

**U.S. Department of Health and Human Services
National Institutes of Health
National Center on Minority Health and Health Disparities
National Advisory Council on Minority Health and Health Disparities
September 12, 2006**

Meeting Minutes

The 13th meeting of the National Advisory Council on Minority Health and Health Disparities (NACMHD/Council) of the National Center on Minority Health and Health Disparities (NCMHD) of the National Institutes of Health (NIH) of the U.S. Department of Health and Human Services (HHS) convened at the Bethesda Marriott-Pooks Hill, 5151 Pooks Hill Road, Bethesda, Maryland. NACMHD Executive Secretary Donna A. Brooks called the meeting to order at 8:33 a.m. Dr. John Ruffin, Chairman of the NACMHD, presided and welcomed members and others.

Council members present:

John Ruffin, Ph.D.; Director, NCMHD; Chair, NACMHD
Nilda Peragallo, Dr.P.H., R.N., FAAN
Warren A. Jones, M.D., FAAFP
Steven R. Lopez, Ph.D.
Pamela V. Hammond, Ph.D., FAAN
Thomas E. Gaiter, M.D.
Regina M. Benjamin, M.D., M.B.A.
Pitambar Somani, M.D., Ph.D.
Jeffrey A. Henderson, M.D., M.P.H.

Ex officio members present:

David Abrams, Ph.D.
Kevin R. Porter, M.D.

Ad hoc members and special guests:

Dr. John Agwunobi, Assistant Secretary for Health, HHS
Dr. Nicole Lurie, Senior Scientist, Rand Corporation
Dr. Maria Soto-Greene, Professor of Medicine, University of Medicine & Dentistry of
New Jersey
Dr. Mario De La Rosa, Associate Professor, School of Social Work, Florida
International University
Dr. Keith Norris, Vice President for Research, Charles R. Drew University
Dr. Luther Williams, Provost, Tuskegee University

Executive Secretary:

Donna A. Brooks

CLOSED SESSION

This portion of the meeting was closed to the public in accordance with the determination that it was concerned with matters exempt from mandatory disclosure under Sections 552b(c)(4) and 552b(c)(6), Title 5, U.S.C., and Section 10(d) of the Federal Advisory Committee Act, as amended, U.S.C. Appendix 2.

The Council considered 6 applications requesting an estimated \$3,193,927 in total costs. Applications that were noncompetitive, unscored, or were not recommended for further consideration by the scientific review groups were not considered by Council. The Council by way of en bloc voting concurred with the first-level peer review on 6 applications.

The closed session adjourned at 9:20 a.m.

OPEN SESSION

Ms. Brooks called the open session to order at 9:30 a.m. Dr. Ruffin welcomed members, ad hoc members, and guests to the 13th NACMHD meeting, saying that the appointment of a new chair would take place next year with the appointment of new members. He reviewed the meeting agenda noting some of the invited speakers who will be in attendance. Introductions of members, guests, and attendees followed.

HHS Greetings, Dr. John O. Agwunobi, Assistant Secretary of Health, U.S. Department of Health and Human Services

In his introduction of Dr. John Agwunobi, the HHS Assistant Secretary of Health, Dr. Ruffin noted that Dr. Agwunobi chairs the HHS Health Disparities Council on which he [Ruffin] serves as the NIH representative. Dr. Agwunobi commended Dr. Ruffin's work. He then referred to his own training as a pediatrician being an influential factor in defining his approach to problems. He emphasized the need for everyone to be around the same table and the need for committed leadership to implement strategies for eliminating disparities, given funding shortfalls and the separations that seem to exist among agencies. Agwunobi pointed out for example, that the HIV pandemic is a minority issue. He thanked members of the Council for their work and asked forgiveness "when we [HHS] have failed you." He said there was a short time left to make a difference, and he urged members to send him ideas and involve him in the Council's efforts. Advisory Council members thanked Dr. Agwunobi for his support of the NCMHD's mission and work.

