



Sandra Steingraber Urges Wisconsinites to Take Action Now

Submitted by Kris Miller, WBCC Board Member

Sandra Steingraber, an internationally respected biologist and environmental activist, spoke recently at the Sturgeon Bay Health Forum, *Environmental Links to Cancer and Human Health*. She described the public health concerns and increased cancer risks associated with frac sand mining in western Wisconsin, Concentrated Animal Feeding Operations (factory farms) in northeast Wisconsin, and potential taconite mining in northern Wisconsin. Ms. Steingraber, author of the book, *Living Downstream: An Ecologist's Personal Investigation of Cancer and the Environment*, stressed that vigorous engagement is necessary to combat further chemical adulteration of our environment. She asks each of us to identify our own skill sets and how best to use them.

Sitting in the audience at the Health Forum, I was proudly reminded of the Wisconsin Breast Cancer Coalition's commitment to research priorities and legislative policies that support prevention of breast cancer by considering possible environmental influences. Members of the WBCC put their advocacy skills to use by participating in the Breast Cancer and the Environment Research Program (BCERP) at the University of Wisconsin-Madison. The BCERP is funded through a joint effort of the National Institute of Environmental Health Sciences and the National Cancer Institute. The UW is one of several sites across the country examining those times in a female's life when environmental exposures to carcinogens are suspected of increasing risk of breast cancer as an adult. (Visit the UW site at www.wibcerp.wisc.edu/wisconsin.)

These times of increased vulnerability are called "windows of susceptibility". Researchers from three different BCERP sites have been studying the puberty window of susceptibility and their work was reported in the journal *Pediatrics* in December 2013. The pooled results from this research confirmed that the age of onset of puberty is earlier than reported in previous, less rigorous studies. According to this report, body mass index was a stronger predictor of early puberty than race or ethnicity. This is relevant to breast cancer because earlier age of puberty increases one's risk of breast cancer in the future. The April 2014 issue of *Parenting* magazine refers to this BCERP research and the association between obesity and early puberty.

Building on the obesity and early puberty connection, some of the BCERP sites are investigating if exposure to specific chemicals in a girl's environment may even contribute to her obesity. There is also concern that the wider window of susceptibility created by early puberty gives carcinogenic chemicals more time to exert their influence.

BCERP research has raised concerns about exposures to environmental chemicals during vulnerable times in a female's life. Researchers and community partners at all the BCERP sites have collaborated in the creation of educational toolkits that offer recommendations for lifestyle choices early in life that may reduce risk for breast cancer later in life. The toolkits are available online at www.info.bcerp.org for audiences of parents and caregivers, outreach organizations and health professionals. Acting on the WBCC commitment to educate, members are using these toolkits to educate community groups about breast cancer risk reduction. To quote Sandra Steingraber, "From the right to know and the duty to inquire flows the obligation to act."

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Moving? Please send your
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P.O. Box 170031
Milwaukee, WI 53217

or email: [wbcc@
standupandspeakout.org](mailto:wbcc@standupandspeakout.org)

President's Letter

Happy Spring!**Greetings to all!**

We have been a busy group over the past several months. There have been a lot of areas of legislation, education, and collaboration that we would like to share with you.

I know spring is late in getting here to Wisconsin, but now that it has arrived let's enjoy everything it has to offer. The flowers are blooming and the grass is green. It is the perfect time to get outside and enjoy this weather and the wonderful summer fruits and vegetables that are in season. As we know, activity and eating right will keep us on the right track to being healthy. This is the first step each person can do to help prevent many diseases including cancer. On our cover, you will read about The Breast Cancer and the Environment Research Program (BCERP) and an environmental health forum held in Sturgeon Bay, WI. BCERP researches how environment exposures may predispose women to breast cancer throughout her life. One of the risk factors we do know of for breast cancer is obesity – so this summer, take advantage of the weather and the fresh produce to begin protecting yourself and your daughters.

