DEPARTMENT OF HEALTH AND HUMAN SERVICES
NATIONAL INSTIUTES OF HEALTH
NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES

NATIONAL ADVISORY COUNCIL ON MINORITY HEALTH AND HEALTH DISPARITES September 16, 2003 MEETING MINUTES

The fourth meeting of the National Advisory Council on Minority Health and Health Disparities (NACMHD) was held on September 16, 2003 at the Marriott Hotel - Pooks Hill in Bethesda, Maryland. Lisa Evans, J.D., Executive Secretary to the Advisory Council, called the meeting to order at 8:35 a.m. John Ruffin, Ph.D., Chairman of the NACMHD and Director of the National Center on Minority Health and Health Disparities (NCMHD), presided over the meeting along with Caroline Kane, Ph.D., Adjunct Professor at the University of California, Berkeley. The meeting was open to the public from 8:35 a.m. to 1:15 p.m. As provided in Sections 552b(c)(4) and 552B(c)(6), Title 5, U.S. Code, and Section 10(d) of Public Law 92-463, the afternoon session from 2:00 p.m. to 5:30 p.m. was closed to the public to allow the NACMHD to conduct the second level of peer review for the applications submitted to the NCMHD for funding through its programs.

COUNCIL MEMBERS PRESENT
John Ruffin, Ph.D. – Chair
Roger Bulger, M.D., F.A.C.P.
Carl Franzblau, Ph.D.
Terone B. Green
Ruth E. Johnson, J.D.
Caroline M. Kane, Ph.D.
Elisa T. Lee, Ph.D.
Melvina McCabe, M.D.
Eric Muñoz, M.D.
Raymond Rodriguez, Ph.D.
Grace L. Shu, D.O.M., Ph.D.
Louis W. Sullivan, M.D.
Selwyn Vickers, M.D., F.A.C.S.
Augustus A. White, III, M.D., Ph.D.
M. Roy Wilson, M.D.

COUNCIL MEMBERS ABSENT
David Satcher, M.D., Ph.D.

EXECUTIVE SECRETARY
Lisa Evans, J.D.

EX-OFFICIO MEMBERS PRESENT
Virginia Cain, Ph.D.
Michael J. Fine, M.D., M.Sc.
Kevin R. Porter, M.D.

OPENING REMARKS:

During the opening remarks, Dr. John Ruffin thanked Dr. Caroline Kane for agreeing to serve as Chair designee to facilitate the meeting. Dr. Ruffin welcomed Council members and attendees to the meeting. He expressed his appreciation to the Council members for making the NACMHD meetings a priority given their busy schedules. Dr. Ruffin informed the members that the Council is now at full capacity with 18 members, with the recent appointment of Regina

Benjamin, M.D., CEO and Founder of the Bayou LaBatre Rural Health Clinic in Bayou LaBatre, Alabama. He hoped that Dr. Benjamin would be able to attend the next meeting.

Dr. Ruffin provided an overview of the agenda. He also announced to the Council that Teresa Chapa, Ph.D., Director of the NCMHD's Office of Extramural Activities would be transferring over to the Office of Minority Health at the Department of Health and Human Services. He thanked Dr. Chapa for her services to the NCMHD.

ADMINISTRATIVE MATTERS

Before proceeding with the introduction of Council members, Dr. Kane reviewed some administrative matters. The Council members reviewed and approved the June 17 meeting minutes and the calendar year 2004 Advisory Council meeting dates were announced: February 24-25, June 15-16 and August 24-25.

REMARKS BY CONGRESSMAN JOHN PORTER

Dr. Ruffin introduced and welcomed former Congressman John Porter to the NACMHD meeting. He thanked Mr. Porter for the influence that he had in the doubling of the NIH budget, as well as the passage of Public Law 106-525, the legislation that created the NCMHD. Dr. Ruffin invited Mr. Porter to share with the Council members his perspective on their role in helping the NCMHD to fulfill the requirements of the law.

