



voice

VOLUME 10, NO. 2 SUMMER 2011

"Ending Breast Cancer: A Baseline Status Report" from the National Breast Cancer Coalition

Before we can begin to "change the conversation" about breast cancer, it's vital that we have a clear understanding of where we're at. NBCC's recently released "Baseline Report" provides a snapshot of the current state of breast cancer. It will be updated annually to track our progress towards achieving Breast Cancer Deadline 2020[®]. Here are some highlights from the report:

- ➤ In 2010, in the United States, it is estimated that 261,100 women and 1,970 men were diagnosed with breast cancer. 39,840 women and 390 men died of the disease. That is one death every 14 minutes.
- ✓ In 1991, in the United States, 119 women died of breast cancer every day. In 2010, that number was 110. If we continue making progress at this rate it will take us a few centuries to end breast cancer.
- ★ The National cost of cancer care in the U.S. in 2010 was estimated to be \$124.6 billion, with female breast cancer leading all cancer sites at \$16.5 billion.
- × 5 year survival statistics don't tell the whole story and can be misleading. Survival rates, commonly used in the media and by policy makers, only calculate the number of women who are alive 5 years from diagnosis. The more we screen, the higher this number is, but it is not an endpoint. "It is estimated that 20-30% of breast cancer patients will have a recurrence and may die of the disease, but they are included as survivors in the fiveyear survival statistics. Between one-half and two-thirds of American women diagnosed with Stage II and Stage III breast cancer will develop metastatic disease within 5 years of diagnosis, though they may still be alive and considered "survivors" at five years." Mortality statistics more accurately tell the story of progress in saving lives.
- Most of the know risk factors for breast cancer are not modifiable: Age, family history, breast density and age at menarche/menopause.
- "For every 2,000 women screened over a 10 year period, one will have her life prolonged (not necessarily saved) and 10 healthy women

- who would not have been diagnosed without screening will be treated unnecessarily."
- "The absolute risk of a woman dying from breast cancer is less than 1% without screening."
- "An estimated 30% of all breast cancer cases (both invasive and DCIS) are considered to be overdiagnosed and overtreated. Many of the tumors that are found "early" would not have become life-threatening metastatic cancers and unfortunately, some of the treatments for these "early" cancers themselves have lifethreatening side effects."
- "The increase in incidence of DCIS as a result of mammography has resulted in overtreatment for many women, without a concurrent decrease in incidence of later stage diagnoses." Much is still unknown about the natural history of DCIS (abnormal cells contained within the milk ducts) which could regress or do no harm if left alone, or, which may become invasive and therefore life threatening.
- "Women do not die of primary disease. Over 90% of breast cancer deaths are due to the spread of the disease to other parts of the body. While we want to believe we have made significant progress in saving lives, that is not the case. The incidence of women diagnosed with advanced breast cancer has not changed. Rates of diagnosis of truly lethal disease have remained stable since 1975."
- More than a billion dollars is invested in breast cancer research each year in the U.S. alone. However, more than 40 years and billions upon billions of dollars have not ended breast cancer. "The current system is perfectly designed to be cautious and incremental."

in this issue

Breast Cancer
Deadline 2020®

page 3

DOD Breast Cancer Research Program

page 4

NBCC Annual Advocacy Training Conference

page 5

Vitamin D Deficiency & Breast Cancer

page 7

NBCC's 2011 Legislative & Public Policy Priorities **Insert**

president

Rhonda Deneka

vice president

Jo DeMars

treasure

Andy Gutierrez

secretary

Colleen Booth

board directors

Kris Miller Phyllis Holder Kathleen Harris Hannah Harris Denise Harris Ann Aschenbrenner

executive director

Dawn Anderson

founding members

Linda Kohlenberg Irwin Elaine Nelles Karla Tildahl

volunteer administrative assistant

Jean Rosenberg

Moving? Please send your address changes to:

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

or email: wbcc@ standupandspeakout.org

President's Letter

Hello, all. I hope you are enjoying the long awaited summer here in Wisconsin. In my last letter to you, I touched briefly on the National Breast Cancer Coalition's 10 year goal – Deadline 2020. After attending the NBCC Annual Conference and Advocacy Day April 30 to May 3, 2011, I along with the rest of the WBCC delegation, learned much more about this ambitious and gutsy campaign!

