# 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 Tuesday, June 21, 2005

## **Meeting Minutes**

The National Advisory Council on Minority Health and Health Disparities met on June 21, 2005 at the Marriott Gaithersburg, Washingtonian Center, 9751 Washingtonian Blvd., Gaithersburg, Maryland. Donna A. Brooks, Executive Secretary, National Center on Minority Health and Health Disparities (NCMHD) called the meeting to order at 8:40 a.m. John Ruffin, Ph.D., Director, NCMHD and Chairman, National Advisory Council on Minority Health and Health Disparities presided over the meeting. Caroline Kane, Ph.D., Adjunct Professor, University of California, Berkeley, served as chair designee and facilitated the proceedings. In accordance with the Federal Advisory Committee Act (FACA), the meeting was open to the public from 8:35 a.m. to 12:45 p.m. and reconvened in open session from 1:30 p.m. to 4:15 p.m.

## **Council members present:**

Council members present.

John Ruffin, Ph.D., Chair

Carl Franzblau, Ph.D.

Thomas E. Gaiter, M.D.

Pamela V. Hammond, Ph.D., F.A.A.N.

Ruth Johnson, J.D.

Caroline M. Kane, Ph.D.

Elisa T. Lee, Ph.D.

Melvina McCabe, M.D.

Eric Munoz, M.D.

Grace L. Shu, D.O.M., Ph.D.

Pitambar Somani, M.D., Ph.D.

Louis W. Sullivan, M.D.

Augustus A. White, III, M.D., Ph.D.

M. Roy Wilson, M.D.

## **Ex-officio members present:**

David B. Abrams, Ph.D.

## **Executive Secretary:**

Donna A. Brooks

#### Council members absent:

Regina M. Benjamin, M.D., M.B.A. Warren A. Jones, M.D. Michael J. Fine, M.D., M.Sc. Kevin R. Porter, M.D.

**OPENING REMARKS:** Dr. Ruffin welcomed the group to the ninth meeting of the National Advisory Council on Minority Health and Health Disparities. He noted that NCMHD has a new executive secretary to the advisory council, Ms. Donna Brooks. Dr. Ruffin also thanked Ms. Lisa Evans, who preceded Donna in the executive secretary role.

Dr. Ruffin gave an overview of the meeting's agenda to include: a briefing on the National Academy of Sciences report on the Assessment of the NIH Minority Research Training Programs; presentations highlighting NCMHD-funded research activities -- Lisa Signorello from the Loan Repayment Program, Dr. Mark Chassin, a Project EXPORT grantee at Mt. Sinai School of Medicine and Dr. Herman Taylor from the University of Mississippi Medical Center to discuss the Jackson Heart Study; Dr. Donald Lindberg, the Director of the National Library of Medicine will also share highlights of the NLM health disparities activities; annual ethics training and the second level review of applications for the Small Business Innovation Research Project, and the Minority Health and Health Disparities International Research Training Program.

## REVIEW OF CONFIDENTIALITY & CONFLICT OF INTEREST

As Chair designee, Dr. Kane reviewed several Advisory Council policies and procedures. Dr. Kane reminded the Council that its meetings are open to the public and that closed sessions were reserved for the review of grant applications. She reminded members that the Advisory Council's standards of conduct were in their desk folder. She reviewed the confidentiality and conflict of interest policies citing a few examples of potential and urged members to reconcile any potential conflicts in advance and to consult the official standards of conduct for more details.

#### CONSIDERATION OF THE ADVISORY COUNCIL'S FEBRUARY 2005 MINUTES

The Advisory Council reviewed the February 23, 2005, meeting minutes and voted to approve the minutes as presented.

#### FUTURE MEETING DATES & OTHER ADMINISTRATIVE MATTERS

September 13-14, 2005; February 21-22, 2006 June 13-14, 2006 September 12-13, 2006.

It was announced that the September 2005 meeting dates will be changed to September 20-21, 2005.