Mr. Porter recognized Dr. Ruffin, the NCMHD and the Council for the work that they do to make a difference in the health of many people across the country. He expressed the continuing need for programs like the Loan Repayment Program and the Research Infrastructure in Minority Institutions Program, which identify and train young investigators and build the necessary infrastructure to assist scientists and researchers to carry out the work that has to be done.

The Congressman reflected on his tenure in Congress and his service on various committees and sub-committees. He expressed his pleasure for the opportunity he had to work on a daily basis with individuals like former Congressman Louis Stokes to make a difference for minorities and those affected by health disparities. He recalled the leadership of Congressman Jessie Jackson Jr., who approached him with the idea of creating a Center for Health Disparities at the National Institutes of Health. Although initially skeptical, he was later convinced that such a Center would make a difference for minority health across America.

Four areas of intervention that Mr. Porter deems as priority to help eliminate health disparities are publicity, advocacy, universal coverage and education. According to Mr. Porter, "people in America do not understand the grave differences in health among minorities and other Americans." Therefore, he calls for greater advocacy, particularly via the media. He informed the Council members that the message has to get to the future leaders of this country so that they can have an impact. The second priority area is universal health care coverage. This is key so that people can get beyond emergency room care, and no one is left outside the health care system.

His third area of priority is publicity. He used the upcoming Presidential election as a potential opportunity for the media to get the message of health disparities and the uninsured into the national debate.

The fourth priority area called for medical schools and institutions granting doctorate degrees, to implement advocacy programs and begin planting seeds of understanding. According to Mr. Porter, "Americans need to understand the rights they have to change things and get involved in activities of change such as public policy."

Mr. Porter made reference to the recently released Institute of Medicine report on the organizational structure of the NIH. He noted that there is disparity in the budget of larger and smaller Institutes and Centers at NIH but reminded the Council that the report calls for giving more authority to the NIH director in disbursing the dollars. Mr. Porter shared his view that the Congress should be guided by what the scientists identify as the priority and that the NIH Director needs to set the priorities. Moreover, health disparities have to be addressed by financial investment in order to make the long-term impact. He encouraged the group to assume their role by being active advocates for the NCMHD. He reminded them that as Council members, they could lobby the NIH Director and the Congress whereas that is something that Dr. Ruffin cannot do. Mr. Porter acknowledged the NIH for the good research that it supports and conducts. However, he challenged Council members to urge the NIH to use a portion of the 2.5 – 3.7% increase that it will receive to translate the research into practice. He suggested that greater emphasis be placed on clinical and outcomes research. Finally, he also suggested that having more scientists in the Congress would help to inform the debate about scientific research.

Discussion

Following Mr. Porter's presentation, the discussion focused on comments and questions raised by Council members including recognition of the inertia of change and getting everyone involved in the effort to eliminate health disparities; empowering the NCMHD and increasing the awareness of the American public about health disparities similarly to how the NIH was able to fund HIV/AIDs research and use it as a model to make a difference; the importance of the educational pipeline and early intervention particularly among minorities; and the impact of Proposition 54 in California as it relates to the collection of racial and ethnic data.

DIRECTOR'S REPORT

NCMHD FY 2003 Budget

Dr. Ruffin opened the Director's Report by announcing the NCMHD's fiscal year (FY) 2003 budget, which is $185.8 million. A breakdown of how the NCMHD allocated its FY 2003 budget will be provided at the next meeting, based on recommendations from today's second level peer review session.

Loan Repayment Program (LRP)

A total of 201 applications were received which is 72 less than the total number of applications received in 2002. The reduction was primarily due to a change in the definition for the eligibility

criteria for the Extramural Clinical Research Loan Repayment Program (ECR-LRP). The Department of Health and Human Services requested that the definition of "an individual from a disadvantaged background" pertain only to the economic status of that individual rather than his/her social status or racial and ethnic identity.

