



**P2 / PRESIDENT'S LETTER**

Rhonda Deneka updates WBCB community about Strategic Planning that is now underway



**P4/ VACCINE**

Carrie Riccobono outlines an NBCC Summit presentation about vaccine research



**P6 / NEW STAFF**

Join the WBCB in welcoming Haley Young as Capitol Advocate



**P7 / KICK OFF**

Survivor Artists kicked-off a summer of painting for the 2016 Rare Chair Affair "Living Beautifully"

# WBCC Collective Voice



Beyond the Pink Ribbon™ SUMMER EDITION 2016

## Taking It Up a Notch Social Media

By Helen Brewer, Communications Committee

For WBCB, social media is about building our community. Our Facebook page recently reached 500 "Likes" and continues to grow, as does our Rare Chair Affair Facebook page.



We are still working on the challenges of Facebook for our unique group of followers. For example, our followers tend to be intellectual and mature, responding to data and articles more than the usual social media "infotainment." We've learned to ignore the typical marketing rules and instead give the people what they want — real news and updates. Example — a recent high-performing

post was about a drug possibly preventing tumors for BRCA1 mutation carriers.

Following WBCB on social media both supports us and links you to the latest breaking developments in the fight against breast cancer. Please like us on Facebook today or follow our Twitter, @WBCC2. When you share or retweet our posts, it means a lot to us.

## Noteworthy:

### LINKED IN

Next on our list is revitalizing our LinkedIn Page with the same energy we've given to Facebook. You can help by networking with us there.

### FUTURE PROJECT

Pinterest is a side project for us right now. We could use a volunteer photographer to help us with content. We'd love to see Pinterest blossom as well.

### HOW DO YOU LIKE OUR REDESIGN?

The WBCB has added more white space and visual elements to our newsletter. We hope to improve readability and visual interest. We would like our readers to tell us how you feel about this new design, and about what content you would like to read. Please contact us at [wbcc@wibreastcancer.org](mailto:wbcc@wibreastcancer.org), or call 414-963-2103 with your feedback.

## ASKING for ANSWERS

WBCC Advocates made an impact with data from a survey of WWWP coordinators



Some legislators are drawing on data provided by the Wisconsin Breast Cancer Coalition to demand accountability from the Department of Health Services and to criticize the governor over the Wisconsin Well Woman Program's current functioning.

The WBCB surveyed WWWP coordinators prior to State Advocacy Day on April 20 about effects they are seeing in light of reorganization and downscaling beginning July

2015. WBCB's ongoing concerns about whether the program has lost ground since the reorganization were confirmed by the survey results. Thirteen of 14 regional coordinators responded, voicing a number of concerns

“Unfortunately, there are real-life consequences for the political games these legislators are playing with women's lives.” ~ Letter by Shilling, Billings, Johnson and Taylor

about access, lowering enrollment, and obstacles to service.

In response to information provided from the WBCB and others, Senator Jennifer Shilling,

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# President's Letter

It seems that summer has actually arrived, according to both the calendar and the beautiful weather we've been having in Wisconsin.

On a recent sunny Saturday afternoon, members of the WBCC Board gathered at the South Milwaukee library to begin to chart the course of our organization for the next 3-5 years.

Thanks to the efforts of Executive Director, Sandra Gines, we received a grant from the Nonprofit Management Fund that enabled us to engage Barbara Markoff to serve as a facilitator to help the Board articulate the vision for WBCC going forward.

Barbara will be continuing to guide the Board in our work to 1) grow the WBCC organization, 2) elevate and

“The WBCC Board is excited and enthusiastic to continue our work to renew, refresh and update ...”

improve fund development, and 3) re-envision the role of our Executive Director.

The WBCC intends the new plan to create unity in our operations, to guide our decision-making, and to demonstrate our organizational responsibility to others.



The WBCC Board is excited and enthusiastic to continue our work to renew, refresh and update WBCC's 2009 Strategic Plan through the process. We will be sharing our progress and outcomes with you. Please let us know your thoughts and ideas.

