

WISCONSIN  
BREAST  
CANCER  
COALITION



voice

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## 2<sup>nd</sup> Annual State Advocacy Day, March 12, 2008

On Wednesday March 12, a group of WBCC advocates took to the halls of the state capitol to talk to legislators about important breast cancer issues in Wisconsin:

Funding for the Wisconsin Well Woman Program (WWWP) is a priority. WWWP is the state implementation program of the National Breast and Cervical Cancer Early Detection Program. This program provides health screenings for uninsured and underinsured women who meet certain age and income eligibility criteria. Federal funding is provided by the Centers for Disease Control, but states are required to also provide funds.

In recent years, WWWP has had to make adjustments to their scope of services and age eligibility requirements in order to stay within budget constraints – demand simply outstrips what current funding can accommodate. One concern WBCC has is that the age eligibility for mammograms covered under the program was raised to 45 years old. We know that according to the American Cancer Society screening should begin annually at age 40 – this leaves a lot of women unable to get the screening recommended to detect breast cancer early, when it is most treatable. The current biennial state budget did not cut funding for WWWP, however the demand for services (as uninsured and underinsured populations grow) and the costs to provide those services continue to rise. Our goal is to ensure that all women who cannot afford screening and treatment can turn to this vital program for help.

Another priority is adequate funding for the Wisconsin Cancer Reporting System (WCRS). WCRS collects cancer incidence and survival data in Wisconsin for use by Wisconsin's Comprehensive Cancer Control Plan, public

health programs, researchers, and national organizations. This data is vital to cancer control and research in the state. The registry exists as a result of both state statutes (Chapter 255.04) and federal legislation (Public Law 102-515) as a way to facilitate the timely and accurate reporting of newly diagnosed cancer cases by hospitals, physicians, and pathology labs.

Unfortunately, Wisconsin's current WCRS staff caseload is among the highest in the nation. Funding to increase staffing is critical to meeting CDC standards. An analysis last year indicated that 7-8 new staff positions would be necessary. WBCC will explain these problems to state legislators and ask their support for fully funding the WCRS.

Prior to legislator visits, during a morning educational session, Amy Trentham-Dietz, PhD, addressed our advocates. Dr. Trentham-Dietz heads the Woman's Health Study at the UW Population Health Institute in Madison and uses WCRS data extensively in her research. Legislative Aide to Representative Sheldon Wasserman, Joseph Hoey, also addressed participants on effective lobbying in preparation for their afternoon meetings with legislators.

Our second annual WBCC State Advocacy Day began at 8:30am at the Best Western Inn on the Park across from the Capitol building. After a morning of preparation, we crossed the street in groups for our legislator meetings. Each group had an experienced advocate to lead the discussion with legislators and their aides – even those who have never done this before learned a lot! WBCC is the most active breast cancer organization in Wisconsin that visits legislators – showing them the true face of breast cancer and bringing important policy issues to them.

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## President's Letter

I have a magnet on my refrigerator that I purchased four years ago, during the last presidential election, from the League of Women Voters that says, "Smart Women Stick to the Issues!" This came along with a fun little pack of trinkets including pencils, buttons, and temporary tattoos stating "Smart Women Vote," which shocked a few of my friends...temporarily. The other day as I was preparing dinner the magnet caught my eye, "...stick to the issues". Let's stick to the issues. We can boil it down to just three issues for WBCC: breast cancer still exists, we don't know what causes breast cancer, and we don't have a cure for breast cancer. These are issues that are at the heart of everything we do in the Wisconsin Breast Cancer Coalition.

Right now there are several things we are doing to try to resolve these issues.

This time of year our Policy committee is very active in helping to educate our members and supporters on current policy and upcoming legislation. We're working on policy changes at both the state and federal level. We've just been to Madison discussing two important policies with our state legislators—fully funding the Wisconsin Cancer Reporting System and making sure there is adequate funding for the Wisconsin Well Woman program.

In order to end breast cancer we must look to research, and research is dependent on data. In Wisconsin data is the issue. You'll notice in the Breast Cancer in Wisconsin article on page 3 that the recent report issued by the Wisconsin Bureau and Health Information and Policy includes data from 2000 to 2004.

