



## WBCC Produces Award-Winning Clinical Trials Book

WBCC recently worked in collaboration with the Wisconsin Cancer Council to produce a simple and easy to read patient's brochure about participation in clinical trials – *You've Just Been Diagnosed with Breast Cancer. Should You Consider a Clinical Trial?* Our clinical trials book *You've Just Been Diagnosed with Breast Cancer. Should You Consider a Clinical Trial?* received an award from the Wisconsin Cancer Council for outstanding service to its programs and mission. It was written by breast cancer survivors for the newly diagnosed, providing information about clinical trials from the patient's perspective. The book has been so popular that we're actively seeking donations for a second printing.

## Reports and Highlights from 2005 Era of Hope (Part 1)

by Kathleen Harris

### Background

The Department of Defense (DoD) Breast Cancer Research Program (BCRP) began as a result of the National Breast Cancer Coalition's (NBCC) 1992 campaign to dramatically increase federal funding targeted toward breast cancer research. Through the efforts of the hundreds of organizations that make up NBCC, this program created a partnership that unites military, scientific, medical, breast cancer survivor, and advocacy communities to develop and carry out research to end breast cancer. It is the Federal Government's only breast cancer research program that involves consumer advocates at both the scientific peer review and the programmatic review stages, and at all levels of a scientific meeting.

Those panels have benefited from the voices (and votes) of 399 consumers who come from 255 organizations, providing an incredible reach into the world of breast cancer nationwide. This year Wisconsin was represented by five WBCC members selected to participate on the peer review panels.

### The Era of Hope Meeting

At the Era of Hope meeting that occurs every two or three years, all research funded by the program in certain years is presented to the public. The Era of Hope program is designed by scientists and consumers, who review reports of funded research and choose themes and presentations. This year's themes : Risk and Prevention; Who Needs Treatment; and Focus on Treatment and Clinical Trials.

### Advocate Involvement in Era of Hope

Consumer advocates – including five WBCC members – were well represented at the meeting. There may be no other forum in the scientific community where such a diversity of scientific disciplines – basic scientists, clinicians, epidemiologists, nano-technologists, mathematicians, physicists, and more – come together on an equal footing with consumers to look at the complexity of breast cancer research, challenge each other, explore controversial issues, and learn and plan together.

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## President's Letter

Happy Holidays to all of you. As we come to the close of another year and reflect on the news and events, joys and tragedies, accomplishments and disappointments, I think – not only have we made it through another year, but 2005 brought us great successes. Many are highlighted in this issue of *Collective Voice*.

For instance, four of our members attended the fourth Era of Hope meeting for the Department of Defense (DoD) Breast Cancer Research Program (BCRP) in Philadelphia, Penn., where they heard about the multidisciplinary and innovative approaches funded by the DoD BCRP in its efforts to eradicate breast cancer.

We saw the fruits of our past successes when we learned early this fall that Wisconsin Act 176 will finance approximately \$320,000 in breast cancer research being conducted right here in Wisconsin. We lobbied actively for passage of this legislation, which establishes the Wisconsin Breast Cancer Research Fund. This is the first year of the program, which we continue to support and promote.

We were instrumental in conceiving and bringing to being the Cancer Patient Protection bill, which requires insurance companies to cover routine care costs of people who are participating in clinical trials. It has already passed in the Wisconsin State Senate and will soon be coming up for a vote in the Assembly.

Our clinical trials book, *You've Just Been Diagnosed with Breast Cancer. Should You Consider a Clinical Trial?* received an award from the Wisconsin Cancer Council.

We are officially **Beyond the pink ribbon.™** You may have noticed we've changed our look. At this year's Rare Chair Affair, we unveiled a new WBCC logo – a pink "X" with Wisconsin Breast Cancer Coalition spelled out across it. This new logo more clearly represents our purpose and mission. We've also trademarked our long-used tag line "Beyond the Pink Ribbon," which is the "action" that WBCC is all about. I'd like to extend our sincere gratitude to Chad Nauta and Bill Kresse of Laughlin/Constable advertising agency for donating their time and wonderful talents to help us with this new look.

