National Advisory Council on Minority Health and Health Disparities

Director’s Report
June 7, 2016

Eliseo J. Pérez-Stable, M.D.
Director, NIMHD
NIH Staff Transitions

• **Colleen Barros**, NIH Deputy Director for Management and Chief Financial Officer, has been on detail at HHS as Acting Assistant Secretary for Administration since last August. Secretary Burwell has now asked Ms. Barros to stay on through the remainder of the administration.

• **Alfred C. Johnson, Ph.D.**, NIH Associate Director for Research Services and Director of the Office of Research Services, will assume the role of Acting Deputy Director for Management.
New NIH Appointments

• **Eric Dishman** has been chosen as Director of the Precision Medicine Initiative (PMI) Cohort Program. Mr. Dishman will lead NIH’s effort to build the PMI landmark longitudinal research study of one million or more U.S. volunteers to expand our ability to improve health and treat disease through precision medicine.

• **Matthew W. Gillman, M.D.**, has been selected as Environmental Influences on Child Health Outcomes (ECHO) Program Director. ECHO is a seven-year NIH initiative to use large, existing study cohorts to conduct research on high-impact pediatric health outcomes. Dr. Gillman will begin his role with NIH in July 2016.
New NIH Appointments

• Patricia Flatley Brennan, R.N., Ph.D., has been appointed director of the National Library of Medicine. The NLM is the world’s largest biomedical library and the producer of digital information services used by scientists, health professionals, and members of the public worldwide. She is expected to begin her new role in August 2016.

• Maureen M. Goodenow, Ph.D., has been appointed NIH Associate Director for AIDS Research and Director of the NIH Office of AIDS Research (OAR). She is expected to join NIH in July 2016 to lead OAR’s efforts, working closely with the NIH Institutes and Centers, to pursue new tools for preventing HIV infection including a vaccine, improved treatments, and, ultimately, a cure.
Fair Labor Act Standards Update
NIH, DOL Response: $47,400

THE BLOG

Fair Pay for Postdocs: Why We Support New Federal Overtime Rules

Our nation should embrace the fact that increasing the salary threshold for postdocs represents an opportunity to encourage more of our brightest young minds to consider choosing careers in science. Biomedical science has never been more exciting or promising than now, and we need to do all we can to support the next generation of scientists.

—NIH Director Francis Collins, M.D., Ph.D., and U.S. Labor Secretary Thomas Perez, J.D.
Huffington Post Blog, May 18, 2016

Ref. U.S. Department of Labor Fair Labor Standards Act
Defining and Delimiting the Exemptions for Executive, Administrative, Professional, Outside Sales and Computer Employees.
THE PRECISION MEDICINE INITIATIVE

NIH Funds Biobank to Support PMI Cohort Program

- Provides $142 million over 5 years to Mayo Clinic in Rochester, MN
- Establishes world’s largest research-cohort biobank
- Supports collection, storage, and distribution of biospecimens
- Enables researchers to study individual differences in health and disease, when combined with volunteer data on lifestyle, medication history, EHR, physical exams, environmental exposures, and real-time physiology tracked through mobile technology

"The more we understand about individual differences, the better able we will be to tailor the prevention and treatment of illness."
—NIH Director Francis S. Collins, M.D., Ph.D.
Precision Medicine Initiative Updates

• Awards for health provider organizations will be made soon
• Coordinating Center under discussion
• Federally Qualified Health Center sites identified — need established EMR
• NIMHD continues involvement through staff
“Red Team” Report on the NIH Clinical Center

• Major changes in leadership planned
• Sentinel event with IV infusion products led to external review
• Fortify culture of safety and quality
• Centralize Clinical Center authority in new CEO and COO separate from ICs
• External Hospital Board
Funding Gap for URM PI Applicants

• Ginther paper follow-up: Gap persists for AA/B applicants even if better

• Proportion of grant applications by AA/B and L/H PIs is very low (5%)

• Proposed intervention to support re-submissions of grants that were scored and not funded by ESI/NI

