

DIRECTOR'S COUNCIL OF PUBLIC REPRESENTATIVES

COPR Alumni

CLASS OF 2007

- [James J. Armstrong](#) (Ohio)
- [Ruth C. Browne](#) (New York)
- [Barbara D. Butler](#) (Missouri)
- [Frances J. Dunston](#) (New York)
- [Robert Michael \(Mike\) Hill](#) (Florida)
- [James Kearns](#) (California)

James J. Armstrong

Term: 2003-2007



Mr. James Armstrong is the Director of Public and Media Relations at the Akron General Medical Center in Akron, Ohio. Mr. Armstrong is the former Director of News and Information at the Cleveland Clinic Foundation, a private not-for-profit group practice that integrates clinical and hospital care with research and education. A veteran of the communications field, Mr. Armstrong has worked in radio, television news, and public affairs for more than 25 years. He has earned three local Emmy awards for his work as a television journalist, which includes a 13-year stint at local Cleveland television station WKYC-TV where he helped oversee news coverage from 1978 to 1991. Since joining the Cleveland Clinic, Mr. Armstrong has worked with journalists from around the globe to bring their readers, listeners, and viewers the latest news in medicine. He has also produced numerous award-winning, medically oriented television programs for the Cleveland Clinic.

In addition to his work in communications, Mr. Armstrong is an advocate of health education and has a special interest in heart and kidney disease. He has been involved in many health-related public awareness campaigns, including efforts to promote colorectal and prostate cancer screening. He also holds several memberships in professional organizations, including the Cleveland Chapter of the National Academy of Television Arts and Sciences and the Press Club of Cleveland. He is a member of the curriculum advisory committee for the Corporate College of Cuyahoga Community College.

Mr. Armstrong is a graduate of Cleveland State University with a degree in communications. In 2001, he was ordained as a Catholic deacon for the Diocese of Cleveland after four years of study at the Center for Pastoral Leadership in Wickliffe, Ohio. He currently ministers as pastoral associate at St. Wendelin Parish, an inner city, ethnic parish near Cleveland's downtown. Mr. Armstrong also currently serves with his wife Loretta on the leadership staff of the diaconate program for the Diocese of Cleveland. In this role, the Armstrongs work together with deacon candidates-in-training and their wives to help them succeed. Mr. and Mrs. Armstrong live in Sagamore Hills, Ohio, with their dog, Nutmeg.

Ruth C. Browne

Term: 2003-2007



Dr. Ruth C. Browne is a nationally recognized visionary and innovator in the field of urban health and education. As Chief Executive Officer of the Arthur Ashe Institute for Urban Health (AAIUH), Dr. Browne has served as the Institute's spokesperson and public persona since its inception. Founded by legendary tennis champion and humanitarian Arthur Ashe just two months prior to his death in 1992, AAIUH has gained national recognition as a pioneer in developing culturally competent programs that address racial, ethnic, and gender disparities in health.

A leader in the development and implementation of community health empowerment programs, Dr. Browne has an unrivaled record in bridging the gap between medical institutions and individuals in underserved urban communities. Determined to encourage people to lead their own efforts to be healthy, she creates model programs that provide health education to culturally diverse and economically disadvantaged communities in non-traditional settings. Using meeting places such as beauty salons, barbershops, laundromats, tattoo and body piercing salons, libraries, and places of worship, Dr. Browne brings health education directly to people within the comfort and familiarity of their communities. Dr. Browne is the architect of AAIUH's successful 13-year partnership with SUNY Downstate Medical

Center and is the principal investigator for several NIH grants that train hair stylists and barbers to promote breast, prostate, and cardiovascular health with their clients.

Prior to working with AAIUH, Dr. Browne held diverse program, research, and health policy positions. With extensive experience in the development and analysis of health policy and the monitoring of health policy implementation through sponsored programs, Dr. Browne has served as staff for major policy commissions for the

Office of New York City Mayor Ed Koch, New York State Governor Mario Cuomo, and the foundation affinity group Funders Concerned About AIDS.

Dr. Browne serves on the Board of Directors of Cable Positive, the cable industry's response to AIDS, and is a member of the Brooklyn Borough President's Task Force on Fiscal and Social Equity. She is also an active member of the National Coalition of 100 Black Women. Dr. Browne is an assistant clinical professor in the College of Health Related Professions and the Department of Preventive Medicine and Community Health at SUNY Downstate Medical Center. She is also a member of the SUNY Downstate Planning Committee for its School of Public Health.

Dr. Browne has been profiled and quoted in numerous media outlets, including the *New York Daily News*, *The New York Times*, *AOL Black Voices*, and *New York Newsday*, and was selected as a "New Yorker of the Week" by NY1 in 2002.

Dr. Browne received her doctorate from the School of Public Health at Harvard University and master's degrees in public health and public policy from the University of Michigan. She received a bachelor's degree from Princeton University and pursued lower undergraduate studies at the University of the West Indies in Jamaica.

Barbara D. Butler

Term: 2003-2007



Ms. Barbara Butler, a native of St. Louis, was diagnosed with systemic lupus erythematosus at the age of 22. She first became an advocate for lupus patients and their families on the local level by developing strong relationships with members of the medical community and the public to increase public and professional awareness of lupus and its impact on both individuals and the families of those afflicted with the disease. She has also helped patients and their families directly by counseling newly diagnosed patients and writing a book for parents on the subject of child rearing while coping with a chronic illness.

Ms. Butler was an original member of the Board of Directors for the Lupus Foundation of America (LFA) and chaired the Board's Public Relations Committee. She was responsible for developing the first series of radio and television public service announcements featuring a nationally recognized spokeswoman. This awareness campaign was distributed to 80 LFA chapters for placement on their local radio and television stations. Also during her tenure as committee chair, Ms. Butler began providing science and medical reporters at major television networks and their local affiliates with direct access to representatives within the NIH.

As her interest in the NIH grew, she created and chaired LFA's Government Relations Committee and was also appointed to the first National Institute of Arthritis, Musculoskeletal, and Skin Diseases (NIAMS) Advisory Council. Ms. Butler was also elected to the Board of Trustees of the National Psoriasis Foundation (NPF) and later became the organization's chair.

Ms. Butler has received many local and national awards. She was given the prestigious St. Louis Woman of Achievement Award and was named the first Health Citizen of the Year by Combined Health Appeal. Nationally, she has received many awards from the LFA, NPF, and the American Skin Association.

She continues her involvement with several organizations and remains an active and passionate advocate for federal funding of medical research and professional training.

Frances J. Dunston

Term: 2003-2007



Dr. Frances Dunston is Chairperson of the Department of Pediatrics at Morehouse School of Medicine, where she is a Professor of Pediatrics and of Community Health and Preventive Medicine (Secondary). She is also a fellow of the American Academy of Pediatrics and is board certified in both Pediatrics and Preventive Medicine.

She served as New Jersey's State Commissioner of Health, which is a cabinet-level position that made her responsible for state health policies, health regulation, health planning, and public health services. During this time, she also served as Chairperson of the New Jersey Health Care Facilities Financing Authority. Dr. Dunston has also served as Assistant State Health Commissioner in Virginia and as the Director of Public Health in Richmond, Virginia.

Her contributions in child health policy at the national level include service on the National Vaccine Advisory Committee, on the National Child Health Leadership Council, and as the Chairperson of the Pediatrics Section of the National Medical Association. Her publications and research interests address the issues of health services delivery for poor and medically underserved children.

She has served as a member of national and regional committees, including the Advisory Committee of the National Institutes of Health's Office of Research on Women's Health (1999-2002), the Advisory Committee to Georgia's Office of Minority Health (2000-present), and the Georgia State Board of Medical Education (2001-present).

Dr. Dunston has received awards and honors from numerous professional societies and community organizations, including the Outstanding Physician Award from the North New Jersey Medical Society, recognition for her Outstanding Contributions to Medical Education by the National Association of Minority Medical Educators, induction into the Alpha Omega Alpha Medical Honor Society and the Delta Omega Honorary Public Health Society, the Alumni Leadership Award by the School of Public Health at the University of North Carolina, Chapel Hill, and the Distinguished Alumni Award from UMDNJ.

Dr. Dunston received her medical degree from UMDNJ-Robert Wood Johnson Medical School in Piscataway, New Jersey, and completed her residency in Pediatrics at the Medical College of Virginia. She obtained a master's degree in Public Health in Health Policy and Health Care Management from the University of North Carolina, Chapel Hill.

Robert Michael (Mike) Hill

Term: 2004-2007



Mr. R. Mike Hill is Executive Director of the Northwest Florida and Big Bend Health Councils, which serve 18 counties in northwest Florida. He is also president of the Florida Association of Health Planning Agencies, representing all 11 of Florida's legislatively mandated Health Councils that serve the state's 15 million residents. In addition to developing and negotiating state and federal legislation for the Certificate of Need and Healthy Kids programs, Mr. Hill has led community coalitions that successfully established a Federally Qualified Community Health Center and an indigent clinic for Florida's Port Saint Joe and Panama City.

Mr. Hill's constituents include racial and ethnic minorities, the economically disadvantaged and their children, the elderly, and migrant and seasonal farm workers. Most live in rural areas with inadequate access to primary health care or in rapidly developing coastal regions. Many, including several of Mr. Hill's relatives and friends, have been fatally affected by cancer, cardiovascular disease, diabetes, hypertension, and end-stage renal disease.

In addition to his Health Council work, Mr. Hill is Executive Director of Hill and Company, Inc., a consulting firm specializing in education, health care, social services, and government relations. Before working with the Health Councils, Mr. Hill held several positions in Florida's educational community, including chief lobbyist for federal and state legislative and regulatory policy activities at the Florida Association of School Administrators. Earlier in his career, he worked for Bay District Public Schools and the Bay Correctional Facility. Over the years, Mr. Hill has received many awards for his work for a broad range of civic and professional organizations.

Mr. Hill completed undergraduate studies in social and political science and graduate studies in Public Administration at the University of West Florida. He earned an Ed.S. in educational leadership from Florida State University. He and his wife Janice live in Panama City, Florida.

