



wbcc mission

The Wisconsin Breast Cancer Coalition unites Wisconsin voices to Stand Up and Speak Out about breast cancer through:

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

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New Mission/Vision/Core Values

Ellen Vander Heyden – Vice President, Communications Chair

In the past few issues you've read about the strategic planning initiative the WBCC board of directors undertook beginning early last fall. The process has been completed. It has given us a chance to carefully reassess our goals as an organization, our mission, our direction... the very needs of people in Wisconsin who have been or will be affected by breast cancer. This important exercise brought us to this conclusion: **the activities of WBCC in Wisconsin and across the country are vital.** We've emerged with renewed motivation and purpose.

Our organizational reassessment made it clear: we are the voice of people concerned about breast cancer in Wisconsin. No other group in Wisconsin is as active

- promoting breast cancer education beyond media sound bytes;
- collaborating with other organizations from other breast cancer groups to those who may not even be health-based, but have complementary goals;
- ensuring that legislators and other policy makers hear from the patient's perspective and have a resource they can go to for information on any breast cancer issue prior to making a decision.

We do not duplicate the efforts of other organizations that provide valuable services directly to breast cancer patients and their families; WBCC supports them by attacking the disease from a different angle.

This made it easy to formulate our goals and action plans for the next five years and to update the organizational structure to facilitate these plans. We've added Membership and Communications committees and redefined our Legislative committee as a Policy committee, splitting it into federal and state legislative initiatives as well as health-based policy initiatives. We still have committees to manage our fund development, (including events such as our annual Rare Chair Affair) education programs and community involvement. We've also updated our Mission, Vision and Core Values:

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wbcc vision

The Wisconsin Breast Cancer Coalition is a statewide organization that is recognized as the premier resource on breast cancer policy issues. Our members are "knocking the door down" to be involved in the eradication of breast cancer.

wbcc core values

Recognizing that all people are important and valuable, the Wisconsin Breast Cancer Coalition believes:

- ✓ Breast cancer is a health crisis for our entire society.
- ✓ All members of society share the costs—emotionally, physically and financially—of breast cancer.
- ✓ Inaccurate perceptions about breast cancer can be changed through education.
- ✓ Appropriate levels of funding for quality breast cancer research are critical.
- ✓ WBCC is the vehicle to unite concerned voices.
- ✓ A COLLECTIVE VOICE in Wisconsin WILL make a difference.

Each of the committees in the new organizational structure is now striving to implement action plans that include ambitious goals to achieve our organizational objectives.

upcoming
events

gallery

Gallery 505 Beer Tasting

Katie Weide and Tom Harris of Gallery 505 in Whitefish Bay are organizing an event at the Gallery in honor of WBCC Board Member, Linda Weide. Proceeds will be donated to WBCC. Lakefront Brewery will be providing nine different beers for the tasting, their seven regular beers and two seasonal beers (Oktoberfest and pumpkin lager).

Roots will cater the event. Thank you to Lakefront Brewery for donating all of the beer and Roots for donating half the cost of the food. Additionally, 10 percent of everything sold in the gallery the evening of the event will be donated to WBCC.

5 0 5

The event will be held on Saturday, October 16 from 6 pm to 9:30 pm. The event will be \$25 per person at the door, \$20 if you pre-register. You can pre-register by calling Katie Weide at (414) 962-6302 ext. 106. Please join us for this fun evening.



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Moving? Please send your
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articles for winter 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 the WBCC's efforts. If you have information you would like included in an upcoming issue, please contact the WBCC at wbcc@standupandspeakout.org or 414.963.2103.

From the President

Karen Maynard

CAN YOU HEAR ME???

Repeat after me:

Me, You, Us, Team

Me, You, Us, Team

I can't hear you!! (OK technically this isn't possible, but work with me.) Try this one!

Say It, Fight it, Cure it

Say It, Fight it, Cure it

My son's 4K principal recited the first chant with the students for all school assemblies (of course you could have guessed he was a past high school football coach).

The second chant--Say it, Fight it, Cure it--was from the NBCC's lobby day rally several years ago, before state contingencies divided up to visit congressional representatives.

My story in this issue might be viewed as a bit twisted but here it goes. I need to tell you that I am thankful that my aunt by marriage died at age 36 of liver cancer. Another aunt by marriage died of breast cancer in her forties. My maternal grandmother and first cousin had endometrial cancer. My paternal grandmother died of colon cancer. My own mother died at the age of 58 of lung cancer and my mother-in-law, Jane lost her 14 year battle with metastatic breast cancer last April also at the age of 58.

