

Minutes  
Membership Meeting

**Consumers United for Evidence-based Healthcare (CUE)**

U. S. Cochrane Center

16 July 2007

Willard InterContinental Hotel

Washington, DC

*This meeting was sponsored by the Agency for Healthcare Research and Quality (Grant No. R13HS13368-04).*

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## **1. Overview**

This report summarizes the Consumers United for Evidence-based Healthcare (CUE) membership meeting hosted by the US Cochrane Center (USCC) (see Agenda in Appendix A). The goal was to bring together CUE's leadership and membership to discuss programmatic and administrative matters relevant to the coalition (see Appendix B for the list of participants).

Selected CUE members were invited to present on a variety of topics, including examples of their organizations' experiences with evidence-based healthcare and how they have interacted with the Cochrane Collaboration. The meeting provided a forum for CUE members from throughout the nation to come together to discuss their work and address common questions. Recurrent themes were: strengthening the CUE infrastructure, obtaining reliable funding for infrastructure and proposed projects, and to maintain the momentum of the coalition.

Continuing challenges include increasing awareness of the coalition in the consumer and health professional communities, building on the potential of new relationships forged during the Advocacy Summit and elsewhere, increasing awareness and use of evidence-based healthcare (EBHC), and obtaining financial support to continue the growth and development of the work of CUE in the United States.

## **2. CUE Membership Meeting Agenda**

The following sections describe agenda items. See agenda in Appendix A.

### **2.1 Introduction of CUE member organizations (Marianne Hamilton)**

The meeting began with introductions of CUE members and members of the USCC staff. Using two PowerPoint slides per organization (see Appendix B), Marianne presented each organization's mission, constituency, and ways in which they use EBHC.

### **2.2 CUE Annual Report (Barbara Warren)**

CUE Steering Committee Co-chair Barbara Warren welcomed the attendees and expressed her appreciation for her co-chair Joy Simha (who was absent due to a family emergency.)

#### **2.2.1 A call to action**

Barbara Warren began by asking how can CUE engage people in important work over the next year or two, given diverse constituencies. She said that CUE is at a "moment in history" that

includes both opportunities and challenges, especially with the healthcare system appearing to move toward a more nationalized program incorporating EBHC. Consumer advocacy organizations can and should participate in ongoing discussions and plans to develop an institute of comparative effectiveness, an agency that would develop and use systematic reviews to direct policy. CUE is the only broad-based coalition of consumer organizations, of which we are aware, in a position to influence upcoming changes. There is increased interest in the consumer voice and the challenge for CUE is to take a prominent role in the process, despite limited funds. CUE's integrity is arguably its most valuable resource and should not be risked in efforts to stabilize its funding.

CUE must ask for a renewal of commitment and increased commitment from CUE members. Barbara also suggested that CUE should maintain its membership criteria and CUE's core mission in considering new members. Kaiser Permanente, the Eisenberg Center and the Center for Medical Technology Policy, have expressed interest in building an ongoing partnership with CUE.

### **2.2.2 CUE Projects**

Current CUE projects include:

- Recruit new CUE members (consumer organizations not beholden to funders or others with potential interest in the group's policies and positions);
- Strengthening and expanding online EBHC course. Barbara noted that she had obtained funding from Wiley-Blackwell to present a "train the trainer" session at the American Public Health Association (APHA) conference;
- Obtain a national license to *The Cochrane Library* for citizens of the United States. In pushing to obtain a national license, CUE must be able to respond to questions: What would this do, how would this be used, what outcomes are sought, how are users trained? Barbara believes that a national subscription to *The Cochrane Library* should be a line item in the U.S. Health and Human Services budget. The upcoming national election is a great opportunity to push for a national subscription. CUE needs to take the issue on now, while the election unfolds.

### **2.3 How CUE members have incorporated evidence-based healthcare into their work (Sallie Bernard)**

With Sallie Bernard of SafeMinds facilitating the panel presentation, CUE members (Maureen Corry of Childbirth Connection, John Otto of the National Center for Transgender Health, and Merrill Goozner of Center for Science in the Public Interest) provided case studies of how their organizations have used EBHC in the last year.

### **2.3.1 Childbirth Connection - Maureen Corry**

In October 2006, the American College of Obstetricians and Gynecologists (ACOG) released a position/policy statement, "Out-of-Hospital Births in the United States". Childbirth Connection believed that the ACOG policy statement ignored available evidence (two large prospective studies) that showed favorable results for out-of-hospital births; both studies met the ACOG standards. Concerned that the ACOG statement was not based on the best available evidence, Childbirth Connection asked for signatures from interested consumer advocates and partners on a letter to the ACOG president responding to the new policy. Numerous CUE member organizations signed, and USCC Director Kay Dickersin wrote a separate letter emphasizing the need for transparency of reporting and public access to ACOG's policies. ACOG issued a revised statement, "Home Births in the US" in May 2007.