Basically, Deadline 2020 is a focused campaign to end breast cancer by January 1, 2020. NBCC believes that we cannot afford to continue along the path we have followed for the past 40 years, as it has not led us anywhere near the goal of ending breast cancer. Deadline 2020 is a "call to action" and a strategic effort that will effectively refocus the evaluation of current research, of healthcare priorities, of funding mechanisms and of advocacy efforts.

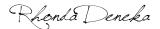


It is understandable that the general public believes that there

has been progress made in ending breast cancer, as much attention and resources have been directed at the disease. Many organizations and public health officials have focused attention on early detection and breast cancer awareness campaigns as the primary ways of addressing breast cancer. And despite the billions of dollars spent on breast cancer research over the past 20 years, we still know little about how to prevent breast cancer or how to prevent individuals from dying from it.

Deadline 2020's purpose is to "create a paradigm shift in the breast cancer world – in government, in the media, research, and advocacy – to refocus resources and efforts to the areas that lead us to the goal of ending breast cancer." NBCC has begun to launch a number of activities to focus on breast cancer prevention and the causes and prevention of metastases. In support of NBBC's efforts and as an organizational member of the NBCC Board of Directors, WBCC will be focusing our work and educational offerings in the coming months on moving "Beyond the Pink Ribbon" to end breast cancer by 1/1/2020.

I urge you to go to BreastCancerDeadline2020.org/ProgressReport to read more about NBCC's progress toward this goal. I also encourage you to read more about WBCC's concurrent efforts in this newsletter and to ask me or other WBCC Board members about how you can become an active participant in this revolutionary campaign!





Save the Date

National Breast Cancer Coalition Annual Advocacy Conference Washington, DC May 5 - May 7, 2012



What Does Breast Cancer Deadline 2020® Mean to You?

Kelly Herda – Bayside

Having both my mother and grandmother lose their battle with breast cancer was not only heartbreaking, it was also very traumatizing. They were both diagnosed in their early 50's and I, at 49, worry that I will be the next woman in my family to be diagnosed. It is a horrible feeling to live with -waiting to hear those dreaded words - but that's my reality. Breast Cancer Deadline 2020 gives me the hope that this fear won't be passed on to my daughters. They will know the causes of this disease, so they can take preventive measures; and, if ever diagnosed, there will be treatments to cure it."

Laura Stratte - Whitefish Bay

I was diagnosed with breast cancer three years ago, when my kids were 2 and 5 years old. When you are faced with a cancer diagnosis, you start to think of your mortality in very real terms. I knew my husband could get by if I died from the disease. My parents, siblings, and friends – they would all be OK, too. But my kids – my kids – they need me to be here, to be alive and healthy, to be their Mom.

Three years later, I'm doing fine. I made it through treatment without complications and have no evidence of disease. But every night I go to bed with the thought, "Please don't let the cancer recur tomorrow - my children need me here." I am constantly on alert. Every cough, headache or unusual physical symptom makes me pause with the realization that a metastatic recurrence is a very real possibility.

The Breast Cancer Deadline means that I am up against a clock. If I make it to January 1, 2020 without a recurrence, I am home free. After that, researchers will have either figured out a way to prevent metastasis outright, or cure it if it does occur. The Breast Cancer Deadline means the end of my vigilance and more importantly, the assurance that my kids will have their Mom around for a long time.

Almost everyone in this country has been affected by breast cancer in some way. If you are no longer satisfied with the status quo of watching more than 3 million women and men in the U.S. alone suffer from a diagnosis of breast cancer and far too many lose their lives from this disease, join us. Let us know how Breast Cancer Deadline 2020® will affect your life or the lives of your loved ones.

We want to hear from you: "What Breast Cancer Deadline 2020® means to Me." Your written response can be a few sentences but no more than 150 words. Please include your name and city with your submission. We will make every effort to print all responses in this newsletter and/or post on WBCC website. Responses may also be shared with the National Breast Cancer Coalition (NBCC).

Send an email, or a video to wbcc@standupandspeakout.org. We will periodically share these with supporters through our newsletter, website, and social media.