So much has been going on in the world of the WBCC in the area of legislation. There was the passing of the Oral Chemotherapy Drug Bill. This bill will allow cancer patients to have access to life saving oral cancer treatments when this wasn't always possible in the past. In addition to the Oral Chemotherapy Drug Bill, we are proud to say that changes to the Wisconsin Well Woman Program, which provides breast and cervical screening to those with little or no health insurance, have been delayed until June 2015. Announced changes to this program would have jeopardized access to screenings for many Wisconsin women, however, through the actions of the WBCC and the collaboration of many other organizations throughout Wisconsin; we were able to keep this important program in place while we determine how many women will still need its services going forward.

As the WBCC does each year, we participated in the National Breast Cancer Coalition's Leadership Summit. We are members of this coalition. Each year the NBCC hosts this summit which brings together advocates, scientists, and leaders from around the world to share the knowledge and research advancements that are happening in the breast cancer community. The last day of the summit is lobby day. During lobby day all the advocates go and speak with their legislators to educate them about important pieces of legislation that we are supporting. Top priorities this year are The Accelerating the End of Breast Cancer Act and Department of Defense Breast Cancer Research Fund. Both of these important pieces will help us achieve Deadline 2020 which will put an end to breast cancer. Our mission is to gain support and sponsorship for the legislation. I am proud to say we have 8 out of 10 of our legislators signed on. Thank you to all our advocates who worked hard to make this happen.

I would like to invite you to 2014 Breast Cancer Symposium. It will be held on June 14th at The Women's Club of Wisconsin in Downtown Milwaukee. This event is for anyone who would like to know more about all aspects of what is going on in the breast cancer community. There is a topic for everyone.

To learn more about this event, please visit: <http://www.standupandspeakout.org/events/> or <http://wi-breastcancersymposium.com> or email wi-breastcancersymposium.com

I appreciate you taking the time to read all that is going in our organization. As you can see we have been working hard to fulfill our mission. As you are thinking about organizations that you would like to support remember us. We gladly accept donations, but we know that time is just as valuable. If you would like to discuss any opportunities for volunteering please reach out to us. We have all different types of opportunities to fit what you are looking.

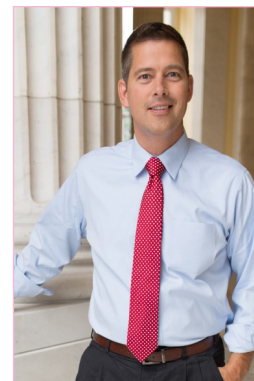
Sincerely,



What Leaders Are Saying About Breast Cancer Deadline 2020®

“On behalf of all of the fathers of little girls out there, I am fully behind the Breast Cancer Deadline 2020.”

Washington D.C. – **U.S. Congressman Sean Duffy (WI-07)** offered the following statement in support of the National Breast Cancer Coalition’s goal to beat Breast Cancer by 2020:



“Breast cancer truly affects everyone. If you haven’t had it yourself, you can name a family member or close friend who has. One in eight women will contract some form of breast cancer in their lifetime. Recently, my wife and I welcomed our fifth daughter into the world. To think that through research, education, support, and continued momentum, our girls might not have to worry about this terrible disease is a thought that lets me rest a little easier at night.

“I’m so grateful for the work the National Breast Cancer Coalition is doing. On behalf of all of the fathers of little girls out there, I am fully behind the Breast Cancer Deadline 2020. I look forward to January 1, 2020, when I hope we can stand together and say triumphantly, ‘we have beat Breast Cancer!’”

“I stand as a strong advocate for the National Breast Cancer Coalition’s (NBCC) Breast Cancer Deadline 2020. We have made invaluable strides in cancer treatment, but finding a cure requires maintaining our investments in research. The Breast Cancer Deadline 2020 aims to do just that and put an end to this terrible disease.

As a Member of Congress I will continue to work with the Wisconsin Breast Cancer Coalition (WBCC) to ensure access to quality screening services for all Wisconsinites and increase the level of investment in breast cancer research funding. I am grateful for all the work the WBCC has done for breast cancer patients and their families, and I applaud WBCC’s commitment to reach the goal of beating breast cancer before the end of the decade.”

