



WBCC 3rd Annual State Advocacy Day A Resounding Success!



*Dr. James Cleary
WBCC State Advocacy Day 2009*

On March 11th the Wisconsin Breast Cancer Coalition (WBCC) hosted the third annual WBCC State Advocacy Day in Madison at the State Capitol. The purpose of Advocacy Day is to inform concerned Wisconsin policymakers on important issues such as cancer screening and treatment in Wisconsin, and to educate and involve voters in effective lobbying techniques at the State Capitol. The event was a tremendous success.

Citizen participants were offered a morning of education on issues and policy information kicked off with a question and answer session with Joseph Hoey, Legislative Aide to State Representative Gary Sherman, who offered tips on how to communicate effectively with legislators and their staff. This

was the second year Mr. Hoey joined us at our event and we thank him for the invaluable information and experience he shared with all who participated.

Our keynote speaker was James F. Cleary, MD, Associate Professor of Medicine, Medical Oncology and a Director of Palliative Medicine at UW Hospital and Clinics, who discussed cancer control in the state, the roles of the Comprehensive Cancer Control Program and the Wisconsin Cancer Reporting System. Dr. Cleary shared important statistics on cancer in the state and pointed out challenges we have in fighting cancer. For instance, the fact that even though overall cancer mortality rates are dropping, we have had little impact on preventing and treating cancer since the 1970s, while heart disease and stroke have seen a much more significant improvement over the same period of time.

Armed with effective lobbying tools and policy information, participants spent the afternoon meeting with Legislators in the Capitol on Health and Healthcare Reform, Public Health, and Joint Finance committees. We discussed the importance of funding and adequate staffing for the Wisconsin Cancer Information Service, funding for the Wisconsin Comprehensive Cancer Control Program, and funding for the Wisconsin Well Woman Program. We also expressed concerns about environmental toxins and breast cancer in the State.

“It is our advocacy activities surrounding legislation and public policy that distinguish us from other breast cancer organizations in the state. For the past 15 years, we have worked to educate and inform our representatives on breast cancer issues, and our members engage in active lobbying for breast cancer-related and other health care legislation,” noted WBCC President, Ellen Vander Heyden. “Plain and simple, it will take more than just money for research and awareness to eliminate the far-reaching effects of breast cancer on our society; it also takes a collective voice to advocate for positive change. We are the voice of people concerned about breast cancer in Wisconsin.”

This was our largest State Advocacy Day group yet, and we are currently planning for an even more successful event next year.



*Joe Hoey
WBCC State Advocacy Day 2009*

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President's Letter

Happy and healthy spring everyone! What a wonderful time of year this is. The weather is getting warmer, plants are beginning to grow, and we're all ready for that renewed spirit spring brings us, that is after we clean the sticks and random trash out of the yard and the rain washes away the last bits of sand and salt off the roads. In spring, all things can start taking root, branching out, growing, creating excitement, and reaching to new heights—that's just what we're doing in the Wisconsin Breast Cancer Coalition.

As you no doubt read on the cover of this newsletter, we had our most successful State Advocacy Day yet. I heard many times while in the Capitol from both elected representatives as well as their legislative staff how great it was to meet with WBCC and how respected we are in Madison. We're also putting significant effort into reaching out to our constituents across the state. (Taking root)

As promised, we are bringing our signature advocacy training event, Beyond the Pink Ribbon: What Else You Can Do in the Fight Against Breast Cancer, to several different areas of the state, including Racine and Madison, and thanks to donations from BLC Community Bank and a grant from the National Breast Cancer Coalition Fund, we are bringing the event to Kimberly, WI, in June. We're also planning to hold the event in other locations around the state, let us know if you would like to help us plan an event in your area. (Branching out)

Each year we bring a delegation of advocates to the National Breast Cancer Coalition Fund's Annual Advocacy Training Conference and Lobby Day. This year of course was no exception, but the most exciting part is we brought some 53 Wisconsin citizens along. This is the largest group we have ever brought to the conference and we made a splash the first day, all donning our WBCC shirts, to let the rest of the country know how dedicated our Wisconsin Delegation is to ending breast cancer. (Growing)