#### **DIRECTOR'S REPORT**

Dr. Ruffin announced two individuals who were joining the NCMHD. Dr. Roger Bulger will join the NCMHD as a consultant. He will serve as a senior executive advisor to the Director, NCMHD, and will assist in the further development and implementation of the NIH health disparities strategic plan. As a liaison to NIH institutes and centers, he will help us to enhance partnerships with NIH ICs and Office of the NIH Director, and other federal agencies and organizations in our pursuit to build a solid and diverse national biomedical research enterprise

of individuals, institutions, and communities dedicated to eliminating health disparities.

Dr. Reuben Warren is the Associate Director for Environmental Justice in the National Center for Environmental Health/Agency for Toxic Substances and Disease Registry. He will assist the NCMHD in developing strategic partnerships to enhance infrastructure development for faith-based organizations, and tribal communities, including tribal colleges and universities; foster unique partnerships with the departments of health and offices of minority health in different states around the country, and with other agencies within the Department of Health and Human Services in an effort to strengthen and advance the work of the NCMHD to eliminate health disparities.

The organizational assessment of the NCMHD conducted by Booz Allen Hamilton, is nearing completion and the findings will be shared with the Council at a future time.

The Council was informed about the new guidelines on convening subcommittee meetings, which require the announcement of subcommittee meetings in the Federal Register one month in advance of the actual meeting. The NCMHD was still working through the guidelines to determine its implementation approach.

Dr. Merlyn Rodrigues, Chief, Office of Extramural Activities gave a status of the review process for the NCMHD extramural programs. She provided a breakdown of the applications received by program: Project EXPORT (P20 33 applications; Research Endowment Program: 8 applications; Research Infrastructure in Minority Institutions Program: 11 applications. The Minority Health and Health Disparities International Research Training (MHIRT) Program: 48 applications referred for second level review that will take place today. The Community-Based Participatory Research program: The response to the RFA was overwhelming –188 applications were received. The initial peer review schedule is as follows: Research Endowment Program: June 2005; Community-Based Participatory Research Program, Centers of Excellence (Project EXPORT) and RIMI: July 2005. For the first time, this year the NCMHD was using the Internet-assisted review process for the Loan Repayment Program, MHIRT and the Community-Based Participatory Research Program.

The NIH Health Disparities Strategic Plan: Fiscal Year 2004-2008, and the NIH Annual Report on Health Disparities Research for Fiscal Years 2002 and 2003 are being finalized for submission to the Office of the NIH Director and the Office of the Secretary, Department of Health and Human Services (DHHS) for clearance. The NIH Budget Methodology Report is now at the DHHS for clearance.

The Institute of Medicine's Assessment of the NIH Strategic Research Plan and Budget on Health Disparities is on-going. The study committee held its most recent meeting on May 10, 2005. Among the presenters were NIH leaders such as Dr. Alan Spiegel, the Director of the National Institute of Diabetes and Digestive and Kidney Diseases; Dr. Vivian Pinn, Associate Director, Office of Research on Women's Health; grantees and community leaders such as Dr. David Satcher, representing Morehouse School of Medicine; Dr. Raymond Garza from the Hispanic Association of Colleges and Universities; Capt. Walter W. Williams, Associate Director for Minority Health at the Centers for Disease Control and Prevention; and Gem Daus, Policy Director for the Asian American-Pacific Islander Health Forum.

Dr. Ruffin informed the Council about his participation in the sixth annual Tribal Budget

Consultation meeting of the DHHS' Intradepartmental Council on Native American Affairs (ICNAA) in May 2005. Each year the meeting brings together the leaders of various tribal organizations with the membership of ICNAA and offers a chance for the tribes to dialogue with DHHS representatives. Some of the issues of interest to the tribes included: health disparities; access to care; continuation support from NIH for research projects such as the Native American Research Center for Health with the Indian Health Service, and the NIH interest in research on the impact of climate change on the health of Alaska Natives. At the meeting, Dr. Ruffin highlighted some of the programs the NIH was supporting in areas such as cardiovascular disease, diabetes, science education, access to care, and substance abuse related to tribal communities.