### **2.3.2 National Center for Transgender Health - John Otto**

The Washington State Department of Social and Health Services commissioned a systematic review on sex reassignment surgery from Hayes Inc., a private company. Results from this 2005 report led to proposed regulations that would allow the state of Washington to deny certain services originally offered through Medicaid to transgendered citizens.

The National Center for Transgender Health believed that this commissioned report was neither transparent, peer-reviewed, nor consistent in its methodologies. Concerned that the report and the proposed regulation was influenced by political concerns instead of evidence, the National Center for Transgender Health spoke at public hearings, gathered the input of other partners within the healthcare field, and asked the USCC to review the case and offer comments. Kay Dickersin wrote a letter noting, for example, that the Hayes Report was not publicly available for feedback, had not undergone peer review, and that reports used for funding decisions should be held to the same standards as any other scientific report.

Despite these efforts, the state of Washington approved the regulations denying certain services once covered under Medicaid. Mr. Otto stated that the National Center for Transgender Health is working with partners to appeal this decision and plan to use evidence from the Cochrane Collaboration and others to overturn the regulation and reinstate coverage.

### **2.3.3 Center for Science in the Public Interest - Merrill Goozner**

The Center for Science in the Public Interest focuses on "who writes the evidence". Mr. Goozner pointed out that two thirds of clinical research is currently funded by industry and one third by the government; studies have shown that a publication bias exists supporting outcomes

favoring the sponsor's interests. Last fall, he heard about a "road tour" of physicians supporting the use of Glaxo Smith Klein's (GSK) treatment for vaginal herpes, in particular, the treatment of women with outbreaks during the time of childbirth, to avoid passing the condition on to their children.

Mr. Goozner noticed that this initiative would increase the market for anti-herpes medications and also that there was no information about the risks associated with these medications for women in their third trimester. The National Institutes of Health (NIH) announced its sponsorship of a meeting on this topic and invited the same GSK-sponsored physicians as the meeting's presenters. Concerned that this meeting would present an unbalanced view of the topic, Mr. Goozner drafted a letter to NIH with input from a variety of partners including physicians, consumer advocates, and CUE members. As a result, the NIH cancelled its meeting. Mr. Goozner concluded his presentation by stating that we are at a pivotal transition point where EBHC is important. As EBHC continues to be defined and implemented, this coalition needs to ensure that the consumer voice is included in key discussions.

A discussion ensued that resulted in a list of ways CUE members can be involved in similar issues, including writing letters on what is evidence, what a good report should be, and the standards to meet in determining the level of evidence. A key message is to demand transparency of reporting and of information on which decisions are made.

#### **2.4 An overview of CUE committees and projects (Ngina Lythcott)**

The group decided that this topic was sufficiently covered in the opening remarks. Therefore, in the interest of time, the group moved on to the next agenda item.

#### **2.5 Dissemination: Spreading the message about CUE (Tara Montgomery)**

CUE member Tara Montgomery of Consumers Union facilitated discussion on how CUE can better disseminate its mission, the online course on EBHC, and information generally about EBHC. Ms. Montgomery stated that CUE, as a coalition, needs to adhere to definitions and principles where we agree. We also, as a collective voice, need to reach consumers, healthcare providers, and policymakers. She noted that reaching out to consumers can be very expensive and that CUE will need to work creatively in grassroots ways (e.g., member should mention CUE in their organizations' communications and through listservs). Additionally, it would be helpful for CUE member organizations to include information about CUE and the USCC, including a link, on their organizations' websites. Currently, few CUE member organizations websites are linked to the CUE webpage. Meeting attendees committed to including this information on their websites. (Action: USCC and CUE members)

The USCC will write a press release for the newly developed online course, which will be made available to CUE members for their websites and communications. CUE has a “product” now which should be shared with a wider network. (Action: USCC and CUE members)

As a result of this discussion, CUE members committed to:

- Decide collectively on a definition of EBHC that reflects the importance of consumer input. The coalition should present a unified voice;
- Continue to teach consumers about evidence and empower them to use it in health decision-making;
- Continue to recruit new member organizations and to work with existing members to strengthen the coalition;
- Add information about EBHC, CUE, and the USCC to CUE organization agendas, meeting workshops, newsletters, and websites; and
- Establish new relationships and work with existing partners to spread the message.

## **2.6 CUE and the Cochrane Collaboration (Marianne Hamilton)**

Ann Fonfa of the Annie Appleseed Project described her involvement with the Cochrane Collaboration. Initially, she became involved by submitting an idea to the Consumers and Communications Review Group. She has gone on to serve as a peer reviewer of systematic reviews. Ann helped develop the possible Adverse Events Field. Ann will be presenting at the 2007 Cochrane Colloquium in Brazil.

