Report

Consumers United for Evidence-based Healthcare (CUE)

July 23, 2008 Annual CUE Membership Meeting

U. S. Cochrane Center

23 July 2008

Nitze Building
1740 Massachusetts Ave., N.W.
Washington, D.C.

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1. **Overview**

   This report summarizes the 2008 Annual Membership Meeting for Consumers United for Evidence-Based Healthcare (CUE), hosted by the US Cochrane Center (USCC). A planning committee (see Appendix B, Planning Committee) was appointed to set meeting goals and objectives. The meeting objectives were to bring together CUE’s leadership and membership to discuss programmatic and administrative matters relevant to the membership and the Coalition as a whole, and to learn about topical issues related to evidence-based healthcare (EBHC). Members heard presentations from outside individuals and groups working on problems related to the CUE mission, namely, a journalist-author writing about “over treatment”; a representative from the Institute of Medicine’s (IOM) Communications Collaborative, associated with the Roundtable on Evidence-based Medicine; the Director of ClinicalTrials.gov; legislative staff associated with a congressional initiative related to comparative effectiveness; and the Director of the South Asian Cochrane Network, from Vellore, India (see Appendix C, Speakers). In addition, a panel of selected CUE members shared their organizations’ experiences with EBHC and how they have interacted with the Cochrane Collaboration.

   Continuing challenges include finding ways to increase awareness of CUE in the consumer and health professional communities, increase awareness and use of EBHC, and obtain financial support to continue the growth and development of the work of CUE in the United States.

2. **CUE membership meeting agenda** (see Appendix A, Conference Program)

2.1 **Introduction of CUE member organizations - Sallie Bernard**, Co-Chair CUE Steering Committee

   The meeting began with introductions of CUE members and USCC staff. Using two PowerPoint slides per organization (see Appendix D, CUE Organizations’ PowerPoint Presentations), each representative briefly summarized his/her organization’s mission, constituency, and ways in which it uses EBHC. CUE Steering Committee Co-Chair Sallie Bernard made comments on behalf of organizations not represented at the meeting. In addition to CUE members’ presentations, guest Mayri Sagady-Leslie spoke briefly about her organization, the Coalition for Improving Maternity Services.

2.2 **CUE annual report - Barbara Warren**, Co-chair CUE Steering Committee

2.2.1 **A call to action**

   CUE Steering Committee Co-chair Barbara Warren welcomed the attendees. She summarized CUE’s major accomplishments since the 2007 annual meeting (see Appendix E,
CUE Accomplishments 2007 - 08). She challenged the group to consider how CUE could best engage consumer advocates in the important work to be done over the next year or two, given limited resources.

Warren outlined the success to date of the CUE online consumer course: *Understanding Evidence-Based Healthcare (EBHC): A Foundation for Action*. She noted that the 6-module online course was launched September 15, 2007. At 10 months since launch, approximately 1,000 people have enrolled in the course. It was noted that one goal is to have a better feedback mechanism for the course, so CUE could get information on enrolles and how they apply what they have learned in their work. Warren noted that groups beyond consumers (nurses, physicians, etc.) have expressed interest in the course and in the possibility of earning professional continuing education credit. She also noted the need for greater outreach about the course to increase dissemination.

Warren reviewed dissemination activities, including the CUE Advocacy Summit: Understanding EBHC: A Foundation for Action held July 17, 2007. She reported that at the 2007 Cochrane Colloquium in São Paulo, Brazil, she and Kay Dickersin (KD) and Janet Wale (representing the Cochrane Consumer Network or CCNet) presented a workshop “Developing a Local Coalition of Consumer Advocates”. She also noted that she and KD made a roundtable presentation about the online course at the American Public Health Association Annual Meeting, Washington, D.C., November 2007. It was also noted that CUE Steering Committee member Maureen Corry would join KD in discussing the Cochrane Collaboration and EBHC as part of the National Healthcare Policy Forum (Congressional Briefing) session, July 25, 2008.

The CUE video, created by Barbara Warren, was shown and much appreciation was expressed to Barbara Warren and Rich Davis for their excellent and important contribution to CUE.

Warren concluded with an appeal to all to help identify funding support to enable CUE to continue and expand its work.

