcome of legislation intended to reauthorization and reform national service programs beginning fiscal year 2003 legislation that is slated by the House and Senate authorizing committees to be considered expeditiously. The current status of the federal budget even more critically dictates that we be

The current status of the federal budget even more critically dictates that we be cost-conscious with our 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. In fiscal year 2001, RSVP volunteers provided over 78 million hours of service in

In fiscal year 2001, RSVP volunteers provided over 78 million hours of service in a variety of settings throughout their communities across the country. The total cost of fielding one RSVP volunteer is far less than \$1 per hour of service. All told, over 470,000 RSVP volunteers serve annually through more than 70,000 public and nonprofit local volunteer stations. Sixty-nine percent of RSVP volunteers are over age 70. Volunteers serve through 766 projects sponsored and managed by local non-profit 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.

ests; they present then communities with a rich array of opened in full spectrum of community needs. As but one example of RSVP, the Senior for Schools program in Forest City, Iowa has served to improve reading skills for fourth graders. In North Central Iowa, 48 percent of fourth graders are reading below grade level. By April 2002, the program had grown to six school districts, 11 classrooms, and 40 volunteers and the improved reading skills of 220 children.

In fiscal year 2001, over 17,000 Federal and non-federally funded Senior Companions served over 55,000 older adults through 219 projects. Senior Companion volunteers contributed over 11 million hours of service to their frail older clients—giving assistance to other adults with physical, mental, or emotional impairments. SCP volunteers serve through programs sponsored and managed by local non-profit 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 \$47,000. The annual federal cost for one Senior Companion is less than \$4,000.

For more than three decades, Federally-supported senior volunteers have been touching lives and helping communities in a variety of ways. Statistics show that RSVP and SCP focus their resources where they will have

Statistics show that RSVP and SCP focus their resources where they will have the largest impact: 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.

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-toone 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 10 percent of RSVP volunteers serve in sites which focus on school-age and

Over 10 percent of RSVP volunteers serve in sites which focus on school-age and pre-school 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 SCP and RSVP produce results: the Corporation's studies as well as numerous 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 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 and Community Service and with the wholehearted support of the three national Directors Associations, have moved to outcome-based activity: Programming for Impact (PFI).

Through PFI, projects and sites where volunteers serve are cooperating to collect and report data to 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 on communities, and supports your current federal investment in our programs as well as our request for increased funds for fiscal year 2003.

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.

voluteer in they were asked. The message is creat, in spice of the general plant'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 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 fiscal year 2003 funding level of \$61 million for the Retired and Senior Volunteer Program (RSVP) and \$50 million for the Senior Companion Program.

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