Consumers United for Evidence-based Healthcare (CUE)

2013 Annual Membership Meeting
July 26, 2013; 8:30 am - 5:00 pm
Barbara Jordan Conference Center
Kaiser Family Foundation
1330 G Street NW, Washington DC 20005

Program Agenda

8:30 am - 8:45 am  Registration & Continental Breakfast

8:45 am - 9:15 am  Welcoming remarks and Steering Committee Report
Rebecca Burkholder, retiring Co-chair, CUE, Vice President of Health Policy, National Consumers League
Lorraine Johnson, Co-chair, CUE, CEO, Lymedisease.org
Ngina Lythcott, incoming Co-chair, CUE, Black Women’s Health Imperative

What’s New in CUE
Nancy Fitton, CUE Coordinator

CUE’s 10th anniversary: Celebrating our accomplishments, anticipating the next 10 years.
Kay Dickersin, Director, US Cochrane Center, Professor, Johns Hopkins Bloomberg School of Public Health

9:15 am - 10:00 am  Panel: CUE in Partnership
- Moderator, Kate Ryan, Senior Program Coordinator, National Women’s Health Network

Guidelines International Network North America (G-I-N NA)
Marguerite Koster, G-I-N NA Steering Group, Practice Leader, Technology Assessment & Guidelines Unit, Kaiser Permanente Southern California

Vision for partnerships on grants: What is needed
Lisa Simpson, President and CEO, AcademyHealth

Advice for CUE partnerships for the next decade
John Santa, Director, Consumers Reports Health Ratings Center

10:10 am - 10:30 am  Discussion

10:30 am - 10:45 am  Break
10:45 am - 11:25 pm  **Panel: PCORI: A Grand Challenge Met Head-On**  
- Moderator, **Ngina Lythcott**, Black Women’s Health Imperative

**My vision for PCORI**
*Sue Sheridan*, Director of Patient Engagement, PCORI

**A CUE member as peer reviewer**
*Ann Fonfa*, President, Annie Appleseed Project

**The PCORI mentorship program for patient merit reviewers**
*Jim Hulbert*, Contracts Administrator, PCORI

**Views of a PCORI grantee: Using patient-reported outcomes data to improve patient and clinician understanding and use**
*Claire Snyder*, Associate Professor of Medicine, Johns Hopkins Medical Institutions.

11:25 pm - 12:00 pm  **Discussion**

12:00 pm - 1:00 pm  **Lunch/Networking Time**

1:00 pm - 1:15 pm  **How to Survive a Plague viewing**
*Barbara Warren*, National Coalition for LGBT Health

1:15 pm - 1:30 pm  **How to Survive a Plague**
*Tim Horn*, Treatment Action Group (TAG)

1:30 pm - 2:00 pm  **Discussion**

2:00 pm - 2:45 pm  **Panel: Open access to clinical trial data**  
- Moderator, **Diana Zuckerman**, President, National Research Center for Women & Families

**New rules about clinical trial data**
*Peter Doshi*, Postdoctoral Fellow in Comparative Effectiveness Research, Johns Hopkins University Medical School

**Open access to genome data**
*Steven Salzberg*, Director, Center for Computational Biology

**Federal initiatives**
*Kate Ryan*, Senior Program Coordinator, National Women’s Health Network
2:45 pm - 3:15 pm  Discussion

3:15 pm - 3:30 pm  Break

3:30 pm - 4:00 pm  Panel:  Where do we get our information?

Using social networking sites to find out what is important to patients
Sally Okun, Vice President of Advocacy, Policy & Patient Safety, PatientsLikeMe

Health Care Consumer Information Sources: Lessons for Advocates from Two New National Studies
Carol Sakala, Director of Programs, Childbirth Connection

4:00 pm - 4:30 pm  Discussion

4:30 pm - 4:40 pm  Evaluation

4:45 pm  Adjourn