The primary focus of Maryann Napoli’s work at the Center for Medical Consumers is in making Cochrane systematic reviews understandable by the public through Plain Language Summaries. She emphasized that the Cochrane Collaboration needs the input of CUE members. Not all of the systematic reviews have Plain Language Summaries nor are they always consistent in their quality or content. Marianne will be presenting at the 2007 Colloquium.

Barbara Warren of the National Coalition for Lesbian, Gay, Bisexual and Transgender Health, has become increasingly involved with the Cochrane Collaboration Consumer Network (CCNet). She is dedicated to reaching out to local consumer organizations in the host Colloquium country. Additionally, she has served as a peer reviewer and currently serves on the CCNet Steering Committee. Barbara believes that CUE members have the tools and methodology peer-review the systematic reviews and make comments. CUE members should provide training to their own organizations’ staff and other consumer advocates so that they too can become involved in Cochrane reviews. She noted that other Cochrane Centers are looking to CUE as a model for

consumer advocacy involvement and that the Canadian Cochrane Center is interested in creating a similar coalition based on CUE.

## **2.7 Open forum: Looking ahead (Kay Dickersin)**

Kay stated that the online EBHCcourse is near completion, with an anticipated launch in August, 2007. Registration is by cohort, and individuals are allowed up to 3 months to complete the course. She would like the first cohort to be a committed group of participants that agree to finish and provide constructive feedback, so that the USCC and CUE can revise the course, if necessary, and determine the short term impact of the course. She noted that she and Musa Mayer would be presenting portions of Modules 1, 3 and 5 during the Summit on Tuesday, July 17, 2007 (the next day).

Funding for the USCC, and therefore CUE, officially ends on September 30, 2007. The USCC has submitted grants but has been unable to secure support for a full-time Consumer Coordinator position. Difficulty in securing federal funding is related to CUE's need for infrastructure support (ie, CUE is not conducting research). Additionally, funds allowable through an AHRQ Large Conference Grant (the USCC previous funding source) have been cut by 80%. The USCC will continue to seek grants from government agencies and private foundations. Kay encouraged members of CUE to seek opportunities for networking and funding.

## **2.8 CUE Administration**

The CUE Steering Committee currently has four openings (up to 7 members total). Steering Committee members provide overall direction and program and policy development. Its members discuss administrative and programmatic topics before they are sent to the general membership. Additionally, Steering Committee members serve as Co-chairs on the project committees. Business is conducted through conference calls and email. During this year's Steering Committee Meeting, the Committee decided to meet, funding permitting, once per month via conference call and three times per year in person.

The current members of the CUE Steering Committee include:

- Sallie Bernard
- Ngina Lythcott
- Barbara Warren (co-chair)
- Joy Simha (co-chair)
- Zobeida Bonilla

CUE Steering Committee members Joy Simha and Zobeida Bonilla will be stepping down. They have both provided great insight and leadership and are appreciated for their years of service to this Committee. Those that were interested were encouraged to indicate their interest in a short paragraph and email it to Kelly Manos, USCC Project Coordinator.

### **3. Summary of CUE Member Evaluations**

CUE members who attended the meeting were asked to complete an evaluation for the meeting as a whole and for each session attended (see Appendix D). Fifteen out of 18 (83%) members attending completed an evaluation form (see Appendix E for the Evaluation Summary), although not all respondents answered all questions. Overall, CUE members were enthusiastic about their experience, rating most sessions as “Excellent” or “Very Good” 71% to 100% of the time. Several members commented that they “needed more time.” Suggestions for improvement included the need to recruit Latina/Native American/Pacific Asian member organizations.

Of those responding to the question “Did the meeting meet your expectations?”, 93% (13/14) responded positively, with the remaining respondent checking “No.” Thirteen respondents also believed that the meeting was free from commercial bias (93%) with one respondent checking “Not certain” (1/14, 7%).

Mean scores for each segment of the meeting are reported in Table 1. Overall, most sessions scored between 5 and 4 on “Informative content,” “Adequate time allotted,” and “Objectives met.” One session scored less well on “Adequate time allotted.”