2.3 Current hot issues and developments in EBHC

2.3.1 How failure to practice EBHC makes us sicker - Shannon Brownlee, Schwartz Senior Fellow, New America Foundation and author of *Overtreated: Why Too Much Medicine is Making Americans Sicker and Poorer*

Ms. Brownlee began by talking about geographic variation in the frequency of medical tests and surgical procedures. Using Medicare claims data in the 1970s, investigators identified geographical variations for several procedures in Vermont and Maine. Further investigation
revealed there was little evidence to inform physicians’ judgments, and that often procedures were done with the potential for little or no patient benefit and for actual harm to the patient.

Ms. Brownlee identified “informed” patient choice as a major patient rights issue. She cited data that suggest patients, when fully informed of the risks/trade-offs of health procedures/medications, tend to make choices that are more conservative than their physicians’ recommendations. This suggests patients may be consenting to treatments that, given full information, they might have declined. Ms. Brownlee illustrated this point by citing the tradeoffs between mastectomy versus lumpectomy for women with breast cancer. This illustration resonated with many of the meeting attendees who commented that women are generally not fully informed about the benefits versus harms of these alternative treatments.

A lively discussion period followed. Ms. Brownlee responded to the question: Do you see a change in the “more is better” attitude, as far as the delivery of medical care goes? She noted that as baby boomers make health care decisions for aging parents they are seeing first-hand that more is not always better, especially in end of life care. She noted that consumers often believe that more tests and procedures than necessary are ordered, to increase physician revenue.

A point was made that there is a fine line between advocating for consumers’ rights and totally destroying patients’ trust in their healthcare providers. Consumer Reports held focus groups in which participants identified other people’s physicians as the problem; not their own physician. This illustrated that people may not understand the inherent potential harms associated with health care and that informed patient choice is needed. The importance of EBHC and tools to find reliable evidence should be incorporated into medical education.

A question was asked regarding how to change existing medical practices when the evidence clearly indicates these practices are not optimal (eg, increased use of Caesarean section and the associated premature birth/respiratory problems). Ms. Brownlee said that she would continue to write about these issues. She noted that CUE has an important role to play in disseminating this information to consumers.

Challenges associated with the pharmaceutical industry were outlined, including the stance on comparative effectiveness.

2.3.2 Legislation on a new institute for comparative effectiveness – Kavita Patel, Deputy Director, Health Subcommittee of Senator Edward M. Kennedy

Dr. Patel explained that while comparative effectiveness is becoming the new buzz phrase on Capitol Hill, it is a concept that goes back to the Clinton Administration’s work on health care. She categorized those on Capitol Hill into one of three categories: either they support
comparative effectiveness because they believe it will contain costs; they are against it because it is an attempt to establish “cookbook medicine” that will take decision-making on behalf of a patient’s best interest out of the hands of physicians; or they are agnostic and don’t understand comparative effectiveness.

She noted there is a drive for legislation that will establish a new institute for clinical effectiveness, which will mean more systematic reviews and randomized clinical trials (RCTs) to build the evidence-base for healthcare services. At this point in time, no one knows whether there will be a new federal agency, or in what existing agency the institute may be placed. Senator Kennedy’s office is working on language to ensure that any institute will go beyond comparing Drug A to Drug B, and will set priorities for effectiveness research. Kennedy wants to ensure funding for research innovation (such as health services research) and dissemination of findings to both healthcare providers and consumers. The consumer voice in policy development will be essential, as it will build political will across jurisdictions. She asked: Will holding spots for consumers on committees be the best way to ensure consumer representation? Kennedy’s office is open to ideas on strategies to include consumers in policy decisions.

Senators Baucus and Conrad have proposed that the comparative effectiveness institute would be a public-private entity. PhARMA’s is concerned that this institute would dictate payment decisions and is lobbying against cost-effectiveness as a component of comparative effectiveness. Conversely, the insurance industry views comparative effectiveness as a means to reduce their costs. Patel asked: How do we ensure consumer voices are heard along with corporate interests?

A discussion period followed. A CUE member suggested that consumer groups prepare the “patient education” materials that are distributed by health agencies. A point was made that any legislation should include RCTs and systematic reviews on interventions beyond drugs, biologics, and devices. For example, procedures such as preventive care, surgery or radiation, behavior change, systems change, physical therapy, screening, and other interventions are important both in terms of costs and existing health concerns. CUE members further recommended including legislative language creating a funding stream to allow meaningful contributions from consumer organizations such as CUE.