Discussion:

- Members of the NACMHD shared with Dr. Agwunobi their request to Dr. Elias Zerhouni to help provide the infrastructure that would allow the NCMHD to meet the challenges of combating disparities. Members encouraged Dr. Agwunobi to follow up on this request with Dr. Zerhouni. Dr. Agwunobi promised to confer with Dr. Ruffin and to follow up.
- When asked what he thought the current health disparity priorities are, Dr. Agwunobi named HIV/AIDS; substance abuse specifically methamphetamine use in Native American communities; and chronic diseases such as obesity, heart disease, and diabetes.

Consideration of June 2006 Minutes

A motion to accept and approve the minutes of the June 2006 meeting was passed and seconded without any changes.

Future Meeting Dates

Tuesday, February 20, 2007	Tuesday February 19, 2008
Tuesday, June 12, 2007	Tuesday, June 10, 2008
Tuesday, September 11, 2007	Tuesday, September 16, 2008

NCMHD DIRECTOR'S REPORT: John Ruffin, Ph.D.

Grant applications for the SBIR/STTR program and two K-awards were reviewed in closed session, completing the FY2006 peer review of funding requests to the NCMHD. A number of applications had been reviewed at the earlier Advisory Council meetings this year and other peer review sessions for the Loan Repayment Program, additional SBIR/STTR applications, the Endowment Program and co-funding requests from the NIH Institutes and Centers. The review workload next year is expected to increase with the review of grant applications for the Centers of Excellence Program.

HHS is currently evaluating its Hurricane Katrina Initiative through which the NCMHD mobilized its Centers of Excellence to establish a Regional Coordinating Center (RCC) to address some of the emergency and on-going health needs in the region. Once the evaluation has been completed, HHS will determine the future of the RCC and its own priorities with the overall Hurricane Katrina Initiative. NCMHD is also participating in the planning of an environmental health project on asthma with the National Institute of Environmental Health Sciences (NIEHS), Merck, the New Orleans Department of Health, and institutions in the region. NCMHD plans to remain actively involved with the health and research challenges in the Gulf Coast communities, and will continue to work with the HHS Office of Minority Health and other NIH ICs in this regard.

Plans are moving ahead to launch a series of forums next year to showcase the NIH efforts in minority health and health disparities. A trans-NIH committee is in place and several subcommittees will also emerge to move the planning efforts forward. Grantees and partners will be involved in these forums to help us identify and better define gaps and priorities in minority health and health disparities, which ultimately will help to inform the NIH health disparities research agenda.

The Institute of Medicine (IOM) Report commissioned by the NCMHD to examine the Health Disparities Strategic Plan of the NIH was released earlier this year. The NCMHD established an Ad-hoc committee of leading scientists and policy leaders to review the IOM report, and develop an implementation action plan to address the recommendations of the report. The committee recently completed its work and has just provided its final report to the NCMHD Director. Key areas that the committee focused on dealt with leadership, the coordination role of the NCMHD, the science of health disparities and resources. The report will be shared with the Advisory Council members. Dr. Ruffin thanked committee members for their work.

The NCMHD is nearing completion of its implementation of the Office of Management Assessment's recommendations, which is scheduled to be completed September 30, 2006. Some of the changes will be more apparent than others, such as the revised organizational structure.

The issue of health disparities continues to attract an increasing amount of attention, witnessed by recent meetings the NCMHD Director attended including the J. Robert Gladden Society of Orthopaedic Surgeons conference on health disparities in Switzerland; the Blacks in Government National Training Conference in New York which included a track on health disparities; and an invitation from Congresswoman Anne Northrup to address policy, academic and community leaders in Louisville, Kentucky.

Some of the recent senior leadership discussions at NIH have involved identifying strategies to train and retain young investigators; peer review trends and issues; the NIH reauthorization; the NIH communication strategy; and priority setting among the NIH Institutes and Centers.

Program officials for the Centers of Excellence, Loan Repayment, Community-Based Participatory Research, and Research Endowment programs supplemented the Director's report with an update on each program.