Your organization can endorse the Breast Cancer Deadline by contacting us or by going to the NBCC website. We are happy to welcome the Young Survival Coalition of Milwaukee to the list of Wisconsin organizations endorsing the Deadline.

William Jefferson Clinton, 42nd President of the United States, Endorses Breast Cancer Deadline 2020 campaign

In his endorsement, former President Clinton says: "...despite all our trying, breast cancer continues to take too many lives every year. It's time to give breast cancer a deadline. That's why I applaud the National Breast Cancer Coalition for the courage to launch this ambitious campaign to end breast cancer by 2020. The stakes are too high, the losses have been too great to let another decade go without a cure."

To hear more about what former President Clinton had to say about Breast Cancer Deadline 2020, go to BreastCancerDeadline2020.org.



Environmental Toxins and Breast Cancer

Hannah Harris

At the annual National Breast Cancer Coalition's Advocacy Training in Washington, DC, I attended a workshop that I'm still thinking about to this day. The presenter was Dr. Julia Brody, Executive Director at of the Silent Spring Institute. She talked about the effect of toxins on our health; how exposure to toxins can cause breast and other cancers; and how the negative effect of toxins on our bodies is cumulative, making it particularly important to reduce or eliminate children's exposure to toxins. Here's an example. Many households and companies apply a weed-and-feed or have their lawns sprayed with herbicides to kill weeds. Even after the little white sign says it's safe, there are still carcinogenic chemicals on the grass. So when we walk on these lawns and then into our houses with our shoes on, we bring these chemicals into our home environment. As a result, anyone who lives in our home (people, pets) is exposed to these toxins. So, in this case, the solution is to avoid using chemicals to treat your lawn, stay off of others' lawns that are chemically treated, and leave your shoes at your door.

The Silent Spring Institute has a wealth of information about what steps you can take to lessen your exposure to harmful chemicals. "Some changes are complex and can only be achieved through

attention to public policy. But other choices are simple. They empower us as individuals to protect our health and to make our homes as safe from environmental toxins as possible." The "Take Action" section of their website offers concrete suggestions for taking action on individual, community, and national levels. For example, you can learn how to take individual action in your personal care (e.g., lotions), in what you eat and drink (e.g., organic), in your selection and care of clothing, in your home (e.g., cleaning products), in your yard and garden (e.g., pesticide and herbicides), in your parenting, and in your approach to life. It's overwhelming, I think, to learn about all of the toxins we are exposed to. It makes me want to go live on the top of a mountain next to a glacier-fed lake. Since that isn't going to happen, I'm content with learning how I can make changes to how I care for our lawn, the food and products I buy for my family, and small changes, like always taking shoes off before walking through our house. Funny thing about that last one -- I grew up in a house where you keep your shoes on, so that one simple step is proving challenging for me!

Resources:

www.silentspring.org | www.silentspring.org/breast-cancer-and-environment/fact-sheets/reducing-your-exposure-toxics www.healtylawnteam.org (based in Madison)

DOD Breast Cancer Research Program: Victory in the House

Kathleen Harris, NBCC Field Coordinator-WI

On July 8th, Fran Visco, President of the National Breast Cancer Coalition (NBCC), reported: "The news is good! Just a few hours ago the FY 2012 Defense Appropriations bill passed the House of Representatives overwhelmingly with the \$120 million for the Department of Defense Breast Cancer research Program (DOD BCRP) intact."

Fran thanked all of the NBCC advocates, which includes WBCC Team Leaders, District Leaders and alert network members, who worked hard over the last several weeks to ensure this funding remained secure.

Action on the Senate Defense Appropriations bill is anticipated in September. We are prepared to once again gear up our advocacy efforts another notch to face the many challenges ahead.

NBCC Team Leaders are: Bonnie Anderson (Milwaukee), Dawn Anderson (Shorewood), Kathleen Harris (Fox Point), Rhonda Deneka (Racine) and Kris Miller (Green Bay).

Changing the Conversation: NBCC Annual Advocacy Training Conference 2011

Dawn Anderson, WBCC Executive Director

On the heels of the announcement last fall of a revolutionary new approach to end breast cancer, the National Breast Cancer Coalition hosted its Annual Advocacy Training Conference to prepare us all for the task of changing the conversations and the systems that will help us reach that goal.

