



CONSUMERS UNITED FOR  
EVIDENCE-BASED HEALTHCARE

## THE CUE QUARTERLY

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

VOL. 1, ISSUE 4

September 2016

### Save the Date!



#### 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 Jeames 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*



### 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 at [rdatar1@jhu.edu](mailto:rdatar1@jhu.edu).



**Reva Datar**

September 22 at 10:46am · Baltimore

Join us on Friday, September 30, 2016 at 12:00pm ET for a Twitter Chat on #DrugPricing in the US! We will be discussing the topic with Consumer Reports and are now taking YOUR questions! What role do consumers play in the pricing of drugs? Examining the current EpiPen controversy is a good place to start.



### EpiPen Maker Lobbies to Shift High Costs to Others

Inclusion on a federal list would mean Mylan could keep its list price high — or even raise it — without patients' complaining. But consumers would feel it indirectly.

NYTIMES.COM | BY ERIC LIPTON AND RACHEL ABRAMS

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**Reva Datar**

September 21 at 4:22pm · Baltimore

<http://www.nature.com/.../us-government-approves-controversia...>

The US Food and Drug Administration (FDA) has approved its first drug to treat Duchenne muscular dystrophy, largely on the basis of data from a trial



**ProPublica Patient Safety Community**

4,265 members

+ Join



**Medical Error Transparency Plan**

1,022 members

+ Join

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### Top Stories from CUE Facebook Group

[EpiPen Maker Lobbies to Shift High Costs to Others](#)

09.16.16 (NYT)

"WASHINGTON — Against a growing outcry over the surging price of EpiPens, a chorus of prominent voices has emerged with a smart-sounding solution: Add the EpiPen, the lifesaving allergy treatment, to a federal list of preventive medical services, a move that would eliminate the out-of-pocket costs of the product for millions of families — and mute the protests".

Posted by: Reva Datar, CUE

[US Toughens Rules for Clinical-Trial Transparency](#)

09.16.16 (Scientific America)

"Investigators are now required to disclose all clinical trials, whether successful or not"

Posted by: Reva Datar, CUE

[Final Rule Webinar Series-Training Materials](#)

09.16 (ClinicalTrials.gov)

"The webinars might be especially helpful in understanding the rules associated with CT.gov."

Posted By: Kay Dickersin, Cochrane US

### [The Primary Outcome Fails — What Next?](#)

09.01.16 (NEJM)

"P-value > 0.05....uh oh? This review article highlights a series of searching questions that researchers should ask when the primary outcome of a trial fails to achieve statistical significance."

Posted by: Jimmy Le, Cochrane US

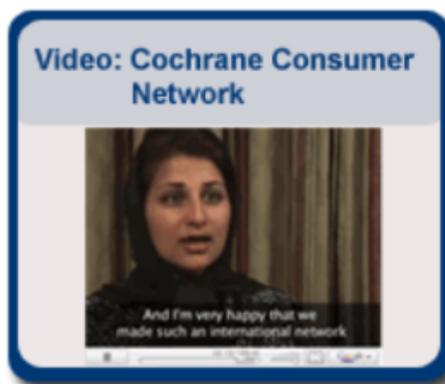
### [How Parents Harnessed the Power of Social Media to Challenge EpiPen Prices](#)

09.01.16 (NYT)

"Parents used social media to challenge EpiPen prices"

Posted by: Kolade Fapohunda, CUE

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



## **Resources and Education**

### **September's 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.

### **The FDA and the Regulation of Healthcare Interventions-A Spotlight Session**

This Spotlight Session on the FDA (US Food and Drug Administration), a supplemental module for the online course Understanding Evidence-Based Healthcare: A Foundation for Action, has been created by the United States Cochrane Center as part of a project undertaken by Consumers United for Evidence-based Healthcare (CUE). It is designed to help users understand the history of drug regulation and the fundamentals of how drugs are approved in the US.

CUE-Consumers United for Evidence-based Healthcare  
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