# U.S. Department of Health and Human Services (HHS) National Institutes of Health (NIH)

# National Institute on Minority Health and Health Disparities (NIMHD) National Advisory Council on Minority Health and Health Disparities (NACMHD)

# Hyatt Regency Bethesda One Bethesda Metro Center Bethesda, Maryland

## June 14, 2011

#### **Meeting Minutes**

#### **Council Members Present**

John Ruffin, Ph.D., Director, NIMHD
Wayne J. Riley, M.D., M.P.H., M.B.A., MACP, Chair, NACMHD
John Alderete, Ph.D.
David Baines, M.D.
Paula A. Braveman, M.D., M.P.H.
Mona N. Fouad, M.D., M.P.H.
Marjorie Mau, M.D., M.S.
Jesus Ramirez-Valles, Ph.D.
Eddie Reed, M.D.
Mr. Raj Shah
Mr. Stephen A. Smith, M.B.A.
José Szapocznik, Ph.D.

#### Ex Officio Members

Michael J. Fine, M.D., M.Sc. Robert M. Kaplan, Ph.D. Gary Martin, D.D.S.

## **Ad Hoc Members**

Jasjit S. Ahluwalia, M.D., M.P.H. The Honorable Kweisi Mfume

#### **Executive Secretary**

Donna A. Brooks

# **Deputy Director, NIMHD**

Joyce A. Hunter, Ph.D.

#### CLOSED SESSION

The first portion of the meeting was closed to the public in accordance with provisions set forth in 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.

Executive Secretary Donna A. Brooks called the closed session to order at 8:13 a.m. Dr. John Ruffin, Director of the National Institute on Minority Health and Health Disparities (NIMHD) gave brief remarks to welcome the Council members and thank Council members and the staff for their efforts in facilitating the Institute's review of grant applications. Dr. Wayne Riley, the designated Chair of the National Advisory Council on Minority Health and Health Disparities (NACMHD), presided over the meeting, leading the deliberations on the review of grant applications.

The Council considered 138 applications requesting an estimated \$34,412,201 in total costs. Applications were considered for the following three programs or initiatives through en bloc voting: 1) The Science Education Initiative; 2) The Scientific Conference grants program; and 3) The Small Business Innovation Research/Small Business Technology Transfer (SBIR/STTR)

Dr. Riley updated the Council on meetings held with the following federal officials: HHS Secretary Kathleen Sebelius and Deputy Secretary William Corr; NIH Director Dr. Francis Collins; and Valerie Jarrett, a Senior Advisor to President Barack Obama. Ms. Brooks adjourned the closed session at 10:13 a.m.

#### **OPEN SESSION**

#### CALL TO ORDER & WELCOME

Ms. Brooks called the Open Session to order at 10:30 a.m. and explained that the Council had convened earlier in Closed Session to review grant applications in accordance with provisions set forth in 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. She then turned the meeting over to Dr. John Ruffin, NIMHD Director.

#### **OPENING REMARKS & INTRODUCTIONS**

Dr. Ruffin welcomed all attendees to the Open Session of the 27<sup>th</sup> NACMHD meeting. He explained that much activity had taken place at both the Institute and NIH since the previous Council meeting, including: the launch of new initiatives by the NIMHD, and the release of new Funding Opportunity Announcements; the development of an updated definition of the term "health disparity population"; the reorganization of NIMHD; finalization of updates to the NIH Health Disparities Strategic Plan; and further progress towards the proposed creation of a new NIH Center – the National Center for Advancing Translational Sciences (NCATS).

Dr. Ruffin also announced that he had been honored to receive the *Yale University Bouchet Leadership Award*, named for Yale alumnus Dr. Edward Alexander Bouchet. In 1876 Dr. Bouchet became the first African-American to earn a Ph.D. in any discipline from an American university – and the sixth person to earn a Ph.D. in physics in the Western Hemisphere. However, racial inequities of the time allowed Dr. Bouchet limited career options despite his stellar academic achievements.

#### MINUTES, FUTURE MEETING DATES AND ADMINISTRATIVE MATTERS

The Advisory Council members reviewed and considered the minutes of the February 2011 meeting, and subsequently unanimously approved the minutes.

