



National Breast Cancer Coalition Advocate Leadership Summit & Lobby Day 2015

By Carrie Riccobono MSN, ACNS-BC, OCN, WBCC Board Member

What an experience to be a part of this amazing summit. I have been in oncology for 20 years, attending numerous local and national conferences and nothing touches the level of experts who presented and who collaborate with the NBCC and attendees. Transparency is real, the respected experts are engaged with the advocates, and a culture of collaborative practice is evident.

The main focus of the 2015 summit was the role of immunology in breast cancer, and work on vaccines to not only prevent the initiation of breast cancer cells, but also vaccine trials to stop metastatic disease. Understanding how vaccines work can be a little daunting, but the nuts and bolts of it is that vaccines work to reduce the risk of developing a disease by working with the body's natural defenses to safely develop immunity to the disease. Our immune system is the body's natural defense against infections and diseases. Antibodies are produced and are part of a healthy immune system. Adaptive (acquired) immunity is the antigen-specific defense mechanisms, taking days to become effective and developed throughout the life span.

• The Immune System-the soldiers in the body to defend against infection.

To understand how vaccines work, we must first understand how the immune system works to fight off every day infections we are exposed to. When germs (bacteria or viruses) invade the body they attack and multiply – resulting in an infection which leads to an illness...think of a cold, sinus, or urinary infection. Our immune system kicks into gear and calls for our first line of defense (our white blood cells) recruiting B-lymphocytes, T-lymphocytes and macrophages to fight off the invasion.

Think of macrophages like “Pacman” ...gobbling up and digesting germs, including dead and dying cells. They leave behind the part of the invading germ called an antigen. Our body then identifies these antigens as dangerous and stimulates further attack.



Antibodies are produced by the white blood cells as B-Lymphocytes, and attack the antigens left behind by the macrophages. **Lymphocytes are responsible for specific immune recognition of pathogens.** They circulate freely throughout the body moving from blood stream to tissue and back. Their role is to act as scouts & destroy pathogens entering the body. B-Cells are genetically programmed to encode a surface receptor specific for a particular antigen. Once the B cell recognizes an antigen, the B cell multiplies and differentiates into antibody producing Plasma Cells. T-cells release cytokines and have direct cell-cell interactions. T-helper cells interact with B cells and phagocytes. Cytotoxic T cells destroy host cells infected by viruses or other intracellular pathogens. T-Lymphocytes, also produced by the white blood cells, attack the cells in the body that have been infected.

Woah...what?? Ok, just remember that the first time the body encounters a germ, it can take several days to make and use all the germ fighting tools to get over the infection. Our immune system never forgets what it was exposed to and after each

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President's Letter

Greetings WBCC Members,

Happy Summer Solstice to all. It does seem like summer may be finally arriving here in Wisconsin! Please take time to read all of the thoughtful articles in this newsletter.

First, I wanted to share the news that Dawn Anderson, our Executive Director, has announced her retirement effective November, 2015. The WBCC Board and I were saddened to receive this news, but are happy for Dawn's plans to spend more time at the lake house she and her soon to be retired husband, Roy, will share. I know that Dawn will not be far from the WBCC action, and she has already voiced her intention to remain active on our Policy Committee.

Needless to say, we formed a Succession Committee, and have been hard at work developing a Plan for Succession, including job descriptions, timelines and budget impact information. A special thanks to the Committee members, Colleen Booth, Mar Brahm, Marsha Connet, Karen Hunt, and Ann Martel. We will have more information to share on this process in the future.

Additionally, there have been a number of National and State policy issues that have been brewing. First, we all received information that NBCC needed our support to protect the Department of Defense Breast Cancer Research Program (DOD BCRP) in light of Senator John McCain's introduction of Amendment 1482. This Amendment to the National Defense Authorization Act (NDAA) would have done irreparable damage to the DOD BCRP. Although the full Senate passed the NDAA without Amendment 1482, NBCC reminded us that we must remain vigilant until this bill and the Appropriations bill become law. Please stay tuned for any additional action that may be needed.

On the State level, a new model for the Wisconsin Well Woman Program is being moved forward. WBCC continues to have concerns about this model and its impact on quality breast cancer screening and treatment for low-income women. Under the new model, many women will have to drive long distances to access services mainly due to the greatly reduced number of providers for Well Woman Program services. It appears that many counties will have no providers which means women may have to drive 100 miles round trip for a mammogram. This is unacceptable. Please again stay tuned for any additional action that may be needed.