• Opportunity for NIMHD
Comparison of Racial and Ethnic Categories of Principal Investigators, NIMHD and NIH, FY 2015

<table>
<thead>
<tr>
<th>Category</th>
<th>NIMHD, %</th>
<th>All NIH, %</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American or Black</td>
<td>19.6</td>
<td>2.2</td>
</tr>
<tr>
<td>AI, AN, NH, or OPI</td>
<td>2.8</td>
<td>0.3</td>
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<tr>
<td>Asian</td>
<td>9.5</td>
<td>17.7</td>
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<tr>
<td>White</td>
<td>50.8</td>
<td>68.6</td>
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<tr>
<td>Multi-Race</td>
<td>0.0</td>
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<td>Unknown</td>
<td>9.3</td>
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<tr>
<td>Withheld</td>
<td>6.4</td>
<td>4.9</td>
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<tr>
<td>Latino or Hispanic</td>
<td>12.9</td>
<td>4.7</td>
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## NIMHD Loan Repayment Program

<table>
<thead>
<tr>
<th>Year</th>
<th>Applications</th>
<th>Funded, N (%)</th>
<th>% URM</th>
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<tbody>
<tr>
<td>2013</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disadvantaged Background</td>
<td>36</td>
<td>18 (50)</td>
<td>50*</td>
</tr>
<tr>
<td>Health Disparities research</td>
<td>493</td>
<td>228 (46)</td>
<td>51</td>
</tr>
<tr>
<td>2014</td>
<td></td>
<td></td>
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<tr>
<td>Disadvantaged Background</td>
<td>42</td>
<td>17 (41)</td>
<td>71*</td>
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<tr>
<td>Health Disparities research</td>
<td>505</td>
<td>194 (38)</td>
<td>59</td>
</tr>
<tr>
<td>2015</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disadvantaged Background</td>
<td>50</td>
<td>25 (50)</td>
<td>52*</td>
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<tr>
<td>Health Disparities research</td>
<td>486</td>
<td>125 (26)</td>
<td>66</td>
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</table>

This information was updated after the council meeting.
## NIMHD Loan Repayment Program

<table>
<thead>
<tr>
<th>Year</th>
<th>Applications</th>
<th>Funded, N (%)</th>
<th>% URM</th>
</tr>
</thead>
<tbody>
<tr>
<td>2016</td>
<td></td>
<td></td>
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<tr>
<td>Disadvantaged Background</td>
<td>40</td>
<td>11</td>
<td>82*</td>
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<tr>
<td>HD Research</td>
<td>516</td>
<td>111</td>
<td>68</td>
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</table>

*100% Disadvantaged Background

This information was updated after the council meeting.
Sharing NIMHD’s Vision and Agenda

Recent Meetings of the NIMHD Director

• University of Puerto Rico RCMI and Other Programs, February 2016
• National Medical Association Colloquium, March 2016
• National Hispanic Medical Association Annual Meeting, April 2016
• University of Alabama Health Disparities Research Symposium, April 2016
• CDC Research Conference on Latino Health, April 2016
• Robert Wood Johnson Foundation Health and Society Scholars Annual Program Meeting, May 2016
• Dialogue on Diversity, 2016 Health Care Symposium, May 2016
• Society of General Internal Medicine 39th Annual Meeting, May 2016
• Advisory Councils at NIDCR, NHGRI, NIGMS, NINDS, NLM, ACD on Diversity
Special Presentations

Commencement Address
Eastern Virginia Medical School, Norfolk, May 21, 2016

Commencement Address
McGovern Medical School, University of Texas Health Science Center, Houston, May 27, 2016
"Based on the strength of available evidence, there are policy initiatives that are feasible and sustainable for improving health in a community setting."