Dr. Riley reviewed a few administrative matters and announced the future meeting dates of the Advisory Council --September 13, 2011; February 28, 2012 and June 12, 2012. He emphasized the importance of having a quorum for each meeting.

#### REPORT OF THE NIMHD DIRECTOR

#### Staff Introductions

Dr. Ruffin introduced the following individuals who recently joined the NIMHD

**Dr. Dionne Smith Coker-Appiah:** is a recipient of the Disparities Research Education Advancing our Mission (DREAM) Career Transition Award. She is a psychologist and assistant professor at the department of psychiatry in Georgetown University's Medical School.

Dr. Coker-Appiah received her Bachelor of Arts degree in sociology from the University of Virginia, a master's degree in education from Wake Forest University, and a Ph.D. in psychology from the University of Tennessee-Knoxville. Her research focuses on using community-based participatory research approaches to study adolescent dating violence, mental health and sexual health among rural African-Americans.

*Jumi Aluko:* joins the NIMHD as a program assistant. She is a recent graduate from the School of Public Health at the University of Maryland, College Park, and received her Bachelor of Science degree in Kinesiology.

#### NIMHD Reorganization

Dr. Ruffin updated the Advisory Council on activities surrounding the reorganization of the NIMHD following the September 2010 *Federal Register Notice* announcing the re-designation of the Center to an Institute. Following a series of exchanges between NIMHD and various Offices within the NIH Office of the Director involved in the reorganization, the NIH Deputy Director for Management approved a reorganization package for the Institute in May 2011. In addition, the NIMHD was granted permission to increase its FTE level by 26 using its existing budget. This would bring the total number of FTEs for the Institute to 56.

Dr. Ruffin reviewed the organizational structure approved by the NIH OD for the Institute, which will consist of the following:

- Division of Intramural Research
- Division of Scientific Programs
- Division of Data Management and Scientific Reporting
- The Office of the Director

The Office of the Director will have four offices:

- The Office of Communications and Public Liaison
- The Office of Extramural Research Administration

- The Office of Administrative Management
- The Office of Strategic Planning, Legislation, and Science Policy

As a part of the plans to dissolve the National Center for Research Resources (NCRR) and create the National Center for Advancing Translational Science (NCATS), it is planned that the *Research Center in Minority Institutions (RCMI)* program will migrate from NCRR to NIMHD.

#### NIMHD Programs and Initiatives

The Advisory Council reviewed grant applications for three programs/initiatives during the earlier closed session of the meeting: the Scientific Conference grants program, which supports scientific conferences and meetings; the Small Business Innovation Research/Small Business Technology Transfer (SBIR/STTR) program, which supports small businesses interested in engaging in research – or research and development – that has the potential for commercialization and public benefit; and the newly established *NIMHD Science Education Initiative*. The *Science Education Initiative* supports educational mentoring and/or career development programs for individuals from health disparity populations and disadvantaged backgrounds that are underrepresented in the biomedical, clinical, behavioral and social sciences.

Dr. Ruffin explained that the *NIMHD Science Education Initiative* has five core areas: the K-12 Science Education Initiative, the National High School Youth Summer Initiative, the Mentoring and Career Development Initiative, the Health Professions Research Capacity-Building Initiative (which supports postdocs and Early Stage Investigators), and the Outreach and Information Dissemination Initiative. The latter supports the communication of health and research information to communities that tend to encounter communications barriers due to the lack of culturally appropriate information dissemination approaches.

## NIMHD Funding Opportunities

Dr. Ruffin announced that NIMHD had launched a second new funding opportunity this year – entitled *NIMHD Resource Related Minority Health and Health Disparities Research (U24)*. This is a cooperative agreement initiative that supports resource-related research activities which enhance the capacity to conduct meaningful, ongoing, sustainable research and/or research dissemination efforts. There are four core areas associated with this initiative: 1) The Bioethics Research Infrastructure Initiative, 2) The Global Health Research Initiative, 3) The Data Infrastructure and Information Dissemination on Health Disparities Research Initiative, and 4) The Healthcare for Rural Populations Research Initiative. Approximately 55 applications have been received for this funding opportunity thus far. The initial peer review for these applications will take place in July, and the Council will have an opportunity to conduct the second-level review in September 2011.