NCMHD Centers of Excellence, Derrick C. Tabor, Ph.D.

Dr. Tabor presented information on the Centers of Excellence programs funded 2002–2005 (R24, P20, P60). All will expire this year. A lists of the institutions supported were available in desk folders. Dr. Tabor distributed an additional handout with other program information including research funded, community outreach and training activities, and conferences. Slides illustrated:

- Grant distribution—heavily weighted in the East.
- Program funding history.
- Priority research areas for the RFAs recently released for FY2007 funding.
- Findings on critical determinants of health and potential discovery of new biomedical and behavioral knowledge.
- Publications: Progress is being made in publicizing disparity grants/results. Most material to date focuses on cardiovascular disease. The NCMHD is analyzing publications to discover more about research results.

NCMHD Research Endowment Program, Leslie Atkinson

Ms. Atkinson noted that the program is small but that it has a large impact. The eligibility criteria were created by legislation. A total of 17 institutions have been funded to date, covering a broad geographical area of 13 states and territories. Ms. Atkinson shared examples of how research endowments are used including: to support new department or program leadership such as the Chair, fellowships, courses, scholarships, research opportunities, and activities that leverage other support.

NCMHD Community-Based Participatory Research Program and Loan Repayment Program, Francisco S. Sy, M.D., Ph.D.

Dr. Sy provided an update on the Community-Based Participatory Research (CBPR) program and the Loan Repayment Program (LRP). The CBPR 25 awardees have just completed the first phase of the program. They have conducted community needs assessments and identified their priority research areas for the intervention phase. Most of the grantees intend to study diabetes and/or its co-morbidities.

For the NCMHD Loan Repayment Program, a total of 282 awards were made in fiscal year 2006 to cover both LRP programs. The Health Disparities Research (HDR) program made 244 awards, and 38 were disbursed through the Extramural Clinical Research (ECR) program. Dr. Sy provided a historical illustration on the NCMHD LRP funding and awards made between 2002-2006. He also provided a comparative analysis of the trends in applications received and funded among the five NIH Loan Repayment Programs.

SCIENCE EDUCATION PARTNERSHIP (SEPA) AWARDS, Dr. Tony Beck, Program Officer, National Center for Research Resources (NCRR)

Dr. Beck provided some background on the SEPA program. One of the projects he highlighted was the Detectives in the Classroom curriculum, which aims to motivate fledgling scientists in middle school. His presentation included the following points:

- The need for science education is reflected in the low health literacy rate. The rate of science knowledge drops off by middle school.
- The SEPA Program is a pipeline of science knowledge. Its philosophy is to encourage “interaction of scientists in teamwork with educators and community organizations to improve K-12 and public understanding of NIH-funded medical research, and to increase the participation of young people in science careers.” Methods include innovative pedagogy, extension and leveraging of existing programs, public education, and widespread dissemination.
- Within NIH, SEPA supports the lion’s share of science education—75 programs by 2007.
- Widely distributed institutions in IDea States are funded for 3 years; the program targets rural and disadvantaged students. Participants number 92,000.
- There is great variation in SEPA models and subject matter that emphasizes hands-on activities.
- The Health, Science, and Technology Academy (HSTA) model has been highly successful in terms of sustainability. Funding has been leveraged from major corporations.
- Successful models include use of mobile laboratories, a concept developed by Dr. Carl Franzblau.
- NIH Institutes and Centers have cooperated in supporting and sharing the use of mobile laboratories. Students have endorsed the program.

General Discussion

- Questions were raised about other sources besides PubMed indexed articles that is being used to assess the success of the Centers of Excellence program. It is important to be able to measure the program's impact.
- Tracking of students that graduate from the SEPA and the Loan Repayment Program were also topics of interest. That is an area that has not been closely looked at. A systematic approach will be taken to collect data and track where program participants end up for example, whether SEPA students go on to college or LRP participants remain in health disparities research.
- Evaluation is important; alternative approaches are now available. While we assume increasing numbers of participants go on to higher education, the loan repayment program should be clearly coupled with the goal of producing active scientists.
- We need to document knowledge/understanding gained, and then find a means to integrate social and behavioral information for aggregate knowledge.