Dr. Patel was asked about policies such as the Medicare Modernization Act that forbid use of comparative effectiveness in Medicare/Medicaid reimbursement decision-making and about the Drug Effectiveness Review Project (DERP). She answered that drug comparisons are easier to address than questions about best practices. State Medicaid Agencies are able to use DERP’s systematic reviews in local decision-making in part because they do not address issues of cost in their reports.
The last question was: Is there any hope for a legislative effort that would restrict the pharmaceutical industry’s funding of medical education? Patel noted that work is underway on The Sunshine Act, which addresses transparency in medical education and medical research funding. State-level legislation is also beginning to address this issue.

2.3.3 IOM Roundtable on Evidence-Based Medicine’s Communication Collaborative -
Gail Shearer, Director Health Policy Analysis, Consumers Union & CUE Member

Gail Shearer began by noting there is much confusion about the meaning of comparative effectiveness research and evidence-based medicine. Such confusion plays into hands of opponents of comparative effectiveness/evidence-based medicine, who paint it as an insurance industry-led movement aiming to ration medical care. Educating the public about comparative effectiveness requires carefully constructed messages that connect with consumers and the general public. She noted that the healthcare reform disaster of the ‘90s speaks to how essential effective communications will be in gaining public support.

Shearer explained that the IOM Roundtable has a shared vision of a healthcare system that draws on best evidence to provide care most appropriate to each patient. The IOM Roundtable participants represent diverse interests, including representatives of academic research, industry, and government, all sharing the common goal of increasing evidence-based practice. Their goal is that by 2020, 90% of medical decisions will be supported by evidence. The Roundtable’s Learning Healthcare System series of reports is an excellent resource supporting the benefits of incorporating evidence based medicine into healthcare practice.

She noted that Jim Guest, President of Consumers Union, is Chair of the IOM Evidence-based Medicine Roundtable’s Communication Collaborative, and the Working Group Chair is Kristin Carman of the American Institutes for Research. The Collaborative is focused on three key strategies to advance the case for EBHC: advance communications, facilitate public engagement, and develop platforms. Overall, their goal is to develop language that will be appropriate for discussing concepts of EBHC with the lay public.

Key questions raised by the Communications Collaborative regarding a new institute for comparative effectiveness include: What will the organizational structure look like? How will the organization be able to engage stakeholders while still avoiding conflicts of interest? Will cost effectiveness be addressed? How will it succeed when so many earlier efforts failed? How will an institute be funded?

In the discussion period, CUE members voiced concern about the lack of “true” consumer voices on IOM and other review panels. The common practice of designating a member’s spouse
or a scientist who has breast cancer as consumers was mentioned. Ms. Shearer noted that the inclusion of stakeholders takes time. She explained that the IOM tends to engage the medical community; through its work with the Communication Collaborative it is trying to engage the public. The Communication Collaborative is addressing effective communication, not policy.

2.3.4 Expansion of ClinicalTrials.gov to include information on clinical trial results - Deborah A. Zarin, Director, ClinicalTrials.gov, Lister National Center for Biomedical Communications, National Library of Medicine

Dr. Zarin presented updates to ClinicalTrials.gov. Currently, 59,000 studies are in the database, of which 15% are observational, 50% are US-based, and 30% are industry supported. The FDAAA 801 (Food and Drug Administration Amendments Act) requiring basic result reporting, enacted Sept 27, 2007, expands the existing legislation to require that Phase II – IV and medical and device trials with at least one US site must register the trial and information on key protocol items. The expansion applies to trials of drugs, biologics, and devices approved for marketing in the U.S and completed on or after Sept 27, 2007. The results reporting component of clinicaltrials.gov must be up and running by Sept 27, 2008, and will be available at http://prsinfo.clinicaltrials.gov/. CUE members recommended that the public have access to full protocols for all clinical trials, not just the types of trial and key data items outlined in the legislation. As of Sept 27, 2009 adverse events reports will be required. The legislation also requires serious and frequent adverse event reporting. Results will be due within 12 months of completion of primary outcome data collection, with penalties associated with non-compliance. Dr. Zarin provided meeting attendees with a tour of the ClinicalTrials.gov website and mockups of proposed results tables. Public comments are welcomed.

During the discussion period, Dr. Zarin responded to the question: Is there a way for consumers to determine if a sponsor is failing to report a primary outcome? Zarin noted that the system has a tracking method to determine if outcome measures have changed since trial registration. In response to another question she noted that there is no way to know what proportion of clinical trials will be captured in this database, since there is currently no way to know about all initiated trials for certain.

Dr. Zarin confirmed that the results database is intended for those who know how to read the medical literature. The mock up is currently available and anyone can sign up for updates to the site.