So 2005 may not have brought us a cure for breast cancer. But I choose to think of this year as full of great success, most importantly it brought us one more year closer to our goal: a world without breast cancer.

*I wish you all good health in the New Year.*

*Ellen Vander Heyden*  
 WBCC President

P.S. You can purchase a t-shirt with the new WBCC logo for only \$10 – great for holiday gift ideas. If you become a WBCC member or renew your membership by January 31st, you will receive a t-shirt for free.

*Reports and Highlights continued from page 1*

Consumers played key roles in every aspect of the Era of Hope meeting:

- The 21 members of the Technical Planning Committee included 6 consumer representatives.
- The 276 consumers from 95 organizations registered for Era of Hope represented 1 in 6 conference attendees, unprecedented for scientific meetings where consumers are usually a rarity.
- Each platform session was co-chaired by a consumer and a scientist.
- A consumer spoke at every plenary session.
- A consumer moderated every plenary session.
- A total of 39 consumers from 35 organizations participated as co-chairs and plenary speakers.
- Consumers at every session challenged the status quo and conventional wisdom, and offered what in many cases was an eye-opening perspective to the researchers whose laboratory careers may be far removed from real world applications.

**Look for more on the Era of Hope in our next issue of *Collective Voice*.**

## Book Review

Lerner, B. H. (2001). Breast Cancer Wars: Hope, Fear and the Pursuit of a Cure in Twentieth-Century America. Oxford University Press.

In this riveting narrative, **Barron H. Lerner** offers a superb medical and cultural history of our century-long battle with breast cancer. Revisiting the past, Lerner argues, can illuminate and clarify the dilemmas confronted by women with – and at risk for – the disease.

Writing with insight and compassion, Lerner tells a compelling story of influential surgeons, anxious patients and committed activists. There are colorful portraits of the leading figures, including the acerbic **Dr. William Halsted**, who pioneered the disfiguring radical mastectomy at the turn of the century, **George Crile, Jr.**, the Cleveland surgeon who shocked the medical establishment by “going public” with his doubts about mastectomy, and **Rose Kushner**, a brash journalist who relentlessly educated American women about breast cancer.

Lerner offers a fascinating account of the breast cancer wars: the insistent efforts of physicians to vanquish the “enemy;” the fights waged by feminists and maverick doctors to combat a paternalistic legacy that discouraged decision-making by patients; and the struggles of statisticians and researchers to generate definitive data in the face of the great risks and uncertainties raised by the disease. As easy as it is to demonize male physicians, the persistence of the radical mastectomy and other invasive treatments has had as much to do with the complicated scientific understandings of breast cancer as with sexism.

Lerner’s account of the fight against breast cancer opens a window on American medical practice over the last century: the pursuit of dramatic cures with sophisticated technologies, the emergence of patients’ rights, the ethical and legal challenges raised by informed consent, and the limited ability of scientific knowledge to provide quick solutions for serious illnesses. A searching and profound work on an emotionally charged issue, ***The Breast Cancer Wars*** tells a story that remains of vital importance to modern breast cancer patients, their families and the clinicians who strive to treat and prevent this dreaded disease.

A practicing physician, Lerner teaches at Columbia University. Annotation (c) 2003 Book News, Inc., Portland, OR

## Complementary & Alternative Medicine

**Q:** *What is complementary and alternative medicine?*

**A:** Medical and health care practices outside the realm of conventional medicine.

Complementary: together with conventional practices

Alternative: in place of conventional practices

**Complementary Alternative Medicine (CAM)** is becoming increasingly popular in many medical situations, particularly among patients with cancer. The objectives of CAM treatments are numerous: the reduction of toxicities of therapy, improvement in cancer-related symptoms, enhancement of the immune system, and even a direct anticancer effect. Some types of CAM are based on ancient forms of medicine, founded on centuries of experience, documented through oral and written text. Nevertheless, current evidence in the clinical setting limits definitive conclusions about the effectiveness or safety of most CAM approaches in breast cancer.