~ Rhonda Deneka

EDUCATION

COLLABORATION

LEGISLATION

## Board of Directors

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MSW, CSW \*, Oncology Patient Navigator, retired

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Karen Hunt  
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RN, Nurse Practitioner, Door County



Eric Ford and Karen Hunt at the Rare Chair Affair last October

THE RARE CHAIR AFFAIR IS OUR SIGNATURE EVENT, FEATURING A LIVE AUCTION OF WORKS OF ART BY BREAST CANCER SURVIVORS

## LIVING BEAUTIFULLY Rare Chair Affair 2016



## Survivor Artists Gather for Kick-Off A mix of experience and new energy fuels creativity



SAVE THE DATE:  
September 30,  
Wisconsin Club Milwaukee

The 2016 Rare Chair Affair has enlisted 15 Survivor Artists to create one-of-a-kind chairs for our signature event. The artists kicked off a summer of painting at the Froedert Cancer Center on May 26. The group, a mix of experienced and new painters, from 10-year-survivors to one just months out of her first course of chemotherapy, introduced themselves and described their cancer journeys.

>> DISCOVER MORE ON [WWW.RARECHAIRAFFAIR.ORG](http://WWW.RARECHAIRAFFAIR.ORG)

Jo DeMars, who has been painting chairs for the WBCC since 2004, said her first experience as a Survivor Artist helped her overcome initial anger.

A friend “pretty much bullied me into it,” she said, but then she found the experience “transformative.”

Jo said she is involved with the WBCC because of its advocacy efforts: “I’m willing to speak for those who can’t or won’t. If those of us who can talk don’t do it, we’re all diminished.”

## UPDATE

### SPONSORS ON BOARD

The WBCC is pleased to have lined up support from the following: **CDI Inc;** **Aurora Sinai Hospital;** **Froedert & the Medical College of Wisconsin.** We are grateful for their support for our hallmark event.

### DAN PRONLEY AUCTIONEER

Dan will once again lead the RCA auction. He has 19 years of experience as an auctioneer and master of ceremonies at more than 330 fundraising events for some of the largest non-profit organizations in the greater Milwaukee area, helping to raise millions of dollars for local charities.



### WHY BE A SURVIVOR ARTIST

“I wanted to be a Survivor Artist because I enjoyed being around so much hope – real people who were having fun and living life ... The people who are the least confident about their ability to create end up surprising themselves.” ~ Jane Moore

### SOME FUN FACTS ABOUT RCA 2016

We have two mother and daughter teams painting chairs this year, as well as a mother and son. One of our artists, a former florist, provided flowers for a past Presidential inaugural. A few artists are choosing furniture pieces other than chairs to transform.

The WBCC's "Reducing Her Risk Now" and "Breast Cancer and the Environment" educational outreach programs are getting attention at health care provider conferences

## Practical Tips to reduce our risk



WBCC's Dawn Anderson volunteers with Oncology Nurse Navigator Laura Stratte to bring information about "windows of susceptibility" to breast cancer risk to area organizations. Drawing on our partnership with the Breast Cancer and the Environment Research Project, the team presents practical ways to avoid exposure to harmful chemicals and consumer products.

**WBCC AIMS TO EXPAND PROGRAMS**  
WBCC volunteers Dawn Anderson and Laura Stratte are being increasingly noticed for their presentations that focus on the science behind risk factors in the environment and practical tips to avoid exposure. Please contact the WBCC if you have a group, school or religious community that might be interested in our presentation.

### CONFERENCE ON OBESITY PLANNED

The WBCC is grateful to the **Cedarburg Junior Women's Club** for funding that will anchor a planned presentation on current research into obesity and breast cancer risk. **Dr. Amy Trentham-Dietz**, Breast Cancer and the Environment Research Program regional coordinator, has agreed to be part of the lineup for a fall conference. The WBCC is in contact with additional BCERP researchers and others who work in the area of lifestyle factors on breast cancer. **Columbia St. Mary's Hospital** has graciously offered to provide a venue for the event. More information to come as plans develop.

## Asking for Answers

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along with Representatives Jill Billings, LaTonya Johnson and Chris Taylor co-signed a letter to the Department of Health Services in May. The legislators noted: "We are very troubled to learn of these statistics and the number of Wisconsin women who are being turned away or not being provided life-saving medical care due to program changes implemented by your agency."