Rare Chair Affair will be fresh and new this year as well. We're working with several new members on the committee this year, we've reserved the new Harley-Davidson Museum, and we're adding some fun new activities to the event—this our 10th year holding this truly unique fundraiser. (Creating excitement)

We're also looking at new and improved ways to reach our membership by streamlining our operations. The WBCC Board of Directors is working on a plan to improve the operational effectiveness of the WBCC so that we can be even more focused, have more impact, communicate better, and realize even more success in our programs. (Reaching to new heights)

With our renewed spirit and "spring" in our step we welcome warmer weather and continue our passionate efforts to end breast cancer in Wisconsin.

Ellen Vander Heyden

WBCC President

Correction: In the last issue of Collective Voice new WBCC Board Director, Phyllis Holder, was inadvertently left off the list of Directors. We apologize and are thrilled to welcome Phyllis, who is also Founder of the local Chapter of the Sisters Network, to the WBCC Board of Directors.



*WBCC Delegates Norma Vargas,
Lana Tash and Ellen Vander Heyden with
Rep Phil Montgomery*

One Advocate's Project LEAD® Experience

By Jo DeMars, WBCC Board Director

Chance and happenstance, I found myself sitting next to a young African American mom at a breast cancer event. I told her I was five months out of treatment for Stage II cancer and, that even with a good prognosis, I felt kind of raw. She told me she'd been diagnosed with a breast cancer recurrence which was now Stage 4. Her doctors treated her with the usual protocol but the cancer seemed to defy every drug. She didn't say it, but her eyes told me she was scared—for herself and for her kids. It made me stop and think about what really matters in life.

I often think of that young mom when I think about Wisconsin Breast Cancer Coalition and its advocacy work. To me, advocacy means speaking up for those who can't or won't. For those of us who can, speaking is a responsibility; and getting training and education establishes the foundation.

The National Breast Cancer Coalition Fund (NBCCF) sponsors several types of training, from advocacy to leadership, and one of its best known and most reputable programs is Project LEAD. The acronym LEAD stands for Leadership, Education, and Advocacy Development. It's an accurate description of what happens during the course, but it doesn't even hint at the world-class science education that is the integral core of the sessions.

I knew if I was going to be an effective advocate that I needed more education. Some members of WBCC recommended applying for Project LEAD. Some scholarships are available through NBCCF to cover the cost of travel, conference fees, meals and lodging (with a roomie who often becomes your new best friend). I paid for my ground transportation, parking at the airport and dinner on one night. In exchange for those modest cash investments, and my time, I brought home new contacts and a much deeper understanding of the complex science of researching and treating breast cancer.

Take for example the scientific diagrams and photos, only part of the four-inch thick, three-ring reference binder I received on the first day of the course. When I look at the page titled "Illustration of a Cell," I now understand something about the function of Growth Factor Receptors, mRNA, DNA, Mitochondrion and Tumors Suppressor Proteins. We learned about research techniques and research results. We toured the cancer research facility at Colorado State University and had hands-on experiences. I looked through a state-of-the-art microscope as a cancer cell went through apoptosis, which I now knew could be defined as "cell suicide." With this experience and newly acquired knowledge I know I am a better advocate.

Breast Cancer Community Mourns the Loss of Advocate and Mentor, Mildred Leigh Gold

On January 31, 2009, a voice was silenced that was well known to many of us in the Wisconsin breast cancer community. Mildred Leigh Gold was compelled to stand up and speak out by not only her own breast cancer diagnosis, but also by the diagnoses of family members and all underserved women in Milwaukee. She became an advocate to ensure that all women have access to screening and treatment.

She took her fight to Milwaukee City Hall, Madison, and Washington DC, serving on the Mayor's Breast Cancer Awareness Task Force, developing the Milwaukee Breast Cancer Awareness Program, participating in statewide cancer control activities, and lobbying in Washington DC with the National Breast Cancer Coalition for research funding and quality care initiatives.

