COLLABORATION IN A DIVIDED WORLD

By Sandra Gines, Executive Director

It’s no surprise that collaboration is a challenge in a politically divided world. Collaboration depends on shared goals, and in the political world, on finding middle ground, even when significant differences and disagreement exists. The Wisconsin Breast Cancer Coalition (WBCC) has always valued collaboration, but as the political landscape has become more polarized in recent years, we have faced increasing challenges to advocacy.

POLARIZED POLITICS

According to WBCC Board of Directors President Rhonda Deneka, things are most difficult on the national level. Like a number of WBCC advocates, Rhonda also has participated in lobbying efforts organized by the National Breast Cancer Coalition (NBCC).

“I have found that our State Advocacy Day is more enjoyable and more productive, and even though we may not feel certain legislators are willing to partner with us, or be supportive of certain legislation or programs we advocate for, I think they pay more attention and are more willing to speak to us. I just found that to be so refreshing, because when you go to D.C., it’s oftentimes just very frustrating,” she said. For one thing, in Washington, D.C., advocates are likely to meet with legislative aides only, not the legislators themselves. In addition, if legislators do meet with advocates, “They usually come to the meeting with you with their own agenda. They’re going to talk at you; it’s not a conversation.”
WBCC POLICY PRIORITIES FOR 2016

- **Well Woman Program** – protect the integrity of the program (assess the new model’s effectiveness) and follow the budget process to ensure adequate funding
- **BadgerCare**
  - Advocate for Expansion
  - Monitor waiver requests
- **Monitor waiver requests** for drug testing/health assessments and efforts to charge premiums to BadgerCare recipients
- **WI Cancer Reporting System** – continue to collaborate with Cancer Council members for increased funding in the next budget (build on near-success of this past cycle)
- **Get Youth Moving (GYM)** – continue collaboration with American Cancer Society and other groups to collect co-sponsors and see passage
- **Breast Density legislation** – continue to oppose any potential legislation and educate legislators about the rationale behind our opposition
Breast cancer is a political issue. For example, the federal government is the largest funder of biomedical research; laws regulate and support access to care and health care systems; and third party payers are subject to state and federal regulations. In fact, every aspect of breast cancer is touched by public policy. It is key that those who influence that policy are educated and trained.

To ensure this, NBCC informs, trains and directs Jim Sensenbrenner, Sean Duffy and Reid Ribble. The following Act has very strong bipartisan support on Capitol Hill with 228 co-sponsors in the House and 50 co-sponsors in the Senate. Co-sponsors from Wisconsin in the current congress include one senator and six congresspersons: Senator Tammy Baldwin and Representatives Mark Pocan, Ron Kind, Gwen Moore, Jim Sensenbrenner, Sean Duffy and Reid Ribble. The following have not yet signed on as co-sponsors: Senator Ron Johnson and Representatives Paul Ryan and Glenn Grothman.

OTHER NBCC POLICY PRIORITIES

PRIORITY #2
$150 Million for the Department of Defense (DOD) Breast Cancer Research Program (BCRP) for FY2016: 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.” The DOD BCRP is widely viewed as an innovative, unique, and efficient medical research model which has proven to be accountable to the public and has produced extraordinary results. NBCC seeks continued funding for this successful program every year. To date, this program has granted over $3.1 billion for breast cancer research, and more than $10 million was granted for breast cancer research in Wisconsin since the program’s inception.

PRIORITY #3
Guaranteed Access to Quality Care for All: Ensuring access to quality, evidence-based health care has been a top priority of NBCC for many years and is an essential component of Breast Cancer Deadline 2020®. NBCC works to identify, advocate for, and support the implementation of laws such as the “Patient Protection and Affordable Care Act,” which marks important steps forward in access to quality health care for individuals with, and at risk of, breast cancer. In addition, NBCC remains committed to protecting vital existing programs, such as the Medicaid Breast and Cervical Cancer Treatment Program (Medicaid BCCTP).

PRIORITY #4
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 which affects their lives.