The Wisconsin Cancer Reporting System (WCRS) collects cancer incidence and survival data in the state of Wisconsin for use by Wisconsin's Comprehensive Cancer Control Plan, public health programs, researchers and national organizations. This data is the basis for much of the educational information provided to the general public. This data must be kept in a timely and comprehensive high quality manner for it to be of value to the health care professionals and researchers. Recently, reports by the Centers for Disease Control (CDC) and Wisconsin's Comprehensive Cancer Control Program revealed shortcomings at WCRS. The WCRS is understaffed, which contributes to these shortcomings. WBCC believes that without good quality data provided in a timely manner, our researchers will have a difficult time finding a cause and a cure for breast cancer.

Secondly, the Wisconsin Well Woman program, which is the state's implementation vehicle of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is inadequately funded. This program provides preventive health screenings for uninsured and underinsured women who meet certain age and income eligibility criteria. In the early 90's WBCC worked hard to get federal legislation passed to create the NBCCEDP and then to get Wisconsin to opt into the program. The number of individuals who need this program continues to increase due to the rising population, the rising cost of health care and health insurance, etc. Early detection is so important in reducing mortality rates in individuals with breast cancer. We must not let this program continue to be under-funded.

On March 12th WBCC visited our legislators in Madison to discuss these very issues. On April 29th we'll be in Washington, DC to discuss preservation of the NBCCEDP with our legislators there, along with funding for the Department of Defense Breast Cancer Research Program and enactment of the Breast Cancer Environmental Research Act.

I am proud to say WBCC, as an organization of smart women and men, is sticking to the issues. We will stick to the issues until they are resolved, until there is no more breast cancer. I look forward to the day.

*Ellen Vander Heyden*

WBCC President

## Breast Cancer in Wisconsin, By the Numbers

Wisconsin's Bureau of Health Information and Policy recently released the following data for the period of January 1, 2000 to December 31, 2004. It is important to note that only *invasive* cancers are reported in this data. *In situ* data is noted separately in the article.

✘ Breast cancer was the most frequently diagnosed cancer among Wisconsin women (30% of all cancer diagnoses), followed by lung (12%) and colorectal (12%). The average annual age-adjusted rate was 129.3 per 100,000 women. Each year approximately 3900 women were diagnosed.

✘ Breast cancer was the 2<sup>nd</sup> most frequent cancer death at 15%, followed by colorectal (10%). The number one cancer death for females was lung cancer (23%). The mortality rate was 24.5 per 100,000 women. Each year, approximately 788 women died of breast cancer.

✘ 62% of breast cancers reported between 2000-2004 were diagnosed at an early, localized stage. 28% were diagnosed at a regional stage and 3.9% at a distant stage. (Regional is defined as a tumor that has spread beyond the organ of origin to adjacent organs or tissue by direct penetration or through regional lymph nodes, or both, but appears to have spread no further. Distant is defined as a tumor that has spread to parts of the body remote from the primary organ.) 5.6% are reported "unstaged" due to insufficient information.

✘ When incidence is broken down by race: (average annual age-adjusted rate per 100,000)

- White 129.6
- African American 116.1
- American Indian 112.2
- Hispanic/Latino 91.4\* (Rate categories are not mutually exclusive from Hispanic/Latino category)
- Asian/Pacific Islander 73.3

✘ When mortality is broken down by race: (average annual age-adjusted rate per 100,000)

- African American 28.6
- White 24.3
- American Indian 18.4
- Asian/Pacific Islander 11.6
- Hispanic/Latino 7.1\* (Rate categories are not mutually exclusive from Hispanic/Latino category)

While *in situ* cancers are generally not included in reports, they are reportable. WBCC requested these rates from the Wisconsin Cancer Reporting System (WCRS), which they kindly provided.

✘ Between 2000-2004, 3,731 *in situ* breast cancers were diagnosed (averaging about 740 annually)

✘ Across all race and ethnicity groups, the highest rates of *in-situ* diagnoses were in the 45-64 age range

The NCI Cancer Trends Progress Report for 2007 provides some interesting information as well. These are national trends related to breast cancer screening, diagnoses and mortality.