Applications for the *NIMHD Health Disparities Research* (R01) funding opportunity were due on June 14, 2011. Initial peer reviews will be conducted in October and a second-level of review will take place during the February 2012 Council meeting.

The NIMHD Research Endowment Program (S21) is currently accepting applications from eligible institutions through July 28. The Patient Protection and Affordable Care Act expanded the types of institutions eligible for this funding opportunity to include NIMHD Centers of

Excellence. This will be in addition to Centers of Excellence for health professions funded through the Health Resources and Services Administration.

The NIMHD released a Request for Applications to support competitive revision supplements to NIMHD Centers of Excellence, through a collaboration with the Environmental Protection Agency. Funds will support environmental health disparities research in U.S. communities. An objective of this funding opportunity is to promote multidisciplinary collaborative projects that address the complex interactions between social, natural and built environmental systems and conditions and policies which may negatively impact the health status of health disparity populations.

The review of applications for the Loan Repayment Program (LRP) was completed in April. It is anticipated that approximately 264 individuals from an applicant pool of 668 will receive funding. Awardees will receive up to \$35,000 per year for two years. A precise breakdown of the make-up of the 2011 cohort will be provided at the September 2011 Council meeting, once the awards have been finalized.

#### Health Disparities Course

Starting on June 20, 2011, NIMHD will again offer its two-week health disparities research course entitled *Integrating Principles of Science, Practice and Policy in Health Disparities Research*.

A total of 70 participants were accepted this year (40 participants were accepted for the inaugural course last year). Approximately 60 percent of those selected are early to mid-level research investigators from academic institutions. Twenty percent are established senior-level researchers, practitioners, organizational leaders or policy experts. Ten percent are government or federal representatives, and the remaining ten percent are individuals from foundations, the nonprofit sector and the for-profit sector.

The course is carefully organized into modules that cover the translational continuum and address key aspects of health disparities. The course is taught by invited faculty or subject matter experts who come from academia, industry, NIH, and the community, with diverse experience in government, public health and health policy.

#### NIH Health Disparities Strategic Plan and Budget (FY2009-2013)

The NIH Health Disparities Strategic Plan and Budget is undergoing clearance in the NIH Director's Office, and will then be transmitted to the HHS Office of the Secretary for review and approval.

#### NIH National Center for Advancing Translational Science

The NIH has proposed creating a new Center, to be called the *National Center for Advancing Translational Science (NCATS)*. The plan contemplates that an existing Center, the National Center for Research Resources (NCRR), will be dismantled and that its programs and resources would be transferred to other ICs. NCRR's RCMI Program is slated for transfer to NIMHD. There was discussion of also transferring an additional NCRR program, the Institutional Development Award (IDeA) program, to NIMHD. However, despite letters from constituents, IDeA investigators, and Congressional leaders advocating for the transfer of the IDeA Program

to NIMHD, the final decision was to assign that program to the National Institute of General Medical Sciences.

#### Robert Wood Johnson Health and Society Scholars

NIMHD was pleased to host the Robert Wood Johnson's Health and Society Scholars on May 5 as part of the program's four-day annual meeting. This is the second year that NIMHD has hosted the Scholars. Several scholars gave presentations on their research and all scholars had the opportunity to interact with program officials from various NIH Institutes and Centers during the breakout sessions. The highlight of the meeting was the keynote speaker, Sir Michael Marmot, who is the Research Professor in Epidemiology at the University College of London as well as the Chair of the World Health Organization's Commission on Social Determinants of Health. His presentation "Fair Society, Healthy Lives, Ideology and Evidence" was well received.

# Federal Collaboration on Health Disparities Research

The Federal Collaboration on Health Disparities Research (FCHDR) was established to engage a wide range of federal agencies in interagency research partnerships to promote more coordinated efforts that target health improvement in populations disproportionately affected by disease, injury and/or disability. Dr. Ruffin co-chairs the group along with Dr. Garth Graham, the HHS Deputy Assistant for Minority Health, and a representative from the Department of Education.