I thank God for this!

Most of you are probably thinking, "This girl is a tad touched."

But prior to being diagnosed, I had to go to four different doctors before being "allowed" to have a diagnostic mammogram at my age. Without the past experiences of those women in my life I would have never questioned the "educated guesses." I was diagnosed at the age of 33, when we had three boys' ages 2, 4, and 6, and pretty much everyone with cancer, with the exception of my mother-in-law, had died. I cried for two days.

Then on the third day it struck me. My aunts, my grandmothers, and my mothers wouldn't want me to sit and cry. Enough was enough... I needed to do something about it!

I would soon find out that I couldn't do much alone. Individually we can say that we need better access to health care for all, better information, better treatment options, better prevention methodologies and better detection. But as a TEAM we can fight cancer through adequate, inclusive legislation, as well as fighting inequalities in the system. As a TEAM we can cure cancer in our lifetime through information, and as advocates demanding new and innovative trials and breast cancer policies.

Advocates working tirelessly, side by side with doctors, researchers, legislators and patients, can eradicate this disease.

The WBCC has been and will continue to be an integral team player with researchers as we work together on Wisconsin's Cancer Control Plan, to continue high quality and innovative research, and with legislators.

Thanks to everyone for making the WBCC's past 10 years a success. I hope that more of YOU will join our TEAM so we can continue, together, to STAND UP AND SPEAK OUT about breast cancer through Education, Collaboration and Legislation.

education

Breast Cancer Treatment: New & Emerging Therapies

Gerry Parenteau, 2004 Sherry Kohlenberg Scholarship Recipient

As I walked into the auditorium of a breakout session at the NBCC Advocacy Training Conference, entitled, "Breast Cancer Treatment: New & Emerging Therapies," I was eager to hear about recent advances in treatment. In this workshop, *Hormonal and Targeted Therapies*, Dr. Dennis Slamon stressed that putting more money into breast cancer is not the only answer. We also need to change public perception about the value and importance of participation in clinical trials. Clinical trials must make more effective use of predictive models. In layman's terms, "using what we already know to perform better trials."

An example of a positive outcome of a clinical trial is the drug Herceptin, which works in a different way than standard cancer therapy (chemotherapy, hormone therapies). Herceptin (generic name Trastuzumabis) works by blocking tumor cell growth in some kinds of breast cancer (those with too many copies of the HER2 gene). Studies show that Herceptin combined with chemotherapy has a 78% survival rate compared to 67% with chemotherapy alone.

Though much research is being done and progress is being made, still we do not yet have a cure for breast cancer. As advocates, we need to encourage participation in clinical trials as well as to advocate for more research dollars.

collaboration

WBCC Builds Partnerships with Cancer Organizations Statewide

Karen Maynard, WBCC President

A Milwaukee Area Cancer Clinical Trials Partnership has been formed with the WBCC; the Cancer Information Services, a service of the National Institutes of Health (NIH); the Wisconsin Cancer Council; the Leukemia and Lymphoma Society of Wisconsin; and the American Cancer Society's Wisconsin Regional Office. The goal of this partnership: to increase participation in cancer clinical trials.

We are planning another clinical trial training program, this time with an emphasis on minority enrollment.

In addition, one of WBCC's annual goals is to look at ways to increase participation in clinical trials through adequate insurance coverage. *In Wisconsin, no legislation or policy ensures that if a clinical trial is available for a patient, it will be offered as an alternative to standard of care and covered by insurance.* WBCC's goal over the next year or so is to work with insurance companies, public health officials, researchers, pharmaceutical companies, and legislators to find a mutually acceptable way for patients to have these alternatives available to them. Advancements in prevention, diagnosis or treatment for breast cancer, and all cancers, cannot be achieved without participation by cancer patients in clinical trials and studies.

If you or your organization would be interested in the planning or participation in either of these programs please email wbcc@standupandspeakout.org.

wbcc alert network

In just 5 minutes, you can make a difference in the fight against Breast Cancer! It's fast, free, and simple. Help the WBCC find a cure! Join hundreds of women and men in Wisconsin who are making their voices heard. With your help, we can find a cure for breast cancer and save the lives of thousands of women. Four or five times a year, you will receive by mail or email a simple alert message with all the information you will need to contact your representatives.

