



## THE CUE QUARTERLY

A quarterly newsletter brought to you by Consumers United for Evidence-based Healthcare (CUE)

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February 2017

### **2017 CUE Advocacy Summit: Leveraging the Power of Patient & Consumer Advocacy to Transform Healthcare**

CUE is excited to announce that it will host its third Consumer Advocacy Summit on March 19, 2017 in New York City! The 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.

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. The Summit also aims to facilitate expansion of patient-centered outcomes research/clinical comparative effectiveness research and improved patient and consumer engagement in research implementation practices. **REGISTER TODAY!**

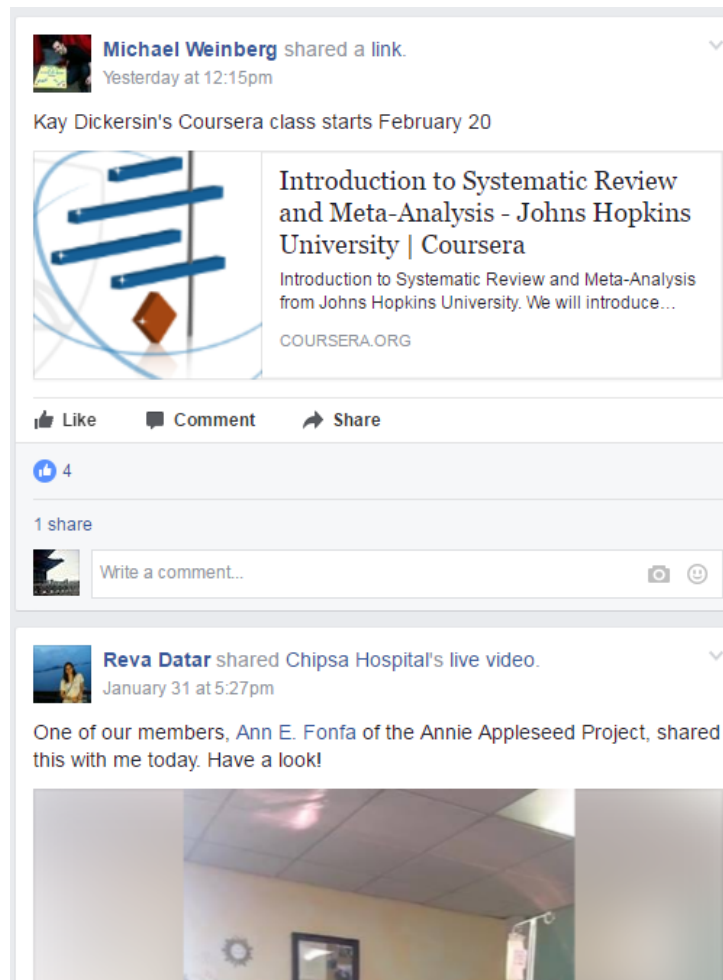
Click [here](#) to access the Summit agenda. Consumers can apply for sponsorship by [clicking here](#).

# Clearinghouse

### **Clearinghouse Opportunities**


1. **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.
2. **The American Academy of Sleep Medicine (AASM)** is seeking patients with non-OSA sleep related breathing disorders, disorders of excessive somnolence, presumed parasomnias, sleep related movement disorder such as restless leg syndrome or patients with OSA undergoing treatment.

If interested, please contact Kolade Fapohunda ([kfapohu1@jhu.edu](mailto:kfapohu1@jhu.edu)) or Reva Datar ([rdatar1@jhu.edu](mailto:rdatar1@jhu.edu)) as soon as possible. The application form is attached [here](#).



**Michael Weinberg** shared a link.  
Yesterday at 12:15pm

Kay Dickersin's Coursera class starts February 20



**Introduction to Systematic Review and Meta-Analysis - Johns Hopkins University | Coursera**

Introduction to Systematic Review and Meta-Analysis from Johns Hopkins University. We will introduce...

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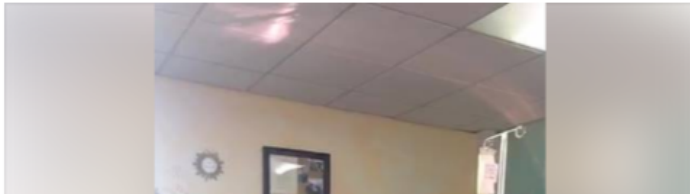
4

1 share

Write a comment..