Legislative and Budget Updates
Engaging with Our Stakeholders

Courtesy Visits with Congressional Members and Staff

• Rep. Xavier Becerra (D-CA)
• Rep. Ami Bera (D-CA), co-chair of the Congressional Asian Pacific American Caucus Healthcare Task Force
• Rep. Michelle Lujan Grisham (D-NM)
• Rep. Robin Kelly (D-IL), Chair of the Congressional Black Caucus Health Braintrust
• Rep. Barbara Lee (D-CA), co-chair of the Congressional Asian Pacific American Caucus Healthcare Task Force
• Rep. Lucille Roybal-Allard (D-CA)
• Majority and minority professional staff, House Energy & Commerce Committee
• Majority and minority clerks of the Senate Appropriations Subcommittee on Labor, HHS

Rep. G.K. Butterfield (D-NC), Chair, CBC
Rep. Lucille Roybal-Allard (D-CA)
## Primary Actions — Competitive Awards
From February 2016 Council

<table>
<thead>
<tr>
<th>RFA/PA Title</th>
<th>No. of Awards</th>
<th>Awarded YTD</th>
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<tbody>
<tr>
<td>MD-15-007: LIMITED COMPETITION: NIMHD ENDOWMENT PROGRAM FOR INCREASING</td>
<td>3</td>
<td>$5,900,000</td>
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<tr>
<td>RESEARCH AND INSTITUTIONAL RESOURCES CAPACITY (S21)</td>
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<td>MD-15-009: INNOVATIONS FOR HEALTHY LIVING - IMPROVING POPULATION HEALTH</td>
<td>2</td>
<td>$413,346</td>
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<tr>
<td>AND ELIMINATING HEALTH DISPARITIES (R43/R44)</td>
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<tr>
<td>MD-15-010: ADVANCING HEALTH DISPARITIES INTERVENTIONS THROUGH</td>
<td>9</td>
<td>$4,556,049</td>
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<tr>
<td>COMMUNITY-BASED PARTICIPATORY RESEARCH (U01) - 6 pending awards</td>
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## Primary Actions — Competitive Awards From February 2016 Council, Cont’d.

<table>
<thead>
<tr>
<th>RFA/PA Title</th>
<th>No. of Awards</th>
<th>Total Award $</th>
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<tr>
<td>MD-15-013: NIMHD TRANSDISCIPLINARY COLLABORATIVE FOR HEALTH DISPARITIES RESEARCH FOCUSED ON PRECISION MEDICINE (U54) - 3 pending awards and NCI co-fund</td>
<td>1</td>
<td>$2,309,824</td>
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<td>EB-15-001: DEVELOPMENT AND TRANSLATION OF MEDICAL TECHNOLOGIES TO REDUCE HEALTH DISPARITIES (R43/R44) - 2 pending awards</td>
<td>1</td>
<td>$397,892</td>
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</table>
On April 27, 2016, NIMHD co-hosted its first National Minority Health Month Twitter chat geared toward #MinorityResearch.

Themes:
Minority research is important because...

Barriers preventing minority participation in clinical research include...

Increasing recruitment and retention of minorities in clinical research will require...

Helpful resources for educating patients on clinical research...

Chat Traffic Volume:
47.9 million impressions
380 participants
1,554 tweets
Departing NIMHD Staff

• Dr. Irene Dankwa-Mullan departed NIMHD in April as Acting Deputy Director of the Division of Extramural Scientific Programs to work for IBM Watson Health as Deputy Health Officer — Data and Evidence, and Lead Scientific Officer responsible for global strategy in IBM Watson Health’s population health, clinical trials, and health services research innovations for Watson acquisitions — including clinical trials matching, genomics, and personalized medicine.
Departing NIMHD Staff

• Dr. Francisco Sy retired from NIMHD at the end of May after 12 years of service to NIH/NIMHD.

• Dr. Sy served as a Program Director and AIDS Coordinator in the Division of Extramural Scientific Programs and has served in various leadership positions, including Director, Office of Community-Based Participatory Research & Collaboration; Director, Office of Extramural Research Administration; and Director, Division of Extramural Activities & Scientific Programs. He is the current President of the NIH Asian and Pacific Islander American Organization.