Dr. Ruffin informed the Advisory Council about the NCMHD's funding history with the Centers for Disease Control and Prevention to support the REACH 2010 program. That relationship began with the NCMHD's predecessor, the Office of Research on Minority Health (ORMH). Dr. Ruffin updated them on the recent concerns raised by Congressional staffers, the media and REACH 2010 grantees because of the reduction in NCMHD funding. The NCMHD met and exceeded its annual commitment of \$5 million to the REACH 2010 program. The fiscal year 2004 funding of \$2 million was the result of competing congressionally mandated programs of the NCMHD. Dr. Ruffin noted that he had to clear up some misunderstandings surrounding the REACH 2010 program, because many individuals did not realize that it was a CDC program and not a NCMHD program.

Dr. Ruffin, along with Dr. Garth Graham, Deputy Assistant Secretary for Minority Health in the Office of the Secretary, DHHS, and NIH/HHS legislative staff, participated in a series of meetings with Congressional staffers related to reauthorization of the NCMHD. Meetings were held with Senator William Frist's staffers and Senate HELP staffers.

This year's congressional hearings on FY 2006 appropriations took a different format. All of the IC directors were invited to participate in the House of Representatives hearing. For the Senate hearing, Senator Arlen Specter identified specific issues that he wanted select IC directors to address before the Senate. All IC directors received a letter from Senator Specter with a number of questions they were responsible for responding to.

#### RECOGNITION OF RETIRING COUNCIL MEMBERS

Dr. Ruffin recognized four Council members whose terms of appointment on the Advisory Council had expired. He thanked Drs. Roger Bulger, Elisa Lee, Eric Munoz, and M. Roy Wilson for their service and commitment to the NACMHD.

# ASSESSMENT OF NIH MINORITY RESEARCH TRAINING PROGRAMS: Phase 3

Dr. Ruffin gave a brief history of the Assessment of NIH minority research and training programs. The assessment originated with the NIH Office of Research on Minority Health, in response to the recommendations of the ORMH Fact-Finding Team. Two reports were published. The Phase 1 report presented an overview of NIH extramural research/training support and summarized available information and trend data for each of the major NIH minority research/training programs. The Phase 2 report examined the feasibility of conducting a trans-NIH assessment. It would further determine the scope of the assessment, primary and secondary research questions, identify the information needed, and examine potential data sources. Dr. Ruffin acknowledged Mr. Vincent Thomas as the liaison for the Phase 3 report, as well as Dr.

Lorrita Watson for her work in coordinating the Phase 1 and Phase 2 reports for the ORMH.

Dr. John Bailar represented the Institute of Medicine's study committee in briefing the NACMHD on the Phase 3 report.

The goal of this study was to assess and analyze NIH minority trainee educational and career outcomes, and to recommend improvements to the NIH coordinated tracking/information system of minority research/training programs and their participants. Dr. Bailar reviewed the questions the Study Committee was asked to address through the assessment. For example:

- 1) Do the NIH minority research/training programs work?
- 2) Which minority programs and which features of minority programs have been most successful in helping individual students and faculty members move a step forward toward productive careers as research scientists?
- 3) How can a system be set up that would better address assessment questions in the future?

To address these questions, the committee divided its work into three parts. The first (part A), was an assessment and analysis of the programs based upon information in existing **NIH** databases on minority trainee educational and career outcomes from the undergraduate years to the faculty level. The second (part B), was aimed at augmenting the insights obtained from the database query. A subset of minority trainees were interviewed by telephone in order to obtain quality of data that was not available through database query, alone. The third (part C), would be recommendations for an improved coordinated tracking/information system that will:

- Provide NIH administrators a means for obtaining improved annual feedback on minority research training programs;
- Assist with the development of future goals;
- Assist with the development of performance measures; and
- Assist with the improvement of program effectiveness.

Some of the key recommendations of the Phase 3 report include:

- By the end of 2005, the NIH director should articulate a set of clear and measurable training goals and objectives specific to minority training.
- NIH should commit to the continued funding of minority-targeted research training programs.
- The training policy of the NIH institutes and centers (ICs) in conducting these programs should emphasize the development of trainees who have already demonstrated promise in the sciences, so that they can overcome the barriers to becoming productive investigators.
- The director of each institute should designate a single individual as minority research training programs coordinator for that institute by the third quarter of FY 2005.
- The committee of minority training program coordinators should establish appropriate guidelines and measures for evaluating NIH minority research training programs.