Please sign up to join the WBCC Alert Network today.

Name _____

Address _____

City/State/Zip _____

Phone _____ Fax _____

Email _____

Send information to the WBCC,
or email to: wbcc@standupandspeakout.org

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

Please notify us if your email address changes!

WBCC Has Success in Madison—AB351 The Wisconsin Breast Cancer Research Fund is Now a Reality

Ellen Vander Heyden – Vice President, Communications Chair

Our hard work has paid off in Madison! WBCC has been working since 2002 to see passage of legislation (AB351) to establish an income tax check-off box, creating a Wisconsin Breast Cancer Research Fund. Wisconsin residents will now have the opportunity to donate all or part of their income tax refund check to a research fund. WBCC Board member and Legislative Chair Rhonda Deneka was present when Governor Doyle signed the bill on April 6, 2004.

“I feel privileged to have represented the WBCC at the signing of AB351. It was the first time I attended an official bill signing, and it was incredible to be there among local and state dignitaries,” said Ms. Deneka about the event. “The real heroine in getting this bill signed was Dawn Anderson. Dawn spent many long hours working with state legislators to ensure the passage of this bill.” Ms. Deneka presented the pen that Governor Doyle used to sign this bill to Dawn as a small token of appreciation and gratitude for her work on this key piece of legislation.

In September of 2003, Anderson, as WBCC’s president, testified on behalf of Assembly Bill 351 before the State Legislative Committee on Public Health. In October, the bill was unanimously passed out of committee. Then in February 2004, Karen Maynard provided

written testimony to the Joint Committee on Finance to ensure advancement of the bill. *Our position: not only is it imperative that we establish this research fund for use only in Wisconsin’s research institutions to conduct breast cancer research, but it is also vital that breast cancer advocates be involved in the grant review process to ensure that the patient’s perspective is considered in this research.*

We were instrumental in drafting an amendment to the bill which required that breast cancer advocates and survivors make up 1/3 of the advisory committee. Unfortunately, this amendment was stricken from the version that passed in March. We believe so strongly in the importance of involving breast cancer advocates that we now plan to work with the recipients of these funds to see that they are spent on innovative research.

The passage of this bill demonstrates the effectiveness of our Legislative Alert Network. When votes were needed to ensure the passage of this bill we sent out alerts to all in the network. Thanks to everyone who contacted state assembly representatives and senators. Your hard work has paid off! You will see this check off box beginning on your 2005 state income tax return.

If you are not yet registered for the alert network, see page 3 for information on how to join.

Stand Up and Speak Out at the State Level: How We Can Advocate for Breast Cancer Issues in Wisconsin

Dawn Anderson, State Legislation Chair

Much of the focus of WBCC over the last 10 years has been on federal legislation regarding breast cancer. This year marks our first active involvement in legislation at the state level.

Many people are intimidated by the prospect of being involved in the legislative process, especially as an advocate. Once they find out how easy it is to lend their voice to making a difference, they become empowered. How can you make a difference in the lives of families affected by breast cancer in Wisconsin? By simply learning a little about the process and joining your voice with ours as we pursue the passage of certain legislation.



WBCC legislative committee members Galena Tash and Mildred Leigh-Gold with NBCC Field Director Sharon Ford Watkins and a fellow advocate at the 2005 Advocacy Conference in Washington, DC.

points in that process that allow advocate involvement. For instance, a legislator may find one of our issues so compelling that he/she will draft a bill addressing it. We may even have a say in what goes into the language of the bill.

Once the bill has its first reading in the originating house of the legislature, it is often sent to the appropriate committee in that house for consideration (ex: the Public Health Committee). What happens at this point is vital to the success or failure of the bill and this is also the point where we, as constituents and advocates, can make a big impact. Committee hearings are open for public testimony either

in favor or opposition of a bill. It is at these hearings that we have an opportunity to speak to legislators about the importance of a bill, or issues we may have regarding a bill. If the committee rec-

continued on next page

Stand Up and Speak Out continued

ommends passage of the bill, it is reported back to the originating house. (If not, the bill remains in committee. You may have heard of a bill being stuck in committee – i.e.: it isn’t going anywhere!)

Back on the floor of the house, the approved bill receives a second reading, where amendments may be offered and voted upon. After a third reading, it may or may not be scheduled for a vote by the leader of that house. When a vote is taken, the bill must be approved by a majority of the members in that house (there are 33 senators and 99 representatives in Wisconsin).