James Kearns

Term: 2004-2007



Mr. James Kearns is an award-winning screenwriter whose work includes the screenplay for John Q., a feature film starring Denzel Washington. The film, released in 2002, addresses issues of the medically underserved and other problems inherent in the health care delivery system. Mr. Kearns believes that tackling world health issues is critical to the nation's well-being. He hatched the idea for John Q. after reading an article about a wealthy businessman who criticized the health care system after receiving a heart transplant, saying, "If I wasn't rich, I'd be dead now."

Mr. Kearns is a member of the nonprofit Entertainment Industries Council (EIC). The Council, in partnership with the National Institute on Drug Abuse and the Robert Wood Johnson Foundation, created the PRISM awards to recognize accurate depictions of drugs, alcohol, tobacco use, and addiction in television, film, music, and comic books. Mr. Kearns is on EIC's Nomination Review Committee and values the opportunity to help reward accurate, creative portrayals of health issues.

Mr. Kearns is a member of the Center for Community Change in Washington, DC, that works to combat poverty in America. He is a long-standing member of the Writers Guild of America and PEN International and currently is adapting for the screen photographer Robert Capa's autobiography Slightly Out Of Focus. He began his writing career as a playwright with Days in the Dark Light. His next full-length play, Favorite Sons, was chosen as a Selection Committee Finalist at the Eugene O'Neill Theater Conference in Waterbury, Connecticut. Both plays attracted the attention of Hollywood producers, who hired Mr. Kearns to write for television and film, including such critically acclaimed shows as NBC's A Year in the Life and CBS's crime drama Wiseguy. During that time, Mr. Kearns sold his first screenplay, Dead of Summer. Although the script was never produced, it opened the door to writing opportunities in feature films.

National Institutes of Health (NIH), 9000 Rockville Pike, Bethesda, Maryland 20892

NIH...Turning Discovery Into Health

NATIONAL INSTITUTES OF HEALTH
DIRECTOR'S COUNCIL OF PUBLIC REPRESENTATIVES (COPR)

MEETING MINUTES

April 20, 2007

**NATIONAL INSTITUTES OF HEALTH (NIH)
OFFICE OF THE DIRECTOR
DIRECTOR'S COUNCIL OF PUBLIC REPRESENTATIVES (COPR)**

**Spring 2007 Meeting
Building 31, C-Wing, Conference Room 6, NIH Campus
Bethesda, Maryland**

April 20, 2007

NIH Participants

Raynard S. Kington, M.D., Ph.D., Deputy Director, NIH
John T. Burklow, M.S., Director for Communications and Public Liaison, Office of the Director, NIH
Jennifer E. Gorman, M.P.A., COPR Coordinator and NIH Public Liaison Officer, Office of Communications and Public Liaison, Office of the Director, NIH
Kelli Carrington, M.A., COPR Special Associate, Office of Communications and Public Liaison, Office of the Director, NIH

COPR Members Attending

Syed M. Ahmed, M.D., Dr.P.H., M.P.H.
Nicole Johnson Baker, M.A., M.P.H.
Wendy Chaite, Esq.
Christina Clark, M.A., M.B.A.
Naomi Cottoms, M.S.
Linda Crew, M.B.A., R.N.
Valda Boyd Ford, M.P.H., M.S., R.N.
Elmer R. Freeman, M.S.W.
Beth Furlong, R.N., Ph.D., J.D.
Brent Jaquet
Nicolas Liñares-Orama, Ph.D., M.P.A.
Cynthia Lindquist, M.P.A., Ph.D.
Michael Manganiello, M.P.A.
Matthew Margo, LL.M.
Marjorie Mau, M.S., M.D.
Anne Muñoz-Furlong
Ann-Gel S. Palermo, M.P.H.
James H. Wendorf, M.A.

COPR Member Not Present

Craig T. Beam

ACD Liaison

Annelise Barron, Ph.D.

COPR Special Expert

John C. Nelson, M.D., M.P.H., FACOG, FACPM, NIH Advisory Committee to the Director

COPR Alumnus

Vicki Kalabokes

Speakers

Elena Bastida, Ph.D., Professor and Director, Center on Aging and Health, University of Texas-Pan American

Joe Coulter, Ph.D., Associate Dean, University of Iowa College of Public Health

David S. Forbes, Ph.D., Professor and Dean, College of Health Professions and Biomedical Sciences, University of Montana

Doug Hussey, Acting Director, Division of Scientific Strategic Planning and Policy Analysis, National Center for Minority Health and Health Disparities, NIH

John Niederhuber, M.D., Director, National Cancer Institute, NIH

Giang Nguyen, M.D., M.P.H., Assistant Professor in Family Medicine and Community Health, School of Medicine, University of Pennsylvania

John Ruffin, M.D., Director, National Center for Minority Health and Health Disparities, NIH

Francisco Sy, M.D., Dr.P.H., Program Director, Community Based Participatory Research Program and Loan Repayment Program, National Center for Minority Health and Health Disparities, NIH

Derrick Tabor, Ph.D., Program Director, Centers of Excellence Program, National Center on Minority Health and Health Disparities, NIH

Stephen B. Thomas, Ph.D., Director, Center for Minority Health, University of Pittsburgh

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EXECUTIVE SUMMARY

The meeting of the National Institutes of Health (NIH) Director's Council of Public Representatives (COPR) was held on April 20, 2007. Elias A. Zerhouni, M.D., NIH Director, was unexpectedly called to the White House and could not attend the meeting. Raynard S. Kington, M.D., Ph.D., NIH Deputy Director, welcomed and introduced the six new COPR Appointees: Naomi Cottoms, M.S., Elmer R. Freedman, M.S.W., Beth Furlong, R.N., Ph.D., J.D., Brent Jaquet, Matthew Margo, LL.M., and Anne Muñoz-Furlong. Dr. Kington introduced John Nelson, M.D., M.P.H., FACOG, FACPM, Special Expert to the COPR, and Annelise E. Barron, Ph.D., NIH Advisory Council to the Director (ACD) Liaison to the COPR.

Dr. Kington provided updates in a number of areas. He singled out the creation of the Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) within the Office of the Director, as the most significant outcome of the NIH Reform Act of 2006. Given the challenging prospect of a reduced budget, NIH has made tough but necessary choices to ensure that the investment in and momentum of biomedical research continues. Dr. Kington stressed the importance of supporting new investigators as they make the transition to becoming independent. On March 3, 2007, NIH announced the NIH Director's New Innovator Award. It will support research by new investigators who propose highly innovative projects with the potential for exceptional influence on biomedical or behavioral science.

Dr. Kington announced several staff changes. Alan Krensky, M.D., is the Director Designee for the NIH Office of Portfolio Analysis and Strategic Initiatives (OPASI). Dr. Krensky, a leading scientist and recognized expert in pediatrics, comes to NIH from the Stanford University School of Medicine. Barbara Alving, M.D., is the new Director of the National Center for Research Resources and Griffin P. Rodgers, M.D., is the new Director of the National Institute of Diabetes and Digestive and Kidney Diseases – both effective April 1, 2007.

Dr. Kington recognized NIH advances over the past six months, including the increase in NIH Funding by \$637 million, which will add another 1,000 research project grants, provide funding for high risk grants, and funding for young investigators. Hearings for the President's budget request for fiscal year 2008 for NIH began on March 6 with an NIH overview hearing before the House Appropriations Subcommittee on Labor, HHS, and Education. Dr. Kington also addressed the Stem Cell Research Enhancement Act and the Hope Offered Through Principled and Ethical Stem Cell Research Act. He related his discussions of NIH issues in recent Congressional hearings and reported progress with the Director's Pathway of Independence Program for innovative research.

John Ruffin, Ph.D., Director of the National Center on Minority Health and Health Disparities (NCMHD), described four minority health initiatives: the Health Disparities Centers of Excellence Program, the Endowment Program Award, the Loan Repayment Program, and the Community-Based Participatory Research Program.

John E. Niederhuber, M.D., Director of the National Cancer Institute (NCI), talked about NCI's efforts to build patient access to science. He described the NCI Community Cancer Centers Program, a pilot program designed to bring science, early-phase clinical research, and evidence-based therapies to patients in community-based locations. Sites will be linked to national databases supporting basic, clinical, and population-based cancer research.

Christina Clark, M.A., M.B.A., and James Wendorf, M.A., Co-Chairs of the COPR Meeting Agenda Work Group, provided an overview of the COPR's Work Group Day. Ms. Clark noted that COPR members participated in a question-and-answer session with Dr. Zerhouni. Select COPR members reported on the following topics:

- Diversity Information Gathering Meeting and Discussion with NIH Staff
- Research, Condition, and Disease Categorization (RCDC) Initiative
- The COPR's two editorials—"The Future Is Now: Enhancing the Role of the Public in Medical Research" and "What Is Trust Worth?"

- Communicating the COPR's Messages—New Media Tools

Ms. Christina Clark reported the results of the consensus-building and priority-setting session from the previous day. COPR confirmed the continuation of the Role of the Public in Research Work Group and selected one area for future efforts: Identify ways to encourage researchers to involve the public including, but not limited to health disparities, diversity, community engagement, and behavioral and social context in research.

COPR members received updates from the liaison to the Advisory Committee to the Director (ACD) and heard public comments.

WELCOME AND INTRODUCTIONS

Raynard S. Kington, M.D., Ph.D.

Deputy Director, National Institutes of Health

The 17th meeting of the National Institutes of Health (NIH) Director's Council of Public Representatives (COPR) was held on April 20, 2007. Elias A. Zerhouni, M.D., NIH Director, could not attend due to an unexpected required meeting at the White House. Raynard S. Kington, M.D., Ph.D., NIH Deputy Director, welcomed the COPR members and presenters, and recognized COPR Special Expert John Nelson, M.D., M.P.H., FACOG, FACPM, member of the NIH Advisory Committee to the Director, and Annelise E. Barron, Ph.D., NIH Advisory Council to the Director (ACD) Liaison to the COPR.