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**Table 1. Mean evaluation scores<sup>1</sup> by session of the CUE Members Meeting, 2007**

Sessions	Informative content	Adequate time allotted	Objectives met
	mean <sup>1</sup> (n) <sup>2</sup>	mean (n)	mean (n)
Panel: How CUE members have incorporated EBHC into their work	4.75 (12)	4.08 (12)	4.67 (12)
Dissemination: Spreading the message about CUE	4.50 (14)	3.93 (14)	4.30 (14)
CUE and the Cochrane Collaboration	4.60 (14)	4.14 (14)	4.43 (14)
Open forum: Looking ahead	4.64 (14)	4.07 (14)	4.27 (15)
<b>Overall Evaluation</b>			
	No (%)	Yes (%)	Not certain
The program was presented without evident commercial bias or influence (n=15) <sup>2</sup>	1 (7)	13 (93)	0 (0)
The program met my expectations (n=15) <sup>2</sup>	0 (0)	13 (93)	1 (7)

<sup>1</sup> 5 = excellent, 4 = very good, 3 = good, 2 = fair, 1 = poor

<sup>2</sup> n= number responding to question

**Appendix A**  
**CUE Membership Meeting Agenda**

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**July 16, 2007**

- 1:00 - 1:05 pm      Welcome: Steering Committee Co-Chairs
- 1:05 - 1:30 pm      Introduction of CUE member organizations  
Facilitator:  
                  Marianne Hamilton, US Cochrane Center
- 1:30 - 2:00 pm      CUE Annual Report:  
Presenter:  
                  Joy Simha, Young Survival Coalition
- 2:00 - 2:45 pm      Panel: How CUE members have incorporated EBHC into their work  
Chair:  
                  Sallie Bernard, SafeMinds  
Panel Members:  
                  Maureen Corry, Childbirth Connection  
                  John Otto, National Center for Transgender Equality  
                  Merrill Goozner, Center for Science in the Public Interest
- 2:45 - 3:00 pm      Break
- 3:00 - 3:15 pm      An overview of CUE committees and projects  
Chair:  
                  Ngina Lythcott, Black Women's Health Imperative
- 3:15 - 3:45 pm      Dissemination: Spreading the message about CUE  
Facilitator:  
                  Tara Montgomery, Consumers Union
- 3:45 - 4:15 pm      CUE and the Cochrane Collaboration  
Chair:  
                  Marianne Hamilton, US Cochrane Center  
Panel Members:  
                  Ann Fonfa, The Annie Appleseed Project  
                  Maryann Napoli, The Center for Medical Consumers  
                  Barbara Warren, The National Coalition for Lesbian, Gay, Bisexual  
                  and Transgender Health
- 4:15 - 4:45 pm      Open forum: Looking ahead  
Facilitator:  
                  Kay Dickersin, US Cochrane Center

4:45 - 5:30 pm CUE administration (Steering Committee elections, membership)  
Facilitator:  
Zobeida Bonilla, Our Bodies Ourselves

5:30 - 5:45 pm Evaluations and adjourn

## Appendix B - Annual CUE Membership Meeting

July 16, 2007  
Washington, DC  
**Participant List**

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### **Annie Appleseed Project**

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# Consumers United for Evidence-based Healthcare



## CUE Member-Organizations



- The Annie Appleseed Project
- Black Women's Health Imperative
- Center for Medical Consumers
- Center for Science in the Public Interest
- Childbirth Connection
- Citizens for Health
- Citizens Health Alliance for Truth
- Consumers Union
- Faces and Voices for Recovery
- Lamaze International
- Mautner Project, the National Lesbian Health Organization
- National Breast Cancer Coalition
- National Center for Transgender Equality
- National Coalition for Lesbian, Gay, Bisexual, Transgender Health
- National Consumers League
- National Council on Aging
- National Environmental Education Foundation
- National Mental Health Consumers' Self-Help Clearinghouse
- National Partnership for Women and Families
- National Vaccine Information Center
- National Women's Health Network
- Our Bodies Ourselves
- Safe Minds
- TMJ Association, Ltd.
- Young Survival Coalition

# Annie Appleseed Project



## Mission Statement:

To provide information, education, advocacy and awareness for people with cancer about complementary, alternative medicine (CAM), and other issues



# Annie Appleseed Project



## Constituency:

- Those with cancer questions and access to the Internet
- Over 1.6 Million people accessed our site in the last 12 months. They come from every state and many other countries

## Evidence-based healthcare applications:

- Evidence **lacking** in CAM
  - Most studies/reviews end with “need studies”
  - Mistrust, Misunderstanding, Misuse
- We have advocated for studies on natural substances but are often told since they cannot be patented, they are not researched. This is now changing

# Black Women's Health Imperative



## Mission:

Founded in 1983, the BWHI empowers, provides health information to, and conducts advocacy in support of the health and well-being of Black women.



# Black Women's Health Imperative



## Constituency:

19.5 million Black women, most living in the U.S We serve as a clearing house for health information to Black women

## Evidence-based healthcare applications:

- We provide health education to Black women
- We provide advocacy and influence public policy that impacts the health of Black women
- We form coalitions with other grassroots organizations

# Center for Medical Consumers



## Mission:

Encourage people to seek the research supporting their doctor's treatment recommendations. First step was a medical library open free to the public at our office.