• Dr. Sy is moving to Las Vegas to be chair of a department in community health and prevention at UNLV.
New Appointments

• **Dr. Patrice Armstrong** has joined the Office of Science Policy, Strategic Planning, Analysis and Reporting, where she will assist with scientific reporting, planning, and policy. Dr. Armstrong has directed and served as a technical expert for collaborative research projects in the U.S., Europe, and Latin America between the government, academia, and industry.

• **Dr. John Tillinghast** has joined the Office of Science Policy, Strategic Planning, Analysis and Reporting. Dr. Tillinghast will be producing the NIMHD 2015 Portfolio Analysis, conducting epidemiological data analysis to identify health disparity conditions, and providing statistical technical assistance to NIMHD.
New Appointments

• **Ms. Whitney Anderson** has joined the Office of Communications and Public Liaison as communications editor. Ms. Anderson holds a bachelor’s degree in journalism from Howard University with a background in health education. She has recently worked as a photojournalist for Naval Support Activity Washington’s Public Affairs Office and as a reporter for the *Calvert Recorder*, a community news source for Maryland’s Calvert County.

• **Ms. Katherine Ramirez** has joined NIMHD under the Office of the Director as executive assistant to Dr. Eliseo J. Pérez-Stable. Ms. Ramirez previously served as a community outreach coordinator at the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development. Ms. Ramirez holds a bachelor’s degree in liberal arts from the Catholic University of America.
NIMHD grantee Dr. Jennifer Lorvick, Associate Director, Utah Health Program at RTI International, received the *Presidential Early Career Award for Scientists and Engineers* for her research examining how criminal justice involvement contributes to health disparities among African American women who use illicit drugs.

“These early-career scientists are leading the way in our efforts to confront and understand challenges from climate change to our health and wellness.” President Barack Obama, February 18, 2016.
Dr. Dorothy Castille, NIMHD Health Science Administrator, has received a Research Associate appointment to the Smithsonian Institution, National Museum of Natural History, in Washington, DC.

Dr. Castille’s appointment is part of a developing trans-Federal collaboration where she and colleagues will work with native public health researchers and community members to record narratives of illness, health, and well-being during their visits to museum collections to enhance understanding of American Indian/Alaska Native cultural perceptions of health and illness.
Noteworthy Among NIMHD Staff

Dr. Xinzhi Zhang, NIMHD Health Science Administrator, co-authored a paper linking socioeconomic status with eye health in the *Journal of Women’s Health*. Results indicate a need for program interventions and health promotion efforts to increase awareness of the importance of regular eye exams and to eliminate barriers to the use and receipt of eye care among women.

*Association of Socioeconomic Status with Eye Health Among Women With and Without Diabetes*

Keri L. Norris, MPH, PhD; Gloria L. Beckles, MD, MSc; Chiu-Fang Chou, PhD; Xinzhi Zhang, MD, PhD; and Jinan Saaddine, MD, MPH

NIMHD Presentations and Workshops
Dr. Joyce Hunter, NIMHD Director Deputy Director, Engaging with Stakeholders

- The Howard University Research Centers in Minority Institutions Program 2016 Health Disparities Mentor Workshop, Washington, DC, March 2016
- The Tribal Epidemiology Centers — Consortium Directors Meeting, Phoenix, AZ, March 2016
Dr. Regina James, NIMHD Director of Clinical and Health Services Research, Engaging with Stakeholders

Advancing Health Equity through Precision Medicine and Health IT Innovation, the Healthcare Information and Management Systems Society Annual Meeting, Washington, DC, March 2016

First Annual NIH-National Hispanic Medical Association Career Development Program, hosted by NIDDK, Washington, DC, April 2016
Health Disparity Research in Diverse Asian American Populations: Present and Future

Presenter: Dr. Grace Ma, Associate Dean for Health Disparities, Founding Director, Center for Asian Health, Laura H. Carnell Professor of Public Health, Temple University

- Asian Americans include very diverse groups and face substantial challenges.