### Common CAM practices

- Biologically Based Systems: diets, herbals, and vitamin supplements
- Manipulative & Body Base: massage, chiropractic, acupuncture, reflexology
- Mind-Body Medicine: yoga, prayer, and meditation
- Alternative Medical Systems: homeopathy, naturopathy
- Energy Therapies: Reiki, magnets, and Qi gong

### Why Do Patients Seek CAM?

- Relieve symptoms, improve prognosis
- Improve quality of life
- Prevent a recurrence
- Rebuild the immune system
- Cure the disease
- Ease the side effects of treatment
- Alternative to what doctors/conventional medicine offers
- Personal control
- Hope

An important note here: some supplements are dangerous. For this reason, you need to know what resources for CAM you can trust. Always inform your physician, oncologist, surgeon or other traditional medical professional what alternative medicines you are using as they may affect or even negate traditional treatments you are receiving.

## Project LEAD® : Leadership, Education and Advocacy Development

by Mary Pat Berry



Mary Pat Berry and Kathleen Harris promoting WBCC's statewide efforts at a recent Sharing the Knowledge conference in Madison.

Whether you are a survivor looking to make lemonade out of some of the lemons breast cancer can bring, a healthcare support person looking to expand your knowledge and gain new perspectives, or an advocate interested in deeper understanding of the science of breast cancer, you will find **Project LEAD®** an excellent experience. It was designed to help cancer activists influence the research and public policy process. Whatever your personal interest – individual advocacy, public policy development, or participating in research grant reviews, this consumer-friendly scientific training course gives you the language and skills to make a difference.

Project LEAD, an innovative training course, was developed by the National Breast Cancer Coalition (NBCC) to teach the basics of molecular biology, genetics, and epidemiology, as well as how to read and evaluate a research study. *No question, the prep work, lectures, and study group tasks are a challenge, but the course provides individual support and encourages group success.*

As a 2004 graduate of the program, I found that the course, taught by some of the country's top medical professionals in the field of breast cancer, provided information in a way that allowed a non-medical person to learn. The benefits are countless.

- I'm now a better reader of research articles
- I'm better able to interpret stories about breast cancer in the media.
- I can speak more clearly about breast cancer to medical professionals, researchers, policy makers, and even to my friends and family.
- I am more confident in my ability to effect change in the world of breast cancer.

Project LEAD is four-day program, held 3-4 times a year in various places around the country. There is an application process. The program is free, but participants must cover the cost of transportation and lodging. Scholarships are available from NBCC. Currently there are about 16 Wisconsin women and men who have benefited from this special training; We'd like to see that number grow. Upcoming Project LEAD dates are:

- March 22-26, 2006 Houston, TX, Application Deadline: January 22, 2006
- August 2-6, 2006 San Jose, CA – Quality Care, Application Deadline: June 2, 2006

Interested in finding out more? Visit the NBCC website: [www.stopbreastcancer.org](http://www.stopbreastcancer.org). If you'd like to speak to a graduate of the program, contact us at [wbcc@standupandspeakout.org](mailto:wbcc@standupandspeakout.org) or call 414-963-2103.

## Donate Your Old Office Equipment to WBCC

Have any old laptops, filing cabinets, or other office equipment lying around? The WBCC office needs these things to continue expanding our operations. We need:

- Laptops to use at our fundraisers or off-site meetings.
- Filing cabinets or other office storage cabinets.
- Trade show booth equipment, display boards, or brochure holders for use at health fairs and medical conferences.
- LCD projectors to use for educational presentations.

Please contact us at 414-963-2103 or [wbcc@standupandspeakout.org](mailto:wbcc@standupandspeakout.org).

### articles for the next issue

Authors of articles in this newsletter are not necessarily limited to WBCC members. We welcome information from individuals and organizations that are supportive of WBCC's efforts. If you have information you would like included in an upcoming issue, please contact WBCC at [wbcc@standupandspeakout.org](mailto:wbcc@standupandspeakout.org) or 414.963.2103.