The WBCC was officially formed in 1994 and has had strong ties with NBCC since its inception. The NBCC’s Team Leaders in Wisconsin also are members of WBCC. The WBCC supports the national policy priorities of the NBCC.
There is no doubt about it; in the summer of 2007 the Wisconsin Well Woman Program (WWWP) literally saved my life. I'm sharing this happy (but old) news with my good neighbors here in Sawyer County, and all of the people of Wisconsin, because the very program that saved my life and the lives of many other women living in Wisconsin has been drastically reduced in an abrupt manner for no apparent reason whatsoever. I offer the following information in the hope that it will encourage readers to voice their concerns about these policy changes to their legislative representatives.

In 2007, and for many years before that, health insurance was well beyond my reach and like many other Americans I simply had to do without and manage my health care expenses as best I could out of my pocket. I felt lucky though to qualify to be enrolled in and receive services through the WWP, a statewide program administered by the Wisconsin Department of Health Services that provides breast and cervical cancer screening services for women ages 45-64 who are underinsured or have no insurance at all. In other words, the WWP pays for the mammograms and pap smears that eligible women receive from their own doctors and medical providers. And if a woman is diagnosed with either breast or cervical cancer while she is enrolled in the WWP, she is provided with full medical coverage through Wisconsin Well Woman Medicaid for the duration of her cancer treatments.

It was the WWP that paid for the mammogram that revealed cancer in my breast that summer, and it was the Sawyer County WWP case manager who ensured that I received the medical services and treatments I needed. And perhaps most important of all, my WWP case manager facilitated the process of me attaining medical coverage through Wisconsin Well Woman Medicaid while I was being treated for breast cancer. Can you imagine my surprise and dismay when I was informed earlier this year that a WWP case manager would no longer be available in Sawyer County? Instead my case would now be managed remotely by an agent located in Oneida County who is responsible for all of the WWP enrollees across NINE counties. But that wasn’t all; I was then told that if I wanted to continue to participate in the WWP I would have to change my provider. I was stunned. Really? I would have to replace my doctor who has been attending to my health for over 20 years? The same doctor who tended to me while I received cancer treatments? I didn’t even have to think about it, there was no way I was switching my doctor, and fortunately for me I now have health insurance and didn’t need to. But I couldn’t stop thinking about the women in Wisconsin who are less fortunate than me, the women who don’t qualify for the UNexpanded Wisconsin Medicaid and can’t afford insurance through the Marketplace. So I decided to do some research. Here’s what I found out:

• The number of women being served by the WWP went from roughly 10,000 in 2013 to roughly 6,000 in 2014. This dramatic reduction in the number of women served is mostly attributable to women acquiring health insurance through the Marketplace.

• The WWP went from 85 coordinating agencies to just 11, and the approved provider network was reduced from over a 1000 to only 33. At least one county, Bayfield, doesn’t even have one approved provider located within its borders.

• The WWP is funded by both federal and state dollars. The current funding structure is in place until June 30, 2017. There was no reason to rush into the new model. A slower transition would have ensured that Wisconsin women who need these services would receive them.

I’m asking you to please think about the thousands of Wisconsin women who don’t have insurance because they don’t qualify for UNexpanded Wisconsin Medicaid and they can’t afford insurance through the Marketplace. In particular I am asking you to think about the fate of the underinsured or uninsured Wisconsin women who can no longer access the WWP for basic breast and cervical cancer screenings simply because they lack access. Finally, I am asking you to contact your Wisconsin legislative representatives and let them know that the cutbacks to the Wisconsin Well Woman Program are unacceptable.

"Thank you to Monk’s Bar and Grill at the Wilderness in Lake Delton, WI, for holding a tee-shirt sale fundraiser for us in the fall. Thank you to our other corporate and group donors since October, including: Aurora Health Care, St. Vincent Pallotti School Student Council (Milwaukee), The ROS Foundation, Wisconsinmade.com, Weather Tight Corporation, Joe’s K Ranch (Cudahy), and the Student Leadership Group at University School of Milwaukee. We are so grateful for our community support!"
Former WBCC Executive Director Dawn Anderson has noticed challenges on the state level. “Because we supported the Affordable Care Act, and because we opposed some of the policies that the current governor brought forward, I think that caused doors to close to us, because we took a position on a partisan issue,” she said. An example would be the WBCC’s support of the Affordable Care Act. The basis of WBCC’s support for this legislation is that women need access to health care before they can get access to screening or treatment. “If you don’t have access to health care, and many poorer women in Wisconsin don’t, all the pink ribbons don’t matter, all the drugs out there don’t matter, because you can’t get them,” Dawn said.