Between 1987 and 2005, mammography screening rates rose until 2000 at which time they became stable for white women, while continuing to rise for other racial/ethnic groups until 2003. For all groups, the trend fell between 2003 and 2005. In 2005, only 67% of women 40 and older had had a mammogram with in the previous 2 years. This was noted as a "statistically significant" drop from 70% in 2003. When looking at the rates across race/ethnicity categories, the report states, "Disparities remain for immigrants and those with lower incomes, with less education, without insurance, and lacking a usual health care provider."

Incidence rates rose between 1980 –2001 and then began to fall through 2004. In 2004, they report 178,480 new female breast cancer cases.

The late stage or distant diagnoses rate has remained stable between 1980-2004.

Mortality rates have been falling since 1990.

NCI projects 178,480 diagnoses and 40,460 deaths from breast cancer will be reported when 2007 data becomes available.

Sources:

✘ Wisconsin Cancer Reporting System, Div. Of Public Health: a partner in the National Program of Cancer Registries, Centers for Disease Control and Prevention – ([www.dhfs.wisconsin.gov/wcrs/](http://www.dhfs.wisconsin.gov/wcrs/))

✘ National Cancer Institute (NCI) Cancer Trends Progress Report – ([www.progressreport.cancer.gov](http://www.progressreport.cancer.gov))



## National Breast Cancer Coalition 2008 Priorities Established

Again this year WBCC advocates will attend the National Breast Cancer Coalition's Annual Advocacy Training Conference and Lobby Day from April 26-29 in Washington DC. On the final day of the conference, we will be meeting with our state's representatives and senators to encourage their support of the following priorities:

- ✗ Guaranteed access to quality health care for all. NBCC has adopted a Framework for a Health Care System Guaranteeing Access to Quality Health Care for All.
- ✗ \$150 million for FY09 for the Department of Defense Breast Cancer Research Program. Over \$2 billion has been invested in this highly regarded, innovative research program since its inception.
- ✗ Enactment of the Breast Cancer and Environmental Research Act (S57/HR1157), which would establish a national strategy for investigating the impact of environmental factors on the development of breast cancer. This bill has had very strong bi-partisan support for years and is overdue for passage.
- ✗ Preservation of the Medicaid Breast and Cervical Cancer Treatment Program, which provides enhanced matching funds to states to provide full Medicaid coverage to low-income, uninsured women screened and diagnosed with breast and/or cervical cancer through a federal program. (In Wisconsin, this is the Well Woman Program, see above article on our State Advocacy Day for more information on this program in Wisconsin.)

For more details on these priorities, visit the National Breast Cancer Coalition's website at [www.stopbreastcancer.org](http://www.stopbreastcancer.org) and go to the Advocacy in Action link.

## Photos from NBCC Annual Advocacy Conference 2007



WBCC Members with NBCC president, Fran Visco



WI delegates during a meeting at Senator Kohl's office



WI delegation with Senator Feingold



WI delegates meeting with Representative Moore



WBCC members at NBCC Conference Dinner



Kathleen Harris leads WBCC in preparing for Lobby Day 2007



Vida Mathews and Phillis Holder during lunch on Lobby Day 2007

## The Wisconsin Comprehensive Cancer Control Program & Wisconsin Cancer Council – 2007 Highlights & 2008 Projects

*Amy Conlon Program Director, WI Comprehensive Cancer Control*

2007 was a busy and productive year for Wisconsin's Comprehensive Cancer Control (WI CCC) Program. The 4<sup>th</sup> Annual Comprehensive Cancer Control (CCC) Summit was held in Milwaukee in April with an emphasis on Cancer Health Disparities, featuring keynote speaker Harold Freeman. In October the University of Wisconsin's 6<sup>th</sup> Annual Symposium Advances in Multidisciplinary Cancer Care was held in Madison. The symposium was co-sponsored<sup>2</sup> with UW Paul P. Carbone Comprehensive Cancer Center and focused on Survivorship issues. Both had their largest attendance records to date.

The Wisconsin Cancer Council (WCC) experienced a significant growth in 2007, with over 15 new organizations joining, enhancing the diversity of membership as well as strengthening the partnership among the various organizations. There are now over 50 statewide and regional or local organizations that serve on the WCC. The WCC is currently working within the WI CCC Program on education, outreach, public policy, and system change. In 2007, specific policy issues included tobacco control, cervical cancer prevention, promotion of "Nick's Law" and enhancing the WI Cancer Reporting System.

