

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

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# NIH Advisory Committees

**Council of  
Public Representatives, COPR  
(Public Input  
and Participation)**

**Advisory Committee to  
the Director, ACD  
(Biomedical Research  
Policy and Administration)**

**NIH Director**

**NEW**

**NEW**

**Scientific Management  
Review Board, SMRB  
(NIH Organizational Review)**

**Council of Councils  
(Division of  
Program Coordination, Planning,  
and Strategic Initiatives)**

# Meeting on October 31, 2008

- **The Science of Genomics**

- *Dr. Alan Guttmacher, Acting Director, National Human Genome Research Institute*

- **Charting the Future of NIH  
Communications: Update**

- *Mr. John Burklow, Associate Director for Communications and Public Liaison*

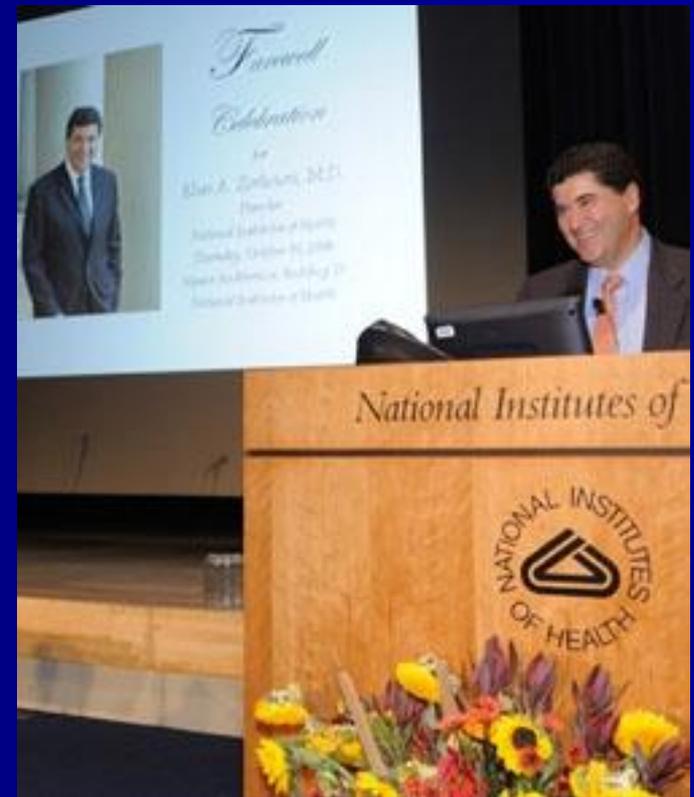
# Meeting on October 31, 2008 (cont.)

- **Genomics in the Public Domain**
  - **Mr. Vence Bonham**, *Chief, Education and Community Involvement Branch, National Human Genome Research Institute*
  - **Mr. John Burklow**, *Associate Director for Communications and Public Liaison*
- **Public Trust Initiative: Update on Partners in Research Awards Program**
  - **Dr. Patricia Grady**, *Director, National Institute of Nursing Research*
  - **Dr. Yvonne Maddox**, *Deputy Director, Eunice Kennedy Shriver National Institute of Child Health and Human Development*

# COPR's Thank You to Dr. Zerhouni



# NIH Farewell to Dr. Zerhouni



# Role of the Public in Research (RPR) Work Group

- Purpose
  - Identify ways to encourage researchers to involve the public in research, with an emphasis on community engagement
- Deliverables
  - Definitions for public participation and community engagement
  - Criteria and/or guidance that peer-review panels can use to gauge community engagement
  - Guidelines for educating researchers and the public about community engagement

# NIH Expert Panel Discussion with RPR Work Group

- **David Armstrong, Ph.D.**, *Chief, Scientific Review Branch, National Institute of Mental Health*
- **Dennis Drayna, Ph.D.**, *NIH Faculty, Office of Intramural Training and Education; Senior Investigator, National Institute of Deafness and Other Communications Disorders*
- **Jared Jobe, Ph.D.**, *Program Director, Clinical Applications and Prevention Branch, Division of Prevention and Population Sciences, National Heart, Lung, and Blood Institute*
- **Donna Jo McCloskey, Ph.D., RN**, *Health Scientist Administrator, Division for Clinical Research Resources, National Center for Research Resources*
- **Alan Willard, Ph.D.**, *Program Manager, NIH Peer Review Enhancement Efforts; Chief, Scientific Review Branch, National Institute of Neurological Disorders and Stroke*