As a bill comes to a vote, we send out a call to action through the WBCC Legislative Alert Network. We ask our network of participants to contact their legislators and ask for their support of (or opposition to) the bill. If it passes, the same process begins over again in the other house. A bill must pass both houses in identical form AND be signed by the governor in order to become a law.

We can be active participants and effective advocates in this process by remembering a few simple things.

1. Know when to approach legislators about an issue – the best times are obviously when the legislature is in session, during the election cycle and during the budget cycle.
2. Know who is important in the process and inform them about your position – the bill’s sponsor(s), the majority party leadership in both houses (since they decide if and when a bill can come to the floor for a vote), the appropriate committee chair(s) and staff, the legislative aides (a.k.a. the gatekeepers – legislators rely heavily on them for research and input from constituents) and finally, the governor, who has the final word on whether it becomes law or not.
3. Help legislators get what they want in order to get what you want – for example, most want good public policy, good publicity, tip offs to what might be election year issues, and of course, to be re-elected.
4. Be passionate, positive, and tenacious – but respectful. You want to be remembered for your message, not your behavior.
5. Be irrefutably well informed and prepared with credible material to support your position. (WBCC provides this information for you!)

The most important thing is to let our voices be heard. WBCC is the vehicle that will allow all of us to take our message to Madison next year. *Watch for news on our state initiatives.*

For more information on state government, go to the WI Legislature’s homepage at www.legis.state.wi.us.

Special Legislative Issue

The next issue of Collective Voice will include statements we received from our State and Federal legislators with their thoughts on breast cancer in Wisconsin. Earlier this year we asked all legislators to respond to two issues we posed to them (What innovative strategy would you recommend to ensure access to quality care for all breast cancer patients in Wisconsin and that adequate funding exists to guarantee quality breast cancer research can be conducted in Wisconsin?) We received such an excellent response that we decided to devote our entire next issue to these statements – just in time for the election.

Enough talk.

If you’re ready, please select one or more than one.

- Yes. I’d like to receive information on the Legislative Alert Network.
- Yes. I’d like to volunteer in a WBCC program.
- Yes. I’d like to become a member of the WBCC. Enclosed is my \$30 membership fee.
- Yes. I’d like to donate to the WBCC.

My gift is In honor of In memory of

Name of person _____

Send acknowledgement to _____

City _____ State _____ Zip _____

Donor Levels

- Platinum \$500 plus Bronze \$50-\$99
- Gold \$250-\$499 Pink Ribbon \$5-\$49
- Silver \$100-\$249

Name _____

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City _____ State _____ Zip _____

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Email _____

Please make your check payable to Wisconsin Breast Cancer Coalition and mail to: Wisconsin Breast Cancer Coalition, P.O. Box 170031, Milwaukee, WI 53217 or call our office (414-963-2103) to apply membership fees or donations to your credit card.

The Fifth Annual "Rare Chair Affair – Bid Farewell to Breast Cancer"

Friday, September 10th
The Pfister Hotel
424 Wisconsin Ave., Milwaukee, WI

We achieved our goal: to raise money to support WBCC's efforts toward eradicating breast cancer. Thanks to all attendees, our donors, and especially our survivor artists who all contributed to the success of the evening. We raised nearly \$55,000!

Our sponsors:

- Astra Zeneca LP
- Columbia-St. Mary's
- Covenant Healthcare
- Extencare Health Services
- Froedtert Hospital Emergency Medicine Department
- Herbert H. Kohl Charities
- Medical Associates
- Pfizer Oncology

For more information and to view photos of the event and survivor artist's chairs, visit our special website at: www.rarechairaffair.org.



Survivor artist Terry matusek's "piCATsso" chair, which was auctioned for a record \$2,200!

products benefitting wbcc



Pink Ribbon Charm

High-Strung Beads in Oshkosh is partnering with WBCC to offer this beautiful charm. Proceeds will benefit WBCC. The charm is approximately 1/2" in size and is available in sterling silver with beautiful pink rhinestones. The charm comes on a pink ribbon ready to tie around your neck, or attach to a charm bracelet. The charm sells for only \$20 plus \$2.50 for shipping and handling. To order, contact WBCC at 414.962.2103 or email wbcc@standupandspeakout.org. Soon you will be able to order this charm online, watch www.standupandspeakout.org for details.