Several CCC projects were implemented and funded within the WI CCC Program in 2007. The Healthy Lifestyle grants, completed in July provided 6 grants to local Nutrition and Physical Activity Coalitions to improve nutrition and increase physical activity through the establishment of worksite wellness programs. In working with the WI Primary Health Care Association, federally qualified health centers have started collecting data on cancer screening which will be used to measure system based quality improvement efforts with each health center. An Assessment of

Cancer Care and Satisfaction (ACCESS) Survey was completed by individuals with cancer and their family members in Wisconsin with an overall response rate of 67.7%. This data will be analyzed in 2008.

In 2008, the WI CCC Program will continue working and completing previous years' projects as well as developing new ones. The Milwaukee Regional Cancer Care Network (MRCCN)<sup>3</sup> Leadership Team will present a strategic plan to the Network on how to improve access across regional health systems. In addition, three taskforces have been developed to look at specific areas of cancer: colorectal, palliative care and clinical trials. Continuing also in 2008, will be Surveillance Briefs. Possible topics in 2008 for Surveillance Briefs include updates on targets from the Plan and an online cancer risk factor tool. For more information on the WI CCC Program and/or the WCC, please view the following website: [www.wicancer.org](http://www.wicancer.org).

#### Notes:

- 1 Amy Conlon is a member of the WBCC Collective Voice Advisory Panel. We would like to thank Amy for this update.
- 2 WBCC also co-sponsored this event in Milwaukee.
- 3 WBCC is an active participant on the MRCCN.



*WBCC members who participated in strategic planning and implementation of Wisconsin's Comprehensive Cancer Control Plan.*

### Honorariums

- ✕ Kate Fitzwilliams in honor of Georgia Fitzwilliams – "Still Going Strong!"
- ✕ Terri Chelmowski in honor of Lisa Marie Arnold
- ✕ William Cohen in honor of Robert Cohen
- ✕ Beth Reidenbach in honor of Laura Goman
- ✕ Mr. And Mrs. Leonard Goldstein in memory of Sherry Kohlenberg – a donation to the Sherry Kohlenberg Scholarship Fund
- ✕ Adunate Word & Design in honor of Sally Davis
- ✕ DeMars & Associates in honor of Jo DeMars
- ✕ William Scherbarth in honor of Kathy Scherbarth and Patricia Henke

## Beyond the pink ribbon.™ Advocacy Training April 12, 2008

Building on the great success of our 2007 training, we are proud to expand this program to the Racine area on Saturday, April 12 at the Roma Lodge.

First Congressional District Representative, Congressman Paul Ryan, will kick off this educational event as our keynote speaker. Congressman Ryan is scheduled to address participants about health care access issues. This will provide a jumping off point for a panel discussion on how citizens can participate in the process of policy change by being well-informed advocates for change. Confirmed panelists at press time include State Senator John Lehman; State Assemblyman Cory Mason; Barb Tylenda, Director of Healthcare Network; and Janelle Grammel, Racine Public Health Administrator.

Following a luncheon, break out sessions will be offered on topics ranging from participation in WBCA Advocacy Days to genetics and the science of breast cancer.

All participants will receive a WBCA Advocacy Tool Kit with information on how to contact state and federal representatives, sample scripts and letters, and tips for productive communications with legislators and their aides.

You don't want to miss this unique and educational event. Call 414-963-2103 or email [wbc@standupandspeakout.org](mailto:wbc@standupandspeakout.org) to register.



*WBCA delegates during a previous Beyond the pink ribbon event preparing for the 2007 trip to Washington, DC.*



*Congressman Ryan with WBCA delegates in 2006.*

## Volunteers Needed

WBCC is looking for volunteers in different parts of the state who might be our coordinators in those areas. Ideally, we would like a lead volunteer in each congressional district, to do outreach in their communities, making residents aware of WBCC's mission and grassroots legislative alert network. Volunteers would represent WBCC at local health fairs/events and speaking opportunities and provide us with feedback from residents in the area about issues of concern related to breast cancer. Training and materials will be provided. If you are interested in becoming an active volunteer for WBCC, please contact us at 414-963-2103.