A total of 196 applications were reviewed and 124 contracts approved for fiscal year 2003 support. This year, 19 individuals received support through the ECR-LRP and 105 individuals were funded through the Loan Repayment Program for Health Disparities Research (HDR-LRP). Some of the disciplines represented among this year's applicants include microbiology, pharmacology, physiology, anthropology, psychiatry, epidemiology and health economics. Since the establishment of the LRP, this year, for the first time, the NCMHD received co-funding support from another NIH Institute or Center. The Office of Research on Women's Health (ORWH) funded seven of the NCMHD's Health Disparities Research awards. Dr. Vivian Pinn, Director of ORWH was recognized for extending that support.

The program announcement for the next award cycle for the June 2004 to June 2006 period, was issued on September 1, 2003 with an application deadline of December 31, 2003. It is anticipated that recipients will be notified of their awards by May 2004.

Several Loan Repayment Program scholars participated in a roundtable forum in July 2003 to discuss future directions of the program. Many expressed concern that biomedical researchers generally do not consider health disparities research as a rigorous research discipline. A few of the participants were from Chicago and were invited by Congressman Jessie Jackson's office to appear on his public affairs cable television show "A Perfect Union."

The Endowment Program

This program is limited to Section 736 institutions that have a Health Resources and Services Administration designated Center of Excellence. Applications were received from four eligible institutions in response to the Request for Application that was released for FY 2003 funding. Additionally, nine institutions submitted applications for non-competing renewal support. Endowed institutions will use the income earned on the awards to support student scholarships, student support services, key staff positions related to the furtherance of goals and objectives outlined in their Strategic Plans, and research infrastructure.

Centers of Excellence (Project EXPORT)

Progress reports and renewal applications have been received from grantees that are concluding their first year of activity. Although some of the programs encountered some unavoidable administrative delays, they have made substantive progress in establishing their infrastructure and in launching their research projects. The development of partnerships at the community level has also been a hallmark of program development.
A total of 43 applications were submitted in response to the FY 2003 RFAs. The NCMHD anticipates the Council's guidance on future directions for expanding the program.

Research Infrastructure In Minority Institutions (RIMI)

In fiscal year 2003, seven RIMI applications were received and reviewed by the initial peer review committee. The overall objective of this Phase II RIMI initiative are to 1) establish an activity that will enhance the institution's biomedical research infrastructure, and 2) utilize collaborative agreements with institutions granting doctoral degrees in the health sciences to encourage and facilitate research and mentoring interactions between research faculty in grantee and collaborating institutions.

Internship Program

This year, in collaboration with the National Hispanic Association of Colleges and Universities (HACU), the National Association for Equal Opportunity in Higher Education (NAFEO) and the Washington Internship for Native Students (WINS), the NCMHD recruited and placed 43 undergraduate and graduate college students in 24 ICs at the NIH.

IC Collaborations

In the spring, the Strategic Plan subcommittee of the Advisory Council reviewed applications for co-funding that were submitted by the other Institutes and Centers and other federal agencies. The subcommittee provided recommendations to the Director, NCMHD for consideration, on behalf of the full Council. This year the Center is co-funding approximately 138 projects with other ICs. Collaborations have continued with other federal agencies such as the Centers for Disease Control and Prevention, the Health Resources and Services Administration, the Agency for Healthcare Quality and Research, the Office of Minority Health and the Indian Health Service.

Director's Report Discussion

Following the Director's Report, the Advisory Council members began discussions about the eligibility and impact of research intensive institutions applying for planning grants under the R24 funding mechanism of the Centers of Excellence (Project EXPORT) program. One suggestion was to have institutions demonstrate their interest and commitment to the issue of health disparity in order to be eligible for funding consideration. For example, research-intensive institutions could be asked to come up with the seed money to launch their initiative before applying for support from the NCMHD. Some members thought that it is important to provide an opportunity for all institutions to apply. Dr. Ruffin shared with the members that the NCMHD's intent in developing the Centers of Excellence program was to level the playing field so that all institutions have an opportunity to apply for funding.