Putting my Project LEAD education to use

Recently I received an e-mail from a cancer alert network which helped demonstrate to me how much I'd learned and why it matters. Dr. Susan Love started an organization to connect women with researchers called the Army of Women, www.armyofwomen.org. Right now they are looking for women to participate in a study called "The Gap Study." Researchers need to better understand the differences in breast cancer treatment experiences between African American women and Caucasian women. Did you know that African American women are more likely to die of breast cancer than Caucasian women, even though fewer African American women are diagnosed with breast cancer each year? Although screening rates have improved, the difference in mortality rates has actually gotten worse over the past 20 years. I learned at Project LEAD that there are many different types of breast cancer and African American women are more likely to have a type that doesn't respond to the drugs we currently have available. The Army of Women is promoting this research to start closing the gap between the health outcomes of African American women and Caucasian women.

We need to know so much more about this disease. If you have been diagnosed with Stage I, II, or III breast cancer in the last twenty weeks, it's likely you are eligible to participate in the Gap Study. You can learn more about the requirements at the Army of Women website.

I only have to think of that young mom who talked with me about her breast cancer diagnosis to know how important the results of this research will be for those with a cancer diagnosis and for those who care for them. Please consider participating if you fit the criteria. If you're not a fit for this study, please consider joining the Army of Women to be on the alert for upcoming studies. I also urge you, as an advocate, to consider attending Project LEAD and join our efforts to spread the knowledge and share your education to help end breast cancer.



Jo Demars



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WBCC Awarded a 2009 Programmatic Capacity Building Grant from NBCCF

WBCC is one of the 14 recipients of a 2009 Programmatic Capacity Building grant from the National Breast Cancer Coalition Fund (NBCCF). We submitted an entry for consideration in February and recently were informed that we were going to be awarded a \$20,000 grant. This grant will help fund our Beyond the Pink Ribbon seminars around the state, furthering our education mission and widening the reach of our advocacy message. In addition we will be able to update our Advocacy Tool Kit that is used at each training and better track our success in motivating participants to join us in advocacy.

The grant, which is generously made possible by the Breast Cancer Fund of National Philanthropic Trust, is a portion of the \$190,000 awarded as part of the Best Practices in Breast Cancer Advocacy Awards Program®. The National Breast Cancer Coalition is a grassroots membership organization dedicated to ending breast cancer through the power of action and advocacy.

“We are excited to make this opportunity available to the WBCC for their difficult and important work to help in our mission to end breast cancer,” said Frances M. Visco, president of NBCCF. “I am confident they will use the grant to continue programs that will have a lasting impact on systems of research, access and/or public policy.”

Involvement and Influence in the Scientific Arena: WBCC Advocates Serve on DoD BCRP Peer Review Panels

By Kathleen Harris, WBCC Representative to the NBCC Board of Directors

WBCC advocates not only get involved in gathering support on Capitol Hill for funding for the Department of Defense (DoD) Breast Cancer Research Program (BCRP), they also serve on scientific peer-review panels alongside scientists. A number of WBCC members have served on these panels since its inception. Survivors put a face on the disease to remind scientists that there is a sense of urgency in finding a cure. Fran Visco, President of NBCC, noted one scientist wrote to her, “Advocates act as our conscience, forcing us to consider whether we are doing science that is important to them and not simply science that is interesting to us.”

Advocates address the uniqueness of a specific proposal, the impact it would have on not only those living with breast cancer but for all women, because all women are at risk for this disease. Many well-informed advocates are also highly qualified to address the scientific portion of the proposal as well. Most of these advocates who have served on scientific research panels have graduated from NBCC’s Project LEAD training program, a five-day intensive course on the science of breast cancer, taught by medical professionals and scientific researchers. For more information about this program, please see NBCC’s website: www.stopbreastcancer.org.

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Mildred Leigh Gold

For those of us in the WBCC, Mildred was a source of inspiration and wisdom who taught many of us how to serve a cause honorably. Her commitment, her patience in mentoring new members, her tireless advocacy, her willingness to always show up – all of these qualities, along with her elegant presence and sly sense of humor will be sorely missed.