Dr. Kington introduced the six new COPR Appointees: Naomi Cottoms, M.S., Director of the Tri County Rural Health Network, Inc.; Elmer R. Freeman, M.S.W., Executive Director of the Center for Community Health Education Research and Service, Inc., and an adjunct assistant professor and Director of Urban Health Programs and Policy for Bouvé College of Health Sciences at Northeastern University; Elizabeth Furlong, J.D., Ph.D., R.N., associate professor at Creighton University's School of Nursing and a faculty associate in the university's Center for Health Policy and Ethics; Brent Jaquet, Senior Vice President at Cavarocchi-Ruscio-Dennis Associates; Matthew Margo, LL.M., Senior Vice President of Program Practices, New York, for CBS Television Network; and Ms. Anne Muñoz-Furlong, CEO of the Food Allergy and Anaphylaxis Network. Dr. Kington acknowledged that COPR member Craig T. Beam could not attend the meeting and recognized Alan Krensky, M.D., Director Designee for the Office of Portfolio Analysis and Strategic Initiatives at NIH, who attended the meeting.

NIH DIRECTOR'S UPDATE

Raynard S. Kington, M.D., Ph.D.

Deputy Director, National Institutes of Health

Dr. Kington reported that during the past year, Dr. Zerhouni and his office have reached out to many groups around the country and around the world, speaking with scientific

associations, advisory councils, and other constituencies offering transparency about the challenges that the current budget poses to NIH, researchers, and the public who ultimately benefits from NIH research.

Status of the NIH Budget

Congress recently passed the Fiscal Year (FY) 2007 Joint Funding Resolution, which increased NIH funding by \$637 million over FY 2006 (post supplemental transfers). This increase supported an additional 1,000 research project grants over the FY 2006 level, provided additional funding for high risk grants, funding for young investigators, and allowed continuation of the National Children's Study. The National Children's Study received \$69 million in the Office of the Director. Base funds of \$11 million for the study were shifted from the National Institute of Child Health and Human Development to the Office of the Director for the National Children's Study.

The Joint Resolution fully funds the NIH Roadmap and Common Fund in the Office of the Director, which resulted in the expected contribution monies remaining in the Institutes and Centers. There was also an allocation of about \$34 million to the National Center for Research Resources for a number of one time projects. Additionally, \$7 million was provided to support implementation of the NIH reauthorization bill. Small increases were also provided to the National Center on Minority Health and Health Disparities and to the National Library of Medicine.

In spite of these additional resources, Dr. Kington stressed the need to strike a balance between maintaining the value of ongoing research and providing opportunities for researchers with new ideas to receive research grants to help surmount public health challenges. This requires a focus on three categories of vulnerable scientists who are integral to continued public health advancements: new investigators, first time grantees

applying for their first renewal, and well established investigators with insufficient other support. NIH plans to support about 10,000 competing research project grants in FY 2007.

In terms of other budget decisions, NIH funded the second cohort of awards in the Pathway to Independence Program. This is a program specifically designed to target young investigators and support their transition towards the status of independent principal investigator.

Dr. Kington also noted that NIH has provided a slight increase in the FY 2008 President's Budget of about \$3 million for the Roadmap, in addition to a total of \$136 million that will be invested in the repair of many of the old buildings on the NIH campus.

Legislative Update

Since the last COPR meeting, Congress passed, and the President signed, the NIH Reform Act of 2006. This legislation reauthorizes NIH programs for the first time since 1993 and provides significant authorities for the agency. Dr. Kington singled out the creation of the Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI) within the NIH Office of the Director, as the most significant outcome of the Reform Act. The legislation also establishes:

- The Common Fund in statute, with no formula for growth and the requirement for a review when the Common Fund reaches 5 percent
- A Council of Councils to advise on research proposals that would be funded by the Common Fund
- A Scientific Management Review Board (SMRB) to conduct periodic organizational reviews of NIH and to make recommendations on the use of NIH organizational authorities

- It also authorizes—but does not appropriate—an increase in NIH funding for each of the next 3 years (\$30.3 billion for FY 2007, \$32.8 billion for FY 2008, and such sums as may be necessary for FY 2009)

Hearings for the President's Budget request for FY 2008 began on March 6 with an NIH overview hearing before the House Appropriations Subcommittee on Labor, Health and Human Services, Education, and Related Agencies (Representative David Obey [D-WI], Chairman). The NIH Director was accompanied by directors of NHLBI, NCI, NIAID, NICHD, NCMHD, NHGRI, NINDS, Acting Director for NIDDK, Deputy Director for NIEHS, and Acting Director for NCRR. The Senate overview hearing was held on March 19. Major issues raised by Subcommittee members at the overview hearings were the adequacy of the FY 2008 President's Budget request for NIH, funding for the National Children's Study, stem cell research, health disparities (House only), and cost savings resulting from research.

In regards to stem cell research, Dr. Kington reported that on April 11th the Senate passed two stem cell bills, S. 5 (Senate Bill), the Stem Cell Research Enhancement Act, and S. 30, the Hope Offered Through Principled and Ethical Stem Cell Research Act, which passed by a vote of 63-34 and 70-28, respectively.

The S. 5 would required the Secretary of HHS to conduct and support research using human embryonic stem cells regardless of the date on which such cells were derived and to conduct and support research involving methods of obtaining pluripotent stem cells that do not involve the use of human embryos. The White House has issued statements of administration policy in opposition to S. 5 and in opposition to a similar House measure.

The S. 30 would require the Secretary to support research to develop pluripotent stem cells using methods that do not involve either the creation of, harm to or the destruction

of human embryos, and the White House has issued a statement of administrative policy in support of S. 30.

NIH Director's Bridge Award (NDBA)

On March 14, 2007, Dr. Zerhouni announced the launch of the NIH Director's Bridge Award (NDBA). The program will provide a single year of bridge funding for more than 200 competing R01 renewal applications. The awards will be at a level approved by individual Institutes and Centers up to total of \$500,000.

NIH Pathways to Independence Awards

NIH continues to support the NIH Pathways to Independence Awards. Dr. Kington stressed the importance of supporting new investigators as they move toward becoming independent researchers. NIH received almost 900 applications and issued between 150 and 200 awards for this program this year. NIH expects to make the same number of awards for each of the next 5 years. During this time, NIH will provide almost \$400 million in support of this program.

National Consortium to Transform Clinical Research

Dr. Kington described the NIH National Consortium to Transform Clinical Research as an effort to reinvigorate the clinical research enterprise in our country. The NIH funded 12 academic health centers as part of the consortium in the past year and plans to award planning grants to 52 additional centers so that they have support to develop proposals for future rounds. These academic health centers will act as central hubs for pulling together academic researchers, local clinicians, community medical centers, professional societies, industry, and the public at large.

Dr. Kington and other members of NIH leadership have heard repeatedly that one of the most important impacts of this Request for Applications (RFA) is that it provides a strong incentive for diverse components of large complex academic centers to communicate

with each other so that they can coordinate a proposal to the NIH. Dr. Kington also noted that previous discussions with COPR on the role of the public were used in framing that part of the RFA.

When the CTSA Awards reach full implementation in 2012, they are expected to provide a total of approximately \$500 million annually to 60 academic centers. These CTSA's were a key initiative within the NIH Roadmap and they were paired with an ongoing program of the Clinical Research Centers funded by the National Center for Research Resources (NCRR).

The NIH Roadmap and Office of Portfolio and Strategic Analysis (OPASI)

Dr. Kington introduced Alan Krensky, M.D., the Director Designee for the NIH Office of Portfolio and Strategic Analysis (OPASI). Dr. Kington described OPASI as creating an incubator space for supporting complex programs that cut across the missions of institutes and centers and that have broad relevance to the NIH mission. The NIH Roadmap for Medical Research, which Dr. Kington referred to as the “brainchild of Dr. Zerhouni,” is housed within OPASI.

OPASI, in consultation with the institutes and centers, is finishing the concept development stage for the next wave of Roadmap initiatives to be selected and funded. As part of this phase, NIH received more than 300 proposals of suggested Roadmap initiatives from around the world. The concept development phase focused on the following areas:

- Inflammation as a common mechanism of disease
- Proteome/protein capture tools
- Training and careers
- Health disparities
- Science of science administration

Dr. Kington noted that a number of COPR members participated in roundtables with scientists from across the country to solicit ideas for potential areas for funding. Over the summer, these specific initiatives will inform new RFAs. These will in turn lead to innovative new research projects that hold great promise for the future of American's health.

NIH Director's New Innovator Award

On March 3, 2007, NIH announced the NIH Director's New Innovator Award, which will support research by new investigators who propose highly innovative projects with the potential for exceptional influence on biomedical or behavioral science. NIH expects to fund 14 awards in September 2007. Each grant will be for five years and up to a total of \$1.5 million in direct costs. The National Institute of General Medical Sciences, under the leadership of Jeremy M. Berg, Ph.D., coordinates this effort.

Leadership Update

Barbara Alving, M.D., is the new Director of the National Center for Research Resources and Griffin P. Rodgers, M.D., is the new Director of the National Institute of Diabetes and Digestive and Kidney Diseases – both effective April 1, 2007. Alan Krensky, M.D., a leading scientist and recognized expert in pediatrics, is the Director Designee for OPASI.

Dr. Kington asked for comments.

COPR Member Discussion

Mr. Wendorf asked Dr. Kington what COPR could do to help communicate the NIH mission and priorities to the public. As a starting point, Dr. Kington encouraged COPR members to use the NIH 101 slides to educate the public about NIH. Dr. Kington reminded members that a COPR representative will participate on the "Council of Councils" that was created by the NIH Reform Act of 2006. He noted two recent NIH

communications successes: *Parade Magazine*'s series on NIH research and the new *NIH NLM MedLine Plus Magazine*, which is appearing in physicians' offices around the United States.

Syed M. Ahmed, M.D., Dr.P.H., M.P.H., asked if community engagement was a requirement for CTSA awardees. He noted that CTSA awardees showed responsiveness to community engagement and that this will be included in the NIH evaluation of the CTSA Awards. Dr. Kington emphasized building bridges between academic and surrounding communities as integral to the CTSA Awards.