## Book Review

**Bazell, R. (1998). Her-2: The Making of Herceptin, a Revolutionary Treatment for Breast Cancer. Random House Publishing Group.**

Robert Bazell presents a riveting account of how Herceptin was born. Her-2 is a story of dramatic discoveries and strong personalities, showing the combination of scientific investigation, money, politics, ego, corporate decisions, patient activism, and luck involved in moving this groundbreaking drug from the lab to a patient's bedside. Bazell's deft portraits introduce us to the remarkable people instrumental in Herceptin's history, including Dr. Dennis Slamon, the driven UCLA oncologist who played the primary role in developing the treatment; Lily Tartikoff, wife of television executive Brandon Tartikoff, who tapped into Hollywood money and glamour to help fund Slamon's research; and Marti Nelson, who inspired the activists who lobbied for a "compassionate use" program that would allow women outside the clinical trials to have access to the limited supplies of Herceptin prior to FDA approval of the drug. And throughout there are the stories of the heroic women with advanced breast cancer who volunteered for the trials, risking what time they had left on an unproven treatment. Meticulously researched, written with clarity and compassion, Her-2 is masterly reporting on cutting-edge science.

## Save a Tree

Would you prefer to receive your quarterly newsletter electronically? You can help us reduce our printing and postage costs, and still be kept informed on current breast cancer issues – contact us at [wbcc@standupandspeakout.org](mailto:wbcc@standupandspeakout.org) if you would prefer a pdf version of "Collective Voice".

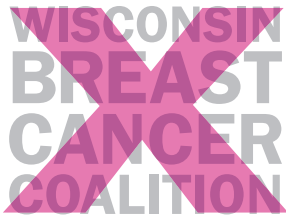
## Are You a WBCC Member?

Many of our newsletter recipients are members of WBCC, many are not. If you are not a member of WBCC, would you consider joining us in 2008? For a \$30 annual membership, you will continue to receive our quarterly newsletter, will receive advance-mailing notices for events, and will have the opportunity to elect new and continuing board members each year. Most importantly though, you will be helping us continue our mission with your financial support. Join us now, and we will send you a free WBCC Beyond the pink ribbon t-shirt. Call 414-963-2103 or you can join online at [www.standupandspeakout.org](http://www.standupandspeakout.org), just click on the Membership button.

## It's Almost Tax Time

Which means you have TWO opportunities to make donations to help fight breast cancer:

Support WBCC by making a tax deductible donation AND make sure you use the check-off box on your WI state tax form to make a donation to the Wisconsin Breast Cancer Research Fund. Proceeds go to the Medical College of Wisconsin and the UW Comprehensive Cancer Center for new breast cancer research grants. WBCC worked hard to see passage of this legislation several years ago and we want to be sure the program continues with your support.



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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.

### TO CONTACT WBCC

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# STAND UP

and  
speak  
out

## Up Coming Events

### Save the Date for Rare Chair Affair '08!

Mark your calendars now for the 9<sup>th</sup> annual Rare Chair Affair on Friday, September 26<sup>th</sup> at Brynwood Country Club. The 2007 event raised over \$50,000 to support WBCC programming initiatives and we hope to top that this year! We are currently looking for volunteers to assist with the silent auction, work with survivor artists, and staff the check in and check out (computer expertise very helpful for this job). If you'd like to be a part of our dynamic planning committee, please contact WBCC Program Coordinator, Dawn Anderson at 414-963-2103.

### June Horse Show to benefit WBCC

Bit n Bridle Stables in Onalaska, near La Crosse, will be hosting a horse show on Sunday June 8<sup>th</sup> with all proceeds benefiting WBCC. Owner Julie Harter does several benefits annually for area groups, but having lost a family member recently to breast cancer, wanted to do something that would increase awareness for the disease. We encourage members and supporters in the western part of the state to contact us if they would like to volunteer with us either the day before or day of the show.

### Cedarburg Wearable Art Show

This event on April 4-5 benefits breast cancer education, prevention, and treatment and features vendors selling clothing, jewelry and handbags. The accompanying Pink Tie Affair is on Friday evening and the 3<sup>rd</sup> annual Bosom Buddy Walk in historic Cedarburg starts Saturday at 9am. For additional information or to purchase tickets to the Pink Tie Affair, please contact Haley Hill 262-376-9978 or Amy McConeghy 262-375-4319.