WBCC board member Kelly Herda believes the past few years have been difficult for women’s health advocates. As an advocate, she has even experienced animosity. However, “I do think we’re at a moment of change. … I think we have reasonable legislators in there who are waiting for the tide to turn.”

“Sadly, far too often I think people focus on the party line, and forget to really focus on issues,” said Carrie Riccobono, WBCC Board Vice President. “Education, not assumption, is the key to making change for all of us. Far too often I hear people say, ‘Oh, they’re so far to the right, or the left…’ Honestly, I have no idea who is on the right or left. I like it that way. I don’t want to be affiliated with a side. I want to make my voice count for what I believe to be my truths.”

Eric Buhler, a board member who has advocated in Washington, D.C. and Madison, said he believes the divide has intensified recently on the state level. He characterized both political parties as becoming more concerned about party loyalty than the issues. He feels that some legislators and aides act like they are not interested in learning about the issues, which feels insulting. On the other hand, he recognizes that “it’s challenging for politicians and staff members, because obviously the WBCC and NBCC aren’t the only organizations they see who are wanting funding.”

BEING COLLABORATIVE

Kelly noted that there is no definitive answer to the problem of collaboration in a highly politicized world, because every legislator is so different. The best strategy is to do your homework. “The key is to figure out ahead of time, do we have common ground? In many cases you can do that. You can spot that common thread, that common goal in the legislation. They might not like all of [your position], but that’s your door.” It is also important to “stick to the facts and not get emotional. Everything you do in a legislator’s office needs to be based on strong data, facts, information that can’t be disputed.”

Carrie agreed: “Focus on the issues, follow the discussion, talk with each other, and be open to other concepts.”

“I think you can’t be passive at all with them,” said Eric. “You really need to speak your mind and know what you’re talking about. I don’t think they give you the time of day if you stand there and stammer.” However, he believes the WBCC is good at demonstrating its seriousness. “We come in there with facts. We come in there with science. That’s what’s making a difference. I think, personally, that’s what throws them off, because we come on strongly.”

Rhonda named consistency and preparation as the best tools for collaboration, and added that it doesn’t hurt to have a good story, too. “They don’t always know what’s involved with some of these programs, and they don’t know if you have a personal story,” she said. “Sometimes you use your own story. Truthfully, because you’re a constituent, most of them care about you. That builds a rapport too.”

MISTAKES ADVOCATES MAKE

Kelly said advocates can work against collaboration when they forget to listen and when their passions get the best of them.

“Always take notes when you’re in there with the legislator … ask them questions. Don’t come in there with just your position, ask them where they are at, and why they don’t support [your position on legislation],” she said. The biggest mistake advocates make is getting carried away by emotion: “Oh my gosh, I’ve seen it too many times, where people without any advocacy training get in there and they go for the jugular… that’s not good.”

Eric described his mistakes as a new advocate years ago. “The first time I went to D.C., I went there solely with passion and passion alone, and I remember stepping out of Paul Ryan’s office, and I was furious, I was almost in tears because I was so angry and upset. Over the years, you learn to harness that passion into an intelligence, so you show that you know what you’re talking about. If you only have passion … you’re sort of throwing yourself to the wolves.”

WITHIN THE COMMUNITY

Political divisiveness on the national and state levels, ironically, may have brought the WBCC together with others in the breast cancer community.

“What I have noticed, since Governor Walker was elected, is that collaboration with other nonprofits has increased,” said Kelly. “We’ve had to combine our resources in order to get any momentum, in order to get that collective voice that we’re looking for.”

Eric notes that there have been tensions between the various breast cancer organizations in Wisconsin in the past, but he believes collaboration can powerfully advance the cause. “The WBCC and NBCC train advocates. It is truly phenomenal. It’s something you don’t have in other organizations. Do I think there needs to be more collaboration? Absolutely, you’re going to be 10 times more likely to get things done.”

Sarah Mroz is the facilitator of the Wisconsin Breast Cancer Task Force, a coalition of breast cancer groups begun in 2009 that has grown to include 42 organizations, including the WBCC. Sarah believes the friction between breast cancer groups arises from inconsistent messages being shared with the public. “Whether the messages are coming from national organizations or local groups, it can be a challenge for the groups who serve the public and have to deal with the confusion that results.”