Mildred was honored on May 2 in Washington DC at the National Breast Cancer Coalition’s Annual Advocacy Training Conference. As the lights dimmed on the opening session, 800 participants saw a picture of a lovely woman on the two screens flanking the podium. To the cheers and tears of our Wisconsin delegation at the conference, NBCC leadership dedicated this year’s conference to Mildred’s memory. We will miss her, and we will continue her fight.



Mildred Leigh Gold with Dawn Anderson and Karen Maynard at the 2005 NBCCF Annual Advocacy Training Conference

Putting an End to the Misdiagnosis and Delayed Diagnosis of Breast Cancer in Young Women

By Karen Maynard, WBCC Health-based Initiatives Chair

Have you ever been diagnosed with breast cancer? Have you been told that it isn't possible that you have breast cancer because you are "too young?" My answer is "yes" on both accounts. Over nine years ago I was guaranteed by three doctors that I didn't have breast cancer because, they said, "young women don't get breast cancer." Thankfully, I was diligent and found a fourth doctor to actually test me for it. A mammogram and a biopsy later, I was finally diagnosed at age 33. As a long-time advocate for young survivors, I was recently presented a young survivor's story of delayed diagnosis that mirrored mine. This is Tina's story.

Tina was diagnosed with breast cancer at age 30. At that time she was just married and hoping to start a family. She shared her concerns about her growing breast mass with a new OB-GYN on her first visit. After feeling the mass, the OB-GYN sent her off for a mammogram, ultrasound, and biopsy, after which she was finally diagnosed with breast cancer. She says "finally" because she had originally felt the mass and discussed it with a doctor about 18 months earlier. That first doctor, and two after that, said she just had a cyst, and made casual remarks about her young age and lack of family history of breast cancer, leaving Tina to assume those factors clouded their professional judgment since she had a growing mass *and* nipple discharge.

Five years later, after chemotherapy to shrink the 7cm tumor, a mastectomy, radiation, and hormone therapy, thankfully, Tina has no evidence of disease. But she still can't help but think about all the young women who will be misdiagnosed because of their age. Because of her experience she has decided to share what she learned from the research she did following her diagnosis. Tina truly believes that an open dialogue with doctors is necessary for a young woman to reduce the risk of a delayed diagnosis. Tina didn't ask her doctors for a definitive diagnosis, and in retrospect, says she should have asked them to rule out breast cancer with additional testing before they diagnosed it as a cyst.

As a result of her experience Tina wrote a pamphlet, "Reducing the Risk of Misdiagnosis and Delayed Diagnosis of Breast Cancer: Information and Tools for Young Women," to share what she learned and assist young women so they can have an effective dialogue with their doctors. The pamphlet simply explains some of the common causes of misdiagnosis and offers strategies for reducing this risk. The Breast Health Conversation Starter is a worksheet that women can use to document their symptoms and concerns and bring to their doctor to facilitate discussion. The importance of and need for this tool is illustrated by the fact that in less than two months it has been downloaded from the website over 150 times!

Tina hopes that no other woman will go through what she did while trying to get a proper diagnosis. She also wrote a memoir, *If I Just Breathe*, in an effort to raise awareness of the misdiagnosis and delayed diagnosis of breast cancer in young women. It chronicles her life during diagnosis and treatment, her experience with a medical malpractice lawsuit, and her struggle to start a family.

Currently, Tina is an active volunteer with the Young Survival Coalition and started a volunteer-led Chicago affiliate.

I once heard a quote that went something like, "If we each move a stone, together we can move a mountain." Hopefully, with the efforts of many women and men with strength and conviction like Tina, we can put an end to delayed breast cancer diagnosis.

The pamphlet, "Reducing the Risk of Misdiagnosis and Delayed Diagnosis of Breast Cancer: Information and Tools for Young Women," can be downloaded for free at www.tinakoral.com, where you can also find more information about Tina and her contact information. *If I Just Breathe* is available for \$14.95 at Amazon.com, and a portion of the proceeds will be donated to the Young Survival Coalition (www.youngsurvival.org) and the I'm Too Young For This! Cancer Foundation.