PROGRAM CONCEPT CLEARANCE: The Faith-Based and Men's Health Initiatives

Faith-Based Health Initiative, Reuben Warren, D.D.S., Dr.P.H.

Dr. Warren began his presentation by referencing an article in today's *Washington Post* documenting that African-American men live 21 fewer years than Asian women, which speaks to the health disparities challenges.

The faith-based initiative highlights and builds on the synergy between medical and spiritual health, a long-term focus of: American Indians and Native Alaskan cultures. There is growing scientific literature on the relationship of spirituality and health—the mind/body interaction. One of the challenges with exploring faith-based approaches to health is a problem of trust. Dr. Warren pointed an example where at a recent conference spiritual healers expressed reluctance to share practices because they feared what policymakers would do with the information. In addition, people are aware of past experimental research by the government or major institutions in which disadvantaged persons were used to test new treatments. Dr. Warren believes the faith-based health initiative can help reestablish trust. The concept paper details a series of recommended ways to address minority health needs. The last phase of this effort would involve measuring effectiveness with evidence-based outcomes. It is expected, he said, that the program will demonstrate evidence-based approaches to incorporating spiritual healing.

Interdisciplinary Initiative on Men's Health Disparities, Jerome Wilson, Ph.D.

Dr. Wilson emphasized the interdisciplinary nature of the proposed men's health initiative. While the program would focus first on African American men, it would then expand to other populations in exploring how maleness and masculinity affect health and behavior. The primary objectives are to research root causes of gender disparities; examine health disparities among African American men and other underserved male populations; and apply biomedical, epidemiological, and psychosocial research into men's health beliefs and behaviors. In addition, Dr. Wilson mentioned concern regarding pharmaceutical companies, which may want to use prisoners as experimental research subjects as they have done in the past.

The initiative would examine pathways between childhood and adult health—the life course of men's health. Factors to examine would include social and behavioral influences (including the reluctance of men to seek medical interventions), and educational gender disparities. Dr. Wilson

suggested creating an advisory group to consider and provide guidance on educational gender disparities. He would like grants to be available by 2008 to look at these issues.

Comments

- While criticism may arise about a return to male-dominated science, this is a worthy undertaking. The issue must be properly framed to gain support. Partnering might be a way of beginning small; several institutes could join on issues related to the “life span.” Dr. Wilson said there were partnering activities under way.
- Many areas of disparities could be studied in men.
- A nexus exists between men’s health and faith-based efforts.
- The time is right for faith-based initiatives in health.
- The male initiative should be framed as a health disparity issue.
- Rather than “faith-based,” the focus should be “faith.”

EXTRAMURAL PROGRAMS HIGHLIGHTS

Community-Based Participatory Research, “Accountable Communities: Healthy Together,” Marshall Kreuter, Ph.D., Georgia State University

Dr. Kreuter gave an overview of his community-based participatory research (CBPR) activities. CBPR involves a strategy for eliciting community participation. He discussed the goals and outcomes of the first year which included: how community assessment led to modifications in the study's strategic approach; and examples of data gathered and used in the planning process. While numerous organizations supported the work being done in the area under study and could be regarded as assets, the lack of communication posed a problem. Consequently, the first activity was a community forum at which helping organizations described their missions, strengths, and activities.

Since it is difficult to obtain reliable data through a single collection method, several approaches are used. The “perception analyzer,” facilitated by a local resident, offers an alternative to traditional focus group research. Findings show extreme contrasts between the prevalence of diabetes, breast cancer, and other forms of cancer in neighborhoods with similar populations but located 4 miles apart. Discrepancies reflect the different socioeconomic conditions of the two areas, despite their proximity.

