## Director's Council of Public Representatives Report to the ACD

December 4, 2009
Elizabeth Furlong, J.D., Ph.D., R.N.
John C. Nelson, M.D., M.P.H.

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

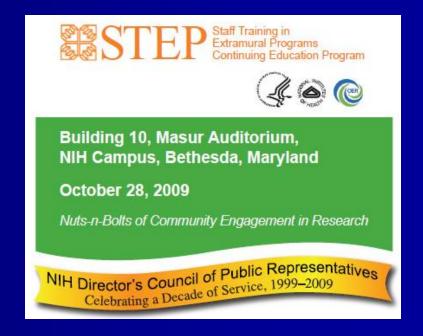


- Partners in Research (PIR) Investigator Workshop, October 26–27.
- NIH Staff Training in Extramural Programs (STEP) Forum: Nuts-and-Bolts of Community Engagement in Research, October 28.
- Meeting of the NIH Director's Council of Public Representatives, October 30.

## 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



# 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 informationseeking 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

# 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 informationgathering initiatives.
- Uses the "ambassador" role of the COPR.

### Closing December 30, 2009



#### 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)

## CBS Cares





# 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.