Open conversation and providing venues for meeting together have helped build bridges between breast cancer groups.

“The Task Force has provided a neutral platform for information exchange and collaboration. Our meetings typically start with a presentation by one of the member organizations, which helps everyone at the table learn more about what services the group offers, who they serve and what projects they are involved in. This has led to a variety of groups making connections and finding ways to partner. Ultimately, our collaboration allows groups to better serve the community,” she said.

Rhonda agreed. “I think what we try to do is just identify and respect that we have different missions, and we are serving the community from different perspectives.”
EDUCATION UPDATE

Former Executive Director Dawn Anderson and WBCC volunteer Laura Stratte are preparing for two area presentations based on research by Dr. Frank Biro and other researchers with the Breast Cancer and the Environment Research Project (BCERP).

On March 5, Dawn and Laura will share BCERP research and risk reduction strategies at the Radiation Therapists of Wisconsin’s annual meeting at Columbia St. Mary’s Hospital in Milwaukee. On April 28, Dawn and Laura will again present BCERP findings at the Aurora Medical Center in Grafton. Biro, the Principle Investigator for the BCERP site at Cincinnati Children’s Hospital Medical Center, described his findings about adolescence as a window of susceptibility to breast cancer at October’s “Reducing Her Risk Now” presentation in Milwaukee. The event was co-sponsored by the WBCC, Columbia St. Mary’s Hospital and the Cedarburg Junior Women’s Club.

The WBCC is grateful to the University School of Milwaukee for donating more than $900 to the WBCC’s educational efforts in January, which will support all BCERP-related events and help us grow our educational outreach efforts.

The WBCC served as a community partner with BCERP during the last round of grant funding, collaborating most closely with Dr. Michael Gould at UW-Madison’s Carbone Cancer Center. BCERP is jointly funded by the National Institute of Environmental Health Sciences and the National Cancer Institute. It brings scientists, clinicians and community partners across the U.S. together to examine environmental effects on a woman that may increase her risk of breast cancer. Community Partners, such as the WBCC, help shape public health messages arising from the research and bring evidence-based information to the public as a resource for making healthy choices.

MEET OUR NEW BOARD MEMBERS

ERIC BUHLER

My name is Eric Buhler, and I am a breast cancer advocate. Those three words are symbolic for me, and truly define who I am. It has shaped who I am, and it has guided me to a career in nursing working with cancer patients.

I grew up in Racine and graduated from Washington Park High School. I had the typical childhood, spending time outside playing sports and keeping involved with school events. However, I never got the chance to meet my grandmother on my father’s side of the family. She passed away when I was an infant, of breast cancer.

Life went on until I was twelve. The year was 2002, and I had just lost my other grandmother to what the oncologist described as “cancer of unknown origin.” I was devastated, as my grandmother was one of my best friends and I held a strong bond with her. If that was not enough, the following summer in 2003, my mother was diagnosed with breast cancer for the first time. This was an extremely difficult time in my life, and as a young teenager, it made a lasting impact emotionally. It was because of this time in my life that I knew that I had to go to college to do something healthcare related, later realizing that nursing was my calling. Unfortunately, in December of 2011, my mom was once again diagnosed with another primary breast cancer, in the opposite breast. You have memories during the course of your life, which I believe shape the person you are. I was there both times my mother was diagnosed, and those memories for me are everlasting. For me, her second diagnosis was my wake up call. From there on out, no matter what it took, or how hard it would be, I would dedicate my life to the eradication of breast cancer. It is what has propelled me to join the WBCC and the National Breast Cancer Coalition.

KELLY L. HERDA

I’ve lived in the North Shore most of my life, growing up in Whitefish Bay and, now, living in Bayside with my husband, John, and our daughters Chelsea, Carly and Cassie. I’m a Navy veteran and studied cryptology while in the service. I am Co-founder and Senior Partner at Prown and Associates, a policy consulting and marketing firm for non-profits and corporations.

I started volunteering for the Wisconsin Breast Cancer Coalition (WBCC) because I needed a healthy way to work through a period of devastating grief after having both my mom and grandmother die from breast cancer. They fought the disease together and died just six months apart from each other. Fighting for research dollars to better understand the disease and finding ways to prevent and eventually eradicate breast cancer is a passion of mine, especially as a mother of three grown daughters who, due to our family history, are at an increased risk of being diagnosed with breast cancer later in their lives.