## Cancer Patient Protection Bill Moves Forward

by Dawn Anderson, WBCC State Policy Chair

Throughout 2005, WBCC has been working together with over 20 other Wisconsin organizations to see legislation enacted that will prohibit health care plans from denying coverage for routine patient care in a cancer clinical trial setting. The resulting bill, introduced by **Representative Scott Gunderson**, **Senator Cathy Stepp**, and **Senator Carol Roessler** and received public hearings in the Senate Committee on Health and the Assembly Committee on Insurance. On November 8, the Senate approved the bill (SB 288). We are now waiting for the bill in the Assembly (AB 617) to be placed on the Assembly schedule.



WBCC Legislation Committee Meeting – L to R: Gerry Parenteau, Galina Tash, Marge Liss, Dawn Anderson, Bonnie Anderson, Kathleen Harris.

Recognizing the importance of clinical trials in bringing new research to the bedside, WBCC has spoken in support of this legislation. Most recently we spoke at press conference held in Madison announcing the bill. We also presented testimony during both committee hearings.

Often cancer clinical trials not only give patients the best chance for a response to treatment, but also they are the setting where the newest drugs and combinations of drugs are studied for future use. Unfortunately, barriers to participation in clinical trials result in less than 5 percent of adult cancer patients participating in clinical trials. Lack of insurance coverage for routine care costs is a significant barrier to many cancer patients who might otherwise enroll in a trial. Over 22 states currently have legislation or agreements with insurers to require coverage of these routine care costs for patients participating in cancer clinical trials.

Wisconsin is fortunate to have so many outstanding cancer research centers that are conducting clinical trials. If we do not work to remove barriers to patient participation in these trials, low accrual rates may impede the progress of good research. We believe this legislation will help advance the process of finding better diagnostic methods, treatments, and cures for cancer.

*Watch for more information on this bill as it moves to the Assembly for a vote.*

## 2003 Wisconsin Act 176: Breast Cancer Research Program

by Ellen Vander Heyden

WBCC was the driving force behind the passage of Wisconsin Assembly Bill 351, which called for creating a check-off box on Wisconsin state income tax forms to fund a breast cancer research program in Wisconsin. This legislation, now called **2003 Wisconsin Act 176**, has shown great promise in just its first year.

What does it mean to us? It's funding breast cancer research being conducted right here in Wisconsin! Wisconsin residents filing a state income tax form now have the opportunity to donate all or part of their refund to this fund. Money accumulated each year is distributed 50/50 between the Medical College of Wisconsin and the University of Wisconsin Comprehensive Cancer Center, to be used only for breast cancer research. The check-off box was first placed on 2004 Wisconsin income tax return forms and the first year results are very exciting – **\$319,170 was divided between the two institutions! Be sure to remember the Breast Cancer Research Fund when filling out your 2005 state income tax returns.**

*Wouldn't it be great if your donation helped fund research in Wisconsin that finds a cure for breast cancer?*

## WBCC Alert Network Sign-up

In just five minutes you can make a difference in the fight to end breast cancer!

Join the Wisconsin Breast Cancer Coalition's ALERT Network. It's fast, free, and simple.

Join hundreds of women and men in Wisconsin who are making their voices heard. Working with a national network of individuals, we've increased federally funded breast cancer research from \$90 million in 1991 to a cumulative total of nearly \$1 billion!

What is the WBCC Alert Network? It's our way of letting you know when you need to contact your legislators about a bill, existing legislation, or other budget item that affects breast cancer, research, or programs. We'll give you everything you need each time – and it will only take you five minutes!

Name \_\_\_\_\_

Address \_\_\_\_\_

City/State/Zip \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_

Email \_\_\_\_\_

**Wisconsin Breast Cancer Coalition**  
P.O. Box 170031  
Milwaukee, WI 53217-0031

Email: [wbcc@standupandspeakout.org](mailto:wbcc@standupandspeakout.org)

*Please notify us if your email address changes!*



## Rare Chair Affair: 2005 Wrap Up to 2006 Planning

"The 2005 Rare Chair Affair was a success! I'm really happy with the turnout and extend a huge thanks to our sponsors and donors," says 2005 Rare Chair Affair Committee Chairperson, Peggy Coffey. The WBCC Board of Directors echoes Peggy's thanks to those whose support and donations made it a successful event – and congratulates Peggy for a job very well done!

