Engaging the Public in Research Week
October 26–30, 2009

• Partners in Research (PIR) Investigator Workshop, October 26–27.

• NIH Staff Training in Extramural Programs (STEP) Forum: Nuts-and-Bolts of Community Engagement in Research, October 28.

• Meeting of the NIH Director’s Council of Public Representatives, October 30.
Staff Training in Extramural Programs
October 28, 2009

Panelists:

• Dr. Syed M. Ahmed, COPR
• Ms. Ann-Gel Palermo, COPR
• Dr. Sarah J. Gehlert, Brown School of Social Work, Washington University in St. Louis
• Dr. Francesco S. Celi, National Institute of Diabetes and Digestive and Kidney Diseases
• Dr. Lisa Rey Thomas, Alcohol and Drug Abuse Institute, University of Washington
• Dr. Claudia R. Baquet, School of Medicine, University of Maryland, Baltimore
COPR Work Group Day Information Gathering Session

Speakers:

- **Ms. Philippa Yeeles**, *United Kingdom Clinical Research Collaboration*
- **Dr. Adel Mahmoud**, *Princeton University*
- **Dr. Rona Hirschberg**, *National Institute of Allergy and Infectious Diseases*
- **Dr. Amy P. Patterson**, *NIH Office of Science Policy*
- **Dr. Robert Croyle**, *National Cancer Institute*
- **Dr. Donna Jo McCloskey**, *National Center for Research Resources*
- **Mr. John Burklow**, *Office of Communications and Public Liaison, NIH*
COPR Work Group Day
Community Engagement in Research Implementation (CERI) Work Group

• NIH formed CERI in response to COPR recommendations on the role of the public in research.
• Charge: to review recommendations and identify NIH programs and processes that may be appropriate for application/incorporation.
• 17 members representing a cross-section of NIH staff covering seven key areas.
October 30, 2009, Meeting

• Current Directions in Research on Complementary Medicine
  • **Dr. Josephine Briggs**, *Director, National Center for Complementary and Alternative Medicine*

• International Biomedical Research Initiatives
  • **Dr. Roger I. Glass**, *Director, John E. Fogarty International Center*

• Comparative Effectiveness Research Initiatives
  • **Dr. Richard J. Hodes**, *Director, National Institute on Aging*
COPR Celebrates a Decade of Service
www.copr.nih.gov/anniversary

COPR's 10-Year Anniversary

Timeline and Reflections presentations require Flash Player 10 or later. Accessible formats require Acrobat Reader.
Role of the Communications Work Group

- Promote awareness about NIH to the public.
- Act as a vehicle for communication from the public to NIH.
- Recommend communication strategies that support the work of the COPR.

Action: Help NIH seek broad public input.
Request for Information on Consumer Health Information-Seeking Behaviors

• **Goal:** to obtain insight and better understanding of the health information needs and information-seeking behaviors of NIH health consumer audiences.

• **Outcome:** The information gathered will assist the NIH in developing and disseminating health, medical and scientific information to a broader variety of audiences.

[http://nihhealthinfoRFI.nih.gov](http://nihhealthinfoRFI.nih.gov)
Request for Information on Consumer Health Information-Seeking Behaviors (cont.)

Seeks broad public input via Request for Information (RFI). Benefits of this process:

- Responds to the presidential directive for transparency and open government.
- Potential to reach a wide and diverse group of health consumers, providers, and organizations, especially by involving COPR members’ constituencies.
- Identifies a process for future information-gathering initiatives.
- Uses the “ambassador” role of the COPR.
Closing December 30, 2009

The NIH Office of Communication and Public Liaison (OCPL) and the NIH Director's Council of Public Representatives (COPR) have partnered to develop a Consumer Health Information RFI in response to a Directive by President Barack Obama to all Federal agencies calling for greater transparency, public participation, and collaboration.

In conjunction with the NIH goals for public input and effective dissemination of science-based health resources and information to the public, the RFI will provide insight and better understanding of the health information needs and information-seeking behaviors of NIH health consumer audiences. Information gathered will assist the agency in developing and disseminating health, medical, and scientific information to a broader variety of audiences.

To begin and submit your responses, click the link below and read the Privacy Act Statement.
Distribution Channels Used to Date

- COPR and Alumni members.
- NIH YouTube and Twitter.
- NIH constituency databases (individual consumers, health organizations, universities and colleges, hospitals and research centers, patient advocacy organizations, and professional societies).
- NIH Public Bulletin.
- NIH public liaison officers and communication directors.
- Publications of the NIH Institutes and Centers (e.g., National Library of Medicine magazine, Clinical Center News, NIH Record, constituency newsletters).
- Meetings attended by NIH staff.
COPR Member Activities
(April 2009–October 2009)
COPR Alumnus Douglas Yee, M.B.A., (pictured at right) arranged for National Human Genome Research Institute Acting Director Alan Guttmacher, M.D., to speak to two high school anatomy classes at Punahou School in Hawaii. Mr. Yee’s involvement demonstrates the continued support COPR alumni provide to both NIH and their communities.
COPR Member Activities (April 2009–October 2009)

COPR Alumnus Valda Ford spread The Heart Truth messages locally and internationally.
COPR Going Forward

• Exploration of new topics important to the NIH Director and the public:
  • Obesity.
  • Human subjects projections.
  • Communication of research stories.