

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

**An Overview of COPR Activities
(April–October 2008)**

**Presentation to the NIH Director
October 31, 2008**

Presented by Elmer Freeman and James Wendorf

Discussion Points

- COPR Agenda Setting
- COPR Moving Forward
- COPR Member Activities (April to October 2008)
- Reports from the two work groups:
 - Role of the Public in Research
 - Communications

COPR Agenda Setting

The Agenda Work Group:

- Engaged the two work groups in joint planning to produce specific, coordinated recommendations and areas for exploration
- Organized the COPR Work Group Day to more effectively carry out the dual functions of the COPR:
 - Bringing the public's perspectives to NIH
 - Identifying ways to help NIH deliver information to the public

COPR Agenda Setting

The Agenda Work Group:

- Worked with the work group co-chairs, the full COPR, and NIH staff to set the agenda for the formal meeting after reviewing and prioritizing emerging areas of interest
 - Genomics
 - Science education
 - Nanotechnology
 - Health literacy and cultural competency

COPR Moving Forward

The COPR has a keen interest in:

- Leveraging its members and their networks to deliver information to the public and to collect information and recommendations for consideration by NIH
- Initiating and promoting more robust public involvement and community engagement policies and processes throughout NIH

COPR Member Activities (April–October 2008)

- COPR Members Ann-Gel Palermo, M.P.H., and Marjorie Mau, M.D., M.S., participated on the review panel for the newly established Partners in Research Awards Program, which is coordinated under the NIH Public Trust Initiative. The program is based on the goals to increase public trust in and understanding of NIH and to foster a new paradigm for the future of medical and behavioral research.
- COPR Member Elizabeth Furlong, RN, Ph.D., J.D., spoke about the importance of developing trusted and long-lasting relationships for successful community research projects at the Creighton University Center for Health Policy and Ethics roundtable forum, entitled “Getting the Public Engaged in Research.”

COPR Member Activities (April–October 2008)

- COPR Member Brent Jaquet spoke about the COPR at the 2008 American Association for Dental Research Conference. Mr. Jaquet addressed the roles and responsibilities of the COPR members and highlighted the Council's accomplishments over the past 10 years.
- COPR Member Jim Wong, Ph.D., presented “The National Institutes of Health: What do they do for you?” at the Adult Congenital Heart Association annual conference. The conference included 380 patients, family members, and medical professionals.

COPR Member Activities (April–October 2008)

COPR Member and Rhode Island State Representative Eileen Naughton, J.D., invited Barbara Alving, M.D., Director of the National Center for Research Resources to give the keynote address at the Rhode Island Science and Technology Advisory Council's second annual Collaborative Research Symposium, entitled "Emerging Biomedical and Life Sciences Research in Rhode Island." More than 300 participants from Rhode Island's research community, legislation, and industry attended. Dr. Alving has overseen the launch of the Clinical and Translational Science Award program.

COPR Member Activities (April–October 2008)

- COPR Member Carlos Pavão, M.P.A., was selected to participate in the National Institute of Mental Health's (NIMH's) Public Reviewer Orientation. As a public reviewer, he will read and provide written critiques of grant applications. NIMH has found that input provided by public reviewers adds important perspective and sensitivity to the review process and helps ensure the public health relevance of funded grants.
- COPR Member James Wendorf, M.A., participated in an expert panel in August convened by the Child Behavior Branch of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development. The panel made recommendations regarding a strategic research agenda to be presented to the Institute director.

COPR Member Activities (April–October 2008)

COPR Member Elmer Freeman, M.S.W., participated on a panel in July to discuss “Partnerships Between Research Institutions and the Local Communities: Important Principles, Key Attributes, and Lessons Learned” as part of a meeting of the Blue Ribbon Panel on the National Emerging Infectious Diseases Laboratory at Boston University Medical Center. The meeting is part of a larger effort to address and expand upon community engagement interests and activities for the newly funded laboratory. In October, Mr. Freeman facilitated a town hall meeting along with Mr. John Burklow of the Office of Communications and Public Liaison in Boston. More than 300 members of the community attended.

COPR Member Activities (April–October 2008)

COPR Members Valda Boyd Ford, M.P.H., M.S., R.N., Carlos Pavao, M.P.A., Elmer Freeman, M.S.W., Naomi Cottoms, M.S., Cynthia Lindquist, Ph.D., and Beth Furlong, J.D., Ph.D., R.N., participated in the Cancer Health Disparities Summit 2008: Eliminating Cancer Health Disparities Through Science, Training, and Community, hosted by the National Cancer Institute's Center to Reduce Cancer Health Disparities. The summit highlighted the scientific achievements of the Institute's cancer health disparities programs, promoted networking, drew attention to promising junior investigators, and demonstrated the importance of community involvement in research.

COPR Member Activities (April–October 2008)



She has your eyes
and your smile.

Will she also have
type 1 diabetes?

"Because I have type 1 diabetes, my daughter is at risk. That's why I had her screened through TrialNet. If type 1 diabetes is in your family, I encourage you to get the rest of your family screened."

— Former Miss America
Nicole Johnson, with daughter Ava.

A SIMPLE BLOOD TEST CAN NOW DETECT AN INCREASED RISK FOR TYPE 1 DIABETES UP TO 10 YEARS BEFORE SYMPTOMS. Finding this disease early is important because there are actions you can take that may help to prevent or delay potential complications.

In partnership with the National Institutes of Health, diabetes specialists at more than 150 locations are offering this test at no cost to family members of people with type 1 diabetes. They are also conducting clinical trials that are exploring ways to prevent, delay and reverse type 1 diabetes.

To learn more, call **1-800-425-8361** or visit www.DiabetesTrialNet.org.

The screening test and research is offered through Type 1 Diabetes TrialNet, an international network of researchers jointly supported by:



COPR Member Nicole Johnson, M.A., M.P.H., spoke at two Florida universities in September and October about NIH research and the TrialNet Type 1 Diabetes Research Study, produced by the Diabetes Research Institute at the University of Miami, supported in part by NIH. On November 12, she will begin a nationwide radio tour with Dr. Desmond Schatz. Ms. Johnson is creating a Web directory of diabetes research opportunities for people affected by diabetes and their families. The site will also be a resource for physicians and researchers.

COPR Member Activities (April–October 2008)

- COPR Member Matthew Margo, LL.M., produced a prostate cancer PSA that promotes screening using the National Cancer Institute's toll-free information line (1-800-4-CANCER) for CBS Cares. The PSA first aired during *60 Minutes* on July 27, 2008.

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COPR Work Group Reports

- Role of the Public in Research
- Communications