Sir Michael Marmot made a presentation at the meeting for the full membership of the FCHDR. He showed great interest in the creation of the FCHDR and the potential of this interagency group to impact so many different levels of the federal government to tackle the complex issue of health disparities. The group also heard from Catherine Hill-Herndon from the U.S. Department of State who presented on "U.S. Foreign Policy and Science Diplomacy Efforts to Promote Social and Economic Progress and Global Health."

#### HHS Action Plan to Reduce Racial and Ethnic Health Disparities

The *HHS Action Plan to Reduce Racial and Ethnic Health Disparities* was released by Secretary Sebelius on April 8, 2011. HHS agencies have been charged with implementing the plan, which will be carried out under the aegis of the HHS Health Disparities Council. That Council is composed of representatives from various agencies including NIMHD. NIMHD will serve as the focal point for coordinating NIH implementation activities associated with the HHS plan.

To ensure synergy among the various NIH Institutes and Centers, a Trans-NIH Committee on Minority Health and Health Disparities will be created. This Committee will be an integral part of the broader NIH effort to institutionalize an integrated process for coordinating minority health and health disparities research.

## Definition of "Health Disparity Population"

Public Law 106-525 gives the NIMHD Director the authority to consult with the Director of the Agency for Healthcare Research and Quality (AHRQ) to define and designate health disparity populations. Over the past few months, the NIMHD and AHRQ have been working together through a working group comprising of staff from both agencies, NIMHD Advisory Council members and other scientists to redefine "health disparity population" and to develop a methodology for designating health disparity population groups. Dr. Paula Braveman, a member of the NIMHD Advisory Council, is chair of the working group. Accompanied by Dr. Nathaniel

Stinson from the NIMHD, she gave the full Council an overview of the working group's deliberations in arriving at the revised definition. Dr. Stinson reviewed the guidance provided in Public Law 106-525 regarding the definition of health disparity and how it formed the basis for the working group's discussions. He also highlighted some of the other data sources that the Council considered. The Council was asked to provide any comments on the draft definition to Dr. Braveman.

#### SCIENTIFIC PROGRAM PRESENTATIONS

# **District of Columbia Partnership for AIDS Progress**

Carl W. Dieffenbach, Ph.D., Director, Division of AIDS, National Institute of Allergy and Infectious Diseases (NIAID)

Dr. Dieffenbach's presentation focused on several HIV/AIDS initiatives supported by the National Institute of Allergy and Infectious Diseases (NIAID), with a particular emphasis on a local project called the D.C. Partnership for HIV/AIDS Progress (DC Partnership). This project is a collaboration between NIAID, the NIH Intramural Research Program and several key institutions in Washington, D.C. The collaborative effort was developed to address the HIV epidemic in Washington, D.C., which has the highest incidence of HIV infection of any city in the United States.

The DC Partnership focuses on four research efforts:

- Identifying populations at high risk for acquiring HIV and developing effective interventions for reducing their risk
- Establishing a D.C.-wide data analysis mechanism to identify and address health issues for people receiving HIV care and treatment
- Augmenting the city's HIV-related subspecialty medical care and enhancing access to research studies Efforts are underway to support the availability of Hepatitis C care as well as mental health services that would be integrated with alcohol and drug addiction services.
- Conducting a pilot program to study the voluntary "test-and-treat" concept aimed at stemming new cases of HIV infection. . "Test and treat" is a concept whereby individuals are automatically enrolled into care and started on antiretroviral therapy once they are identified as HIV positive.

The DC Partnership will also evaluate whether this program could be replicated in other U.S. cities. Work is currently underway to establish a city-wide data system, which will take advantage of the city's unique structure of health care delivery. In Washington, 10 of the largest health care providers cover 80 percent of all the HIV-infected population. The ultimate goal is for clinics to share their patient data through electronic medical records. Data is currently being pulled together and will eventually assist both in treatment and in determining who is lost to follow-up, so that individuals can be tracked. Ultimately, it is hoped that real time data on viral load and CD4 cell count will be available as well. The system will also help to monitor the effectiveness of interventions over time.