Shilling and Taylor also wrote an Op-Ed piece for *Urban Milwaukee* in May that again cited WBCC's survey of WWWP coordinators as evidence of WWWP problems caused by the reorganization. The legislators argue here that the Walker administration is using "a behind-the-scenes tactic" to undermine women's health efforts, screening and treatment for women, particularly as a



Rep. Gordon Hintz with WBCC representatives Sandra Gines, Kelly Herda and Zandra Clevert on State Advocacy Day in April. Rep. Hintz expressed support for WBCC's policy priorities, including expanding Medicaid.

strategy to eliminate Planned Parenthood in Wisconsin. The authors argue that insufficient funding for preventative care like breast cancer screening services is leading to the closing of at least five rural clinics: Johnson Creek, Beaver Dam,

Chippewa Falls, Shawano, and Fon du Lac, and possibly others, on top of creating a travel burden for women needing services. A link to the full article is here: <http://urbanmilwaukee.com/2016/05/22/op-ed-walker-has-slashed-womens-health-care/>.

## WBCC Hires Capitol Advocate



Hayley Young.

Hayley graduated from UW-Madison with a degree in Political Science and International Studies with a Certificate in Gender and Women's studies in May of 2015.

In all her work, Hayley is drawn to activism and affecting the political process, especially where it impacts women's health. Hayley hopes to bring her policy and advocacy background to the WBCC, and help create stronger relationships with change makers in Madison.

Hayley is currently a Legislative Aide, and a Dane County Board Supervisor where she serves on the Health and Human needs committee. When she isn't working, Hayley enjoys exploring downtown Madison with friends, going for walks, and curling up with a good book and a strong cup of coffee.



A new staff member will help us build collaborative relationships

The WBCC is taking action to forge stronger connections at the state capitol and with other advocacy groups with the hiring of Capitol Advocate,

>> READ ABOUT POLICY PRIORITIES ON [WWW.WIBREASTCANCER.ORG](http://WWW.WIBREASTCANCER.ORG)



Wisconsin delegates with George Washington at the NBCC Summit in early May in Washington DC.

## NBCC News National Breast Cancer Coalition



Thanks to advocacy efforts across the nation, the Durbin Amendment #4369 passed overwhelmingly in early June by a vote of 66-32. Responsiveness to the NBCC's action alerts to save the Department of Defense Breast Cancer Research Program (DOD BCRP) truly helped make the difference. The amendment protected breast cancer research funding at the Department of Defense, after Sen. John McCain moved against it in the "National Defense Authorization Act."

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On May 3, 2016, the Wisconsin delegation for NBCC's Lobby Day descended on Capitol Hill for meetings in the offices of our members of Congress. This year the main focus of Lobby Day was on S.746/HR1197 Accelerating the End of Breast Cancer Act, with the goal of getting this bill on the House floor for a vote and securing additional co-sponsors for the senate version S.746. This bill would establish a commission that would focus on identifying strategies for the primary prevention of breast cancer and identifying methods to prevent breast cancer metastasis-which accounts for over 90% of breast cancer deaths.

At the time we went to print, the Accelerating the End of Breast Cancer Act had strong bi-partisan support with 268 House co-sponsors and 51 in the Senate.

Carrie Riccobono, WBCC Vice-President, attended the National Breast Cancer Coalition Advocate Leadership Summit in Washington DC from April 30-May 3, where she heard Dr. Keith Knutson's presentation on "Vaccine Development: A Primer." Knutson is a founding member of Immunology at the Mayo Clinic since 2005. He also is the director of Cancer Vaccines and Immune Therapies program at the Vaccine and Gene Therapy Institute in Florida.



Carrie Riccobono with Dr. Keith Knutson

## In Search of a Vaccine and challenges in unlocking the immune system

By Carrie Riccobono, WBCC Board of Directors

The immune system is very complex. We know it can even turn around and attack ourselves, as seen in Lupus and Rheumatoid Arthritis. We know our natural immune system protects against cancer. Why does our body then not recognize the offending cells, chomp them up, and spit them out? This has boggled the minds of researchers for years. We know cancers can adapt, resist cell death, and trick the immune system. We know cancer is resistant to cell death. Some say cancer is, at its core, a failure of the immune system.