- More than 70% of Asian Americans are foreign-born, and many have limited English proficiency.

- Other challenges include differing cultural beliefs and behaviors and unfamiliarity with the U.S. health system.

- Asian Americans have the most difficulty understanding instructions in a doctor’s office, are the least satisfied with cancer care coordination, and experience unique health disparities from other ethnic populations.

NIH Seminar co-sponsored by the NIH Asian and Pacific Islander American Organization and NIMHD, February 23, 2016
NIMHD Science Vision Workshop
Methods and Measurement Science in Health Disparities

*Charge*: Evaluate methods used to assess health disparities research and to identify what new methods, approaches, tools, and models are needed

*Workshop date*: April 22, 2016
Key Gaps to Develop Visioning

- **Indicators**: Need equivalence among diseases and conditions; need core variables and common data elements
- **Methodologies**: Need best practices for understanding HD etiology; how to deal with small samples; use of complex systems analysis; consider bi-directionality
- **Evaluation**: Policy interventions and natural experiments; when to generalize for action; determine impact
- **Data**: Utility of Big Data for HD research; how to combine different kinds of data to learn more; inclusion of core HD variables

Vision results expected in August 2016.
Charge: Identify priority recommendations to elucidate the causes of health disparities and inform the design and implementation of interventions to reduce and eliminate health disparities.
Workshop Information and Next Steps

- Focused on two pillars of the science vision: *Etiology* and *Interventions*
  - **Etiology**: Social determinants, biological and environmental mechanisms, health services, lifecourse
  - **Interventions**: Guiding principles, approaches, evaluation, scalability
- Brought together a diverse group of 80 scientists
- Generated more than 200 recommendations
  - Initiated prioritization of recommendations
- Next steps
  - Identify priority recommendations to inform strategic planning
  - Publish manuscripts
Extramural Research Activity
<table>
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<tr>
<th>Funding Opportunities</th>
<th>Funding Number</th>
<th>Released</th>
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<tbody>
<tr>
<td>Clinical Sequencing Evidence-Generating Research (CSER2) - Clinical Sites with Enhanced Diversity (U01)</td>
<td>RFA-HG-16-011</td>
<td>05-06-16</td>
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<tr>
<td>Health Services Research on Minority Health and Health Disparities (R01 and R21)</td>
<td>PAR-16-221-2</td>
<td>05-04-16</td>
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<tr>
<td>The Health of Sexual and Gender Minority (SGM) Populations (R21)</td>
<td>PA-15-263</td>
<td>05-18-15</td>
</tr>
<tr>
<td>The Health of Sexual and Gender Minority (SGM) Populations (R03)</td>
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<td>05-18-15</td>
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<tr>
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<tr>
<td>The Health of Sexual and Gender Minority (SGM) Populations (R15)</td>
<td>PA-15-260</td>
<td>05-18-15</td>
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<tr>
<td>Notice of Intent to Publish a Funding Opportunity Announcement for Research on Disparities in Surgical Care and Outcomes (R01 and R21)</td>
<td>NOT-MD-16-006</td>
<td>04-18-16</td>
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<td>Notice of Participation in PA-16-288 Research Supplements to Promote Diversity in Health-Related Research (Admin Supp)</td>
<td>NOT-MD-16-008</td>
<td>05-31-16</td>
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</table>
NIMHD to Establish New Research Program in Surgical Disparities

Key Components

- Provides R01 and R21 opportunities to understand and address disparities in surgical care and outcomes
- Builds on the concerted efforts of the American College of Surgeons and its affiliates in improving access, quality, and safe surgical care for all population groups
New Research in Environmental Health Disparities with NIEHS and EPA

Funded Institutions

- Harvard and Boston Universities, Boston
- Johns Hopkins University, Baltimore
- University of Arizona, Tucson
- University of New Mexico, Albuquerque
- University of Southern California, Los Angeles
NIMHD-Funded Science Advances
Researchers Identify Genetic Links to Kidney Disease in African Americans


Two APOL1 gene variants account for disproportionately high kidney failure rates in African Americans, but the underlying mechanisms are poorly understood.