# Center for Medical Consumers



## Constituency:

- Our monthly articles provide a critical appraisal of the latest studies.
- Our articles appear in the country's largest electronic information services (Gale Group, EBSCO, Lexis/Nexus, ProQuest) that are used by private and public libraries.
- Our Web site gets 40,000 visits a month

## Evidence-based healthcare applications:

- Evidence-based advocacy: hospital patient safety, FDA watchdogs, deceptive prescription drug advertising, etc.

# Childbirth Connection



## Mission Statement:

Childbirth Connection is a national not-for-profit organization founded in 1918 as Maternity Center Association. Our mission is to improve the quality of maternity care through research, education, advocacy and policy. Childbirth Connection promotes safe, effective and satisfying evidence-based maternity care for all women and their families



# Childbirth Connection



**Constituency:** Women and health professionals

## Evidence-based healthcare applications:

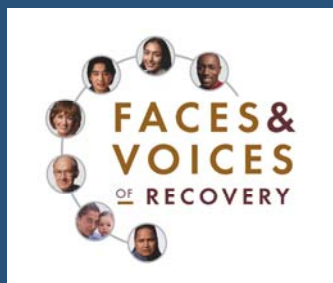
- Childbirth Connection launched our long-term national program to promote evidence-based maternity care in 1999.
- Our award-winning website provides evidence-based information and resources for women and health professionals to help them make informed maternity care decisions. The website provides access to the electronic version (2000) of the renowned “Guide to Effective Care in Pregnancy and Childbirth”.
- Childbirth Connection has commissioned systematic and narrative reviews and pioneering national *Listening to Mothers* surveys to illuminate women's childbearing experiences and clarify evidence-practice gaps. Accompanying media outreach campaigns help publicize results and products.
- The organization is the long-term North American sponsor of the Consumer Panel of the Cochrane Collaboration Pregnancy and Childbirth Group, which involves consumers as referees to strengthen the quality of systematic reviews.
- Childbirth Connection also works to build awareness of maternity care quality issues among federal and state policy makers.

# Faces and Voices of Recovery



## Mission:

Faces & Voices of Recovery is committed to organizing and mobilizing the millions of Americans in long-term recovery from alcohol and other drug addiction, our families, friends, and allies to speak with one voice. Our organization is dedicated to changing public perceptions of recovery, promoting effective public policy in Washington and in all 50 states, and demonstrating that recovery is working for millions of Americans. It is our collective strength that will ensure our success, and it is our mission to bring the power and proof of recovery to everyone in America.



# Faces and Voices of Recovery



## Constituency:

People in recovery from addiction to alcohol and other drugs, families, friends and allies

## Evidence-based healthcare applications:

Getting out information about pathways to recovery; involvement of individuals and families who are using this information in developing policy and programs

# Lamaze International



## Mission Statement:

- The mission of Lamaze International is to promote, support and protect normal birth through education and advocacy.
- The Lamaze Institute for Normal Birth is a vehicle for advocacy, information and coalition building to advance the Lamaze International mission to promote, support and protect normal birth through education and advocacy.



# Lamaze International



## Constituency:

The entire autism community of families, affected individuals, scientists, clinicians, and other professionals

## Evidence-based healthcare applications:

- In our Autism Treatment Network, we are writing and implementing standards of care using the best available evidence
- Funding 2 and soon a third phase III trial of compounds to treat symptom or underlying biology of autism through our Clinical Trials Network
- We inserted language in the federal Combating Autism Act that treatment should be evidence based.

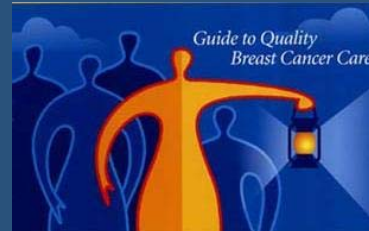
# National Breast Cancer Coalition



## Mission:

To eradicate breast cancer.  
Primary goals:

- **RESEARCH:** increase funding and accountability, and foster innovative research with high, meaningful impact
- **ACCESS:** to high quality health care and breast cancer clinical trials for all women
- **INFLUENCE:** expand influence of well-trained advocates throughout breast cancer decision-making proc



# National Breast Cancer Coalition



## Constituency:

Hundreds of grassroots organizations, thousands of individuals, breast cancer survivors, stakeholders in breast cancer community

## Evidence-based healthcare applications:

- Training Programs –
  - basis for Project LEAD® courses
- Beyond the Headlines, Positions
  - Basis for critical analyses, position papers, response to research in the news, literature and controversies
- Clinical Trials Initiatives
  - Criteria for clinical trials, industry, research partnerships
- Legislative Agenda
  - Basis for support or lack of support for legislation

## National Center for Transgender Equality



### **Mission:**

- The National Center for Transgender Equality is a national social justice organization devoted to ending discrimination and violence against transgender people through education and advocacy on issues of importance to transgender people.
- By empowering transgender people and our allies to educate and influence policymakers and others, NCTE facilitates a strong and clear voice for transgender equality in our nation's capital and around the country.