Under the aegis of the Neighborhood Planning Unit-V (NPU-V), CBPR has held forums in which residents define local health-related problems and assets in their communities. Forum II, which set priorities by voting for the problems and social needs to address first, was an example of “public health democracy.” Residents selected depression/mental health and drug/alcohol abuse as their critical health problems, and they named crime/safety, lack of employment, youth support, and development as the key social determinants. While the voting group may not be a representative sample, it includes representatives from all parts of the area. The NPU-V's endorsement takes the place of a governing body.

Loan Repayment Program

Janice Bowie, Ph.D., M.P.H., Johns Hopkins Bloomberg School of Public Health

Dr. Bowie discussed how the NCMHD Loan Repayment Program (LRP) has enabled her career through scholarship, career development, and mentorship. She defined herself as one of the

atypical LRP participants given that in general, LRP awardees are younger investigators. Now an Assistant Professor on the tenure track at Johns Hopkins University, she came late to academia. While Baltimore has a majority African American population, few African Americans are tenure-track faculty in the School of Public Health School at Johns Hopkins, which is located in the heart of Baltimore. Her LRP scholarship has allowed her to focus on interests in health disparities, and develop a portfolio including work with faith-based approaches, cancer, and other diseases disproportionately affecting minorities. Proficiency in grant application has played a role in her career development, and she is now mentoring others potential LRP applicants through the application process.

Giang Nguyen, M.D, M.P.H., University of Pennsylvania

Dr. Nguyen began his presentation acknowledging the support of the NCMHD LRP program, which made it possible for him to move forward in his career and gain awards in addition to loans to assist with medical school costs. An Asian immigrant, he is currently studying cancer information-seeking among Vietnamese immigrants.” The Asian and Pacific Islander population is growing in this country, and many do not speak English. While Asians are thought of as the “model minority,” a significant portion of this population experiences poverty and/or a lack of education, as well as a disproportionate rate of cervical and colon cancer. Dr. Nguyen is seeking to discover the effectiveness of health-related media intervention efforts to address common diseases affecting this population. Specifically, he is exploring how a group of Vietnamese immigrants gets their health information regarding cancer.

A qualitative study is conducted to allow for ground-up information, as well as the collection of demographics and measures of acculturation. Individuals are interviewed in Vietnamese on a one-on-one basis. Findings show that many respondents avoid or receive little or no cancer information because of fear, lack of source knowledge, poor or no English skills, financial barriers, low baseline health knowledge, laziness, reluctance to bother the doctor, misconceptions about screening, or non-disclosure by the English-speaking translator. Primary sources of cancer information are interpersonal contacts, and the free ethnic news media that generally offers cancer information in the form of corporate advertising.

Bringing about appropriate health behavior on the part of this population is a major challenge, which will be addressed in a series of future steps.

Comments:

- The LRP should be commended for achieving its goals.
- Other minorities face similar problems to the Asian American community. However, some populations have strong connections, so project findings/messages in Philadelphia may be transferable to other cities such as Houston.
- Asked what they would have done without the LRP, Drs. Bowie and Nguyen gave examples of additional constraints they would have faced in career paths, including financial limitations and quality of life issues.

NCMHD Centers of Excellence Program, Ken Harewood, Ph.D., North Carolina Central University (NCCU)

Dr. Harewood started by describing the background of NCCU, formerly a teaching and now a research institution and one of 16 institutions in the University of North Carolina system. The EXPORT Center at NCCU was established in 2002; it focuses on health disparities research in cardiovascular disease, cancer, and drug abuse/addiction. Research cores include genomics, bioinformatics, animal resources, and transgenic genotyping.

The NCCU Community Outreach Core achievements include four plays focused on building awareness of diseases and positive behavioral change. Other accomplishments include recruitment of a fulltime director who heads the training program; 11 post-doctoral fellows; and approximately 70 fellows supported by the NCMHD EXPORT Center grant.

