Save the Date! March 19, 2017: CUE Summit

2017 CUE Advocacy Summit:
Leveraging the Power of Patient & Consumer Advocacy to Transform Healthcare
March 19, 2017
The New York Academy of Medicine
1216 Fifth Avenue, NYC 10029

Featured talks include:
- Clinical Practice Guidelines: Do we make a difference?
  Sandra Zelman Lewis, Immediate Past Chair of G-I-N/North America
  Maryann Napoli, Retired Associate Director, Center for Medical Consumers
  William Vaughan, Consumer Advocate
- How PCORI "priority populations" are engaging in research implementation
  Adjunct Professor, Huston-Tillotson University
- What does Sanford James patient engagement look like to marginalized communities?
  Laura Logie, Director of Research, Nueva Vida
- If it works in the UK will it work in the US?
  Sally Crowe, INVOLVE

To register for the 2017 CUE Summit, visit consumersunited.org or click here.

Sponsorship needed for Healthcare Consumer Participation

The 2017 CUE Summit will be held in conjunction with the Guidelines International Network/North America’s Evidence-based Guidelines Affecting Policy, Practice, and Stakeholders (E-GAPPS III) conference in New York City. Although the Summit and E-GAPPS III are separate, we expect that they will bring patients and consumer advocates together with guideline developers, methodologists, and other stakeholders in the clinical guideline enterprise for the purpose of constructive dialogue and initiation of durable relationships between them.

CUE is seeking funds to subsidize consumer travel to the CUE Summit in 2017 and the E-GAPPS III conference. Consumers will be given the choice to attend the CUE Summit or both. By subsidizing consumer participation, we can ensure attendance of qualified patients/consumer advocates from across North America, including Canada and Mexico.
If you know of any foundations or health organizations that might be willing to provide funds, please contact Reva Datar, CUE Coordinator, at rdatar1@jhu.edu.

Clearinghouse Opportunities

The American Society of Hematology - ASH is requesting a non-physician volunteer to serve as a patient representative on the Management of Acute and Chronic Complications of Sickle Cell Disease (SCD) clinical practice guideline. If interested, please contact Reva Datar (rdatar1@jhu.edu) as soon as possible. The application form is attached here.
Top Stories from CUE Facebook Group

Patients Increasingly Influence the Direction Of Medical Research
11.28.16 (NPR)
"Patients and their advocates are getting an ever-larger voice in how medical research is carried out. They participate in the design of experiments and have a greater say in what outcomes they care about most — and it's not always simply living longer."
Posted by: Reva Datar, CUE

How to Fool the Public with a Clinical Trial That Can’t Fail
11.16.16 (Spectator Health)
"When it comes to testing whether a therapy works, the randomized clinical trial (RCT) is usually the methodology of choice. Its principle could not be simpler: one has a group of patients, subdivides them at random into typically two subgroups, treats one with the experimental and the other with a control treatment and eventually compares the outcomes."
Posted by: Michael Weinberg, CUE

Understanding Your Drug Costs: Follow the Pill
11.15.16 (NPR)
"Understanding Your Drug Costs: Follow the Pill begins with a typical transaction at your local pharmacy. It then
traces that purchase back through a series of complex transactions that occur throughout the pharmaceutical distribution and insurance chain".

Posted by: Kay Dickersin, CUE

When a Clinician Becomes a Patient
11.7.16 (PCORI)
"I was 25 when I was diagnosed with multiple sclerosis (MS), five years ago. I was young, an athlete, and an intensive care unit nurse. I had recently begun a competitive graduate program to become a nurse anesthetist. I had been having numbness and other symptoms on and off for quite some time, but I told myself it was just stress and tried not to worry about it too much".

Posted by: Jimmy Lê, Cochrane US

Many Clinical Trials’ Findings Never Get Published. Here’s Why that’s Bad
10.17.16 (STAT)
"When a bearded dude at a Brooklyn coffee house says he's shopping his novel around to agents, no one expects to see it on bookstore shelves in their lifetime. When a scientist says she's got a pile of data ready to publish, well, that seems like it should see the light of day. But it just as likely won’t.".

Posted by: Kay Dickersin, CUE

For more top stories, please visit our Facebook.

Resources and Education

Featured Course: Understanding Evidence-based Healthcare: A Foundation for Action
This free online course has been created by the United States Cochrane Center as part of a project undertaken by Consumers United for Evidence-based Healthcare (CUE), and is designed to help consumer advocates understand the fundamentals of evidence-based healthcare concepts and skills. Registration is open and free of charge.
Participants are encouraged to finish the course in three months. We recommend that participants complete only 1-2 modules at a time. Participants must commit to filling out evaluation forms upon completion of each module.
Serving on an Advisory Panel - Case Study Series

CUE has created a series of case studies for the purpose of informing health professionals/advisory panel organizers as well as consumer representatives about effective engagement and communication on advisory panels. Feedback is welcome!

CUE-Consumers United for Evidence-based Healthcare
(http://us.cochrane.org/CUE)

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