- Further study of the relative effectiveness of minority-targeted versus non-targeted programs should be carried out by NIH institutes and centers under coordination from the Office of the Director.
- The director of NIH training should administer the funds for evaluation, data collection, and marketing by FY 2006.

Council members thanked Dr. Bailar and the NAS for the report and commented that the report is extremely helpful in understanding the problem and what can be done to address the concerns.

**Jackson Heart Study:** Dr. Herman Taylor serves as Director and Principal Investigator of the Jackson Heart Study, at the University of Mississippi Medical Center.

The Jackson Heart Study (JHS) is a single-site prospective epidemiologic investigation of cardiovascular disease (CVD) among African-Americans from the Jackson, Mississippi metropolitan area. This study represents an expansion of one of the study sites of the Atherosclerosis Risk in Communities (ARIC) Study which included four geographically diverse communities in the U.S. (northwestern suburbs of Minneapolis, Minnesota; Washington County, Maryland; Forysth County, North Carolina; and the city of Jackson, Mississippi).

The JHS is sponsored by the National Heart, Lung, and Blood Institute (NHLBI) and the National Center on Minority Health and Health Disparities (NCMHD) at the National Institutes of Health (NIH). It is a partnership between NHLBI, NCMHD and three local institutions: Jackson State University, Tougaloo College, and the University of Mississippi Medical Center.

The ARIC Study included a comprehensive baseline examination (1987-1989) and three subsequent follow-up examinations occurring at approximately three-year intervals (1990-1992, 1993-1995, and 1996-1999). A total of 15,792 individuals between 45 and 64 years of age were initially examined and 3,732 were from the Jackson ARIC cohort. Participants have been followed for CVD events and will continue to be followed for several additional years.

The Jackson Heart Study includes up to 5,307 African-American men and women between the ages of 35 and 84 including 1,624 previous ARIC participants (approximately 59 to 78 years of age in 2000) along with younger and older men and women from a larger geographic area.

Dr. Taylor described the Jackson Heart Study Scholars Programs, and the Science, Language and Math (SLAM) High School Program. Currently, there are 33 Jackson Heart Study scholars. There are 332 graduates of the SLAM high school program. Over the past seven years, eight annual summer courses in epidemiology have been offered.

The Jackson Heart Study Scholars Program: Each year 10 freshmen are selected and designated as Jackson Heart Study Scholars. This year 12 scholars were chosen. The scholars encompass various fields of study, and are all introduced to the area of public health through the Undergraduate Training Program. Upon becoming a Jackson Heart Study Scholar there are several requirements including working with high school students in the SLAM workshops and other UTC sponsored activities for 10 weeks during the first summer. During their sophomore and junior years, they participate in a practicum for eight to ten weeks.

National Library of Medicine Health Disparities Report: Dr. Donald Lindberg briefed the Council on the health disparities activities of the National Library of Medicine (NLM). The

NLM is directing many of its efforts toward remedying the disparity in health opportunities experienced by important segments of the American population. These efforts are based on the belief that improving access to affordable and easy-to-use health-related information (in the form of published literature, databases, and the authoritative content of others) can help solve health disparities. The advanced information products and services of the National Library of Medicine are built on the foundation of its unparalleled collections. The Library is seen as a principal source of biomedical information and the NLM's many high-technology programs are infused with the confidence and competence resulting from a century and a half of experience in filling the information needs of health professionals. The Library continues to place primary emphasis on its role as acquirer, organizer, and disseminator of health-related information.

The Library is devoting considerable attention and resources to improving access by health professionals, patients, families, community-based organizations, and the general public to information, with special emphasis on rural, minority, and other underserved populations. NLM firmly believes that improved access to health information in MEDLINE, MEDLINEplus, ClinicalTrials.gov, and the Library's other computerized databases will result in higher quality health care for the Nation's citizens.