Congressman Mark Pocan (WI-02)



“Modern American society wasn’t created overnight. It was crafted, constructed, and refined by taking what most people thought was impossible and making it possible. In just a half-century, we went from traveling by horse and buggy to landing a man on the moon 240,000 miles away. We did that by setting goals and then blowing them away. America has shown over and over again that everything is possible, it only takes a committed effort.

That commitment is no small task however. It will take our nation’s best doctors, scientists, and researchers to commit themselves to solving one of our world’s largest problems—cancer. After talking with the Wisconsin Breast Cancer Coalition, I fully support their efforts to tackle this dreaded disease and I encourage others—regardless of their political party or persuasion—to join them.”

Reid Ribble (WI-08)



Has your representative co-sponsored The Accelerating the End of Breast Cancer Act? (S.865/HR. 1830)

Senator Tammy Baldwin	✓	Please say thank you! 202-224-5653
Senator Ron Johnson	NO	202-224-5323 ronjohnson.senate.gov
Congressman Paul Ryan WI-01	NO	202-225-3031 paulryan.house.gov
Congressman Mark Pocan WI-02	✓	Please say thank you! 202-225-2906
Congressman Ron Kind WI-03	✓	Please say thank you! 202-225-5506
Congresswoman Gwen Moore WI-04	✓	Please say thank you! 202-225-4572
Congressman Jim Sensenbrenner WI-05	✓	Please say thank you! 202-225-5101
Congressman Tom Petri WI-06	✓	Please say thank you! 202-225-2476
Congressman Sean Duffy WI-07	✓	Please say thank you! 202-225-3365
Congressman Reid Ribble WI-08	✓	Please say thank you! 202-225-5665

8th Annual State Advocacy Day in Madison



Advocates Karen Borley, Dawn Anderson, Caroline Alexander and Pam Thompson, with Senator Fred Risser March 4



WBCC advocates took to the halls of the State Capitol on March 4, visiting over 65 legislator offices about our policy priorities for 2014.

Our top priority was to discuss the dramatic changes, that had been announced without warning in December, to the Wisconsin Well Woman Program. This vital safety net program provides free breast and cervical cancer screenings to low income women as part of the National Breast and Cervical Cancer Early Detection Program. The program is funded jointly by the state and the CDC. The changes amounted to essentially “blowing up” the program model, and, in a 6 month time frame, recreating a new model using a drastically smaller number of providers and discontinuing the use of local coordinators to enroll women and help them navigate getting the services they need. WBCC, and members of other breast cancer stakeholder groups convened, shared information, pressured the Department of Health Services (DHS) and the Governor to delay the changes – and importantly, WBCC began informing legislators about the changes being planned. We discovered early that they had NOT been informed about a change that would have a dramatic impact on their low income constituents. Many legislators then began making calls to the Governor’s office and DHS. **ADVOCACY WORKED.** On March 21, the Department sent a letter to all legislative offices informing them the changes

would be delayed for one year, while they collect and analyze data regarding how many women will still need these services as they enroll in health plans either through the state (BadgerCare, if they are below 100% of the Federal Poverty Level), or purchase plans through the insurance exchange. We are continuing to monitor the program overhaul, most recently attending a meeting with DHS Deputy Secretary, Kevin Moore, in April. More information should be available this fall. Stay tuned.

Our other priority was passage of the Cancer Treatment Fairness Act—also known as the Oral Chemotherapy Bill. This bill passed, albeit with modifications, after much shuffling around among committees and subsequent media coverage. Calls from constituents flooded legislative offices, forcing leadership to hold votes on the bill. On April 3, Governor Walker signed it into law.

While this legislative session is done, policy makers will begin work on the state budget over the next several months. WBCC will be watching funding for the Well Woman Program, the State’s Comprehensive Cancer Control Program, and the State Cancer Reporting System.

Register Now for the Wisconsin Breast Cancer Symposium!