- Using a human embryonic kidney cell culture system, investigators tested the hypothesis that APOL1-induced nephrotoxicity reflects dysregulation of intracellular signaling pathways key to cell survival.
- Results indicate that expression of APOL1 risk variants increases cell death via net loss of intracellular potassium and induction of stress-activated protein kinase pathways.
Kidneys from deceased African American donors with certain APOL1 nephropathy risk variants reproducibly associate with higher risk for allograft failure after transplantation.

- Investigators observed shorter renal allograft survival after transplantation from donors with two APOL1 risk variants.
- Younger recipient age and older donor age had independent adverse effects on allograft survival.
- Findings indicate that rapid genotyping of deceased African American kidney donors for APOL1 risk variants at organ recovery may improve transplantation outcomes.
Trauma and Suicidal Ideation Among Ethnically Diverse Adults


Examined the relationship between trauma exposure and lifetime suicidal ideation (SI) in non-Hispanic white, African American, Latino, and Asian American adults from the Collaborative Psychiatric Epidemiology Surveys.

- Interpersonal violence and child maltreatment was associated with higher odds of SI for all groups. Asian Americans had the highest odds of SI after these types of trauma exposures.
- Warzone trauma was associated with lower odds of SI for NHWs and Latinos.
- Experiencing trauma of a loved one was associated with lower odds of SI in African Americans, Latinos, and NHWs.
Systemic lupus erythematosus (SLE) has a strong but incompletely understood genetic architecture.

- In a genotyping study with 4,478 cases and 12,656 controls from six East Asian cohorts, investigators identified 10 new genetic loci associated with SLE disease risk.
- Functional variants at each locus were found by analyzing epigenetic marks and gene expression data; these novel variants are predicted to alter gene expression in various immune cell types, particularly B cells.
- To assess their potential effects in African Americans, these new loci will be included in deep re-sequencing genotyping studies with African American SLE patients.
Many studies on organ donation use self-reported willingness to donate, which may be subject to social desirability bias. This study used driver’s license and EHR data to identify correlates of donor willingness in 2,070 primary care patients in a safety net medical system.

- Driver’s license donor designation (46%) was lower than in studies of self-reported willingness (66%).
- Individuals who were female, non-Hispanic white, English- or Spanish-speaking, employed, and privately insured were more likely to be designated as donors.
NIMHD Going Forward
NIMHD Division of Extramural Scientific Programs: Functional Branches

• Clinical and Health Services Research, led by Regina James, M.D.

• Integrative Biological and Behavioral Sciences, led by Michael Sayre, Ph.D.

• Community Health and Population Sciences (searching)
New Research Areas for FY 2017

• R01 grants on Youth and Young Adults from Health Disparity Populations in the HIV Treatment Cascade

• Health Disparities Among Immigrant Populations: Etiologies and Interventions

• Disparities in Surgical Care and Outcomes

• Social Epigenomics for Minority Health and Health Disparities
NIMHD Scientific Workshops

- Use of IT Technologies in Minority Health and Health Disparities (NSF partner)
- Self-Identified Race and Ethnicity in Genomic and Biomedical Research (NHGRI partner) with October
- Structural Racism and Cultural Competence: Impact on Minority Health and Health Disparities (OMH partner)
2016 NIMHD Health Disparities Research Institute

Supports the development of new scientists in the disciplines supported by science on minority health and health disparities.

- August 15–19, 2016
- NIH Bethesda Campus
- >300 applications for up to 50 spots
- Support air travel
- Engage in selected topics and facilitate network
NIMHD Intramural Program

• Population science emphasis, with possible clinical component
• Recruit scientific director and senior scientist: epidemiology, clinician, social/behavioral; ad is out
• Possible new cohort study on immigrants or other disparity groups
• Network with other IRP scientists with similar interests: new investigators
Council Discussion and Questions