Over 700 women and men gathered in Arlington, Virginia for three days of plenary sessions and workshops that addressed current controversies and issues around breast cancer science and research, explored the contexts in which we'll have to work in order to change conversations, and helped us create action plans to do so in our own states.

What does it mean to "change the conversation"? It means moving beyond talking about pink ribbons and mammograms. It means saying "awareness" isn't enough. It means pointing out that the incremental improvements we've seen in mortality rates aren't enough.

In her opening remarks, NBCC President Fran Visco highlighted the difference between "Accomplishments" and "Success". We've certainly had accomplishments – but that expanded knowledge of the biology of breast cancer hasn't translated to "success" in ending the disease. It's not enough for us to be satisfied with new therapies that extend lives by a month or two, at great physical and monetary costs.

The Deadline is focused on success. All of our efforts must be focused on changing the conversation from screening and awareness to prevention of metastasis and primary prevention. In the opening plenary on "What's New in Breast Cancer?", NBCC Board member and co-founder of the Young Survival Coalition, Joy Simha pointed out that "there's been nothing big since Herceptin. The culture is invested in maintaining the status quo" and so we've seen "miniscule" progress. On the same panel, Dr. Susan Love affirmed this sentiment, saying that much promising research doesn't get done because scientists chose to work by what's fundable, shareholders in pharmaceutical companies are "risk averse" and NIH (National Institutes of Health) doesn't fund anything really NEW because it's too risky.

In the plenary on "Barriers to Success", panelists explored the problem of mainstream media and how it plays an important role in creating the perceptions of the public about the "war on breast cancer". The main message in the press for 30 years is that things are going well due to early detection through screening. This sounds great until you consider that more screenings means finding more "cancers" – many of which may not have been lethal – and that detection, through screenings, of advanced disease has not changed. The media also have reported extensively on "prevention" and/or "risk reduction" through exercise and diet. As panelist Sharon Begley of Newsweek said, this suggests, "it's on you to prevent breast cancer", and in effect, because that's what we believe, we let researchers off the hook for more in depth research. "Mammograms and broccoli won't do it," she says.

The press, she says, needs to focus on what more needs to be done – the reality of where we're at. When the public gets more of that message, perhaps they will have a better understanding of how little progress we've really made in saving lives. Closing thoughts from panelist and NBCC Board Member, Shirley Brown, summed things up by reiterating that we must focus on the right things in order to end breast cancer, and to do so there must be collaboration – the cancer community cannot continue to "work in silos".

Later in the day, NBCC Director of Research, Laura Nikolaides, gave some examples of the kinds of innovation that are not moving us forward. Mammotome, a market leader in vacuum assisted breast biopsies had revenue of just under \$200 million in 2009 - despite most biopsies being negative. Identified as a "top stock pick" in 2009, Hologic's newly FDA approved Selenia Dimensions System is the first 3 dimensional mammogram devise. There is no evidence that it will save lives, and exposes women to more radiation than traditional mammograms. Avastin is forecast to make \$9.2 billion despite set backs in clinical trials and the recent decision by the FDA to repeal its approval for use in advanced breast cancer. Nikolaides says "What we need is disruptive innovation... We have to engineer the innovation we want and be bold about it. We can't wait for something to appear out of mountains of data. We need to find the right people and the right path to be successful."

Day 3 began with a plenary session on Prevention and Metastasis. This is where the conversation starts! Julia Brody, PhD, Executive Director of the Silent Spring Institute emphasized the correlations between environmental toxins and breast cancer risk, pointing out that the risk of developing breast cancer is five times higher in the United States than in other industrialized countries and that we need to look at and act on the strength of biologic evidence, not human "proof". Human studies for environmental exposures all have limitations (we've all been "exposed", for instance, so there is no control group) and breast cancer causation is multifactorial, across our lifespans. Most of the chemicals with "relevant" biological activity have not been tested in a human breast cancer study – so is it "better to be safe than sorry"? Or do we treat these chemicals as "innocent until proven guilty"? Policy change through legislation like the Safe Chemicals Act is one way to address the problem.