### Thanks to Our 2005 Sponsors:

Astra Zeneca  
 Medical College of Wisconsin  
 Northwestern Mutual Foundation  
 Extendicare, Inc.  
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Ellen Vander Heyden giving an opening speech before the live auction.



Mary Inglis and Galina Tash, survivor artist, with her "I will Survive" chair.



Long-time WBCC Administrative volunteer Jean Rosenberg with the Malaguti Scooter auctioned off at this year's Rare Chair Affair



Dawn Anderson with survivor artist Ina Kasper and her chair "87 Stars."

## Mark Your Calendars Friday, September 15<sup>th</sup> is the Date for the 2006 Rare Chair Affair!

**Calling for 2006 Volunteers.** The 2006 Rare Chair Affair Committee will soon be organizing volunteers, acquiring silent auction items, and assembling our corporate sponsors. We're looking for people who would like to be on the committee and lend their talents to making next year's event even more successful. The committee meets about once a month; volunteers can choose location planning, music, silent auction, finding sponsors, public relations, creating printed materials, menu, and much more.

**Attention Breast Cancer Survivors!** Be a Survivor Artist and create a chair for the live auction. Each year we ask 15 to 20 breast cancer survivors to work with other survivors and trained artists during the months of July and August to create personalized chairs for the live auction. Absolutely no experience is necessary; trained volunteers will help you create your own work of art.

**Chairs, Chairs, Chairs.** We always need chairs for our Survivor Artists to use to create their beautiful works of art. Please let us know if you have a chair (in any condition) that you can donate.

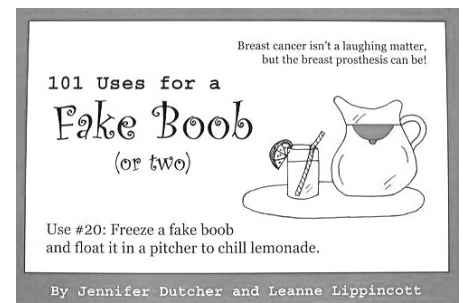
If you would like more information or would like to participate, please contact our office at 414-963-2103 or email [info@rarechairaffair.org](mailto:info@rarechairaffair.org).

## WBCC Annual Membership Meeting

WBCC will hold its **Annual Business Meeting on Thursday, January 12, 2006 from 6:00–6:30 p.m. at the Fox Bay Cinema Grill, 334 E. Silver Spring, Whitefish Bay, WI 53217.** This year's Annual Meeting will be followed by a humorous and fun presentation by Leanne Lippincott and Jennifer Dutcher, authors of the book, *101 Uses for a Fake Boob (or two)*. The special presentation will be from 7:00–8:00 p.m.

Leanne and Jennifer will be available to sign copies of their book and will donate a portion of book sales the night of the event to WBCC.

Board of Director Elections will take place at the Annual Meeting, and all mail-in ballots will be counted at the meeting. Prior to the close of the meeting, all officers and new board directors will be inducted. All Wisconsin Breast Cancer Coalition members are welcome to attend the Annual Meeting. The public is welcome to hear our speakers for \$5; there is no charge for WBCC members.



## Pick 'n Save WE CARE Program Benefits WBCC – #940586



You can help WBCC just by going grocery shopping at Pick 'n Save! Each time you use their Advantage Plus® Savers Club card, you can help WBCC through their community dollar program, the Pick 'n Save Advantage® WE CARE Program.

When you make a purchase and the cashier scans your card, your purchase amount will automatically be accumulated, earning WBCC a share of the total dollars Pick 'n Save makes available to non-profit organizations – a great way for you to help support WBCC programs by just doing the things you already do.