## National Center for Transgender Equality



**Constituency:** Transgender people in the United States, LGBT advocates and allies, members of Congress and other elected officials

### **Evidence-based healthcare applications:**

We have used evidence-based healthcare/medicine in the Washington State Medicaid case and we look forward to using it more in the future

## National Coalition for Lesbian, Gay, Bisexual and Transgender Health



### Mission:

The National Coalition for LGBT Health is committed to improving the health and well being of lesbian, gay, bisexual and transgender individuals and communities through public education, coalition building and advocacy that focuses on research, policy, education and training

## National Coalition for Lesbian, Gay, Bisexual and Transgender Health



Evidence-based medicine is critical to insuring that the needs of the lesbian, gay, bisexual and transgender communities for relevant, sensitive and effective health care are developed and disseminated to providers and consumers. For example :

- **HIV/AIDS is still the most critical health care issue facing gay, bisexual and other men who sex with men;**
- **Lesbians still have significantly higher rates of breast cancer than heterosexual women;**
- **Transsexual men and women need effective hormone therapy and gender reassignment surgeries;**
- **As more and more gay and lesbian couples are seeking to have children, LGBT sensitive reproductive healthcare is becoming a growing area of need.**

# National Consumers League



## Mission Statement:

- Founded in 1899, NCL is the oldest, private, nonprofit consumer advocacy organization in the United States.
- Our mission is to identify, protect, represent, and advance the economic and social interests of consumers.



# National Consumers League



**Constituency:** We represent consumers and workers in the marketplace and workplace. Work in numerous policy areas, including health care; focus on safe medication use, access to information.

## Evidence-based healthcare applications:

- Environment for consumers - context of self-care, access to information, marketing
- Public Education
  - Safe use of OTC medications
  - SOS Rx - coalition promoting outpatient medication safety

# National Environmental Education Foundation



## **Mission:**

The National Environmental Education Foundation is a private, non-profit organization committed to improving environmental literacy and advancing environmental health knowledge among healthcare providers. Working with health professional organizations, healthcare providers, and other stakeholders, the Foundation creates tools, conducts trainings and other educational and outreach activities in order to incorporate environmental health into health care, with a special emphasis on protecting children, minorities and other vulnerable populations.



# National Environmental Education Foundation



## **Constituency:**

Our constituents are health professional organizations, healthcare providers, public health organizations and the general public.

## **Evidence-based healthcare applications:**

We use evidence evidence-based healthcare information in developing all our tools, resources and trainings.

# National Partnership for Women and Families



## Mission Statement:

- Founded in 1971 as the Women's Legal Defense Fund, the National Partnership for Women & Families is a leader on issues that affect women and families--issues like increasing access to quality, affordable health care; ensuring equal opportunity and fair treatment in the workplace; and helping Americans balance their work and family responsibilities.
- Our mission is to help create a society that is free, fair and just, and where nobody has to experience discrimination, all workplaces are family-friendly, and no family is without quality, affordable health care and real economic security.

**National Partnership**  
for Women & Families

# National Partnership for Women and Families



## Constituency:

We represent consumers and workers. Our *Americans for Quality Health Care (AQHC)* initiative is engaging consumer advocates in activities to improve health care quality. The AQHC project is also working to provide consumers with performance information about their health care providers so that they can make educated health care decisions

## Evidence-based healthcare applications:

*Advocacy and Public Education:* The consumer groups we work with advocate for increased use of EBM as a way to improve health care quality; they also use EBM to raise their constituents' awareness about informed decision-making and better self-management of their health.