2.4 Getting the most from The Cochrane Library: Demonstration - Kay Dickersin, Director, U.S. Cochrane Center

Kay Dickersin demonstrated how to navigate within The Cochrane Library.
2.5 **Campaign for national license to *The Cochrane Library*: Experience in India - Prathap Tharyan, Director South Asian Cochrane Network**

The South Asian Cochrane Network (SCAN) is the newest Cochrane Center. SCAN seeks to increase awareness of *The Cochrane Library*, train people in the region to conduct systematic reviews, increase the use of evidence in medicine in South Asia, increase the demand for high quality research, and create a sustainable network to continue SCAN. SCAN’s mission includes preparing quality systematic reviews that will assist people in making well informed healthcare decisions.

With these goals in mind, Dr. Tharyan negotiated with Wiley publishers to offer India an initial national subscription to *The Cochrane Library*, free of charge in 2006-2007, to create demand among users. Use of *The Cochrane Library* in India went up 700%, primarily from full text downloads. This large increase in demand was used as leverage to obtain funding for a national license.

Dr. Tharyan presented an example of how nationwide awareness of the results of a systematic review on primaquine led to a change in India’s national malaria-prevention policy. He noted that India is now anxiously awaiting the development of a national clinical trials registry.

2.6 **Panel discussion. CUE members’ experience in dissemination and incorporating evidence into advocacy**

2.6.1 **Requiring CUE’s online course as a prerequisite for quality care Project LEAD - Annette Bar-Cohen, National Breast Cancer Coalition (NBCC)**

Ms. Bar Cohen stated that evidence is the foundation for NBCC’s work and helps inform its policies and responses to breaking health news, public queries, and setting legislative priorities.

She explained that Project LEAD provides basic science training to consumer advocates, including training in research design, epidemiology, clinical medicine, and advocacy skills. Since 1995, the program has graduated more than 1,300 participants. Participants must first complete the CUE online course to be admitted to Quality Care Project LEAD, a more training program focusing on health systems change.

Ms. Bar-Cohen discussed the NBCC’s Quality Care Initiative, which aims to increase access to and improve the quality of breast cancer care for everyone. The initiative is guided by NBCC's patient-centered, evidence-based vision of quality care, which includes six overlapping core values: access, information, choice, respect, accountability and improvement. To implement
these core values, NBCC is educating breast cancer patients, advocates, and the public at large, working to influence health care providers to embrace and implement NBCC’s vision of quality care, and influencing policymakers to create a national health care system that reflects NBCC’s vision and establish other policies that nurture and protect quality breast cancer care.

2.6.2 Evidence-based complementary and alternative cancer therapies - Ann Fonfa, Annie Appleseed Project

Ms. Fonfa spoke about the first evidence-based complementary and alternative medicine for cancer conference held in January 2008, and sponsored by Annie Appleseed. She reported there were 165 attendees, more than 20 speakers and over 16 exhibitors. Meeting results, speakers’ bios and agenda are available at the Annie Appleseed Project’s website (http://www.annieappleseedproject.org/evcamforadc.html).

2.7 CUE projects: updates & future directions

2.7.1 Campaign for national license to The Cochrane Library in the US - Prathap Tharyan, Director, South Asian Cochrane Network; Kay Dickersin, Director, U.S. Cochrane Center

Dr. Dickersin asked whether the US Cochrane Center should sponsor a petition for a national license to The Cochrane Library. Currently, Canada and the EU have web-based petitions for national licenses. She noted that the US has the largest number of people accessing The Cochrane Library, and the second largest number of individuals contributing to systematic reviews, yet we have no national license.

From experience at US-sponsored workshops, it appears that most medical institutions and the National Institutes of Health already have access to The Cochrane Library. However, it’s difficult to know the accessibility of Cochrane full-text reviews for certain, since Ovid bundles Cochrane with its other offerings. Most practicing doctors don’t have ties to medical libraries, although they may be able to get access through medical societies. It was noted that the plain language summary and review abstracts are probably most helpful to practicing physicians, and these are available free online. The state of Wyoming provides free access to The Cochrane Library to all of its residents. Initially, Representative (Charlie) Scott and librarians were alerted to the importance of systematic reviews and The Cochrane Library through an initiative for policy makers, funded by the Milbank Memorial Fund, and including educational opportunities through the Rocky Mountain Workshop on Evidence-based Healthcare. The small population of Wyoming made the subscription cost, which is calculated on a per person rate, comparatively low. NCI is making access to The Library available to all members of CancerPlanet.
It was noted that at $0.10 per person, the annual subscription cost for a U.S. national license would be $3.5 million per annum.