Saturday, June 14: 8am-2pm

Woman’s Club of Wisconsin Milwaukee

Today, scientists, breast cancer advocates, and health care professionals are partnering in unprecedented ways, in efforts to not only treat breast cancer, but to prevent it and end it. This Symposium is a collaborative effort of a group of dedicated individuals from diverse organizations who form the Wisconsin Breast Cancer Symposium Planning Committee.

Join national and local leaders, scientists, innovators and visionaries who will present on topics related to:

- tumor dormancy (what causes cancer cells to hide out in a dormant state and what wakes them up)
- next generation sequencing for personalized treatment
- successful patient/scientific collaborations and the role breast cancer survivors and advocates can play in helping us reach our goal of ending breast cancer...and more.

www.wi-breastcancersymposium.com to register

DCIS: What Do We Know and What Do We Need To Know? Advanced Seminar Topic NBCC Summit 2014

Dawn Anderson, WBCC Executive Director

DCIS, or ductal carcinoma in situ, refers to what is commonly considered a “pre-cancer”, where cancerous cells are confined to the breast duct. They have not spread and therefore are not considered an invasive cancer. If they do not spread outside the duct, they are unlikely to be a threat to a woman’s health. Because they are almost always identified through mammography, detection of DCIS has risen dramatically since the wide spread use of screening began in the early 80’s. This increase is estimated to be about 500% over detection prior to widespread mammography screening. About 25% of all breast cancer diagnoses are now DCIS.

Although long term survival rates for women diagnosed with DCIS are high, many of these women undergo treatments that may have long term physical and emotional consequences and which, as research evolves, may show to have been unnecessary. Addressing DCIS is part of the National Breast Cancer Coalition’s Artemis Project, one component of the Breast Cancer Deadline 2020 campaign to know how to prevent primary disease and metastasis of the disease by January 1 of 2020.

H. Kim Lyerly, MD of Duke University, and Thea Tlsty, PhD, of University of California San Francisco (UCSF), conducted an advanced seminar on where we’re at in our understanding of DCIS and why this knowledge is so important.

Dr. Lyerly began his presentation by referencing the 2009 National Institutes of Health Consensus Conference on the state of the science around DCIS. We have not had the knowledge needed to tell which of these pre-cancers would simply go away on their own, which might just sit there and not grow, and which might progress to invasive cancers – so virtually all women who receive a diagnosis of DCIS are treated in one way or another. He pointed out that because it is presumed that progression of cancer is a linear process (from non-invasive to invasive), treatment for DCIS has been a “one size fits all” proposition.

But is DCIS *always* a precursor to invasive cancer? Given the widespread use of screening and the subsequent increase in detection of DCIS, it would be expected that we would therefore see a *decrease* in the number of invasive cancers diagnosed. If we are finding more “early” cancers, then we should be finding fewer invasive cancers. That is not the case. Incidence of invasive breast cancers has remained fairly stable. We are simply treating more women, many of whom – it may turn out – may not have needed treatment to reduce their risk of invasive cancer. From the perspective of an advocate interested in finding ways to prevent invasive breast cancer (thereby *truly* saving lives), research around DCIS is an opportunity that mainstream science doesn’t seem to have embraced. Dr. Lyerly and Dr. Gregory Hannon of Cold Spring Harbor Laboratory received a seed grant in November 2013 from the NBCC through the Artemis Project to look for vaccine targets in DCIS samples. They will also study the healthy tissue around DCIS samples to learn more about how DCIS progresses to invasive disease. If antigen targets can be identified, they may be able to advance important work on vaccines to prevent potentially deadly spread of the disease.

Gene expression analysis indicates that DCIS is nearly identical to invasive cancer – but what is the difference between breast cancer cells that can “break through” the duct wall and ones that can’t? Are there biomarkers that could be used to predict which DCIS cases might be most likely to become invasive and therefore warrant treatment, and which are more likely to only warrant careful monitoring?