**Here's how.** If you already have a card, call corporate customer service at (866) 742-6728 to change your charity code. Give them your Pick 'n Save Advantage card number and our charity code and they'll change it right over the phone. Or the next time you visit Pick 'n Save, ask to fill out a "change" application and enter the WBCC # 940586. If you don't have a card, visit your local Pick 'n Save store and ask for an application, then write in # 940586 as your designated organization.

## Give the Gift of WBCC for the Holidays

Be sure to remember WBCC in your holiday gift-giving. You can support WBCC by sending a tax-deductible\* donation to help fund our efforts toward eradicating breast cancer. Here are some creative ways you can help fight breast cancer over the holidays.

- Make a donation someone's name in lieu of giving a gift, we will mail the recipient a card letting them know of your thoughtfulness.
- Make a donation in honor of or in memory of someone special.
- Ask for a donation to WBCC instead of getting a gift.
- Gift the gift of a WBCC membership.
- Check with your employer to see if they have a gift matching program.
- Purchase a pink ribbon charm to give as a gift
- Purchase a t-shirt with the new WBCC logo to give as a gift.
- Put out a donation jar at your holiday party for friends and family to drop their spare change; let them know you will be sending their donations to WBCC.

\*WBCC is a 501(c) 3 organization; donations are tax-deductible to the extent allowed by law.



## Pink Ribbon Charm

A beautiful holiday or birthday gift that also supports WBCC.

It's sterling silver with beautiful pink Swarovski crystals, about ½" in size, and comes on a pink ribbon ready to tie around your neck or attach to a charm bracelet. It's only \$25 plus \$2.50 for shipping and handling. To order, contact WBCC at 414-963-2103 or email [wbcc@standupandspeakout.org](mailto:wbcc@standupandspeakout.org).

Soon you'll be able to order it online; check [www.standupandspeakout.org](http://www.standupandspeakout.org) for details.

## Volunteers Needed

Ever thought about volunteering for a nonprofit organization, but aren't sure what you could do? Do you have a few extra hours here and there and wonder if you could do something to help the fight against breast cancer?

Check out our volunteer opportunities – they're fun and easy and take only an hour or two. WBCC needs volunteers to stuff envelopes, contact and schedule other volunteers, enter data, distribute brochures, join a committee, etc. In addition, we need people with the following skills to lend us their talents and some of their time:

- Accounting/Finance/Investments
- Computers/Technology
- Fundraising/Development
- Advertising/Marketing/Public Relations
- Government
- Legal
- Research/Evaluation
- Organizational Development
- Written Communications
- Administration/Management
- Education
- Human Resources
- Retail
- Advocacy

**Interested?** Please email [wbcc@standupandspeakout.org](mailto:wbcc@standupandspeakout.org) or call our office at 414-963-2103. We'd love to hear from you.



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**WBCC MISSION**

The Wisconsin Breast Cancer Coalition brings Wisconsin voices together to Stand Up and Speak Out about breast cancer with:

- Education** – spotlighting critical breast cancer issues
- Collaboration** – empowering through strategic alliances
- Legislation** – influencing policymaking.

**TO CONTACT WBCC**

414.963.2103  
888.295.2622  
wbcc@standupandspeakout.org

**STAND UP**

**and  
speak  
out**

- I'd like to become a member of WBCC.
- I'd like to donate\* to WBCC.
- I'd like to become a WBCC volunteer.
- I'd like to join the WBCC Alert Network. (Please be sure to enter your email.)

Annual Membership: **\$30**\_\_\_\_\_

Please enter the amount you would like to donate\*: \_\_\_\_\_

Total Amount: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City, State, Zip: \_\_\_\_\_

Email: \_\_\_\_\_

Please find my enclosed check made payable to the **Wisconsin Breast Cancer Coalition**.

Please charge my credit card:  VISA  MasterCard

# \_\_\_\_\_

Expiration Date: \_\_\_\_\_ Signature: \_\_\_\_\_

*\*All donations are tax-deductible to the extent provided by law.*