Members requested more information about current use of *The Cochrane Library* in the US, to determine demand. A free trial period of access was also suggested as a way to create interest among consumers and other decision makers. A key question was, who would utilize full access to systematic reviews the most, and how would we “sell” this need to Congress in order to secure funding? A member raised questions as to whether the “average” American would be able to navigate and understand the information in *The Library*. Would access to the full text be of practical added value to the abstracts and plain language summaries currently available for free to the general public? It might not be necessary to make the case that the average person on the street would use it, but perhaps making the case for expanded access for consumer organizations would be justification enough for a national license. Additional plain language summaries are needed, regardless, for decision makers of all types (The Evidence Informed Policy Network was mentioned for comparison.)

Other suggestions included advocating for librarian access to *The Cochrane Library*, which might be well-received in Congress. Public libraries were mentioned as an untapped resource that could be an access point for a national subscription.

### 2.8 Open forum. Looking ahead: Goals for upcoming year

The primary CUE goals for the upcoming year are to secure funding for infrastructure support and to expand membership and the reach of CUE. Current funding expires September 2008. The need to maintain CUE’s membership criteria that limit industry funding of applicant organizations was emphasized. A member noted that the website Guidestar.com is a good source to view funding sources of consumer groups.

KD reported that she is working on resubmission of a large conference grant to Agency for Healthcare Research and Quality (AHRQ), due to the Agency on August 12, 2008. She noted the application’s proposal regarding proposed CUE meetings. To take advantage of the 2010 Cochrane Colloquium being in Keystone, Colorado, a major CUE conference is proposed to precede the Colloquium. Smaller membership meetings in Washington D.C. are proposed for 2009 and 2011. She thanked CUE members for their excellent letters of support, which effectively outlined CUE’s dissemination and outreach activities.

KD has received numerous requests for recommendations of CUE advocates to serve on advisory committees. She asked whether the CUE membership was interested in the USCC and CUE serving as a clearinghouse for scientists/policy makers looking for informed consumer advocate representatives. There was cautious support for the activity, with CUE members
expressing concern that recommended advocates should have completed the online training course and be knowledgeable about evidence-based healthcare.

2.9 **Summary of CUE member evaluations**

Twenty-one organizational representatives registered and 18 attended the 2008 CUE Membership Meeting, coordinated by the USCC and sponsored by the AHRQ. Participants were asked to complete a detailed evaluation form (see Appendix F, Evaluation Survey Instrument).

The evaluation scores and comments indicate that respondents were positive (scoring excellent or very good) about the meeting’s presenters, content, and organization. Twelve respondents returned the evaluation, although not all questions were answered by all respondents. Of the 12 respondents who answered the question, 100% (12/12) noted the CUE Meeting met their expectations. Suggestions primarily focused on improving time management of the meeting and allocating more time for discussion.

The survey instrument consisted of questions measured on a five-point Likert scale (excellent was scored as 5 and poor was scored as 1) on quality of the sessions and quality of the presentations by speaker. Open-ended comments were also solicited.
Appendix A

Program Agenda
Consumers United for Evidence-based Healthcare (CUE)
2008 Annual Membership Meeting
July 23, 2008
Washington, D.C.
Johns Hopkins University School of Advanced International Studies

7:30 am - 8:30 am  Registration and continental breakfast

8:30 am - 8:45 am  Welcoming remarks  Janie Gordon, Kay Dickersin, Barbara Warren, Sallie Bernard

8:45 am - 9:15 am  Introduction of new and current member organizations  Sallie Bernard

We ask all members to introduce themselves and their organization’s mission and evidence-based healthcare (EBHC) focus.

9:15 am - 9:45 am  CUE 2007 Report  Barbara Warren
Accomplishments for the year including demonstrations of three new videos
Challenges ahead!