BRITE (Biomanufacturing Research Institute & Technology Enterprise) is a new institution that has received \$22 million in funding to prepare students for careers in pharmaceutical science and biomanufacturing. Masters and doctoral curricula are being planned, and 35 mostly minority students are enrolled in the program for this fall term. The joint entity of JLC-BBRI-BRITE (Julius L. Chambers Biomedical and Biotechnology Research Institute) signifies expansion of NCCU's capacity to develop competitive research and core technologies. New programs are being developed in neuro-degenerative disorders, infectious disease, and nutrition. Support for the EXPORT Center has allowed a small institution to move to new, much more competitive levels; heightened awareness of health disparities; and attracted academic/industry partners to assist with curriculum development, research training, and community outreach.

National Human Genome Research Institute (NHGRI) Health Disparities Research Highlights, Dr. Francis Collins, Director, NHGRI

Dr. Collins gave a PowerPoint presentation illustrating what has grown from the Human Genome Project. He believes health disparities mostly emanate from the environment and not genetics, but he is interested in finding what "time bombs" are held in DNA. The International HapMap Project shows how genetic variation emerges. *Nature* published Phase 1, and Phase 2 will be out at the end of the year. Findings show age-related macular degeneration and risk variants and genetic relationship to prostate cancer. The fact that African Americans are shown to have a genetic predisposition to prostate cancer could be viewed as—or could explain—a health disparity, a significant example of how genetic information can explain health disparities. Another example is African Americans' risk factor for type 2 diabetes.

The Genetic Association Information Network (GAIN) is a new public-private partnership between NIH, the Foundation for the NIH, and private sector companies. GAIN's goal is to encourage whole genome association studies of common diseases; GAIN will provide

genotyping for nine studies with 1,000 cases each. The Genes and Environment Initiative (GEI) proposed in the President's budget aims to accelerate understanding of genetic and environmental contributions to health and disease. Dr. Collins showed a graph illustrating the potential connection of self-identified race/ethnicity and health/disease. Running through the line were such factors as environmental exposure, ancestral origins, and variances in disease genes. Other factors were education, access to care, and socioeconomic status.

The study of health disparities represents a high priority for NHGRI. Major initiatives include:

- Research (HapMap, GAIN, GEI, genomic medicine for the underserved);
- Research capacity-building (includes a minority action plan, intramural Visiting Investigator Program, annual summer short courses for mostly minority faculty members and students); and
- Community outreach (community genetics forums, K-12 activities, DNA Day).

Comments

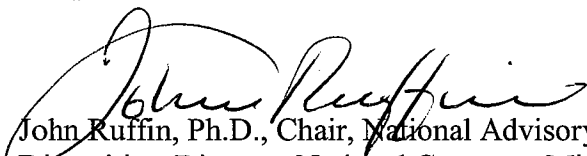
- Despite ethical component requirements, is there a danger for people who are being tested for predisposition to a disease? There are ethical risks of genetic testing. Dr. Collins stated that legislation is needed to prohibit genetic discrimination. He said a proposed bill has failed in the House of Representatives twice, primarily because of objection from the business community.
- Regarding the effects of genetics-versus-environmental impacts, genetics plays a role. Disparities are probably most attributable to the environment. However, findings such as predisposition to prostate cancer may be primarily related to genetic risk.

CLOSING REMARKS, Dr. John Ruffin

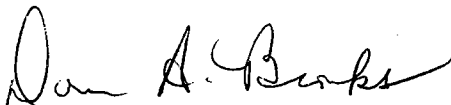
Dr. Ruffin thanked presenters, grantees, ad hoc members, and Council members for their time, participation, and reports. He committed the NCMHD to continuing its work on combating health disparities, and he said that the Council would continue to invite NIH officials to its Advisory Council meetings for regular updates on related NIH activities.

The Executive Secretary, Ms. Donna Brooks, adjourned the meeting at 5:04 p.m.

I hereby certify that, to the best of my knowledge, the foregoing minutes are accurate and complete.



John Ruffin, Ph.D., Chair, National Advisory Council on Minority Health and Health Disparities; Director, National Center on Minority Health and Health Disparities, NIH



Donna A. Brooks, Executive Secretary, National Center on Minority Health and Health Disparities, NIH