Mr. Jaquet suggested that NIH develop an educational workshop for research investigators to learn about community engagement approaches. Dr. Kington responded enthusiastically and noted that this could be an opportunity to merge the activities and interests of COPR with NIH-funded investigators. Dr. Kington referred to past discussions about COPR preparing guidance material on different ways the public has input (serving on councils, study sections, and community advisory committees). He plans to discuss this suggestion with NCRR.

During a COPR member inquiry about trans-NIH activities, Dr. Kington remarked that some of the best science advances have come from overseas. Roger I. Glass, M.D., Ph.D., Director of the Fogarty International Center (FIC) at NIH, encouraged COPR members to think about results and discoveries overseas that benefit the American public. FIC works with many NIH Institutes and Centers (ICs).

Michael Manganiello, M.P.A., asked Dr. Kington for clarification on the role of the new Common Fund. Dr. Kington reviewed the purpose of the Common Fund: to support trans-NIH research that pushes the frontiers of science and cuts across the missions of individual institutes and centers. The Common Fund was created to address broad cross-cutting public health challenges.

DIALOGUE WITH THE DIRECTOR OF THE NATIONAL CENTER ON MINORITY HEALTH AND HEALTH DISPARITIES

John Ruffin, Ph.D.

John Ruffin, Ph.D., Director of the National Center on Minority Health and Health Disparities (NCHMD), provided an overview of NCMHD programs and initiatives. Dr. Ruffin invited the following members of his senior staff to present: Derrick C. Tabor, Ph.D., Director, NCMHD Centers of Excellence Program; Francisco Sy, M.D., Dr.P.H., Director, NCMHD Community-Based Participatory Research and Loan Repayment Programs; and Douglas Hussey, Acting Director, Division of Scientific Strategic Planning and Policy Analysis, NCMHD.

The passage of the Minority Health and Health Disparities Research and Education Act of 2000, Public Law 106-525 established NCMHD, which works to promote minority health and to eliminate health disparities. NIH defines health disparities as differences in the incidence, prevalence, morbidity, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups.

Since its creation in 2001, NCMHD has provided more than \$300 million to support several hundred research, training, community-outreach, and capacity-building projects around the United States (including Puerto Rico and the U.S. Virgin Islands).

Dr. Ruffin introduced Dr. Tabor, who heads the NCMHD Centers of Excellence Program. Dr. Tabor told COPR members that at its peak, NCMHD funded 76 centers of excellence, the first of which focused on partnerships for community outreach, research on health disparities, and training. New centers will focus on research excellence; specifically research for improving minority health and eliminating health disparities.

Dr. Francisco Sy described the NCMHD Research Endowment Program that builds research and training capacity in institutions that make significant investments in the education and training of individuals from health disparity populations. Awards range

from \$300,000 to \$5 million per institution. NCMHD funds 13 institutions across the United States.

Dr. Ruffin told COPR members about the NCMHD Loan Repayment Programs. Dr. Sy added to the presentation. The NCMHD Loan Repayment Programs seek to recruit and retain highly qualified professionals with doctoral degrees to pursue health disparities or clinical research by repaying their educational loans. The Loan Repayment Program for Health Disparities Research encourages health professionals to engage in basic, clinical, behavioral, community-based, and health services research that is directly relevant to health disparities. The Extramural Clinical Research Loan Repayment Program for Individuals from Disadvantaged Backgrounds aims to recruit highly qualified health professionals from disadvantaged backgrounds to and retain them in clinical research careers.

All of these programs aim to increase the pool of researchers in the health disparities field. NCMHD provides individual loan repayments of \$35,000 a year for 2 years, including taxes and interest. Since 2002, when the program began, NCMHD has funded 1,100 individuals.

The NCMHD Community-Based Participatory Research Program promotes collaboration between researchers and the communities. The initiative has three phases: a pilot or planning phase, a competitive 5-year research intervention phase, and then a 3-year research dissemination phase. In 2005, when this initiative was launched, NCMHD received 188 applications and has funded 25 grantees.

Dr. Ruffin introduced Mr. Hussey, Acting Director, Division of Scientific Strategic Planning and Policy Analysis, NCMHD, who reported on the NIH Health Disparities Strategic Plan and Budget. The FY 2002-2006 plan is available on the NCMHD Web site at http://www.ncmhd.nih.gov/our_programs/strategic/volumes.asp. The Strategic Plan focuses on three major goals: research, research infrastructure, and public information and community outreach. It includes objectives, priorities, action plans, and time frames.

The NCMHD also contracted with the Institute of Medicine (IOM) to assess the implementation of the plan at NIH. The 2006 IOM Report, *Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business*, was the result of the assessment. NIH is awaiting Departmental clearance of the second iteration of the strategic plan which covers FY 2004-2008. After receiving public comment on the second version of the strategic plan, the NIH will begin developing the third strategic plan, taking into account the recommendations of the IOM and all other public comments received. In addition, during fiscal years 2007 and 2008, NCHMD, in collaboration with the other NIH ICs, will convene forums to identify best practices to further enhance Institute and Center activities, as a part of NIH's response to the IOM report.

To illustrate how each of the NCMHD programs are working and what is being accomplished, Dr. Ruffin invited five NCMHD program award recipients to briefly contribute to the presentation: Elena Bastida, Ph.D., professor and director, Center on Aging and Health, University of Texas-Pan American; Joe Coulter, Ph.D., associate dean, University of Iowa College of Public Health; David S. Forbes, Ph.D., professor and dean, College of Health Professions and Biomedical Sciences, University of Montana; Giang Nguyen, M.D., M.P.H., assistant professor in family medicine and community health, School of Medicine, University of Pennsylvania; and Stephen B. Thomas, Ph.D., director, Center for Minority Health, University of Pittsburgh.

COPR Member Discussion

Dr. Nelson asked about NCMHD collaboration with outside organizations. "We set aside 20 percent to 30 percent of our budget for collaboration," said Dr. Ruffin. NCMHD works with many governmental agencies including the Indian Health Service (IHS), the Centers for Disease Control and Prevention (CDC), the Agency for Healthcare Research and Quality (AHRQ), the Centers for Medicaid and Medicare Services (CMS), and others. Since its creation in 2001, NCMHD has provided more than \$300 million to

support several hundred research, training, community outreach, and capacity-building projects.

COPR members wondered how NCMHD receives public input. Dr. Ruffin noted that the NIH Health Disparities Strategic Plan provides an excellent way for both NIH and NCMHD to receive public input. Wendy Chaite, Esq., suggested that the collaboration demonstrated by Dr. Ruffin and NCMHD could be used as a model for all of NIH, including the new OPASI initiative.

COPR members inquired how they could assist NCMHD in reducing health disparities. Dr. Ruffin suggested that COPR could help NCMHD recruit candidates for the loan repayment programs. “I can think of no better way to build a health disparity workforce than through the Loan Repayment Program,” said Dr. Ruffin. He recommended that NCMHD develop a career development track to retain this new workforce.

COPR members shared their passion about health disparity issues with Dr. Ruffin and thanked him for NCMHD’s hard work in the community.

BUILDING PATIENT ACCESS TO SCIENCE

John Niederhuber, M.D.

John Niederhuber, M.D., Director of the National Cancer Institute (NCI), reviewed the NCI’s efforts to build patient access to science. He described the NCI Community Cancer Centers Program, a pilot program designed to bring science, early-phase clinical research, and evidence-based therapies to patients in community-based locations. Currently only approximately 16 percent of cancer patients in the United States have access to the 61 NCI-designated cancer centers. Community hospitals and physician offices care account for the remaining 84 percent. For most Americans, especially senior citizens and minorities, who bear a heavy burden of cancer, an NCI-designated cancer center may be too far away or economically out of reach. “I firmly believe that access to health care and to good cancer care will actually be a greater determinant of cancer

mortality in the decades to come than any of the things that we commonly consider to be risks, such as tobacco,” said Dr. Nieberhuber.

The NCI Community Cancer Centers Program aims to bring state-of-the-art cancer research and treatment to communities where people live. It will support multiple pilot sites (for a total of \$9 million over a 3-year period) to identify the critical factors that define a state-of-the-art community center, which will be incorporated into a future program. Year one will focus on infrastructure development and refinement of pilot program research questions. Implementation and evaluation of the model takes place in years two and three.

The selection criteria for sites are broad. NCI hopes to fund centers in settings with underserved populations such as Appalachia and Indian reservations. The program seeks to bring more patients into clinical trials in community-based settings, reduce health care disparities, prepare sites for standardizing the collection and storage of biological specimens for cancer research, and link sites to national databases supporting basic, clinical, and population-based cancer research.

Dr. Niederhuber views this program as a tremendous resource for genomic and proteomic research, which depends on quality tissue specimens. Participating community-based hospital systems will provide these tissue resources. Dr. Niederhuber also noted that this program gives NCI an opportunity to make progress on HHS Secretary’s agenda to establish electronic medical records.

COPR Member Discussion

COPR members asked about community involvement in the NCI Community Cancer Centers Program. Dr. Niederhuber responded that NCI plans to have community members involved in planning the pilot sites. An incentive for community involvement is built into the contract process.

Dr. Niederhuber suggested that COPR assist NCI in answering questions critical to the success of this program: What methods are effective to increase accrual of patients into clinical trials especially for our minority populations? How can we reduce disparities in cancer care? And, can NCI's biorepository guidelines be implemented at the community level?

Valda Boyd Ford, M.P.H., M.S., R.N., expressed concern about medical records and patient privacy and protection issues. Dr. Niederhuber responded that NIH is aware of these fears and that pending legislation addresses these concerns. Dr. Kington agreed that patient privacy is important. He noted that a trans-NIH Working Group on Bioinformatics was formed to weigh the benefits of genetic databases against privacy concerns and issues.

Nicolas Liñares-Orama, Ph.D., M.P.A., asked about research progress on environmental factors that influence cancer. Dr. Niederhuber responded that the NCI Community Cancer Centers Program will help researchers learn more about the effect of environmental factors on cancer because they will have access to tissue samples from cancer patients around the United States.

COPR WORK GROUP DAY OVERVIEW AND REPORT FOR THE NIH DIRECTOR

Christina Clark, M.A., M.B.A. and James Wendorf, M.A.