Dr. Tlsty is a biologist who works to understand very early events in the process – for instance, how cells communicate with each other. UCSF has developed a risk assay based on cell behavior when certain biomarkers are present. The specific behaviors she studied could be seen as “barriers to malignancy”: Senescence (gradual deterioration of cell function), Apoptosis (programmed cell death), and Arrest (induced stoppage of cell division). Activation of these behaviors is observable through biomarkers. If one of the behaviors is compromised, there is progression to malignancy. In other words, if something prevents apoptosis, the cells will continue to proliferate and could become invasive. The assay can stratify risk for progression to invasive cancer within 10 years for DCIS patients. There are four studies using this assay worldwide right now (two in the US) but it is not ready for full clinical trials yet.

Results of research at UCSF by Dr. Tlsty and Dr. Karla Kerlikowski have identified a gene that is repressed in cancer tumors. It could be that this gene affects *the environment around the cancer cells* (the stroma) in a way that could allow or prohibit invasion of the DCIS cells out of the duct – where it then becomes a potentially lethal invasive cancer. She pointed out that only 1 in 10 women diagnosed with DCIS dies from the disease within 10 years – how do we identify that one woman and make sure she gets treatment that is appropriate to her unique form of DCIS? And can we then identify women who may not need treatment at all?

Dr. Lyerly is collecting and analyzing DCIS tissue at Duke. He pointed out that the National Cancer Institute (NCI) has analyzed 993 stage I-IV breast cancers for the The Cancer Genome Atlas, but 0 of DCIS (as of 4/25/14). Duke is proactively banking DCIS tissue for study as they diagnosis and treat women. Why isn’t research around DCIS being prioritized? From this advocate’s perspective it appears to hold so much promise – to prevent women who don’t need costly physical and financial treatments from undergoing them – and to identify biomarkers that could advance a vaccine that would prevent rogue cells from becoming killers.

Many years ago at one of my first NBCC Summits, Dr. Susan Love described DCIS as being akin to a bunch of rowdy high school students: some may eventually straighten out and fly right, and others may go on to a life of crime. This analogy has always stayed with me. Unfortunately, the progress she hoped for almost 15 years ago is only now beginning to be prioritized. Advocates need to insist that federal cancer research puts it at the top of the list as an excellent opportunity for understanding breast cancer progression and how we might prevent it.

Disruption, Innovation, and Transformation

By Eric Buhler, WBCC Sherry Kohlenberg Scholarship Recipient 2014

What is research? A definition for research is deemed as the systematic investigation into and study of materials and sources in order to establish facts and reach new conclusions. The 2014 NBCC Leadership Summit offered a new look into research, and asked the question, Is it time we tried it another way? For myself, I always was in awe of research coming out of MD Anderson, or institutions such as the Cleveland Clinic, yet always curious as to why things were never getting any better in the breast cancer world. We still use the same classic therapies of surgery, chemo, and radiation, and yet the estimated chance of a woman be diagnosed with invasive breast cancer is higher now than it was in 1975. The problem, while unfortunate, is rather simple. Billions of dollars every year are wasted on research that's being done, or already been done. You ask why? The hard to stomach answer is the fact that researchers choose not to share their work amongst each other. Institutions are focused on their own interests, instead of focusing on the big picture. This is extremely frustrating as an advocate. However, it is up to us to change this. We need to hold

these institutions accountable. We heard interesting advice given on the matter; that advice was to treat breast cancer as a business model. As survivors, you expect a return on your investment, something that shows where all of your dollars have been used. Have your dollars been worth it? When your oncologist says, "your 5 year survival rate is in the 90th percentile," is that worth the investment? At this point in the history of medical science and research, shouldn't there be a lot more years added to those five? This type of mismanagement must not go unnoted. As advocates, as survivors, we must disrupt the system with consumer feedback, and let these institutions know we deem the value of their product unworthy. We need fresh eyes and new ideas. We need people who are not afraid to act and not afraid to upset the status quo. We must continue to add pressure, and keep research honest. Research is to solve problems, not just to find further knowledge. It is solving the mystery of why something happens. It is difficult, it is time-consuming, but whatever the cause of the problem, we can't, and no longer will accept the solution of, "it's hard."