But because researchers have yet to find the virus that causes breast cancer, it is difficult to make a vaccine to provide immunity. Compounding this difficulty is the fact that there are 17 different molecular subtypes of breast cancer, all behaving differently, with more than 30,000 gene mutations involved. Researchers are focusing on predicting what gene mutations will happen and what kind

of cancer these generate. Researchers also are tracking how breast cancer tends to produce proteins at very high levels. Cancers upregulate the expression of these proteins, and researchers are working to develop targeted therapies to block or manage protein expression.

Vaccines work BEST when used PRIOR to any exposure, so that the memory cells of the body recognize the invader, attacking at the next exposure and preventing disease and infection – just like with the HPV vaccine. A specific molecule takes weeks to develop immunity naturally the first time it sees a foreign invader. The second time the exposure happens, the immune system is trained to make the specific molecules and launch an immune attack super fast. This kind of response is the hope for a current vaccine study for DCIS that is investigating whether the lesions of DCIS can be dissolved by the mechanisms of a vaccine, thus eliminating the need for surgery.

"Good immune health is important for a wide variety of diseases," Knutson said at the Summit. "Patients with a good immune system that get Herceptin plus chemotherapy do much better than those individuals who have a poor response in terms of their immune system."

### TRIPLE NEGATIVE VACCINE

A vaccine is in development for a particularly aggressive type of breast cancer commonly referred to as "Triple Negative Breast Cancer" (TNBC). TNBC strikes 15-20% of breast cancer patients. Right now, the only treatment is chemotherapy, and the disease, even when treated, is likely to come back and spread. On average, 40% of patients will relapse in 7 years.

More on that trial: <http://www.tampabay.com/news/health/medicine/experts-say-research-shows-promise-for-a-breast-cancer-vaccine/2271460?linkId=22969430>

## Building Alliances to make a difference

### COALITIONS IN ACTION

The WBCC attends monthly Wisconsin Breast Cancer Task Force meetings, where a new initiative has developed. Called Coalitions in Action, this smaller group is charged with developing a program to use a \$50,000 grant. Grant priorities include: consistent messaging, awareness of resources, and health literacy. Sandra Gines and Carrie Riccobono represent the WBCC on this committee, which is planning to address mortality disparities in Milwaukee.

### BC RESEARCH ADVISORY NETWORK

WBCC is represented in this new advisory network of advocates at the University of Wisconsin's Carbone Cancer Center. Advocates are paired with researchers across disciplines to help guide and lend support to their research grant proposals, develop criteria for clinical trials, and to eventually help disseminate important outcomes from their research to the public. Former Executive Director Dawn Anderson represents the WBCC in this work.



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## Immunotherapy Advances "More incredible discoveries like this are ahead"



By Eric Buhler,  
WBCC Board of Directors

Cancer has long been known for its radical treatments and therapies. It wasn't too long ago that one of the only treatments for breast cancer was a radical mastectomy. This required removing the breast, the chest wall muscle under the breast, and lymph nodes in the armpit. This was, and still is, an incredibly invasive procedure, leaving its patient severely scarred.

We still are using chemotherapy, radiation and surgery, and while these treatments are needed,

they are incredibly toxic and take their toll on the patient. The truth is, today, statistics estimate 1 in 6 women will be diagnosed with breast cancer, and 40,290 will die, along with another 400 or so men who develop this disease. In 1994, that same estimated mortality was 46,000.

So, in 22 years, we've managed to save about 5,300 lives. Enter a new hope, immunotherapy. *Immunotherapy* is treatment that uses your body's own immune system to help fight cancer. For years now,

### POLIO LENDS OPPORTUNITY

"A recent clinic trial at *Duke University* has reported incredible results. So incredible, that the FDA has fast tracked this particular therapy. The therapy you ask? Using polio to kill cancer. Researchers at Duke have bound the poliovirus to tumor receptors, thus allowing the immune system to recognize the disease, and subsequently destroy it."

no one has been able to crack the code of why our immune system is essentially blind to cancer. The disease is extraordinarily crafty and complex. However, it may have just met its match. We are beginning to figure out ways to wake up our immune systems, in order to attack cancer. Immunotherapy may be the way to breast cancer prevention and better treatment.