9:45 am - 10:00 am  Discussion and feedback from group

10:00 am - 10:15 am  Break

10:15 am - 11:30 am  Current hot issues and developments in EBHC

How failure to practice EBHC makes us sicker and poorer  Shannon Brownlee, Schwartz Senior Fellow, New America Foundation and author of Overtreated: Why Too Much Medicine is Making Americans Sicker and Poorer

Legislation on a new Institute for Comparative Effectiveness  Kavita Patel, Deputy Director, Health Subcommittee of Senator Edward M. Kennedy
IOM Roundtable on Evidence-Based Medicine’s Communications Collaborative  Gail Shearer, Director Health Policy Analysis, Consumers Union & CUE Member

Expansion of ClinicalTrials.gov to include information on clinical trial results  Deborah A. Zarin, Director ClinicalTrials.gov, Lister National Center for Biomedical Communications, National Library of Medicine

11:30 am - 11:45 am  Discussion

11:45 am - 12:30 pm  Getting the most from The Cochrane Library: Demonstration  Kay Dickersin

12:30 pm - 1:15 pm  Lunch and Speaker

Campaign for National License to The Cochrane Library: Experience in India  Prathap Tharyan, Director South Asian Cochrane Network

1:15 pm - 2:15 pm  Panel Discussion: CUE members’ experience in dissemination and incorporating evidence into advocacy

Requiring CUE’s online course as a prerequisite for Quality Care: Project LEAD  Annette Bar-Cohen, National Breast Cancer Coalition

Evidence-based Complementary and Alternative Cancer Therapies  Ann Fonfa, Annie Appleseed Project

2:15 pm - 2:30 pm  Break

2:30 pm - 3:30 pm  CUE projects: updates & future directions

Campaign for National License to The Cochrane Library in the U.S. Prathap Tharyan, Director, South Asian Cochrane Network and Kay Dickersin, Director, U.S. Cochrane Center
CUE Annual Membership Meeting, 23 July 2008 (cont’d)

CUE online course update; Dissemination of ebhc; educating ourselves educating others Kay Dickersin, Director, U.S. Cochrane Center

3:30 pm - 4:15 pm Open Forum Looking Ahead: Goals for upcoming year

4:15 pm - 4:30 pm Wrap Up and Adjourn
Appendix B

Planning Committee Members
Consumers United for Evidence-based Healthcare (CUE)
2008 Annual Membership Meeting
July 23, 2007
Washington, DC

Sallie Bernard
Rebecca Burkholder
Maureen Corry
Kay Dickersin
Janie Gordon
Ngina Lythcott
Jennifer Sweeney
Barbra Warren
Kiki Zeldes
### Appendix C

#### Speaker List

Consumers United for Evidence-based Healthcare (CUE)

2008 Annual Membership Meeting

July 23, 2007

Washington, DC

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Appendix D
CUE Organizations' Powerpoint Presentations

Consumers United for Evidence-based Healthcare

CUE Member-O rganizations

- 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
- Medtrix 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 M inds
- 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.

Constituency:
- Those with cancer questions and access to the Internet
- Just under 2 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 advocate for studies on natural substances but are often told since they cannot be patented, they are not researched. This is changing.


Black Women’s Health Imperative

Mission:

Founded in 1983, Black Women’s Health Imperative (Imperative) promotes optimum health for Black women across the life span—physically, mentally and spiritually.

Constituency:

Broad-based constituency of 19.5 million Black women and girls and other women of color living in the U.S.

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 community-based organizations.
- We offer Black women culturally appropriate tools and information to be informed and empowered healthcare consumers.
Center for Medical Consumers

Mission:
To help people look for and understand the research supporting their doctor's treatment recommendations.

Our advocacy work in Albany and Washington centers on the reduction of hospital-acquired infections and medical errors and improving the FDA's drug safety and drug promotion standards.

Center for Medical Consumers
Constituency:
- Our monthly articles provide a critical appraisal of the latest studies. We concentrate on medical interventions aimed at healthy people (e.g., screening tests, drugs for bone loss);
- Our articles appear in the country's largest electronic information services (Gale Group, EBSCO, Lexis/Nexis, ProQuest) that are used by private and public libraries;
- Our Web site gets about 40,000 visits a month;

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

Mission Statement:

- We are a world-wide nonprofit organization working to improve the communication skills, education, and advocacy of the verbal disabled, all those with speech and language delays or impairments. Our area of emphasis is verbal apraxia, a severe, neurologically-based communication disorder that used to be rare in children but has been on the rise within the past two decades.
- We are committed to assisting with the development of new therapeutic approaches, preventions and cures to neurologically-based speech disorders that affect all ages with a focus on children.
- We bring together families, affected individuals, and medical, research, speech, and educational professionals.