Lastly, I want to remind you to "Save the Date" for the Rare Chair Affair (RCA). This is the 16th Annual RCA, which is our major fund raising venue. This year's event will be on Friday, October 9, 2015, at the Wisconsin Club – Good Hope Road in Milwaukee. Please plan to join us for an evening of fun, friendship, and fundraising! Hope to see you all there.

Take good care,

Rhonda Deneka



Save the Date! The 16th Annual Rare Chair Affair – October 9

It's our signature event – featuring the most moving and exciting live auction you'll ever see!

Our 16th class of Breast Cancer Survivor Artists will begin work on their chairs this month and they'll continue to create these testimonials to their survivorship throughout the summer. On October 9, they will be the stars of the show as we auction their masterpieces to benefit the Wisconsin Breast Cancer Coalition.

Save the date now so you don't miss out! Friday, October 9 at 5:30pm. We'll be returning to the lovely Wisconsin Club on Good Hope Rd. in Milwaukee. If you aren't on our email list, please sign up on our website so we can notify you when registration opens in August. (You can also follow us on Facebook and Twitter!)

We are very grateful for and thank sponsors Froedtert & Medical College of Wisconsin, and Wheaton Franciscan Healthcare – St Francis, for providing the spaces in which the Survivor Artists will work over the summer.

We are still recruiting sponsors and donors for Rare Chair Affair! If you or your company would like to be part of this incredibly special event, please contact us at 414-963-2103.



Article continued from page 1

new infection, it remembers and is prepared next time it is exposed to that germ. **So how does a vaccine work?** Vaccines help develop immunity by imitating an infection, tricking the immune system to produce T-lymphocytes and antibodies. The vaccine does not produce an infection in our bodies, but leaves our body prepared with a supply of memory T-Lymphocytes and B-lymphocytes that can fight off the disease (before we ever know we were exposed) resulting in no illness.

Does one vaccine fit all? No, because we need to know what the specific antigens are causing the disruption of cells, or infections. Each vaccine is specific to defend and protect. Scientists take many approaches and years of research (20-30 years!) to design vaccines. The specific approach is based on which virus or bacteria the vaccine will prevent (how does it affect our specific cells) and how our immune system responds to it. **This is where the research around breast cancer fits in; What is causing the cells to divide? What is the trigger? What is the immune response?** We are close to knowing the answer and clinical trials may not be far off.

So back to the summit, leading experts from the National Cancer Institute, John Hopkins, Duke and others were speaking on their mission to end breast cancer by 2020. The experts who have partnered with NBCC spoke to the research on vaccines within the goals of the Artemis project <http://www.breastcancerdeadline2020.org/about-the-deadline/artemis-project.html>

The secondary theme of the summit was engaging all stakeholders to understand the deadline. Many sessions empowered advocates and professionals to challenge the data, challenge the proposals, and to raise our voices in the endorsement of the Breast Cancer Deadline 2020.

The final day, we went to our representatives to help them understand the sense of urgency and to continue to support the deadline. Specifically our first priority was to increase support for the Accelerating the End of Breast Cancer Act (S. 746/H.R. 1197). The bill focuses leveraging what we already know about breast cancer and other diseases to identify strategies for primary prevention - stopping women from getting breast cancer- and on understanding and preventing metastasis (the spread of cancer), which is responsible for 90% of breast cancer deaths. It would create the Commission to Accelerate the End of Breast Cancer comprised of a few representatives of biomedical research, business, breast cancer advocacy, and other related and unrelated disciplines, who have demonstrated an ability to be innovative. This tactical Commission would be tasked with identifying promising opportunities, tools, technology and ideas not currently being prioritized for breast cancer by the public and private sectors, but which hold true promise in ending breast cancer. (See which Wisconsin representatives have signed on as co-sponsors in this issue).

The second priority is securing level funding of \$150 million for the Department of Defense Breast Cancer Research Program.

With this charge, I and six others from the state of Wisconsin met with our representatives. Of note, I had along with me my 75 year old mother, who is a seven year breast cancer survivor, and my 15 year old daughter who has been brought up understanding the importance of health policy.

We encourage you to also please contact your congressman and our senators for their support of this legislation. It is with our collective voice change can happen.