In D.C., two studies have been conducted to identify high-risk populations. One was a study to determine how best to identify, recruit and retain high-risk African-American women in the city. This was achieved, in part, by using a unique set of approaches based on demographics and

geospatial mapping. The second clinical research study is HPTN 061, which aims to recruit and enroll another high-risk group: African-American men who have sex with men. Work is underway to plan follow-up studies for these two populations. In addition to being implemented in D.C., the HPTN 061 study has also been implemented other cities across the United States.

# Integrating Markers of Social Status into Clinical Risk Stratification Models to Predict Aggressive Prostate Cancer in Black Men

Shanita Williams, Ph.D., M.P.H., APRN, Research Fellow, NIMHD DREAM Program

Dr. Williams provided a brief background on prostate cancer disparities in the U.S., with a specific focus on Black men. She also discussed a prostate cancer prediction model she is currently developing. The model will use social status measures – as well as other clinical measures – to predict aggressive prostate cancer disease in Black men. The model will eventually be validated on a population of Black men.

Dr. Williams noted that Black men bear an unequal disease burden, as they are 2.4 times more likely to die from prostate cancer when compared with White men. They are also 4 times more likely to be diagnosed with the more aggressive form of the disease. Black men are more likely to go untreated or receive inappropriate treatment after their diagnosis. In addition, Black men experience more severe illness as well as more side effects and have, on average, a shorter survival time.

One of the major overarching challenges within the field of prostate cancer is the difficulty in distinguishing between indolent and aggressive cancer. This is especially true during early diagnosis. Indolent prostate cancer – specifically those referred to as early-stage at diagnosis – are characterized as localized or regional. Nearly 90 percent of prostate cancer cases are diagnosed as indolent prostate cancers. The five-year survival rates are high, which is why these cancers are generally considered non-lethal.

Aggressive forms of prostate cancer, however, are characterized as late-stage at diagnosis. They are generally more advanced and characterized as distant or unknown stages. The five-year survival rates drop off significantly with aggressive forms. This is one of the reasons these cancers are often called lethal (or potentially lethal). There's a much higher incidence of aggressive prostate cancer in Black men.

Dr. Williams explained that an effective risk prediction model for prostate cancer could help physicians make timely and accurate diagnoses and help categorize levels of aggressiveness. It could also assist in making a distinction between cancers that require intensive treatment from those that require less intensive treatment, or no treatment at all. Some clinicians are currently using risk prediction models in the field, but these models do not generally incorporate social factors.

To develop a model using social factors, Dr. Williams conducted some exploratory work using the National Longitudinal and Mortality Study – a current population survey based on the Census – and the Surveillance Epidemiology and End Results (SEER) cancer registry. A combined data set exists that provides access to cancer cases as well as specific social factors.

The hypothesis under consideration is that social status contributes to variations in aggressive prostate outcomes among Black men, and more specifically that higher social status is protective

against aggressive disease. Predictors of aggressiveness include late-stage diagnosis, a more differentiated tumor grade, and higher tumor volume.

Preliminary findings show that – of the 407 Black men identified from the data set containing approximately 6,000 cases of prostate cancer – nearly 75 percent were staged as localized or regional. When looking at tumor stage by age at diagnosis, it was found that distant stage was associated with men that were considered younger while localized and regional stages were associated with older men (i.e. 65 years or older). Dr. Williams also examined tumor grade by age of diagnosis and found that well to moderately differentiated tumors were associated with younger age.

With regard to income, men reporting an income level of \$35,000 per year or higher were significantly less likely to be diagnosed with distant or unstaged cancer at diagnosis. Also, employed men were significantly less likely to be diagnosed with unstaged or distant stage cancers. Men above the poverty level were less likely to be diagnosed with distant stage prostate cancer, compared with men living at or below the poverty level. Education attainment variables were not significant, but rather only borderline significant (at a P=0.07 level). Men who were less likely to be diagnosed with late-stage or unstaged cancer, were those who had a high school education or higher.