CHERAB Foundation

Evidence-based healthcare applications:

1. We educate the rights of the verbal disabled to families, affected individuals, schools, policy makers and the public.
2. We currently are seeking research funds through various sources to validate our group’s anecdotal findings for fish oil and vitamin E as a treatment for apraxia and other communication impairments.
3. As a grassroots organization we work with other organizations to raise awareness about various communication impairments and their impact on the individual and society when not addressed or when misdiagnosed.
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 childbirth 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.
**Consumer Reports**

- Consumers Union, the publisher of *Consumer Reports,* is a powerful consumer organization and social change agent.
- CU has a long history of giving people the expert, unbiased facts they need to make informed decisions in the consumer marketplace.
- Our mission since 1936 ... An expert, independent, nonprofit organization, whose mission is to work for a fair, just, and safe marketplace for all consumers.
- What we do: test, inform and protect.

---

**Our Health-Care Mission**

- To build on CU’s unique strengths and trusted reputation to help consumers make better-informed health-care decisions and influence health-care reform.
- We believe that through a combination of evidence-based information and community action, we can make high-quality, safe and affordable healthcare a reality for many more Americans.
- Because *Consumer Reports* is without commercial agendas or advertiser influence, we are in a unique position to provide this information.
- Our areas of focus over the next 3 years are Health-Care Reform, Patient Safety, Evidence-based Medicine, Provider Ratings, Doctor-Patient Relationships, and Healthy Living Guidance.
Consumer Reports Health

- Our goal is to become the source that more consumers turn to first when making health-care decisions, because our information is evidence-based, relevant, and transparent.
- In June 2008, we launched a new consumer health website ConsumerReportsHealth.org as the platform for our work.
- In June 2008, we also announced the Consumer Reports Health Ratings Center, led by Dr. John Santa, to develop unique research and ratings to guide consumers.
- In July 2008, we began the next phase of Consumer Reports Best Buy Drugs, supported by a major new AG grant.
- We have developed a community of citizen-advocates who work with us to achieve reform in the healthcare arena.
- With them we can increase CU's impact with policy makers, ultimately securing passage of laws & regulations that provide needed consumer protections.

Faces & 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 & 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.
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
  - Critical for clinical trials, industry, research partnerships
- Legislative Agenda
  - Basis for support or lack of support for legislation
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 ensuring 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:

- Our mission is to protect and promote economic justice for consumers and workers in the U.S. and abroad. Represent consumers on marketplace & workplace issues.
- Founded in 1899, NCL is the oldest consumer organization in the U.S.
National Consumers League
Health Policy

- Carried out through: education projects, general advocacy, forums
- Focus on:
  - Safe use of medications – SOS Rx, medication reconciliation, adherence, OTCs, communication, DTC
  - Quality of health care
  - National health reform/coverage

National Environmental Education Foundation

Mission:

The National Environmental Education Foundation is a private, non-profit organization committed to advancing environmental knowledge among health professionals in order to improve health care and public health, with a special emphasis on protecting children and other populations disproportionately impacted by environmental pollutants. Through the development of national agendas, trainings, curriculum integration, and strategic partnerships, NEFF facilitates the integration of environmental health into health care provider education and practice.
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-based healthcare information in developing all our tools, resources and trainings.

National Partnership for Women & Families

Mission Statement:
- Founded in 1971 as the Women's Legal Defence Fund, the National Partnership for Women & Families is a leader on issues that affect women and families—issues like increasing access to quality, affordable healthcare, ensuring equal opportunity and fair treatment in the workplace; and helping Americans balance their work and family responsibilities.
Americans for Quality Health Care: a Project of the National Partnership for Women & 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.

National Vaccine Information Center

Mission Statement:
- Oldest and largest consumer organization advocating the institution of vaccine safety and informed consent protections in the mass vaccination system
- We have been dedicated to the prevention of vaccine injuries and deaths through public education and defending the informed consent ethic since 1982.
National Vaccine Information Center

Evidence-based healthcare applications:

- Independent clearinghouse for information on diseases and vaccines, NVIC does not promote the use of vaccines and does not advise against the use of vaccines. We support the availability of all preventive health care options, including vaccination, and the right of consumers to make educated, voluntary health care choices.

- NVIC has provided information about diseases and vaccines to hundreds of thousands of parents, health care providers and other individuals who have contacted our organization during the past three decades.

National Women's Health Network

Mission Statement:

- Founded in 1975 to give women a greater voice within the healthcare system
- Our mission is to improve the health of all women by developing and promoting a critical analysis of health issues in order to affect policy and support consumer decision-making.
National Women's Health Network

Constituency:
NWHN is a membership-based organization supported by thousands of individuals and organizations nationwide.