James Wendorf, M.A., and Christina Clark, M.A., M.B.A., Co-Chairs, Spring 2007 Meeting Agenda Work Group, provided Dr. Kington with an overview of the Work Group Day that took place the previous day (April 19). Ms. Clark noted that COPR members participated in a question-and-answer session with Dr. Zerhouni, which informed COPR's consensus-building and priority-setting process. Mr. Wendorf summarized the agenda:

- Report from the COPR Sub-Work Group on the April 18th information-sharing discussion with NIH staff on diversity training, underrepresented scientists, and health disparities research training
- An update by Timothy Hays, Ph.D., on the NIH Research, Condition, and Disease Categorization (RCDC) initiative
- A communications update by John Burklow, M.S., and an invitation to brainstorm about using new media to amplify the COPR voice
- A review by Jennifer Gorman, M.P.A., of COPR accomplishments as a context for the work group session
- A consensus-building and priority-setting session with facilitator Sue Harris, M.S.
- An update by Dr. Alan Krensky on the Office of Portfolio Analysis and Strategic Initiatives

DIVERSITY INFORMATION GATHERING MEETING AND DISCUSSION REPORT

Marjorie Mau, M.D., and Ann-Gel Palermo, M.P.H.

Marjorie Mau, M.S., M.D., and Ann-Gel Palermo, M.P.H., reviewed the agenda and lessons learned from the April 18 informational meeting with NIH staff. COPR requested this meeting to learn about diversity training and health disparities research at NIH. Topics covered included underrepresented scientists in training and recruitment; the research infrastructure and minority health; clinical trials recruitment and retention for minority and health disparity issues; and the research agenda for minority health and health disparities. COPR participants learned the following about diversity at NIH:

- Equal employment opportunity (EEO) is different from diversity management
- EEO data and comparative relevant labor force
- There is a lack of consensus on the definition of diversity
- All NIH Institutes and Centers have strategic plans targeting health disparities
- Current efforts have varying levels of effectiveness
- COPR can assist NIH in addressing health disparities
- Effective management strategies are critical for advancing diversity

- The 2006 Institute of Medicine Report *Examining the Health Disparities Research Plan of the National Institutes of Health: Unfinished Business* is a good starting point
- Accountability across the NIH needs to be recognized
- Education and training pipeline programs are critical to addressing diversity and health disparities
- NIH requests that COPR keep asking questions

COPR selected diversity training and health disparities research as two possible separate target areas for the Role of the Public in Research Work Group.

RESEARCH, CONDITION, AND DISEASE CATEGORIZATION (RCDC) INITIATIVE REPORT

James Wendorf, M.A. and Christina Clark, M.A., M.B.A.

Mr. Wendorf shared COPR's perspective on the RCDC initiative. COPR views RCDC as an important project for both Congress and the public. The RCDC reporting approach offers a method for consistent reporting across all of NIH. It will promote transparency, accountability, and expedite the reporting process for NIH.

The COPR recognizes that RCDC can result in two key outcomes: (1) increasing public access to federal investment in medical research and (2) providing NIH with a powerful tool to communicate with the public. COPR agrees to give input to NIH on development and implementation of RCDC and to assist in informing and engaging the public on this new reporting tool. Introduction of the RCDC to the public will take place in early 2008.

THE COPR'S TWO EDITORIALS: VALUE OF THE ROLE OF THE PUBLIC IN RESEARCH

Syed Ahmed, M.D., Dr.P.H., M.P.H., and Cynthia Lindquist, M.P.A., Ph.D.

Syed Ahmed, M.D., Dr.P.H., M.P.H., and Cynthia Lindquist, M.P.A., Ph.D., reviewed COPR's two proposed editorials: "The Future Is Now: Enhancing the Role of the Public in Medical Research" and "What is Trust Worth?" Dr. Ahmed reviewed considerations for advancing the role of the public in research:

- Educate researchers about potential public roles
- Provide guidance to applicants and grantees and enhance training programs
- Create tools to educate researchers on community involvement and engagement
- Identify and disseminate best practices of community engagement
- Establish a baseline of NIH community participation
- Bridge gaps between organizations and research institutions
- Build partnerships that expand community involvement in research

Dr. Lindquist reported on COPR's intention to create awareness and inspire action for greater public involvement in research. A strong public research partnership will enhance dissemination and application of research findings. COPR members agreed that a diverse spectrum of public voices enriches the research process.

COMMUNICATION THE COPR'S MESSAGES WORK GROUP REPORT

Nicole Johnson Baker, M.A., M.P.H., and Michael Manganiello, M.P.A.

Nicole Johnson Baker, M.A., M.P.H., and Michael Manganiello, M.P.A., reviewed recent communications successes:

- Development of COPR Editorials
- Initiation of NIH Ambassadors Program
- Increased visibility of NIH in the media (vodcast)
- Development of Grantee Public Information Officers Network

Continued recommendations include exploring new ways to enhance NIH visibility, continuing to produce COPR editorials, and exploring ways to reach youth (NIH Kids Web site and new media). New recommendations include:

- Co-branding NIH with network public service programs
- YouTube videos of families that put a face on NIH
- TV spots focused on children and health habits
- A phase II editorial that includes a literature review on the value of public participation in research
- Expanding the Discovery project
- Create incentives for the media by establishing an excellence award
- Collaboration with the Foundation for the NIH

OUTCOMES AND NEXT STEPS FOR THE COPR
Christina Clark, M.A., M.B.A., and James Wendorf, M.A.

Ms. Clark reported the results of the consensus-building and priority-setting session from the previous day. During this session, COPR members discussed four broad topics: community engagement, diversity and health disparities, disenfranchised areas, and emerging issues. Ms. Harris facilitated the discussion and the COPR reached consensus on priority issues and next steps. COPR confirmed the continuation of the Role of the Public in Research Work Group and selected one area of exploration for future efforts: Identify ways to encourage researchers to involve the public including, but not limited to:

- health disparities
- diversity
- community engagement
- behavioral and social context in research

Next steps for COPR include identifying the specific activities and potential deliverables to support this action item.

PUBLIC COMMENT

Vlady Rozenbaum, Ph.D., founder-administrator of COPD-ALERT, a national support and advocacy group for people suffering from chronic obstructive pulmonary disease (COPD), encouraged NIH to address the health disparities caused by COPD. He described the rising public health challenges associated with COPD. According to Dr. Rosenbaum, COPD is the fourth major cause of death in the United States, the second major cause of disability, and treatment options are inadequate. Dr. Rosenbaum suggested that the provisions of the NIH Reform Act support an increased commitment to COPD research.

Carlos Vázquez-Rivera, Ph.D., director of the Centro de Investigación y Refortalecimiento Comunitario, FILIUS Institute, University of Puerto Rico, presented a letter from his organization, encouraging NIH and COPR to increase diversity in science so that the health of all citizens can improve. He suggested that NIH promote diverse community participation in the design and implementation of research.

ACD LIAISON REPORT

Annelise Barron, Ph.D., and Wendy Chaite, Esq., reported on the meeting of the Advisory Committee to the Director (ACD), which occurred on December 1, 2006. The ACD members also held a teleconference on February 21, 2007. The ACD welcomed three new members at the December 1, 2006, meeting: Mary-Claire King, Ph.D., American Cancer Society Professor, Departments of Medicine and Genome Sciences, University of Washington; Karen A. Holbrook, Ph.D., president, The Ohio State University; and Barbara L. Wolfe, Ph.D., professor, Departments of Population Health Sciences, Economics, and Public Affairs, and director of the Robert M. La Follette School of Public Affairs, University of Wisconsin-Madison.

ACD members and invited speakers discussed the Clinical Research Policy Analysis and Coordination Program (Amy P. Patterson, M.D.), a proposed NIH policy on data sharing

for NIH-supported genome-wide association studies (Elizabeth G. Nabel, M.D.), the electronic application system for NIH grants (Norka Ruiz Bravo, Ph.D.), a history of the Fogarty International Center (Roger Glass, M.D., Ph.D.), and a report on outside awards for NIH employees (Raynard S. Kington, M.D., Ph.D.).

ACD members discussed concerns about how NIH peer-review process would be affected in the current fiscal environment and ongoing NIH efforts to address this issue, including special funding and turnaround criteria for first-time grantees, Pathway to Independence and New Innovator Awards, and potential changes to the grant proposal guidelines. Ms. Chaite suggested increasing the synergy and exchange between the ACD and COPR.

NIH DIRECTOR AND COPR MEMBER SUMMARY AND NEXT STEPS

Dr. Kington noted the development and accomplishments of the COPR over the past nine years. He encouraged COPR to continue to inform and advise NIH on matters of public interest and emphasized that NIH is committed to addressing diversity issues. He also acknowledged that NIH and COPR should consider ways to integrate activities of the COPR and ACD. Dr. Kington commented that NIH will have follow-up meetings on diversity and community engagement issues.

Dr. Kington thanked the COPR members for their input. The COPR meeting will take place October 25–26, 2007. Ms. Gorman noted that Kelli Carrington, M.A., will send out dates for the 2008 spring COPR meeting.

ADJOURNMENT

Dr. Kington and Ms. Clark adjourned the meeting.