NCI HEALTH DISPARITIES STRATEGIC PLAN

Harold Freeman, M.D., Director of the National Cancer Institute's (NCI) Center to Reduce Cancer Health Disparities, was invited to share the NCI's minority health and health disparities research agenda with the Council. According to Freeman, NCI's support for minority health and health disparities is approximately $122 million with specific dollars for targeted and non-

targeted research. Several years ago, the National Cancer Advisory Board recommended the development of several leadership initiatives to address cancer awareness in minority communities. Among the initiatives that emerged was the Special Populations Networks in Cancer Awareness Research and Training (SPNS). Eighteen grants have been funded through this program, and the NCMHD has been supporting some of those grants prior to becoming a Center.

In 2001, the NCI's Special Populations Branch was elevated to a Center –the Center to Reduce Cancer Health Disparities (CRCHD). The Center's objectives are to: a) direct the implementation and coordination of NCI health disparities research opportunities; b) provide an integrated system within NCI for planning and reporting on matters of research and policy on cancer health disparities; and c) provide a framework for creating communication networks and partnerships across NCI. The overarching research objectives of the Center are to provide leadership, coordination, and advice on community-based research; support research programs that address scientific questions pertinent to low-income, minority, and underserved populations; develop concepts for new programs with potential to close the gap between the research and delivery; and create unique network of partnerships to leverage support for disparities research.

Examples of the major health disparities research, training, education and outreach initiatives that the NCI is undertaking through the CRCHD include:

- Minority Biomedical Research Support (MGRS) Program.
- Centers for Population Health and Health Disparities (NIEHS, NIA, NCI, OBSSR)
- Cooperative Planning Grant for Cancer Disparities Research Partnership
- Radiation Oncology Research in Populations with Cancer-Related Health Disparities
- Southern Cohort Study
- Pacific Basin Study
- Comprehensive Minority Biomedical Branch (CMBB) - Minority Investigator Supplement (MIS).
- Minority Enhancement Awards (MEA) - increased involvement of primary care providers
- Cancer Information Service (CIS)
- 5-9 A Day Initiative for Black men
- Translations of cancer patient education materials
- Comprehensive Cancer Control Planning Institute in Puerto Rico (May 2003)
- Vietnamese Cervical Cancer Screening Educational Project
- Asian American Pacific Islander (AAPI) Educational Outreach Project

The future plans of the CRCHD according to Dr. Freeman include:

- Enhancing communication and collaboration within NCI, NIH Institutes and Centers, and DHHS agencies to address cancer health disparities
- Coordinating and integrating NCI's plans and response to health disparities issues across all NCI Divisions
- Developing partnerships with federal, state, and community entities to support the implementation of effective disparities research and

- Investigating factors that influence the quality of cancer care among racial and ethnic minorities and other underserved populations

Discussion

Following Dr. Freeman's presentation, the Council expressed great concern for the apparent lack of coordination at the NIH of health disparities activities and the role that the NCMHD has been authorized by congressional legislation to play. One suggestion was to effectively use the NIH *Strategic Research Plan and Budget to Reduce and Eliminate Health Disparities* as one way to coordinate the NIH minority health and health disparities activities. The group agreed that it was important to have the Strategic Plan monitored in order to ensure that it achieves what it proposes to do.

Cancer Health Disparities Progress Review Group

Louis Sullivan, M.D., provided an update on the Department of Health and Human Services Cancer Health Disparities Review Group (CHDPRG) meeting at which he and Dr. Mireille Kanda, Acting Deputy Director of the NCMHD represented the NCMHD in August. The purpose of the CHDPRG is to facilitate a coordinated and comprehensive analysis to identify new opportunities for HHS agencies to address cancer health disparities, implement new cancer health disparities initiatives, and evaluate their progress. The CHDPRG will serve as a demonstration project to test approaches that will be used to review and evaluate progress against health disparities related to other diseases as well. The goals of the CHDPRG are to:

- Comprehensively define and describe issues related to cancer health disparities.
- Identify areas of strength, gaps, opportunities, and priorities to address cancer health disparities in research and intervention development.
- Facilitate the adoption and implementation of evidence-based research, policy, community programs, and clinical interventions and evaluate their impact on specific cancer health disparities.
- Ensure unbiased access to standard and continuous preventive care, early detection, and treatment of cancer for every American.