# Communications Work Group

- Purpose
  - 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
- Recommendations
  - Establish an NIH Communications Roadmap
  - Use the COPR's firepower to obtain public perspectives as part of consumer research

# Consumer Research: Request for Information

- The COPR recognizes the need to use an RFI for consumer research and notes it has certain limitations
  - Target audiences do not read the *Federal Register*
  - RFI is more likely to be answered by organizations than individuals
  - RFI is not consumer friendly

# Consumer Research: Request for Information (cont.)

- **The COPR responds to the RFI limitations**
  - Base questions on those used for the NIH Communication Director's Workshop
  - Disseminate the RFI to constituents by e-mail, mail, phone, focus group, etc.
  - Involve COPR alumni

# Additional Communications Strategies

- Communicate through a variety of methods:
  - Directly to health consumers
  - Through consumer/advocacy groups
- Develop a formal communications network that any nonprofit/advocacy group can sign up for to receive information
- Partner with:
  - Professional organizations that interact with large numbers of health consumers (e.g., AMA)
  - State groups that set health policy legislation

# Additional Communications Strategies (cont.)

- Communicate information in traditional and nontraditional ways:
  - Establishments that exist in every community (e.g., pharmacies, grocery stores, barber shops)
  - Tailor communications vehicle to target audiences (e.g., places of worship, small/ethnic newspapers)

# Additional Communication Strategies (cont.)

- Link an “NIH Awareness Month” campaign to high-powered television exposure, such as arranging for the NIH Director to appear on *Oprah*
- Provide lapel pins or stickers that say “Ask me about NIH” to COPR members, COPR alumni, physicians, health care providers, and advocacy groups
- Blue Sky: Use Facebook or MySpace to form a group, such as “Friends of NIH,” to attract interest and encourage dialogue

# Select COPR Ambassador Activities

## Meeting of the National Institutes of Health Blue Ribbon Panel to advise on the Risk Assessment of the National Emerging Infectious Diseases Laboratories (NEIDL) at Boston University Medical Center (BUMC)

**WHAT:** An opportunity for the public to comment on questions related to community engagement and communication regarding the planning and oversight of biocontainment laboratories.

**WHEN:** Tuesday, October 14, 2008, 6:30 PM– 9:30 PM

**WHERE:** Roxbury Center for the Arts, Hibernian Hall  
184 Dudley Street, Roxbury, MA

**DETAILS:** The National Institutes of Health (NIH) has assembled a Blue Ribbon Panel to advise the NIH Director on matters regarding the NIH-funded Regional and National Biocontainment Laboratories (RBLs and NBLs), including the BUMC NEIDL. A key element of the Blue Ribbon Panel's charge is to recommend ways to promote community engagement and communications regarding biocontainment research programs and facilities. Toward that end, the Panel has developed a series of draft principles to assist RBLs and NBLs to optimize their programs of community engagement, which include:

- Rigorous, balanced, and transparent local biosafety review of proposed biocontainment research
- Transparency regarding the operation of NIH RBLs and NBLs, the nature of the research, and process for oversight of research
- Engagement of local communities
- Appropriate technical expertise
- Engagement of local public health authorities
- Ongoing operations oversight

The Panel is also interested in your views on the following questions:

- How can institutions most effectively reach out to local communities and educate about these laboratories?
- What kind of information regarding the planning and oversight of biocontainment research facilities should community members know?
- What are appropriate ways for institutions to seek out community perspectives on the oversight of biocontainment research facilities?

Sign-up for public comment will begin at approximately 5:30 PM on site. In the event that time does not allow for all those interested to present oral comments, members of the public may also file written comments to the following address: NIH Blue Ribbon Panel, Office of the Director, National Institutes of Health, Mail Stop Code 7985, Bethesda, MD 20892-7985 or by sending an email to: nih\_brp@od.nih.gov.



**MORE INFORMATION:** To learn more about the NIH Blue Ribbon Panel, please visit: <http://nihblueribbonpanel-bumc-neidl.od.nih.gov/index.htm>



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](http://www.DiabetesTrialNet.org).

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



**CBS Cares PSA with NCI on prostate cancer**  
**(Click to watch)**

# COPR Going Forward

Next steps for members include:

- Development of a manuscript to publish the COPR's recommendations for:
  - Researcher training in community engagement
  - Guidance for peer review panels involving community engagement proposals
- Develop RFI questions for consumer research in health communications and disseminate to constituents for increased response