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

Kelli L. Carrington, MA
Executive Secretary
Director's Council of Public Representatives

Elias A. Zerhouni, MD
Director
National Institutes of Health

LIST OF ABBREVIATIONS AND ACRONYMS

ACD	Advisory Committee to the Director
AHRQ	Agency for Healthcare Research and Quality
CBPR	Community-Based Participatory Research
CDC	Centers for Disease Control and Prevention
CMS	Center for Medicaid and Medicare Services
COPD	Chronic Obstructive Pulmonary Disease
COPR	Council of Public Representatives
CTSA	Clinical and Translational Science Awards
DPCPSI	Division of Program Coordination, Planning, and Strategic Initiatives
DHHS	Department of Health and Human Services
EEO	Equal Employment Opportunity
FIC	Fogarty International Center
FY	Fiscal Year
FNIH	Foundation for the National Institutes of Health
ICs	NIH Institutes and Centers
IHS	Indian Health Service
IOM	Institute of Medicine
IRB	Institutional Review Board
NCHMD	National Center for Minority Health and Health Disparities
NCI	National Cancer Institute
NCRR	National Center for Research Resources
NDBA	Director's Bridge Award Program

NHLBI	National Heart, Lung, and Blood Institute
NHGRI	National Human Genome Research Institute
NIAID	National Institute of Allergy and Infectious Diseases
NICHD	National Institute of Child Health and Human Development
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases
NIEHS	National Institute of Environmental Health Sciences
NIGMS	National Institute of General Medical Sciences
NIH	National Institutes of Health
OBSSR	Office of Behavioral and Social Sciences Research
OPASI	Office of Portfolio and Strategic Analysis
RCDC	Research, Condition, and Disease Categorization
RFA	Request for Applications
SMRB	Scientific Management Review Board

NATIONAL INSTITUTES OF HEALTH
DIRECTOR'S COUNCIL OF PUBLIC REPRESENTATIVES (COPR)

MEETING MINUTES

October 26, 2007

**NATIONAL INSTITUTES OF HEALTH (NIH)
OFFICE OF THE DIRECTOR
DIRECTOR'S COUNCIL OF PUBLIC REPRESENTATIVES (COPR)**

**Fall 2007 Meeting
Building 31, C-Wing, Conference Room 6, NIH Campus
Bethesda, Maryland**

October 26, 2007

NIH Participants

Raynard S. Kington, M.D., Ph.D., Deputy Director, NIH
John T. Burklow, Director for Communications and Public Liaison, Office of the
Director, NIH
Kelli L. Carrington, M.A., Executive Secretary, COPR, and Public Liaison Officer, Office of
Communications and Public
Liaison, Office of the Director, NIH

COPR Members Attending

Syed M. Ahmed, M.D., Dr. P.H., M.P.H.
Craig T. Beam
Christina L. Clark, M.A., M.B.A.
Naomi Cottoms, M.S.
Linda Crew, M.B.A., R.N.
Valda Boyd Ford, M.P.H., M.S., R.N.
Elmer R. Freeman, M.S.W.
Elizabeth Furlong, R.N., Ph.D., J.D.
Brent M. Jaquet
Nicole Johnson, M.A., M.P.H.
Nicolas Linares-Orama, Ph.D.
Cynthia A. Lindquist, Ph.D., M.P.A.
Matthew Margo, LL.M.
Marjorie K. Mau, M.D., M.S.
Anne Muñoz-Furlong
Ann-Gel S. Palermo, M.P.H.
James H. Wendorf, M.A.

COPR Members Not Present

Wendy Chaite, Esq.
Michael Manganiello, M.P.A.

ACD Liaison

Annelise E. Barron, Ph.D.

Speakers

Barbara Alving, M.D., Director, National Center for Research Resources, NIH

Jeremy M. Berg, Ph.D., Director, National Institute of General Medical Sciences, NIH

Patricia A. Grady, Ph.D., Director, National Institute of Nursing Research, NIH

Alan I. Leshner, Ph.D., Chief Executive Officer, American Association for the Advancement of Science

Yvonne T. Maddox, Ph.D., Deputy Director, National Institute of Child Health and Human Development, NIH

Lawrence A. Tabak, D.D.S., Ph.D., Director, National Institute of Dental and Craniofacial Research, NIH

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EXECUTIVE SUMMARY

The meeting of the National Institutes of Health (NIH) Director's Council of Public Representatives (COPR) was held on October 26, 2007. Elias A. Zerhouni, M.D., NIH Director, could not attend the meeting because of unexpected family commitments. Raynard S. Kington, M.D., Ph.D., NIH Deputy Director, welcomed the COPR members and presenters; in addition, he recognized Ms. Kelli L. Carrington as the new Executive Secretary for the COPR.

Dr. Kington thanked Christina L. Clark, M.A., M.B.A., and James H. Wendorf, M.A., COPR's Meeting Agenda Work Group Cochairs, for their extensive support of both the Council and the NIH staff during the Council's recent transition period.

Dr. Kington recognized and thanked the four retiring COPR members: Wendy Chaite, Esq.; Craig T. Beam; Michael Manganiello, M.P.A.; and Nicolas Linares-Orama, Ph.D., M.P.A. Dr. Kington gave a special thanks to COPR member Marjorie K. Mau, M.D., M.S., for agreeing to participate in the Director's Advisory Council's Working Group on Peer Review and on the newly established NIH Council of Councils.

Dr. Kington thanked Matthew Margo, LL.M., for helping NIH produce a 30-minute interview with Dr. Zerhouni and CBS reporter Charles Osgood for the CBS Cares radio program. He also noted that Annelise E. Barron, Ph.D., liaison to COPR from the Director's Advisory Council (ACD), would be retiring in December and thanked her for working so well with Wendy Chaite, COPR liaison to ACD, to enhance communications between the two committees.

Dr. Kington provided updates in a number of areas.

First, he reported that in September 2007, NIH launched the New Innovator Award with 30 recipients; these awards reinforce the notion that novel ideas and new investigators are essential ingredients for scientific progress.

Also in September, 12 new Pioneer Award recipients were announced; these awards support scientists at any career stage.

Anthony S. Fauci, M.D., Director of the National Institute of Allergy and Infectious Diseases, received three distinguished honors this year: National Medal of Science, Lasker Prize, and George M. Kober Medal.

Nobel prizes were awarded to two longtime NIH grantees, Mario R. Capecchi, Ph.D., of the University of Utah School of Medicine, and Oliver Smithies, Ph.D., of the University of North Carolina at Chapel Hill.

The National Institute on Alcohol Abuse and Alcoholism and the National Institute on Drug Abuse were honored with the prestigious Governor's Award by the Academy of Television Arts and Sciences.

The NIH Public Trust Initiative recently launched the Partners in Research program to identify and encourage innovative models of community partnerships in research.

On September 12, in a ceremony in the U.S. Capitol, NIH and the National Aeronautics and Space Administration (NASA) signed a memorandum of understanding that will help American scientists use the International Space Station to answer important questions about human health and disease.

This past summer the Biomarkers Consortium launched a Web site (www.biomarkersconsortium.org) as part of its efforts to encourage researchers to submit projects that involve possible biomarkers.

Earlier this month, Dr. Zerhouni traveled to India and Japan, where he participated in meetings with high-level scientists and officials and delivered three major presentations. He was accompanied by Roderic I. Pettigrew, M.D., Ph.D., Director of National Institute of Biomedical Imaging and Bioengineering (NIBIB), and Roger I. Glass, M.D., Ph.D., Director of the Fogarty International Center (FIC). These meetings underscore NIH's commitment to enhancing global collaboration in biomedical research and to improving global health.

Dr. Kington took time to reflect on the NIH's loss of the Director of the National Center for Complementary and Alternative Medicine (NCCAM) Stephen E. Straus, M.D, who died of brain cancer on May 14, 2007 after a valiant struggle.

Dr. Kington announced the August 2007 release of the NIH Genome Wide Association Policy, which promotes data sharing to identify common genetic factors that influence health and disease. The NIH continues to implement the policy on enhancing public access to archived publications resulting from NIH-funded research (Public Access Policy), which took effect on May 2, 2005 (<http://publicaccess.nih.gov>).

David A. Schwartz, M.D., Director of the National Institute of Environmental Health Sciences, has stepped down from his position so that a comprehensive management assessment of that institute could be conducted. Sam H. Wilson, M.D., is the Acting Director.

Dr. Kington recognized numerous NIH advances during the previous 6 months, including the participation of NIH staff in 31 congressional hearings on topics including Alzheimer's disease, pandemic influenza, stem cell research, emergency preparedness, postpartum depression, and drug-resistant tuberculosis. President Bush has vowed to veto both the House and Senate fiscal year (FY) 2008 appropriations bills, which include \$110.9 million for the National Children's Study, a \$300 million transfer for global AIDS (the amount for fiscal year 2007 was \$99 million), and direct funding for the Common Fund (\$495.153 million in the House and \$531.3 million in the Senate); these bills include language on mandatory public access.

In all, 10 appropriations hearings were held on the FY 2008 NIH budget—3 in the House and 7 in the Senate. NIH continues to move forward with implementing the requirements of the NIH Reform Act. In FY 2008, the NIH plans to spend a combined \$30 million from the Common Fund on the first year of funding for two new initiatives associated with the general theme of “new pathways to discovery”—the Human Microbiome Project and the Epigenomics Program.

Patricia A. Grady, Ph.D., Director of the National Institute of Nursing Research, and Yvonne T. Maddox, Ph.D., Deputy Director of the National Institute of Child Health and Human

Development, talked about the innovative, new NIH Partners in Research program, a part of the NIH Public Trust Initiative that grew from the Public Trust Workshop, hosted by COPR in October 2004.

Jeremy M. Berg, Ph.D., Director of the National Institute of General Medical Sciences provided an overview of the NIH Director's Pioneer and New Innovator Awards, which evolved out of the NIH Roadmap.

Barbara Alving, M.D., Director of NCCR, reviewed NCCR's efforts in community engagement, including the Clinical and Translational Science Award, Institutional Development Award, and the Research Centers in Minority Institutions programs.

Alan I. Leshner, Ph.D., Chief Executive Officer of the American Association for the Advancement of Science and former director of the National Institute on Drug Abuse, talked about the evolving relationship between science and society.

Lawrence A. Tabak, D.D.S., Ph.D., Director of the National Institute of Dental and Craniofacial Research, discussed the efforts of NIH to enhance the peer review process.

Christina L. Clark, M.A., M.B.A., and James H. Wendorf, M.A., cochairs of the COPR Meeting Agenda Work Group, provided an overview of the COPR's Work Group Day.

Syed M. Ahmed, M.D., Dr. P.H., M.P.H., and Ann-Gel S. Palermo, M.P.H., cochairs of the COPR Role of the Public in Research Work Group, reported the recommendations and the action items discussed during the breakout session of their work group the previous day:

- Develop proposed criteria and/or guidance for review panels to use for gauging community engagement.
- Create broad guidelines for educating researchers and the lay public on community engagement.
- Identify and propose definitions for community engagement and public participation.