Dr. Peter Lee of Stanford University is doing research on immune cells and how they might be used to develop a preventive vaccine. NBCC is already conducting workshops on the development of a vaccine (The Artemis Project) and has a goal of having one ready for clinical trials in 5 years. Dr. Lee noted research that showed that 22 years after treatment, 1/3 of breast cancer patients still had circulating cancer cells. The question is what's stopping them all from becoming metastases? Can we harness our own immune system to prevent or eradicate metastasis through vaccine?

Changing the Conversation:

Article continued from page 5

The final plenary session focused on changing the conversation with policy makers. We know that without support from the government, the goal of ending breast cancer will not be achieved. All stakeholders – advocates, media, researchers, scientists and policy makers – must support the plan. The problem is that the extreme partisanship that currently exists has the potential to slow us down. We must and will find ways to make our voices as consumer advocates heard. We will convince whoever needs convincing that breast cancer is not a partisan issue.

As advocates, we have a big job ahead of us. We will work for necessary changes in the way breast cancer is portrayed in culture, science, the media, and policy. We will insist – by changing the conversations had in those contexts – that the focus be on ending breast cancer. Not finding more of it. Not making people more "aware" of it. Not passing meaningless resolutions and legislation. Not lighting things up in pink. Not

spending precious resources on research that doesn't help us find a way to prevent it. As the saying goes, we'll be "keeping our eyes on the prize." The Prize of course, being the end of breast cancer by 2020.

The WBCC is proud to be an endorsing organization of Breast Cancer Deadline 2020[®]. You'll hear a lot more about it from us over the next year. Will you be with us?

Are you, or your organization, interested in officially endorsing Breast Cancer Deadline 2020®? Please contact our office for details. wbcc@standupandspeakout.org. We will regularly be publishing our list of endorsers.

For more information on the Deadline campaign or the Annual Advocacy Training Conference, please visit the NBCC website at www.breastcancerdeadline2020.org

Come One! Come All! The Circus is coming to town! Rare Chair Affair 2011 – Friday, October 14

Remember how much fun you had at the circus when you were a kid? Join us for Rare Chair Affair 2011 and take a little trip back in time!

Our fantastic Rare Chair Affair committee and event planner extraordinaire, David Caruso of Dynamic Events, are working on an old time circus atmosphere that'll have you craving cotton candy and a trip to the kissing booth! (No scary clowns - we promise!) Mark your calendars now for Friday, October 14 and join us at the historic Pritzlaff Building in downtown Milwaukee for a fabulous evening of auctions, entertainment and a raffle for a special piece being created just for us by renowned Milwaukee artist Reginald Baylor!

Of course, the stars of the show will be the Survivor Artists - who this year, for the first time ever, are creating MORE THAN JUST CHAIRS! There will be tables, mirrors, dressers - even a bar on wheels! So if you've got more chairs than you can use - we hope you'll join us, and our good friend Ringmaster/Auctioneer Dan Pronley, in some super high bidding to support the efforts of WBCC to end breast cancer. Watch for more information soon on the Rare Chair Affair website – www.rarechairaffair.org.









Breast Cancer in the News

Kathleen Harris

FDA Upholds its Decision to Remove Breast Cancer Indication from Avastin

On June 29, 2011, the U.S. Food and Drug Administration (FDA) upheld its former decision to remove the breast cancer indication from the drug Avastin for women with metastatic breast cancer. The decision was based on the results of randomized clinical trials and the fact there is not enough evidence Avastin is safe and effective for this one indication. In addition, there is evidence of increased risk of serious harmful side effects with the use of this drug.

July 28, 2011 is the deadline to file additional written submissions on the use of Avastin for metastatic breast cancer. The final decision will then be made by Commissioner Hamburg.

More Evidence Links Vitamin D Deficiency to Breast Cancer

The ASCO Post; issue July 1, 2011. Caroline Helwick, June 15, 2011

Patients with breast cancer and deficient levels of vitamin D are more likely to have aggressive tumor profiles and unfavorable prognostic markers than women with optimal levels of vitamin D, according to research presented at the 12th Annual Meeting of the American Society of Breast Surgeons, held in Washington, DC.

The study,conducted at the University of Rochester Medical Center, is one of the first to examine vitamin D and breast cancer progression. Lead researcher Luke J. Peppone, Ph.D., M.P.H., commented, "Based on these results, doctors should strongly consider monitoring vitamin D levels among breast cancer patients and correcting them as needed."