Here's what's going on...

By Kelly Herda, 2014 Sherry Kohlenberg Scholarship Recipient

That was the opening statement from a researcher during one of our plenary sessions, and it got my attention! I learned why so little has been accomplished over the past decades in breast cancer research; I learned that since the launch of the National Breast Cancer Coalition's (NBCC) Breast Cancer Deadline 2020, back in 2010, real breakthroughs are being made in a preventative vaccine and our understanding of metastases; and I learned that without a grassroots movement of concerned Americans voicing their support to continue funding the Department of Defense (DOD) Breast Cancer Research Program (BCRP), we may not be able to make our deadline.

One of the most disturbing lessons we learned was why so little has been accomplished in breast cancer research. First, we have the drug companies that refuse to share their findings, or medications, for clinical trials in order to protect potential profits. Then there are scientists who are only interested in doing research that will allow them to write a paper that gets published and, therefore, secures their tenure – and they refuse to collaborate with other scientists until they get their paper published. The National Institutes of Health has perpetuated this poor performance by only giving grants for projects with "proven methods", even though these proven methods have produced no real advances in finding a cure. They also don't make public the results of the research, which is where redundancy occurs. Scientists are being funded to perform research that has already shown little to no results in curing or preventing breast cancer. This has been the status quo for far too long and we need your voice to help put a stop to this extraordinary waste of time and money.

On a more encouraging note, NBCC's Artemis Projects are collaborations between patient advocates and researchers, who direct seed grants for different and innovative studies in primary prevention and preventing metastases. In just the past few years, real breakthroughs are being made. We are hoping to have a preventative vaccine for breast cancer by the 2020 deadline and scientists are looking at repurposed drugs, which are already FDA approved, to stop metastasis.

But, in order to make our deadline, it is imperative that we preserve funding for the DOD BCRP for FY2015. The appropriated dollars in this program are directed at eradicating breast cancer by funding innovative, high impact research through a partnership between scientists and consumers. In fact, the vaccine research that received a seed grant from the Artemis Project, just received a DOD BCRP grant to continue their important work. Another important aspect of the DOD BCRP is that all findings, whether successful or not, are made public. Every year, NBCC advocates from around the country go to Washington D.C to ask our Representatives and Senators to continue this program – and we hope you will support our efforts by becoming a Wisconsin Breast Coalition member and become part of our collective voice to end breast cancer by January 1, 2020!

**WISCONSIN
BREAST
CANCER
COALITION**

National Breast Cancer Coalition Leadership Summit and Lobby Day: May 3-6, 2014



*Kelly Herda, Eric Buhler, Bonnie Anderson, Executive Director
Dawn Anderson, State Field Coordinator Kathleen Harris*



! SAVE THE DATE !

For A Special 15th Anniversary Celebration of Rare Chair Affair

Survivorship is something we always celebrate at the Rare Chair Affair – with breast cancer survivors taking center stage during the live auction of art pieces they've created. Their family and friends cheer for them, bid on their pieces and the entire audience just feeds into the joy – sometimes resulting in an exciting bidding war!

We wanted to do something special this year to commemorate our 15th Rare Chair Affair, and of course, we thought of the survivors. Sadly, over the years, we've lost many of the over 120 survivor artists who've participated in RCA. It reminds us that we have a long way to go before our work is done and women stop dying from breast cancer. This year, we will honor fifteen extraordinary "Encore Artists" from over the years, reminding us also, that there are many, many survivors out there who continue to thrive after breast cancer.

SAVE THE DATE NOW FOR THIS SPECIAL EVENING:

Friday, October 10, 2014 – 5:30pm

The Wisconsin Club

6200 W. Good Hope Rd., Brown Deer

Online registrations and mailed invitations will be available this summer. Be sure you are on our email list to be notified! Go to our website at standupandspeakout.org to sign up.



Don't forget to follow us on Twitter (@wbcc2) and Facebook to get the most current updates and articles on WBCC and breast cancer research.



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

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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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