# Our Bodies Ourselves



## Mission:

- Our Bodies Ourselves (OBOS), also known as the Boston Women's Health Book Collective, is best known for the publications *Our Bodies, Ourselves* and *Nuestros Cuerpos, Nuestras Vidas*
- Our mission is to empower women with information about health, sexuality and reproduction
- We work in and for the public interest, promote equality between women and men, and build bridges among social justice movements



# Our Bodies Ourselves



## Constituency:

- Women's health groups, community-based groups, community health centers, hospitals, women's studies programs, women's resources centers in college campuses
- Latinas in the US and Latin America; OBOS Global Network

## Evidence-based healthcare applications:

- **Latina Health Initiative** – In addition to *Nuestros Cuerpos, Nuestras Vidas (NCNV)*, the organization has produced *Promotoras de Salud*, a training guide for community lay health workers based on NCNV, and *Journey to Parenthood, De Camino a la Maternidad*, a booklet about childbirth.
- **Global Translation/Adaptation Program** – An Albanian edition of *Our Bodies, Ourselves* has just been published and we are working with groups in Nepal, Russia, and Turkey to develop culturally adapted translations. Upcoming projects include adaptations for East Africa, India, Israel, and Jordan.
- **Public Voice and Action** – Our organization is a critical voice in policy, advocacy, and educational efforts on women's health. We have reached a wide audience with a feminist and consumer perspective on such issues as breast implants, direct-to-consumer advertising of prescription drugs, and cloning and genetics.

# Safe Minds



## Mission:

- The mission of SafeMinds is to end the devastation to human health manifested as autism and other developmental disorders from early life exposures to all manmade sources of mercury, the second most toxic substance on earth.
- Our mission will be achieved through scientifically based research, increased awareness, and advocacy in the public policy and legal arenas.



# Safe Minds



## Constituency:

- Families, individuals with autism, scientists, clinicians, and policymakers who feel that environmental factors play a role in autism causality

## Evidence-based healthcare applications:

- We are in funding clinical research that we hope can provide evidence for treatment approaches.
- We are partnering with other groups in making the case that the underlying mechanisms of autism are treatable and recovery is possible.
- With other groups, we are trying to identify ways to determine the effectiveness of complex, individualized treatment regimens using alternate approaches to the RCT, such as large clinical data bases

# The Young Survival Coalition



## Mission:

The Young Survival Coalition's mission is to increase the quantity and quality of life for young women affected by breast cancer.



# The Young Survival Coalition



## Constituency:

- 17,000 people in the network; 9000 cancer survivors
- professionals and friends and family who care about young women affected by breast cancer

## Evidence-based healthcare applications:

We try to encourage our constituents to make their decisions based upon available evidence. We seek to educate them about what information constitutes evidence. Our website is a premier resource of information available to young women and they can ask our resourcelink coordinator questions and communicate with each other on our bulletin boards.

## Vaccines for preventing influenza in healthy adults (Cochrane Review)

Demicheli V, Rivetti D, Deeks JJ, Jefferson TO

### ABSTRACT

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A substantive amendment to this systematic review was last made on 21 May 2004. Cochrane reviews are regularly checked and updated if necessary.

**Background:** Three different types of influenza vaccines are currently produced worldwide. None is traditionally targeted to healthy adults. Despite the publication of a large number of clinical trials, there is still substantial uncertainty about the clinical effectiveness of influenza vaccines and this has negative impact on the vaccines acceptance and uptake.

**Objectives:** To assess the effects of vaccines on influenza in healthy adults. To assess the effectiveness of vaccines in preventing cases of influenza in healthy adults. To estimate the frequency of adverse effects associated with influenza vaccination in healthy adults.

**Search strategy:** We searched the Cochrane Central Register of Controlled Trials (CENTRAL) (The Cochrane Library, Issue 1, 2004) which contains the Cochrane Acute Respiratory Infections Group trials register; MEDLINE (January 1966 to December 2003); and EMBASE (1990 to December 2003). We wrote to vaccine manufacturers and first or corresponding authors of studies in the review.

**Selection criteria:** Any randomised or quasi-randomised studies comparing influenza vaccines in humans with placebo, control vaccines or no intervention, or comparing types, doses or schedules of influenza vaccine. Live, attenuated or killed vaccines or fractions thereof administered by any route, irrespective of antigenic configuration were considered. Only studies assessing protection from exposure to naturally occurring influenza in healthy individuals aged 14 to 60 (irrespective of influenza immune status) were considered.

**Data collection and analysis:** Two reviewers independently assessed trial quality and extracted data.

**Main results:** Twenty five reports of studies involving 59,566 people were included. The recommended live aerosol vaccines reduced the number of cases of serologically confirmed influenza by 48% (95% confidence interval (CI) 24% to 64%), whilst recommended inactivated parenteral vaccines had a vaccine efficacy of 70% (95% CI 56% to 80%). The yearly recommended vaccines had low effectiveness against clinical influenza cases: 15% (95% CI 8% to 21%) and 25% (95% CI 13% to 35%) respectively. Overall the percentage of participants experiencing clinical influenza decreased by 6%. Use of the vaccine significantly reduced time off work but only by 0.16 days for each influenza episode (95% CI 0.04 to 0.29 days). Analysis of vaccines matching the circulating strain gave higher estimates of efficacy, whilst inclusion of all other vaccines reduced the efficacy.

