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**