The NIH Director's Council of Public Representatives (COPR)

An Overview of COPR Activities (April–October 2007)

Presentation to the NIH Director October 26, 2007

Presented by Christina Clark and James Wendorf

Discussion Points

- COPR Consensus Building Cycle
- Selection of COPR Action Item
- COPR Work Group Day
- COPR Member Activities (April–October 2007)
- Reports from the Communications and the Role of the Public in Research Work Groups

COPR Consensus Building Cycle

- COPR identified a need to develop a systematic way of making decision-making.
- The process was inclusive of all members and encouraged input from all COPR members.
- Incorporated into the COPR operations.
- Consensus building cycle was used to identify the COPR action item for the October 2007 meeting.
- Resulted in increased communication and continuous participation among COPR members between meetings.

COPR Action Item

 Identify ways to encourage researchers to involve the public in research with emphasis on community engagement

- Organize the COPR Work Day to increase effectiveness and efficiency of the Council by empowering its Work Groups: Communications and the Role of the Public in Research Work Group.
- Format of the day consisted of expert speakers within and outside NIH and COPR Work Group sessions.

- Minorities and Community Engagement in Research
 - **Dr. Ezekiel J. Emanuel,** Chair, Department of Bioethics, NIH Clinical Center
- The Importance of Social and Cultural Factors in Population-Based Health Research
 - **Dr. Diane R. Brown,** *Executive Director, Institute for the Elimination of Health Disparities, University of Medicine and Dentistry of New Jersey*

- Community Engagement and the National Children's Study
 - Ms. Sara A. Keim, Study Coordinator, National Children's Study, National Institute of Child Health and Human Development, NIH
- Public Involvement in the 21st Century
 - Mr. Joseph P. Goldman, Vice President of Citizen Engagement, AmericaSpeaks

- University of Pittsburgh CTSI Community PARTners (Partnering to Assist Research and Translation) Program
 - **Dr. Jacqueline Dunbar-Jacob,** *Dean, University of Pittsburgh School of Nursing, and Co-Director, Community PARTners Program, University of Pittsburgh Clinical and Translational Science Institute, NIH*
 - **Mr. Lee Hipps,** Executive Vice President and Chief Operations Officer, Urban League of Greater Pittsburgh, and Co-Director, Community PARTners Program, University of Pittsburgh Clinical and Translational Science Institute, NIH

Communications Update

- **Mr. John Burklow**, Associate Director for Communications and Public Liaison, NIH
- **Dr. Marin Allen**, *Deputy Associate Director for Communications and Public Liaison, NIH*

NIH Staff Resources

- Beth Bowers, Social Science Analyst, Division of Services and Intervention Research, National Institute of Mental Health
- Kathleen Cravedi, Acting Director/Officer of Public Liaison, Office of Communications and Public Liaison, National Library of Medicine
- **Cindy Caughman**, Health Science Policy Analyst/Officer of Public Liaison, Office of Science Policy and Public Liaison, National Center for Research Resources
- **Dinora Dominguez**, Acting Chief, Patient Recruitment and Public Liaison Office, NIH Clinical Center
- William Elwood, Steering Committee Chair, NIH Community-Based Participatory Research Scientific Interest Group
- Lisa Kaeser, Senior Program Analyst, National Institute of Child Health and Human Development

NIH Staff Resources

- Betsy Lordan, Officer of Public Liaison, National Institute of Arthritis and Musculoskeletal and Skin Diseases
- **Dr. Shelia McClure,** Health Scientist Administrator, Division of Research Infrastructure, National Center for Research Resources
- **Dr. Barbara Mittleman,** *Director, Public-Private Partnership Program,* Office of Science Policy, Office of the Director, NIH
- **Dr. G. Iris Obrams,** *Medical Officer, Division of Clinical Research, National Center for Research Resources*
- **Phyllis Quartey,** *Program Analyst, Office of Constituency Relations and Public Liaison, National Institute of Mental Health*
- **Dr. Michael Sayre,** Health Scientist Administrator, Division of Research Infrastructure, National Center for Research Resources

- Marjorie Mau, M.D., M.S., has joined the Working Group Advisory Committee to the NIH Director on Peer Review as part of NIH's efforts to enhance the peer review process. Consultative meetings were held in July and September for the research community and October for research and advocacy communities. Dr. Mau has also been invited to join the NIH Council of Councils, newly established as part of the 2006 NIH Reauthorization. The Council's first meeting will be November 8, 2007, at NIH.
- Ann-Gel Palermo, M.P.H., presented comments at the NIH Peer Review Regional Consultation Meeting in New York City on October 8.

- Beth Furlong, R.N., Ph.D., J.D., presented the Overview of the National Institutes of Health slide presentation and discussed her role as a COPR member to nursing students at Creighton University School of Nursing in Omaha, NE, in October.
- Linda Crew, R.N., M.B.A., presented "How NIH Advances Help Address Health Care Costs" to business leaders and members of the Greer Chamber of Commerce in South Carolina in September. Ms. Crew was asked to provide advice on outreach about lupus to the Hispanic/Latino community for the Lupus Genetics Study sponsored by the Oklahoma Medical Research Foundation in May.

- Elmer Freeman, M.P.H., facilitated sessions at the National Center for Research Resources (NCRR) Workshop on Fostering Collaborative Community-Based Clinical and Translational Research in May in Bethesda, MD, and in September in Los Angeles, CA.
- Marjorie Mau, M.D., M.S., and Naomi Cottoms, M.S., attended the NCRR Workshop on Fostering Collaborative Community-Based Clinical and Translational Research in Los Angeles, CA.

- Syed Ahmed, M.D., M.P.H., Dr.P.H., interviewed with WUWM Lake Effect (89.7 FM), his local National Public Radio station in Milwaukee, WI. Dr. Ahmed also participated in the National Library of Medicine's Board of Regents Subcommittee on Outreach and Public Liaison, which is seeking new approaches to outreach and information dissemination with the public.
- Matthew Margo, LL.M., produced a 30-minute CBS Cares Radio interview with Dr. Zerhouni and the internationally recognized reporter Charles Osgood in July.