**Reviewers' conclusions:** Influenza vaccines are effective in reducing serologically confirmed cases of influenza. However, they are not as effective in reducing cases of clinical influenza and number of working days lost. Universal immunisation of healthy adults is not supported by the results of this review.

**Citation:** Demicheli V, Rivetti D, Deeks JJ, Jefferson TO. Vaccines for preventing influenza in healthy adults (Cochrane Review). In: The Cochrane Library, Issue 4, 2004, Chichester, UK: John Wiley & Sons, Ltd.



## Appendix D

Consumers United for Evidence-based Healthcare (CUE) Membership Meeting

### Understanding Evidence-based Healthcare: A Foundation for Action

July 16, 2007

Washington, DC

### Program Evaluation

**Panel:** How CUE members have incorporated EBHC into their work

**Objectives:**

1. Present examples, from the last year, about CUE members' experiences with evidence-based healthcare (EBHC).

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Objectives were met	5	4	3	2	1

**Dissemination: Spreading the message about CUE**

**Objectives:**

- Discuss strategies in which CUE members and the USCC staff can better disseminate information about EBHC, CUE, ongoing projects, and the online course.

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Objectives were met	5	4	3	2	1

**CUE and the Cochrane Collaboration**

**Objectives:**

- Provide examples of how CUE members have worked with the Cochrane Collaboration as reviewers, review group participants, and members of CCNet; and
- Discuss other means for participation.

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Objectives were met	5	4	3	2	1

Summit evaluation (cont'd)

**Open forum: Looking ahead**

**Objectives:**

- Discuss the future of CUE.

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Objectives were met	5	4	3	2	1

**Overall Evaluation**

1. The program was presented without evident commercial bias or influence.

- ( )<sub>0</sub> No
- ( )<sub>1</sub> Yes
- ( )<sub>2</sub> Not Certain

2. The program met my expectations

- ( )<sub>0</sub> No
- ( )<sub>1</sub> Yes
- ( )<sub>2</sub> Not Certain

3. Please provide comments or suggestions: \_\_\_\_\_

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**Appendix E**  
**Evaluation Summary**  
**CUE Membership Meeting**  
 Evaluation Summary  
 (16 July 2007)

	Excellent	Very Good	Good	Fair	Poor	Total Respondants
<b>1. Panel: How CUE members have incorporated EBHC into their work</b>						
<b>A. Quality of session</b>						
Informative content	10 83%	1 8%	1 8%	0 0%	0 0%	12
Adequate time allotted	5 42%	4 33%	2 17%	1 8%	0 0%	12
Objectives were met	9 75%	2 17%	1 8%	0 0%	0 0%	12
<b>2. Dissemination: Spreading the message about CUE</b>						
<b>A. Quality of session</b>						
Informative content	7 50%	7 50%	0 0%	0 0%	0 0%	14
Adequate time allotted	5 36%	5 36%	3 21%	0 0%	1 7%	14
Objectives were met	6 43%	6 43%	2 14%	0 0%	0 0%	14
<b>3. CUE and the Cochrane Collaboration</b>						
<b>A. Quality of session</b>						
Informative content	9 64%	4 29%	1 7%	0 0%	0 0%	14
Adequate time allotted	6 43%	4 29%	4 29%	0 0%	0 0%	14
Objectives were met	8 57%	4 29%	2 14%	0 0%	0 0%	14
<b>4. Open Forum: looking ahead</b>						
<b>A. Quality of session</b>						
Informative content	10 71%	3 21%	1 7%	0 0%	0 0%	14
Adequate time allotted	7 50%	3 21%	3 21%	0 0%	1 7%	14
Objectives were met	8 53%	5 33%	1 7%	0 0%	1 7%	15

<b>Overall Evaluation for the 2007 Annual CUE Meeting (Circle one):</b>				
<b>1. The Program was Presented without evident commercial bias or influence.</b>				
	NO	YES	NOT CERTAIN	
	1	13		14
	7%	93%	0%	
<b>2. The Program Met My Expectations.</b>				
	NO	YES	NOT CERTAIN	
		13	1	14
	0%	93%	7%	

**Additional Comments:**

**1. Panel: How CUE members have incorporated EBHC into their work**

Really like the variety of examples  
Not enough time

**2. Dissemination: Spreading the message about CUE**

Needed more time

**4. Open Forum: looking ahead**

Perfect, exactly what I needed

**5. Overall**

Must recruit Latina/Native American/Asian Participants  
Good working meeting  
Great meeting, just need more time for discussion.  
Thanks, CUE has come so far, congrats  
I look forward to helping promote CUE when I get home, thanks to all  
Well run, well put together  
This was our best meeting so far!!