Dr. Sullivan shared with the Council a resolution that he proposed and that was passed at the meeting. The resolution calls for the CHDPRG to provide clarification to the NCMHD Director and the NACMHD on the impact of the current process being used by the CHDPRG on the NCMHD's mandate, as well as identification and resolution to the satisfaction of the NCMHD Director and Advisory Council, of the implications and/or conflicts of interest that may emerge from the process.

The Council also agreed to send a letter to Dr. Elias Zerhouni, NIH Director, and Dr. Andrew von Eschenbach, NCI Director inviting them to meet with the Council to discuss the issue of the coordination of health disparities activities at the NIH and the role of the NCMHD.

THE SULLIVAN COMMISSION

Dr. Louis Sullivan briefed the Council on the activities of the Kellogg Foundation's Sullivan Commission. The purpose of the Commission is to focus on increasing the number of underrepresented minorities in the health professions as a means of addressing the nation's health disparities. The Commission has scheduled a series of public forums to gather information from various communities about the challenges, gaps and potential solutions in diversifying the health professions. Some of the professions that the Commission is currently concentrating on are medicine, dentistry and nursing. Upcoming meetings are scheduled for October 3 in New York, New York and October 20 in Chicago, Illinois. The Commission's final report with recommendations will be issued at a press conference in Washington, D.C. in April 2004. The ultimate goal of the Commission is to have a campaign to encourage all the appropriate communities to adopt the recommendations of the report.

NIH MINORITY HEALTH AND HEALTH DISPARITIES DEFINITIONS

Carl Roth, Ph.D., provided the preliminary results of the draft definitions and application methodology that six NIH Institutes and Centers piloted. Dr. Roth opened the presentation by informing the Council that Dr. Claude Lenfant, Co-chair of the Committee, retired from the National Heart, Lung and Blood Institute (NHLBI) in August, after approximately 21 years of service. Barbara Alving, M.D., M.A.C.P., now serves as the Co-Chair to the Committee and as the NHLBI Acting Director.

According to Dr. Roth, when the NIH refers to "reporting," it is equivalent to the amount of dollars allocated or spent. He provided examples of proposed definitions, including targeted research which is to reported at 100% and non-targeted research as a percent of minority participation so long as it exceeds a set threshold value; targeted research should be reported at 100% if it is coded as primary low socio-economic status (SES) or rural health. Dr. Roth noted that this particular definition required some refining. The proposed definition for targeted infrastructure was programs that are designed specifically for minority investigators and those are to be reported at 100%. Although targeted outreach was defined as programs that focus exclusively on providing health-related information to low SES or rural health populations, there were no provisions for reporting non-targeted outreach. Roth indicated that the Committee would be meeting within the next two weeks to finalize the draft definitions and reporting guidelines.

Minority Health and Health Disparities Definitions Discussion

Members of the Council raised several areas that they thought the Committee might wish to examine more closely as it finalizes the guidelines. For example, reporting targeted infrastructure at a minority serving academic institution that either serve significant numbers of a specific population or several minority populations. Although an institution may be a minority serving institution not every dollar that it receives can be counted as support for minority health. Socio-economic status is sometimes used synonymously with race and ethnicity and since the terms are different, clarification is necessary to assure accurate reporting. Consideration should

also be given to reporting on diseases that exclusively affect certain minority or health disparity populations.

CLOSED SESSION

The afternoon session of the meeting was closed to the general public to allow the Council to deliberate on the applications that were under consideration for funding from the NCMHD. After reviewing, discussing and voting on the applications under consideration, Dr. Ruffin thanked the Council members for attending the meeting and the NCMHD staff for their contributions to the meeting and their work throughout the year.

Adjournment
With no further business for the Council to consider, the meeting was adjourned by the Executive Secretary, Ms. Evans.

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

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

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Lisa Evans, J.D.
Executive Secretary
National Advisory Council on Minority Health
and Health Disparities