**Reva Datar** shared Chipsa Hospital's live video.  
January 31 at 5:27pm

One of our members, **Ann E. Fonfa** of the Annie Appleseed Project, shared this with me today. Have a look!



### Top Stories from CUE Facebook Group

**Approval of 'breakthrough' hepatitis C drugs isn't even half the story; now come the harms**

**2.2.17 (Healthnewsreview)**

"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: Kolade Fapohunda, CUE

**How accurately do physicians estimate risk and benefit?**

**1.26.17 (Science-Based Medicine)**

"The era of medical paternalism has largely disappeared. Few of us are willing to permit health decisions to be made on our behalf, without our input. Today the goal is "shared decision making,..."

Posted by: Mark Weinberg, CUE

**Patient Advocacy Organizations, Industry Funding, and Conflicts of Interest**

**1.17.17 (JAMA Internal Medicine)**

"Another article of possible interest--What are the implications of industry support for patient advocacy organizations, particularly when advocacy organizations have the power to influence health care and public policy?"

Posted by: Jimmy Le, CUE

**Drug, Patient, and Physician Characteristics Associated With Off-label Prescribing in Primary Care**

**1.17.17 (JAMA Internal Medicine)**

"Doctors routinely (and legally) prescribe drugs "off label"—that is, for conditions not approved by the FDA—for any use they see fit. Most don't tell their patients. The results of this practice are alarming. A recent analysis in the journal JAMA Internal Medicine revealed that more than 80 percent of off-label prescribing by doctors lacked strong scientific evidence."

Posted by: Reva Datar, CUE

**A supplement maker tried to silence this Harvard doctor — and put academic freedom on trial**

**1.11.17 (STAT)**

"The dietary supplements had ominous names, like Black Widow and Yellow Scorpion. They contained an illegal and potentially dangerous

molecule, similar in structure to amphetamines."  
Posted by: Kay Dickersin, CUE

For more top stories, please visit our [Facebook](#).

## Education & Training



**Free Cochrane Courses:** Select from the menu on the left to view and register for free online courses offered by the US Cochrane Center. The courses are designed to help consumer advocates and other stakeholders understand the fundamentals of evidence-based healthcare concepts and skills and are accompanied by self-tests.



### Conversations Learning Evidence Opportunities

**CLEO - Free Online Resources:** CLEO is CUE's resource library for free online media regarding evidence-based healthcare. The library includes links to TedTalks, free online courses, and other useful websites. The library is updated on a regular basis, ensuring that the resources are up-to-date and timely



**Advisory Panel Engagement:** CUE has produced a comprehensive resource bank for consumers interested in participating on advisory panels and for panel organizers seeking consumer engagement. Resources include case studies, printable handouts with helpful hints, and instructional lessons from experienced patients and professionals

### Resources and Education

#### [Series I: Introduction to participation on advisory panels](#)

These are the first six videos in CUE's three-part series of "short-shorts" about serving on advisory panels. The "Series I" videos target consumers/patients and other stakeholders. They detail the following: 1) to serve on an advisory panel; 2) how to successfully contribute; 3) how to avoid pitfalls; 4) how a chair can encourage consumer contribution; 5) highlights the importance of consumer contribution; 6) resources for consumers.

#### [Series II: Case studies of consumer engagement on advisory panels](#)

CUE has created its "Series II" of its three-part series for the purpose of informing health professionals/advisory panel organizers and patients/consumers about effective engagement and communication practices on advisory panels. These videos highlight case studies of consumer engagement on advisory panels. Self-tests are included at the end of each video.

The case studies are broken up into two parts: Part one (videos 1-4) includes videos aimed at informing patient/consumer representatives interested in serving on advisory panels. Part two (videos 5-8) includes videos aimed at informing health professionals/advisory panel organizers about consumer engagement. Each video indicates the expected level of experience for the target audience. We define each level of experience as follows:

**Novice:** Viewer has never participated as/engaged with a consumer representative serving on an advisory panel

**Moderate:** Viewer has served on 1-2 advisory panels as or with a consumer representative

**High:** Viewer has served on 3 or more advisory panels as or with a consumer representative

Feedback is welcome! [CUE@jhu.edu](mailto:CUE@jhu.edu)

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