Evidence-based healthcare applications:
- Factsheets, position papers, outside resources, and a newsletter to support individual decision-making by providing evidence-based information.
- Menopause & Aging Program is working to promote women's access to accurate health information from sources free from financial conflicts of interest, as well as products, services & resources that are backed up by solid evidence showing effectiveness for use during mid-life & late-life.

Our Bodies Ourselves

Our Bodies Ourselves (OBOS), also known as the Boston Women’s Health Book Collective, is best known for the publications Our Bodies, Ourselves and Nuestras Cuerpos, Nuestras Vidas.

Mission:
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.
Constituency:
- Women’s health groups, community-based groups, community health centers, hospitals, women’s studies programs, women’s resource centers in college campuses
- Women around the world through the OBOS Global Network
- Individuals who read our books and visit our website

Evidence-based health care applications:
- *Latina Health Initiative* – In addition to *Nuestra Cuerpos Nuestra Vida* (NCNV), the organization has produced *Promotoras de Salud*, a training guide for community health workers based on NCNV and *Journey to Parenthood*. *De Camino a La Maternidad* booklet about childbirth.
- *Global Translation/Adaptation Program* – A Russian edition of *Our Bodies, Ourselves* has just been published and Nepal, Russia, and Turkey are developing culturally adapted translations. Upcoming projects include adaptations for East Africa, India, 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 drug and doping.

Safe Minds

Mission:
- SafeMinds seeks to prevent and find effective treatments for the disabling conditions of autism spectrum disorder caused by early life exposures to manmade sources of mercury, the second most toxic substance on earth.
- Our mission is achieved through scientific research, public awareness, and advocacy in the public policy and legal arenas.
Safe Minds

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

Evidence-based healthcare applications:
- We advocate for 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:
- 24,000 in our network
- Constituents are breast 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 resource link coordinator questions and communicate with each other on our bulletin boards.
Appendix E
CUE Accomplishments 2007-08

Education and Training for Consumer Advocacy Groups

- As of November 15, 2007, enrollment is open to any interested individual and almost 1000 have enrolled in the course as of July 2008.

Dissemination

- **First Inaugural CUE Advocacy Summit**: "Understanding Evidence-based Healthcare: A Foundation for Action", held July 17, 2007, Washington DC and hosted by CUE and the USCC. One-hundred three people registered and 93 attended, coming from 15 states, the District of Columbia, and Canada.
- **Developing A Local Consumer Coalition Of Consumer Advocacy Groups**
  Kay Dickersin, Barbara Warren with Janet Wale (CCNet) International Cochrane Colloquium, São Paulo Brazil October, 2007
- **Access To Evidence-based Healthcare Information: Web-based Training For Consumers And Providers**
Healthcare Policy

On July 25, Maureen Corry will speak on behalf of CUE at the National Health Policy Forum’s session “Introduction to the Cochrane Collaboration and Fundamentals of Evidence-based Health”, the first in a series for Congressional staff on “Everything You Always Wanted to Know about Comparative Effectiveness but Were Afraid to Ask”.
Appendix F
Program Evaluation

Consumers United for Evidence-based Healthcare (CUE)
2008 Annual Membership Meeting
July 23, 2007
Washington, DC

Introduction of new and current member organizations

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CUE 2007 Report

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| Current hot issues and developments in EBHC |

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<td>Deborah A. Zarin</td>
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| Getting the most from The Cochrane Library: Demonstration |

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November 13, 2008   Page 42 of 45
Campaign for National License to *The Cochrane Library*: Experience in India

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Prathap Tharyan

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Panel Discussion: CUE members’ experience in dissemination and incorporating evidence into advocacy

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Annette Bar-Cohen

Requiring CUE’s online course as a prerequisite for Quality Care: Project LEAD

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Evidence-based Complementary and Alternative Cancer Therapies

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Barbara Warren

CCNet participation

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November 13, 2008 Page 43 of 45
CUE Annual Membership Meeting, 23 July 2008 (cont’d)

CUE projects: updates & future directions

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Campaign for National License to *The Cochrane Library* in the U.S.

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Kay Dickersin
Campaign for National License to *The Cochrane Library* in the U.S.

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Kay Dickersin
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Open Forum Looking Ahead: Goals for upcoming year

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### Overall Evaluation

1. The program was presented without evident commercial bias or influence.
   - ( )₀ No
   - ( )₁ Yes
   - ( )₂ Not Certain

2. The program met my expectations
   - ( )₀ No
   - ( )₁ Yes
   - ( )₂ Not Certain

3. Please provide comments or suggestions:

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