What is DOD and Why Do You Want To Be A Part Of It?

Valeria Spinner-Banks, Breast Cancer Survivor for 21 years first time - 18 years second time

The Department of Defense Breast Cancer Research Program (DOD-BCRP) is the brainchild of NBCC. Why is it important? It is important because it gives faces to the people that scientists are researching cures for in their labs. Why should I be a part of this what benefit will I get from this by attending a session? Let's look at these questions and try to really get an understanding about DOD and BRCP.

When I was first approached to be a part of DOD, it was very intimidating since I had no science background. I found it difficult to read the proposals and to understand what it was that the scientists were asking for. I felt that I would be laughed at and maybe say the wrong things in the sessions. What I found out was that the scientists really wanted to hear what I had to say and I really could make a difference in the way they look at the research. I have been active with DOD since 2000, and each time that I do a session I feel more and more confident. To be able to voice your opinion and have it count is very empowering. As breast cancer survivors we have to be strong if we are to beat this disease and we also have to be able to voice our opinions and thoughts on what we believe would help the breast cancer community. That's what we are, a community of survivors that want and need answers about how to cure this disease that is taking a life every hour of every day.

Given a chance to sit with researchers and scientists that are deciding what would work for our community means that we also

must be at the table to speak for those who cannot speak. We are not consumers for nothing. It means that they have a product they must sell and they have to convince us that this product will help us to live and also cure us. This cannot be done unless we are willing to be present at the table to voice our opinions about whether or not we feel that this product will work for us within the breast cancer community. Is it hard work, yes it is, but it is work that has to be done if we are looking for a cure to end breast cancer by 2020. Just the other day I said to my Oncologist, Gynecologist that we are looking for a cure to breast cancer by 2020 and he said good luck. I said to him you need to help us not mock us and we need you to be a voice for us and hold the people that are in the labs accountable to find a cure for this disease that is killing us. He stopped and said, you are right, we all need to be held accountable for what we do for our patients. If I can convince one doctor to stand up and be accountable to his or her patients then I can convince the scientist and the researchers to be accountable also. This is why we get involved with DOD so that we can hold their feet to the fire and say loud and clear you will not get money for research if you don't try to look for a cure that will work. Use us, not mice, for clinical trials. Even if we don't make it, then the next generation will.

If someone is asking you to be a consumer for DOD, do it. You will be able to help someone, if not yourself, and you will come away feeling proud that you had a hand in deciding what research could really help the breast cancer community.



standupandspeakout.org / po box 170031 milwaukee wi 53217-0031

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

414.963.2103 888.295.2622 wbcc@standupandspeakout.org



NBCC's 2011 Legislative and Public Policy Priorities

PRIORITY #1:

Accelerating the End of Breast Cancer Act: On September 20, 2010, NBCC launched Breast Cancer Deadline 2020®, a call to action for policymakers, researchers, breast cancer advocates and other stakeholders to end the disease by January 1, 2020. The Accelerating the End of Breast Cancer Act, which has not yet been introduced, will provide a strategic approach to address questions NBCC has identified as vital to end the disease; identify barriers which hamper progress; and set forth a mission-oriented, transparent and focused process to help overcome these barriers and meet the goal of Breast Cancer Deadline 2020®.

PRIORITY #2:

Guaranteed Access to Quality Care for All: For many years now, NBCC has made access to quality health care for all a top priority. The "Patient Protection and Affordable Care Act" passed last year represents a significant step forward towards this goal and provides many important protections for breast cancer survivors. Repealing or invalidating this law would have many direct consequences for breast cancer survivors.

PRIORITY #3:

\$150 Million for the Department of Defense Breast Cancer Research Program (BCRP)

As a result of NBCC's grassroots advocacy, the DOD BCRP was created in 1992 to "eradicate breast cancer by funding innovative, high-impact research through a partnership of scientists and consumers." NBCC seeks continued level funding for this successful program.

PRIORITY #4:

Preservation of the Medicaid Breast and Cervical Cancer Treatment Program: Congress enacted the Breast and Cervical Cancer Treatment Act in 2000 after years of NBCC grassroots lobbying and influence. NBCC remains committed to ensuring all women and men screened and diagnosed with breast cancer through federal screening programs have access to the treatment they need.