#### **NCMHD Programs Highlights**

Loan Repayment Program: Dr. Lisa Signorello is a NCMHD Loan Repayment Program scholar. She is the co-investigator and overall project coordinator of the Southern Community Cohort Study, a landmark epidemiologic cohort study that focuses on the issues of racial disparities in cancer occurrence. The study was funded by the NCI in 2001. Recruitment of participants began in the spring of 2002.

The Southern Community Cohort Study is a collaboration between Vanderbilt University, Meharry Medical College, and the Epidemiology Institute in Rockville, Maryland. The goal is to create a cohort of approximately 100,000 participants aged 40-79 from 12 states in the Southeastern US. The Southeast was chosen as the setting because of distinctive patterns of disease in the South; high rates of certain cancers such as lung cancer in the South; high rates of stroke and heart disease in the region; a high proportion of long-term African American residents, and a high proportion of long-term rural residents.

Through the support and cooperation gained with the community health center network, the community health centers became the study enrollment sites. Funding is provided to the community health centers to hire interviewers from the local community to work in the community health center to enroll participants and administer interviews. To date, 39,000 participants have enrolled in the study. On average, approximately 1,000 new participants enroll every month. About 60 percent of our participants are female and 40 percent male. Seventy-eight percent of the participants are African-Americans.

Centers of Excellence (Project EXPORT): Dr. Mark Chassin, is the Edmund A. Guggenheim Professor of Health Policy and Chairman of the Department of Health Policy at the Mt. Sinai School of Medicine.

The Department of Health Policy of the Mount Sinai School of Medicine aims to build research capacity targeting underrepresented minority medical faculty and students at Mount Sinai School of Medicine and North General Hospital. A goal of the EXPORT Center is to promote

participation and training in biomedical and behavioral research among health disparity populations. The EXPORT Center is comprised of three activity cores, each focusing on developing the research, training, and community capacity to conduct effective and meaningful research aimed at eliminating health disparities.

The purpose of the "Overcoming Barriers to Effective Care for Minorities" study is to conduct focus groups with residents from North General Hospital and the Mount Sinai School of Medicine to explore their knowledge, attitudes, beliefs about, and experiences with minority patients they care for, and how their training environment fosters or detracts from the development of cultural competency. The relationship between culture, health beliefs and health seeking behavior has been well established by medical anthropologists. Disparities in health and health care have been linked to patients' health behavior based on cultural beliefs, and to clinicians who provide differential care to minority patients. Social and cultural differences between physicians and minority patients may exaggerate disparities. One accomplishment of the program is a community newsletter -- to enhance understanding of disparities, understanding of research, and to strengthen partnerships and collaborations.

The Project EXPORT program also allowed them to test a new intervention, a community-based, peer led chronic disease self-management program adapted from Stanford to East and Central Harlem. It has deepened the institution's partnerships with North General Hospital --a minority run and private hospital. The EXPORT program offers training in research for North General's faculty, and the program has already produced two master's degree awardees.

A chronic disease self-management course was established. It is embedded in the communities and run by community-based organizations. Patients who have had problems for years with smoking addiction, with losing weight, with getting into exercise programs, report improvement in their own self-management skills after completing the course. The EXPORT program's approach to getting rid of health disparities in East Harlem is to focus on reducing the under-use of effective care by understanding exactly what causes it in the community, tailoring interventions to those specific causes, focusing on improving patient self-management capacities, because those interventions are most likely to be sustainable and embedded in the community and in its health care delivery systems.

#### **CLOSED PORTION - NCMHD**

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. Code and Section 10(d) of the Federal Advisory Committee Act, as amended (5 U.S.C. appendix 2).

Ms. Gretchen Weaver conducted the annual ethics training. The session was a presentation on NIH procedures and policies regarding conflict of interest and confidentiality for special government employees.

#### **REVIEW OF APPLICATIONS**

The Council considered 58 applications requesting an estimate \$13,741,519 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 58 applications.

## Certification

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

John Ruffin, Ph.D.

Chairman, 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