Brighton Collectibles Bracelet

The Brighton Collectibles store at Mayfair Mall in Wauwatosa is donating \$10 from the purchase of each "2004 Think Pink" bracelet to WBCC. Pre-orders are now being taken. The bracelets are beautiful silver with Swarovski crystals and a shadow box heart and are on sale for \$37. Be sure to order early, quantities are limited.



Once again, the generous folks at WisconsinMade.com, an Internet-based specialty food and gift store, are donating 10 percent of their Internet sales to the WBCC during the first week of October (Oct. 1-10), to commemorate Breast Cancer Awareness Month and support the fight against breast cancer. Customers who place an order at www.WisconsinMade.com will have a portion of their purchase donated to help fund breast cancer research and lobbying efforts.

Remembering Maggie Dillon

Linda Weide, WBCC Board Member

It certainly isn't difficult for anyone diagnosed with breast cancer to list all the negatives. Eventually though, you may come to realize that there can be some positives. Although this list is much shorter, I have discovered that one is meeting people who I would not have met otherwise.

Maggie Dillon was one of my best "finds."

She was "an exception to the rule" human being – an exuberant, beautiful, fun-loving, altruistic and inspirational woman. Whatever she became involved with, she gave her all.

She was an active volunteer for ABCD and posed for one of their fund-raising calendars. Maggie was an enthusiastic cheerleader for the Columbia-St. Mary's Breast Cancer Support Group. She enjoyed being able to advise and mentor newly diagnosed attendees. I met her several years ago at that support group when I was recruiting artists for the RCA. She immediately agreed to participate and encouraged other members to do the same.

The first year she participated as a survivor artist for the Rare Chair Affair she painted not 1 but 2 creations. The next year she chaired the Survivor Artist Committee and painted a chair that still ranks as the highest bid – \$1200. During our painting sessions she constantly encouraged and inspired the other women in both their painting and their emotional healing.

That is an impressive resume of breast cancer volunteerism and activism. But Maggie wasn't finished yet.

Early in 2003, Maggie was told by her oncologist that they had run out of treatment options. She was to view the remainder of her life in finite terms – 2 years.

She took several trips, including one to Paris. She enjoyed planning and hosting several Christmas parties. She arranged the details of her funeral so that her daughter Ellen wouldn't be burdened with it. And she began volunteering on 5 West – Columbia Hospital's cancer ward – to impart positive vibes to patients who so desperately need them. This act epitomizes Maggie Dillon. Instead of feeling sorry for herself, she sought another avenue to give of herself.

Maggie was an example of the old adage, "Only the good die young." She happened to be 71, but to look at her and talk with her she might as well have been 41.

I knew her only a few years, but I was enriched and privileged to have had our lives intersect. She has left her footprints in this world, and it is a better place for her having been here.

Note: A special thank you to all of Maggie's friends and family who donated in her name to WBCC

WBCC Seeking Program Coordinator

WBCC is currently interviewing applicants to fill a Program Coordinator position. The ideal candidate will provide support for the WBCC by assisting with execution of programs and membership support, fundraising events, educational events, and marketing activities. This is a half-time position (approximately 20 hours per week) without benefits exempt from overtime and is currently the sole staff person for the organization. If you would like to find out more information or to apply for this position, please send your resume and salary requirements by 10/20/04 to wbcc@standupandspeakout.org.



Dr. Bodai Chooses WBCC's Celebrating 10 Years in Advocacy Gala to Make Major Announcement

Dr. Ernie Bodai, M.D. mastermind of the Breast Cancer Research Postage Stamp – the first fundraising stamp in U.S. history – chose the WBCC's 10th Anniversary Gala to announce that the breast cancer stamp is now going worldwide!

Dr. Bodai, a breast surgeon from Kaiser Permanente in California as well as a prostate cancer survivor, has been named as one of Fast Company's "Fast 50 Trend Setters." He had just returned from China when he joined us as keynote speaker. We were thrilled to be the first to hear his announcement, along with his experiences lobbying Congress to establish the breast cancer stamp.

Other highlights of the evening included a speech by WBCC President Karen Maynard about what made her want to become a breast cancer advocate and how bringing our voices together can generate one powerful collective voice. WBCC Vice President Ellen Vander Heyden also showed images and photos of WBCC members and past events, accompanied by inspiring music.

Thanks to all of who contributed to the great success of the evening.