Anne Muñoz-Furlong and Brent M. Jaquet, cochairs of the COPR Communications Work Group, reported communications strategies discussed during the breakout session of the Communications Work Group on the previous day:

- Embrace the NIH “Ambassador Program” to promote bilateral communication.
- Promote the Ad Council Campaign in partnership with nonfederal groups.
- Support a NIH community engagement activity modeled after AmericaSpeaks.
- Examine the NIH Internet strategy and make suggestions to increase NIH’s visibility among the public.
- Explore opportunities for alliances with national civic organizations.
- Increase activities aimed at children.

COPR members received updates from Annelise E. Barron, Ph.D., the Advisory Committee Director liaison to COPR. Public Comments were presented by Vlady Rosenbaum, Ph.D. of COPD-ALERT.

WELCOME AND INTRODUCTIONS

Raynard S. Kington, M.D., Ph.D.

Deputy Director, National Institutes of Health

The 18th meeting of the National Institutes of Health (NIH) Director's Council of Public Representatives (COPR) was held on October 26, 2007. NIH Director Elias A. Zerhouni, M.D., could not attend because of unexpected family commitments. NIH Deputy Director Raynard S. Kington, M.D., Ph.D., welcomed the COPR members and presenters, and he recognized the new Executive Secretary for the COPR, Kelli L. Carrington, M.A., and thanked her for her hard work. Dr. Kington acknowledged Christina L. Clark, M.A., M.B.A., and James H. Wendorf, M.A., the COPR's Meeting Agenda Work Group cochairs, for their support of both the Council and the NIH staff during the Council's recent transition period.

Dr. Kington recognized and thanked the four retiring COPR members: Wendy Chaite, Esq.; Craig T. Beam; Michael Manganiello, M.P.A.; and Nicolas Linares-Orama, Ph.D., M.P.A. Dr. Kington reported that Ms. Chaite and Mr. Manganiello were unable to attend because of a family emergencies. Dr. Kington gave a special thanks to COPR member Marjorie K. Mau, M.D., M.S., for agreeing to participate in the Director's Advisory Council's Working Group on Peer Review and on the newly established NIH Council of Councils. Dr. Kington thanked Matthew Margo, LL.M., for helping NIH to produce a 30-minute interview with Dr. Zerhouni and CBS reporter Charles Osgood for the CBS radio program CBS Cares.

NIH DIRECTOR'S UPDATE

Raynard S. Kington, M.D., Ph.D.

Deputy Director, National Institutes of Health

Dr. Kington reported that during the past year Dr. Zerhouni and his office reached out to many groups around the country and around the world, speaking with scientific associations, advisory councils, and other constituencies in an effort to offer transparency about the challenges that the current budget poses to NIH, researchers, and the public, which ultimately benefits from NIH research.

Status of the NIH Budget

The President has vowed to veto both the House and Senate fiscal year (FY) 2008 appropriations bills, which include \$110.9 million for the National Children's Study, a \$300 million transfer for global AIDS (the amount for FY 2007 was \$99 million), direct funding for the Common Fund (\$495.153 million in the House and \$531.3 million in the Senate), and language on mandatory public access. Dr. Kington stressed the need to remain "cautiously optimistic" during a time of uncertain budgets. In all, 10 appropriations hearings were held on the FY 2008 NIH budget—3 in the House and 7 in the Senate.

Legislative Update

NIH staff participated in 31 congressional hearings on such topics as Alzheimer's disease, pandemic influenza, stem cell research, emergency preparedness, postpartum depression, and drug-resistant tuberculosis. NIH continues to move forward with implementing the requirements in the NIH Reform Act of 2006.

The centerpiece of the act is the creation of the Division of Program Coordination, Planning, and Strategic Initiatives (DPCPSI), which empowers NIH to move nimbly and quickly to address issues that will have an effect on the broader field of biomedical research. The new law restructured the reporting of NIH to Congress, eliminating many reports and creating several others, including a new biennial report that is intended to provide a more comprehensive, transparent, and accessible portrait of NIH. This report is due to Congress in January 2008.

The act establishes the Council of Councils to advise the NIH Director on matters related to DPCPSI policies and activities, including making recommendations on trans-NIH research that would be supported by the Common Fund, and establishes a Scientific Management Review Board to review the organizational structure of NIH every 7 years.

In the House, in addition to the NIH Overview Hearing under the chairmanship of Representative David R. Obey (D-WI), a single-theme hearing was held: "Substance Abuse and

Mental Health.” In the Senate, Senator Tom R. Harkin (D-IA) held an NIH Overview hearing and six thematic hearings, which allowed each NIH Institute and Center to testify before his subcommittee. This marked the first time in more than a decade that such hearings have been held in the Senate.

New Common Fund Initiatives

The two initiatives to be launched in fiscal year 2008—the Human Microbiome Project and the Epigenomics Program—are associated with the general theme of “New Pathways to Discovery.” These programs both respond to the Common Fund goals of advancing basic knowledge and developing new tools or resources that will be broadly applicable to many research fields. The Human Microbiome Project will support the development of new technologies and improve our knowledge of how changes in the microbiome (e.g., bacteria, fungi, viruses) correlate with changes in human health. The Epigenomics Program will facilitate the development of new tools to more efficiently detect epigenetic changes in the human genome structure and correlate them with specific diseases or health conditions.

Dr. Anthony S. Fauci Receives the National Medal of Science, the Lasker Prize, and the George M. Kober Medal

Anthony S. Fauci, M.D., Director of the National Institute of Allergy and Infectious Diseases, received three distinguished honors this year. On July 27, 2007, President George W. Bush awarded Dr. Fauci the 2005 National Medal of Science “for pioneering the understanding of the mechanisms whereby the human immune system is regulated, and for his work on dissecting the mechanisms of pathogenesis of human immunodeficiency virus that has served as the underpinning for the current strategies for the treatment of HIV diseases.” Earlier this year, Dr. Fauci also received the George M. Kober Medal of the Association of American Physicians for his work in clinical medicine. On September 28, 2007, Dr. Fauci received the 2007 Mary Wood Lasker Award for Public Service for his role in developing two major U.S. public health programs in AIDS and biodefense: the President’s Emergency Plan for AIDS Relief and Project Bioshield. Upon the announcement, Dr. Zerhouni said, “As a clinician, researcher, and scientific leader, Dr. Fauci has channeled his intellect, compassion, and vision into discoveries and

research programs that have transformed medicine and public health. NIH is extremely proud of him.”

Nobel Prize Winners

The 2007 Nobel Prize in physiology or medicine was shared by two longtime NIH grantees, Mario R. Capecchi, Ph.D., of the University of Utah School of Medicine, and Oliver Smithies, Ph.D., of the University of North Carolina at Chapel Hill. The two researchers were honored, along with Sir Martin J. Evans, Ph.D., of Cardiff University (Wales, United Kingdom), for developing the powerful technology known as “gene targeting.”

NIDA and NIAAA Receive Emmy Award

The Academy of Television Arts and Sciences honored the National Institute on Drug Abuse (NIDA) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) with the prestigious Governors Award for their work with HBO (Home Box Office) on the Addiction Project. This documentary television series reveals the science of addiction and its treatment, recovery, and costs to families and society. The award was displayed for the Council members and meeting attendees.

Public Trust Initiative: Partners in Research Program

The NIH Public Trust Initiative recently launched the Partners in Research program to identify and encourage innovative models of community partnerships in research to facilitate the discovery of new knowledge about the causation, treatment, and prevention of disease. This innovative, new program solicits applications for research grants to develop partnerships between scientific or research institutions and their community organizations. COPR, through its work with the PTI and the 2004 Public Trust Workshop, played an integral role in developing the program.

NIH and NASA Partner for Health Research in Space

On September 12, 2007, in a ceremony at the U.S. Capitol, NIH and the National Aeronautics and Space Administration (NASA) signed a memorandum of understanding that will help American scientists use the International Space Station (ISS) to answer important questions about human health and disease. Dr. Zerhouni and NASA Administrator Michael D. Griffin, Ph.D., welcomed scientists, astronauts, and senators to the event, including Senators Kay Bailey Hutchison (R-TX), Barbara A. Mikulski (D-MD), and Bill Nelson (D-FL). Senator Hutchison was responsible for the legislation that formally designated the U.S. portion of the ISS as a national laboratory. NIH is not funding NASA research; instead, it is publicizing to the scientific community the availability of the space station as an environment for research. NASA, in turn, will advise researchers on implementing NIH-funded projects.

Biomarkers Consortium Update

During the summer of 2007, the Biomarkers Consortium launched a Web site (www.biomarkersconsortium.org) as part of its efforts to encourage researchers to submit projects that involve possible biomarkers. Biomarkers can measure the risk for disease and the status of disease. They can be genetic, biochemical, or immunological measurements of health, images, and cognitive measures, among others.

Dr. Zerhouni Travels to India and Japan

Roderic I. Pettigrew, Ph.D., M.D., Director of National Institute of Biomedical Imaging and Bioengineering (NIBIB), and Roger I. Glass, M.D., Ph.D., Director of the Fogarty International Center (FIC), accompanied Dr. Zerhouni on a trip to India and Japan earlier this month. In India, they met with the Prime Minister, Manmohan Singh, Ph.D., D.C.L. (hon), and the Minister of Science & Technology, Kapil Sibal, LL.M., M.A. Dr. Zerhouni spoke with representatives from the Department of Biotechnology, and the Indian Council of Medical Research. Two agreements were signed, the Letter of Intent on Translational Research and the Joint Statement on the Development of Low-Cost Diagnostic and Therapeutic Medical Technologies. The latter agreement, which will be spearheaded by Dr. Pettigrew, is based on a shared commitment to

improve the health and well-being of the people of both countries by encouraging collaborations and cooperation on the development of diagnostic and therapeutic medical technologies that are inexpensive and operate at the initial point of physician contact, or point of care. Directly following the trip to India, they traveled to Kyoto, Japan, to participate in the Science and Technology in Society (STS) Forum's fourth annual meeting. These meetings underscore NIH's commitment to enhancing global collaboration in biomedical research and to improving global health.