PRIORITY #5:

Ensuring the Participation of Educated Patient Advocates in all Levels of Health Care Decision Making: NBCC continues to work to ensure that educated patient advocates have a "seat at the table" in all levels of health care decision making that affects their lives.

NBCC's Call To Action

NBCC's mission is to eradicate breast cancer by designing and acting on effective strategies addressed to the administration, Congress, research institutions and health care providers to end this disease. The Coalition informs, trains, and directs patients and others in effective advocacy efforts. Nationwide, the women and men who have been trained are shaping breast cancer public policy by participating in legislative, scientific and regulatory decisions; promoting critical analysis of breast cancer information, media coverage and actively working to change all systems that affect our mission to eradicate breast cancer.

Find out how you can sign up and act now! Go to: BreastCancerDeadline2020.org and to participate locally, go to Wisconsin Breast Cancer Coalition website: www.standupandspeakout.org







State Policy Updates

On June 8, WBCC advocates conducted nearly 40 appointments with the legislative offices of key members on the Finance, Insurance, Health and Public Health committees. Our priorities for 2011 are:

#1 - Ensure access to breast cancer screening and treatment for uninsured and underinsured women

Thousands of women in Wisconsin rely on medical assistance programs to access mammograms – either for screening or diagnostic reasons – and treatment of their breast cancer if they are diagnosed. Access to those programs was and continues to be threatened in the state budget. Funding for the Wisconsin Well Woman Program (WWWP), which provides free breast and cervical screenings for underserved women, was spared the 10% cut originally proposed. However, the Finance Committee and Legislature, by passing the budget bill, gave virtually unchecked power to the Secretary of Health Services, Dennis Smith, to reduce spending on medical assistance programs by \$466.6 million in the fiscal year 2011-13. He may make these changes with out public hearings and without approval of the legislature. It remains to be seen where Secretary Smith will make those cuts. He may also make changes to eligibility for programs, restrict or eliminate presumptive eligibility for Medicaid coverage (critical for a woman who has received a diagnosis and needs to start treatment promptly) and other policy changes that could potentially limit access. WBCC will continue to follow Secretary Smith's actions, as are several state health advocacy organizations.

#2 - Oral Chemotherapy Access Act (SB101/AB151)

Intravenous or injected chemotherapy treatments are typically covered under a health plan's medical benefits. Orally administered anti-cancer medications, however, are typically covered under a health plan's pharmacy benefit and are classified in the highest tier of a health plan's cost sharing system, requiring patients to pay much higher co-payments amounting to thousands of dollars each month. As a member of the Wisconsin Coalition on Cancer Treatment Access, the WBCC is urging support for this legislation, which will prohibit state regulated plans for requiring patients to pay a higher co-payment, deductible, or co-insurance for oral chemotherapy than is required for injected chemotherapy.

#3 - WI Comprehensive Cancer Control Program and Plan

WBCC has supported appropriate funding for the WCCCP for a number of years. This plan, which is produced by hundreds of stakeholders around the state, provides a road map for cancer control in Wisconsin. It sets goals for improvement, identifies evidence based strategies and brings partners together to work collaboratively towards shared goals – using resources more efficiently. It unfortunately suffered another cut in the recently passed FY2011-13 Budget – reducing the amount to \$334,440. We will continue to be active participants with the program and the plan.

#4 - Recognition of the role environmental toxins play in the development of breast and other cancers.

WBCC advocates often have to make clear to legislators that early detection is not prevention. While acknowledging the difficulty of doing research on the role toxins play in a human population, WBCC stands by our position that where the public health is concerned, the Precautionary Principle should prevail. We were happy to support the BPA Free Kids Act, passed and signed last year – but there is much more work to be done. Research is evolving on this topic and we will continue this dialogue with legislators about the importance of regulation of cancer causing chemicals.

**WBCC has also endorsed the Safe Cosmetics Act of 2011 (HR2359), recently introduced by Representatives Tammy Baldwin (D-WI), Jan Schakowsky (D-IL), and Edward Markey (D-MA). The bill would give the FDA authority to ensure that personal care products are free of chemicals linked to cancer and other serious health problems. Check out www.breastcancerfund.org for more information.