Accelerating Thanks

Thank you to the following members of the Wisconsin Delegation for co-sponsoring The Accelerating the End of Breast Cancer Act! Please thank YOUR representative, and Senator Baldwin for stepping up to support this vital component of the Breast Cancer Deadline 2020 strategic plan being advanced by the National Breast Cancer Coalition. If your representative is not listed here, please call their office today and ask them to sign on! Find their numbers here: www.house.gov



Senator
Tammy Baldwin
(202) 224-5653



Congressman
Ron Kind
(202) 225-5506



Congressman
Mark Pocan
(202) 225-2906



Congresswoman
Gwen Moore
(202) 225-4572



Congressman
Jim Sensenbrenner
(202) 225-5101



Congressman
Sean Duffy
(202) 225-3365

WBCC 2015 State Policy Priorities

(more details can be found on the State Policy page of our website)

Priority I

Ensure Access to Quality Breast Cancer Screening and Treatment for Low-income Women

Status:

- The state is proceeding with a new model for the Wisconsin Well Woman Program. We continue to have concerns about the distance many women will have to drive for services due to the greatly reduced number of providers. Many counties have no providers and many women may have to drive 100 miles round trip for a mammogram. We continue to monitor how well this new model of service coordination will work and whether it has the capacity to serve the number of women who need it.
- The state has again indicated it will not accept federal funds available to cover more people through Medicaid.

Priority II

Obesity Prevention

Status:

- The GYM Bill (Get Youth Moving) is circulating and has a good start on co-sponsors. A number of organizations are supporting this legislation.



2015 State Advocacy Day Participants

Priority III

Increased funding for the Wisconsin Cancer Reporting System (WCRS)

Status:

- Our request was for funding, which was expected to be in the Governor's budget but didn't show up or was taken out, be put back in. A motion to do so was offered in the Joint Committee on Finance but was voted down. Subsequently, the Department of Health Services approved funding for one additional WCRS position for one year to address reporting along the border, in Minnesota and in smaller clinics and hospitals in rural areas. Additional funding for a contractor to work with pathology labs was approved. These are a step in the right direction but are for one year only and don't qualify for the CDC matching funds.



"Goin' in!"

Wisconsin's Comprehensive Cancer Control Plan 2015-2020 Released at Summit

By Dawn Anderson, WBCC Executive Director

On May 28, the Wisconsin's "roadmap" for cancer control for the next five years was released at the Wisconsin Comprehensive Cancer Control Program's Annual Summit.

The WI CCC Plan is a document developed every five years by stakeholders from around the state, including advocates, nurses, physicians, public health professionals, researchers, social workers, survivors and more. This collaborative effort results in a strategic plan with five overarching goals and several priority areas in cancer control. Strategies within each priority area present opportunities for anyone who cares about reducing the burden of cancer in our state – from advocacy organizations, to healthcare providers/professionals, to school groups. There is a role for everyone to play in the plan. The plan can be downloaded, or ordered, at www.wicancer.gov.

The Summit also featured keynote speaker, Dr. Otis Brawley, Chief Medical Officer of the American Cancer Society and author of the bestseller "How We Do Harm: A Doctor Breaks Rank About Being Sick In America." Dr. Brawley is a compelling speaker on the topic of health disparities in this country and his keynote addressed this issue, with the Dr. saying bluntly "There is discrimination against people in this country because they are poor" and comparing poverty to a carcinogen. Some points he made brought this observation home:

- The US spends \$2.7 trillion annually on health care – amounting to almost 18% of our GDP. This is more than we spend on food! And yet...
- We have poorer health outcomes across the board and more health disparities than other industrialized countries.
- The US is 49th in life expectancy, and yet we spend nearly double per person/per year on health care.
- An estimated 80,000 people die annually in the US due to not having access to necessary health care
- 2/3 of black women and 3/4 of Hispanic women get less than optimal breast cancer care

So what are we doing wrong? Dr. Brawley emphasized the need to include preventive services in access to care. We also need to use screening and treatment more wisely to reduce costs. He pointed out that breast cancer screening results in a 20% relative risk reduction in death. That means that 80% of the women who are "destined" to die from it, still die from it. "We need a better tool" was a mantra that he repeated a few times during his address.

On the same theme, Dr. David Varness of the UW Department of Population Health Sciences highlighted the costs of cancer care in the country. In 2014 the US spent \$142 billion on cancer care – the majority of which is attributed to "continuing care". (Breast cancer care tops all other cancer sites according to the NCI). Improved treatments are keeping some cancer patients alive longer – but at staggering financial costs. Dr. Varness pointed to an analysis that shows that the costs of new drugs aren't justified by the magnitude of success in disease free survival. We do not use cost effectiveness as a criteria for drug approval in the US.