Genome-Wide Association Studies

NIH is interested in advancing genome-wide association studies (GWAS) to identify common genetic factors that influence health and disease and is working to ensure that GWAS data are used ethically and with the highest possible standards for protecting the privacy and confidentiality of participants. The final GWAS policy was released in August. NIH had received more than 200 comments from the public during development of the policy. The NIH GWAS policy will advance science for the benefit of the public through the creation of a centralized data repository; this policy becomes effective January 25, 2008. NIH has established a working group to serve as the Advisory Committee to the Director; this group will provide independent advice on protecting participants as well as the data. A member of the COPR will be asked to participate in the working group. A full update will be provided to the COPR at the Council's meeting in April 2008.

Leadership Update

Dr. Kington memorialized for those present "an extraordinary leader, outstanding scientist, and close friend to many," Stephen E. Straus, M.D., former Director of the National Center for Complementary and Alternative Medicine (NCCAM), who succumbed to brain cancer on May 14, 2007. As the first director of NCCAM, Dr. Straus was instrumental in establishing it as a credible, rigorous scientific center. On June 11, NIH held a memorial service in remembrance of Dr. Straus, his accomplishments, and his contributions to science and public health. Ruth L. Kirschstein, M.D., is acting Director of NCCAM.

David A. Schwartz, M.D., Director of the National Institute of Environmental Health Sciences, stepped down from his position so that a comprehensive management assessment of the institute could be conducted. Samuel H. Wilson, M.D., is the Acting Director during this process. Dr. Kington asked for comments.

Discussion (COPR Members)

Brent M. Jaquet asked Dr. Kington for an update on the scientific management review board. Dr. Kington explained that this new board, created under the NIH Reform Act of 2006, will create a forum to provide advice related to NIH structure and functions. NIH IC (Institute or Center) directors will hold 9 spots on the board, and the remaining 12 spots will be filled by members of the public. This committee will develop a series of initiatives over the next year that could benefit from the input of the advisory committee.

Mr. Wendorf asked Dr. Kington to identify the NIH programs that will receive cuts in the coming year. Dr. Kington responded that NIH does not expect to make cuts in the coming year, but that the increases will vary widely across NIH. Dr. Kington pointed out that every NIH IC has its own process for setting priorities and that NIH research moves more slowly with less funding. However, it is unusual for NIH to completely stop research in a particular area. Ms. Clark asked for science and research highlights within the NIH intramural programs. Dr. Kington emphasized that the NIH intramural program is a responsive, flexible, and unique resource. It includes the NIH Clinical Center, which helps to translate research from the bench to the bedside. Dr. Kington suggested that COPR members receive a tour of the NIH Clinical Center at a future COPR meeting.

Alan M. Krensky, M.D., NIH Deputy Director for the Office of Portfolio Analysis and Strategic Initiatives, reported on discussions from a recent NIH intramural retreat. More than 400 members of the NIH immunology community came together as part of the NIH autoimmunity initiative to discuss how to apply the current understanding of the immune system to various diseases. Dr. Kington concluded by saying that NIH hopes to develop initiatives in autoimmunity to allow synergy across NIH.

Retiring member Dr. Linares-Orama read a poem he composed for the Council entitled *Diversidad Esplendor (Splendid Diversity)*. See the Appendix.

NIH PUBLIC TRUST INITIATIVE: COPR UPDATE
Patricia A. Grady, Ph.D., and Yvonne T. Maddox, Ph.D.

Dr. Grady, Director of the National Institute of Nursing Research, and Yvonne T. Maddox, Ph.D., Deputy Director of the National Institute of Child Health and Human Development, described the NIH Partners in Research (PIR) program, a part of the NIH Public Trust Initiative (PTI). The mission of the NIH PTI is to enable the public to understand and to have full confidence in the research that NIH conducts and supports across the country and throughout the world. The PIR program promotes collaboration between community leaders and NIH-supported scientists to improve the public's understanding of the benefits of health care research. Researchers and community leaders apply as co-investigators to receive grant funds.

Dr. Grady expects the scientific community to develop a deeper and better understanding of what is important to the public and of how to work with the public. "If people in the community do not learn about health-related research findings, then we are not doing our job," said Dr. Grady. She stressed the importance of improving the communication of health-related findings to communities. In addition, NIH investigators need to learn about the research needs and interests of the community. Lastly, we expect our scientific community to have a deeper and better understanding of what is important to the public and how to work with the public area so that we can be better informed. Community leaders from voluntary or professional organizations, health groups, faith-based groups, and housing organizations will participate in research that addresses the health needs of their communities. They will play a key role in communicating health-related findings back to their communities.

Dr. Grady pointed out that the COPR, through its work with the PTI and the 2004 Public Trust Workshop, played an integral role in developing the program. A Request for Applications (RFA) was released October 12, 2007. Phase 1 of the initiative will provide grant support for innovative activities for the Community Leader-Scientist partnership.

To receive funding, applicants must describe a proposed collaboration between community partners and investigators. Phase II will consist of the NIH Partners Workshop, where all the partners will meet at NIH to discuss their programs, looking at their successes and challenges along with their plans for the next project year. In 2008, 40 partner pairs will receive funding through the Small Research Grant mechanism (R03). Members of underrepresented groups are strongly encouraged to apply

Dr. Maddox described the NIH Partners Workshop and thanked the 27 NIH Institutes and Centers for their support and willingness to review applications. Community partners, research organizations, and program officials from NIH will attend the workshop, where participants will learn about true partnerships. Dr. Maddox provided examples of currently funded true partnerships: HIV/AIDS researchers collaborating with advocates on adherence to trials and researchers in behavior working with faith-based organizations to test methods for disseminating messages on preventing obesity. Partners will learn how to share research findings with the media. Dr. Maddox emphasized that progress in research depends on the community's understanding and endorsing the benefits of research. Her office plans to disseminate information on the needs of the researchers to communities. Dr. Maddox expects this will increase the community's willingness to partner with researchers.

Discussion (COPR Members)

Syed M. Ahmed, M.D., Dr. P.H., M.P.H., expressed concern that 1 year would not be enough time for the NIH PIR program grantees to demonstrate results; Dr. Grady agreed. She explained this is a pilot focused on starting small discrete projects that will ideally demonstrate new approaches for potential long-term studies.

Mr. Jaquet asked about NIH outreach plans to nonscientists unfamiliar with the NIH grant proposal process. He wondered whether NIH would depend on scientists in the community to spread the word. Dr. Grady responded that NIH is circulating the RFA widely to public groups. "More often the scientists will approach the community member, but we anticipate it can go either way," explained Dr. Grady. She also pointed out that the NIH PTI Web site includes a

Frequently Asked Questions section where community members can ask questions to NIH staff. Dr. Kington added that a number of medical schools are beginning to create dean-like positions at medical schools to facilitate community outreach, serving as common touch stones for the program.

Ann-Gel S. Palermo, M.P.H., expressed interest in participating in the NIH Partners Workshop to learn about the experiences of the grantees, because the program relates to the COPR's broad focus on the role of the public in research. Dr. Kington stated that NIH would plan to involve the COPR during that time.

COPR members shared their passion for disseminating research results to the public. Dr. Grady pointed out that the NIH Clinical Center is pioneering an effort to share information on research with trial participants sooner than was the case in past years.

Dr. Maddox added that NIH ICs are developing communications documents to increase the dissemination of research results to the public.

NIH PIONEER AND NEW INNOVATOR AWARDS

Jeremy M. Berg, Ph.D.

Jeremy Berg, Ph.D., Director of the National Institute of General Medical Sciences, talked about the NIH Director's Pioneer and New Innovator Awards. The Pioneer Award evolved out of the NIH Roadmap. "We are looking for innovative projects that probably would not be funded through the regular NIH peer-review process," reported Dr. Berg. The program seeks scientists with a track record of innovation who are interested in working on novel projects with potentially high impact.

Dr. Berg described the five-page essay included in the application as a critical component. Electronic reviewers independently evaluate applications. The first year, NIH received more than 1,300 applicants, interviewed approximately 20 finalists, and then made 9 awards in September 2004. The second year, NIH made adjustments to prepare for the large number of applications and to increase outreach to women and members of underrepresented groups. NIH

received more than 800 applications and ultimately made 13 awards in September 2005. This second cohort included a younger, more diverse group of scientists. In 2006, more than 400 applications were reviewed, and 13 awards were made. In 2007, NIH announced 12 awards. Information on the Pioneer Award, including details on the 47 awardees since the program's inception, is available at <http://nihroadmap.nih.gov/pioneer>.

A Joint Resolution of Congress in 2007 included funds to start a junior pioneer-like program called the NIH Director's New Innovator Award program. This program, launched in February 2007, funds exceptionally innovative research with a potential for significant impact.

Information on the 2007 NIH Director's New Innovator Award is at

http://grants.nih.gov/grants/new_investigators/innovator_award/index.htm. Awards will total up to \$1.5 million in direct costs over 5 years. Only new investigators are eligible to apply (a new investigator is someone who received his/her most recent doctoral degree or completed medical internship and residency in 1997 or later). This person must never have been a principal investigator on an R01 or equivalent NIH grant; in addition, he or she must hold an independent research position at a U.S. institution. Applicants must submit a 10-page essay that describes the project's innovativeness, the investigator's qualifications (including evidence of creativity and innovativeness), a biographical sketch, and a list of current and pending research support. After receiving more than 2,100 applications, NIH announced 30 awardees in September 2007.

Discussion (COPR Members)

Annelise E. Barron, Ph.D., suggested that NIH broaden the Pioneer and New Innovator Awards programs and noted the potential global impact of these awards.

Ms. Clark asked how applicants responded to the concept of high-risk, high-return projects. Dr. Berg responded that future evaluations of outcomes may begin to answer this question. Dr. Kington pointed out the importance of considering the willingness of the agency to tolerate failure. If all projects succeed they are probably not high risk.

Dr. Mau asked whether New Innovator awardees could become Pioneer awardees in the future. Dr. Berg explained that both the New Innovator and Pioneer Awards are one-time opportunities