WBCC Advocates Attend Era of Hope and Challenge Scientists

By Kathleen Harris, WBCC Representative to the NBCC Board of Directors

The Era of Hope meeting is a forum for presenting progress and results of research studies funded by the Department of Defense Breast Cancer Research Program (BCRP). Plenary sessions at the most recent Era of Hope focused on emerging issues in breast cancer; symposia sessions spotlighted the research of over 216 BCRP-funded investigators; and poster sessions highlighted over 1,200 BCRP-funded research projects.

Breast cancer survivor participation, a hallmark of the Era of Hope meeting, was evident throughout the forum. Seventy-two survivors were speakers, co-chairs or moderators of sessions, and fifteen survivors presented abstracts. Breast cancer survivors challenged the status quo and offered the patient and survivor perspective.

WBCC advocates have attended every Era of Hope Meeting, which convenes every 2-3 years, and has had at least one advocate who has served as symposium co-chair for the past three forums.

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WBCC Hosts Beyond the Pink Ribbon: What Else You Can Do in the Fight Against Breast Cancer in Kimberly, WI, Saturday, June, 20, 2009

By Megan Moyer, WBCC Volunteer

The Wisconsin Breast Cancer Coalition (WBCC) is hosting “Beyond the Pink Ribbon: What Else You Can Do in the Fight Against Breast Cancer” in Kimberly Wisconsin on June 20, 2009 at Liberty Hall, 800 Eisenhower Drive. This educational seminar for Fox Valley residents will include an overview of the WBCC’s mission, successes and challenges; a keynote presentation from Wisconsin Representative Steve Kagen; a panel discussion about the most effective techniques for constituents to contact their local legislators and participate in the legislative process; and afternoon break-out sessions for more individual interaction on important related topics, such as clinical trials and the role of genetics.

The overview session will discuss advocacy both at the federal and state levels and how it is most successful when a large number of people can come together to collectively express their views and wishes. Ellen Vander Heyden, President of the WBCC commented, “We sometimes have to be reminded that our elected officials are just that - our representatives - and they are in office to fight for the issues that are important to their constituents. The WBCC brings together Wisconsin residents who want to help eradicate breast cancer and continuously communicates that message to our representatives around the state.”

The keynote presentation will support that message, with Congressman Kagen emphasizing the importance of knowing what is important to his constituents and encouraging attendees to get involved and contact their local representative. Congressman Kagen will also share what he is doing specifically to help end breast cancer.

A panel discussion will conclude the morning, and will continue the conversation about getting involved and actively participating in legislation that impacts funding for breast cancer research and finding a cure.



Sen. Erpenbach and Rep. Berceau at the February Beyond the Pink Ribbon event in Madison



Pictured from left: Phyllis Holder, Anita Oliver, Kim Melcher, Lisa Phillips, Sen. Mary Lazich, Jennifer Krenz, and Dawn Anderson at the 2009 WBCC State Advocacy Day

There are approximately 51,000 women in Wisconsin living with breast cancer and part of the charter of the WBCC is to hold events around the state to reach constituents in each congressional district to bring Wisconsin voices together to stand up and speak out about breast cancer. Stated Vander Heyden, “We need to engage as many people as possible in the political process, because we know with certainty that breast cancer is a political issue. Policy made at the state and federal levels affects the research being done, the quality of service provided, access to care, quality of life post-treatment, and more. The WBCC is continuing to expand our influence with legislators in all Wisconsin districts—but we cannot do this alone. We need Wisconsin constituents to take up the fight in each of their home districts. Our process is effective and our objective is to educate others to use it. Good policy is the ultimate measurement of success.”

The Beyond the Pink Ribbon event is free and open to the public and includes an onsite luncheon. Anyone interested in participating can reserve their spot at this event, by contacting the WBCC office at 414-963-2103 or wbcc@standupandspeakout.org. As more details about this event become available they will be published on the WBCC website, www.standupandspeakout.org.

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Era of Hope 2008: Unanswered Questions

The subtitle for the most recent Era of Hope was “Time for Action.” I thought the opening session/panel entitled “Unanswered Questions” was right on target. Christine Brunswick of NBCC was asked to tell the story of her recent diagnosis of metastatic breast cancer, seventeen years following her first diagnosis. Fran Visco, President of NBCC and co-host for the panel, challenged the scientists on the panel and asked “why is this still happening?” and “why aren’t we further along in finding a cure for breast cancer?”