The next step for Dr. Williams is to strengthen the sample size by adding cases from 2003 to 2007. With additional data from SEER, Dr. Williams will be able to explore more complex associations.

Oral Health Disparities among Diabetic and Non-diabetic Adults in Baltimore
Julia Hastings, M.S.W., Ph.D., Research Fellow, NIMHD DREAM Program and HANDLS
Research Scientist

Dr. Hastings spoke about oral health disparities with a focus on the African-American population of Baltimore, MD. Oral health disparities have been recognized as leading to a decline in general health for many racial and ethnic populations, especially among African-Americans and those with low-income status.

Several lifestyle behaviors such as tobacco use, frequency of alcohol use and poor dietary choices can affect oral health. Untreated periodontal disease can also adversely affect general health and influence the development of cardiovascular disease, peripheral vascular disease, nonhemorrhagic stroke and poor control of serum glucose.

Dr. Hastings is part of a study of the National Institute on Aging – the Healthy Aging in Neighborhoods of Diversity across the Life Span (HANDLS), supported by the NIMHD. HANDLS is looking at health issues, problems and concerns in communities around Baltimore. HANDLS data were used in Dr. Hastings' research.

Dr. Hastings study sample included 2,077 participants. Overall, 47 percent of the sample held dental insurance compared with 17.2 percent of individuals with diabetes in the same study sample. The dependent measure in the study was the number of natural teeth reported by each participant. The results from the study yielded three significant findings. First, adults with diabetes are more likely to report fewer natural teeth than adults without diabetes (25 vs. 26 teeth on average, respectively). Second, race and poverty status were found to be independent

variables associated with the decrease in the number of natural teeth (African-Americans in this study reported the fewest natural teeth overall). Smoking emerged as the most important factor in natural tooth loss.

The study presented some limitations. One of them was the fact that the HANDLS survey did not ask three very important questions: 1) The type of dental care services provided; 2) The reason for tooth loss; and 3) Detailed questions about the type of dental insurance held. These questions could have greatly enhanced the study.

Possible directions for future research include more rigorous diabetes-related measures of oral health and exploring the cost-effectiveness of early interventions for oral health conditions. In addition, it would be useful to develop an increased understanding about policies that support funding of dental care programs in low-income neighborhoods.

## **COUNCIL DISCUSSION**

After the scientific presentation, the Council followed up with questions and discussion of action items based on the Director's Report. The Council engaged in conversations pertaining to:

- 1. The creation of NCATS and the transfer of the NCRR RCMI and IDeA programs to NIMHD, and what that meant in terms of support and resources for the Institute.
- 2. The reorganization of the Institute, its budget and FTE situation.
- 3. The intent of the laws establishing the NIMHD (Public Law 111-148) and its predecessor NCMHD (Public Law 106-525), and the coordination responsibilities of the NIMHD for minority health and health disparities activities at NIH.

The Council agreed to contact the NIH and HHS leadership about their concerns relative to the above issues. In addition, the group agreed to the formation of a working group and task forces as necessary, to advise the NIMHD Director on strategies for ensuring the Institute's implementation of P.L. 106-525 and P.L. 111-148. In particular, the Council is interested in making sure the NIMHD has the support and resources it needs to carry out the full scope of its legislative mandate to plan, review, coordinate, and evaluate all research conducted and supported by the NIH Institutes and Centers on minority health and health disparities. The group will examine both external and internal impediments to properly fulfilling the NIMHD's statutory mandates, and how to address them.

#### **PUBLIC COMMENTS**

Following completion of the scientific presentations, Dr. Riley asked whether members of the public wished to offer any comments. Hearing none, Dr. Ruffin proceeded to offer closing remarks.

#### CLOSING REMARKS

Dr. Ruffin emphasized the importance of the Council's advice to the NIMHD Director, to the NIH Director and to the Secretary of Health and Human Services. He thanked both Council members and staff for their advice and active participation in the meeting.

# ADJOURNMENT OF OPEN SESSION

Ms. Brooks adjourned the Open Session at 3:50 p.m.

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

/John Ruffin/

John Ruffin, Ph.D., Director, National Institute on Minority Health and Health Disparities, NIH

/Donna A. Brooks/

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