Taken together, the take home message from these two speakers seemed to be that the US needs to find better and more equitable ways to diagnose and treat cancer. Income or race should not be a factor in determining who gets the best treatment for disease – all of us deserve access to optimal health care. If we can increase access to health care, emphasize disease prevention and reduce the costs of cancer care by being smarter about how we use health care, we could begin to reduce health disparities in the US and have a healthier population as a whole. And if we can implement the strategies outlined in the WI CCC Plan, we can begin to reduce the burden of cancer in our own backyards. It's an important and useful plan. Please check it out at www.wicancer.gov.



Wisconsin Breast Cancer Research and Advocacy Boot Camp

By Kathleen Harris, NBCC Field Coordinator

The Wisconsin Breast Cancer Research and Advocacy BOOT CAMP was held at the Medical College of Wisconsin (MCW) on May 30.

Breast Cancer BOOT CAMP 2015 was the third in a series of three events: "Wisconsin Breast Cancer Symposium: A Conversation to End Breast Cancer and What It Will Take" in 2012 and "Wisconsin Breast Cancer Symposium: Innovation and Action to End Breast Cancer" in 2014. These three events were collaborative efforts of community leaders, advocates, researchers, health care professionals and organizations in Wisconsin. The Wisconsin Breast Cancer Coalition has played a key role in the sponsorship and support of these events.

The BOOT CAMP was a full day training program in a class room setting at MCW. The program was open to everyone interested in learning the science of breast cancer on an introductory level. Participants who completed the program will have a better understanding of breast cancer research and issues in the media and scientific presentations at local and national conferences. The planning committee for BOOT CAMP 2015 included Kathleen Harris, National Breast Cancer Coalition Field Coordinator-WI as Event Chair, Dr. J. Frank Wilson and Dr. Carmen Bergom, MCW faculty as Program Co-Chairs and Carlos Marquez-Barrientos, Program Manager, CTSI (Clinical & Translational Science Institute of Southeast WI).

Participants accepted into the program completed homework/reading assignments and had the opportunity to view research video presentations online to help prepare for the program on May 30th.

There were six small discussion groups of about ten participants each for the morning breakout session to discuss homework/readings and the morning presentations. Discussion group leaders were NBCC Project LEAD grads: WBCC Executive Director, Dawn Anderson, Bonnie Anderson, Kathleen Harris and Eric Buhler along

with Dr. Sandra Underwood and Dr. Carmen Bergom. The morning presenters - Dr. Frank Wilson, Michael Dwinell, PhD and Bryon Johnson, PhD - rotated around the groups and sat in on the various discussions as participants reviewed what was most interesting to them so far and what questions they would like further clarification on.

At the conclusion of the breakout session, all participants returned to the main plenary room to report out key points of discussion in their group and the one question or clarification participants in the group wanted to ask a morning presenter. This interactive format encouraged lively discussion and exchange of information between participants and researchers.

Topics included basic biological concepts of breast cancer, the role of genes and microenvironment in cancer, breast cancer immunology and exciting potential for immunotherapy, the role of advocates in the research and political arenas and more.

Lectures for this program were presented by Medical College of Wisconsin physicians and researchers, the National Breast Cancer Coalition Field Coordinator-WI and the Executive Director of Wisconsin Breast Cancer Coalition.

The program concluded with a session on opportunities and activities available to participants and others in our community in the coming months.

If you would like to receive notice of similar programs and other opportunities, please sign up on our website: wi-breastcancersymposium.com.



WBCC is teaming up with Hamburger Mary's for Ham-BINGO Charity Night! This is NOT your grandmothers Bingo!

THURSDAY AUGUST 27

What Is It?

Ham-BINGO is a charity bingo event held in the dining room at Hamburger Mary's from 8pm to approximately 9:30pm. Please plan on arriving around 7-7:30 to get settled in.

The cost for Bingo is only what you choose to donate! 100% of the money will go to Wisconsin Breast Cancer Coalition

Caution: These Bingo games can be a little risqué, but always in good fun! Be ready to bust a gut laughing, and keep your serious side at home! Please no children under 18 to attend.

Wonderful menu is available to order dinner or drinks as well. Please share this event – we look forward to seeing you! Reservations are encouraged as sometimes the events can be sold out.

**Hamburger Mary's is located at
2130 S Kinnickinnic Ave.
Milwaukee, WI 53207
Ph (414) 988-9324**

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

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888.295.2622
wbcc@standupandspeakout.org



This lovely couple would only do

THIS

if their guests did

THIS

Thank you to WBCC volunteer, Lauren Roberts, and her new husband Kyle Alban for the donation!

AND CONGRATULATIONS FROM ALL OF US!