Unfortunately, many of us have heard similar stories to Christine’s...family members or friends who are being diagnosed with metastatic breast cancer fourteen or fifteen years after the first diagnosis.

There are so many unanswered questions and yes, it is time for action and the time is now. Why aren’t we further along?

10th Annual Rare Chair Affair to be Held Saturday, October 10th at the Harley-Davidson Museum®

By Dawn Anderson, WBCC Program Coordinator

WBCC is excited to announce that the 10th anniversary of the Rare Chair Affair: Bid Farewell to Breast Cancer will be held at the fabulous Harley-Davidson Museum in downtown Milwaukee. Our planning committee chose the October 10th date (10/10) for our 10th anniversary to help you remember it. So mark your calendars now! Pick 10 friends to attend with you and plan to spend at least \$100 (\$10 x 10 friends)!

There will be new activities taking place throughout the evening, but the highlight of the night – the live auction of breast cancer survivors' chairs – will remain the centerpiece of all the action. New this year will be dancing till midnight after the auctions are concluded, games, and maybe even some performance art. If you've been to Rare Chair Affair in the past, but haven't come recently, this is the year to come back because it's going to be a great party!

Watch for the new Rare Chair Affair website to go live soon (www.rarechairaffair.org). You'll be able to purchase tickets, read about this year's survivor artists and our artist advisors who so generously donate their time over the summer, as well as watch the transformation of the chairs as they become works of art that will be auctioned off in October.

If you would like to donate an item for the silent auction, become a sponsor of the 10th Annual Rare Chair Affair, or purchase a reserved table, please contact us at 414-963-2103 or info@rarechairaffair.org.

Wisconsin Breast Cancer Coalition – the Value of Membership

By Rhonda Deneka, Membership Chairperson

The statistics are staggering: in the United States, 1 in 8 women will be diagnosed with breast cancer in her lifetime. In 2008, in the United States, 182,480 women were diagnosed with invasive breast cancer, 67,770 were diagnosed with non-invasive breast cancer, and 1,990 men were diagnosed with invasive breast cancer. In 2008, in the United States, 40,480 women died of breast cancer.

These statistics are not only staggering, but also unacceptable. But what can be done?

One important action that can be taken to address and change these unacceptable statistics is to join the Wisconsin Breast Cancer Coalition. WBCC is the premier organization in the state of Wisconsin that advocates on both the state and national levels for legislation and policy that will change the face of breast cancer.

WBCC membership brings you into the collective Wisconsin voice that will stand up and speak out about breast cancer. WBCC believes that all people are important and valuable. WBCC also believes that:

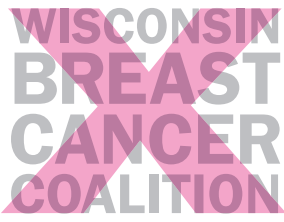
- ✗ breast cancer is a health crisis for our entire society
- ✗ all members of society share the costs – emotional, physical and financial
- ✗ inaccurate perceptions about breast cancer can be changed through education
- ✗ appropriate levels of funding for quality breast cancer research are critical
- ✗ WBCC is the vehicle to unite concerned voices
- ✗ A Collective Voice in Wisconsin WILL make a difference

WBCC membership has numerous benefits including receipt of our newsletter, invitations to all WBCC events including Rare Chair Affair, Beyond the Pink Ribbon, Wisconsin State Advocacy Day and the annual National Breast Cancer Coalition Advocacy Training & Lobby Day in Washington, D.C. More importantly, WBCC membership introduces you to some of the most energetic, compassionate, and politically savvy women and men in Wisconsin.

I know I have at least piqued your interest in membership, so here is the important follow up information:

- ✗ membership is \$30.00 annually
- ✗ to join contact WBCC at 414-963-2103 or visit the website www.standupandspeakout.org

I know you will not regret joining the Wisconsin Breast Cancer Coalition. It will change your life and also help to change the face of breast cancer in Wisconsin and the U.S.A.



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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 policy making.

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