I’m thrilled to be joining such an esteemed group of professionals on the board of the WBCC. I have volunteered for the WBCC for nearly a decade tabling events, handling registration at the Rare Chair events, administrative support, attending the National Breast Cancer Coalition Conference (twice) and serving on the Policy Committee. Joining the WBCC Board of Directors is a natural progression for me. I will work with my fellow board members to ensure all women have access to health screenings and care, and strive to end breast cancer by 2020.
REMEmBERING PAT SKOWRONSKI
By Dawn Anderson

In June of 2009, a sassy, spiky-haired, smiling, vivacious woman joined our group of Rare Chair Affair Survivor Artists. She charmed us all, won our hearts with her own open heart and her sense of fun. Her “Betty Boop” chair that year set a new standard for over-the-top creativity.

At that time, Patricia “Pat” Skowronski was seven years out from a diagnosis of Stage IV Inflammatory Breast Cancer. She had already defied her doctors’ “one year to live” prognosis by six years, and she continued to defy that prognosis for another six years. She lived every day to the fullest, sharing her love and generous spirit with her family, her friends and the charitable causes that were close to her heart.

We, as an organization, were fortunate to be one of those causes. Pat served on the Rare Chair Affair committee every year following 2009, participating fully in all aspects of the event. But it was her work with the Survivor Artists that gave her so much joy and satisfaction. She inspired and encouraged them each year to find often unknown depths of creativity that reflected their breast cancer journeys in a meaningful way. “The girls” loved her, and she loved being a source of inspiration to them.

2015 was a struggle for Pat as she dealt with a recurrence and complications that left her voice strained and her body weak. Undaunted, while helping the other girls with their chairs, she created yet another Pat Skowronski masterpiece for the Rare Chair Affair - “C’est Magnifique.”

There is a photo from the 2015 RCA, of Pat sitting at her table as the bidding rose higher and higher for her chair. She looks a little stunned, but very moved. There were likely tears in her eyes. Pat often seemed to me to be surprised by the depth of love others had for her. If you told her how amazing you thought she was, she would brush it off and say, “Oh I just love doing this. It helps me more than I’m helping them.”

Pat’s unbroken spirit left her broken body on Christmas Eve. It is a sorely felt loss for all of us who’ve been privileged to work alongside her these past seven years and call her “friend”. At her funeral service, Pat’s daughters shared a passage that she read each morning. Reading it reassures me that Pat’s unbroken spirit continues to surround those of us who loved her, and encourages us to “use the gifts we’ve received and pass on the love that’s been shared with us,” just as she did. We will all miss her greatly.

RARE CHAIR AFFAIR SUMMARY

The 2015 Rare Chair Affair – “Bid Farewell to Breast Cancer” – raised nearly $31,000 for the WBCC while also creating fun and drama during the live auction of 17 chairs painted by Survivor Artists at the Wisconsin Club on Oct. 9. Former WBCC Executive Director Dawn Anderson announced her retirement at the event, which drew about 200. The event also featured a wine pull, silent auction and 50-50 raffle.

We warmly thank our amazing artists and their advisors for their contribution of time, labor and heart: Amberlea Childs, Jessica Davies, Kelly Herda & Cory Johnson, Kelly Krohn, Jo DeMars, Pilar Moller, Jane Moore, Sandra Pelzek, Carrie Danhieux Poole & Natalie Akins (Advisor), Monica Scharmer, Pat Skowronski, Anne Thompson, Tina Van Handel, Marge Vetter, Debbie Voelker, and the Young Survival Coalition Gals (Kristal Clegg, Sherie Drees, Lindsey O’Connor, Meredith Polewski, Stacy Scnp).

We couldn’t have had a successful event without our 2015 Event Partners and Sponsors. Thank you to: Confluence Graphics, Froedert & Medical College of Wisconsin, Froedert and Medical College of Wisconsin Center for Diagnostic Imaging, Harley Davidson, Partnership Bank of Ozaukee County, Paula Schulze (website), Two Men and a Truck, Wheaton Franciscan Health Care, and the Wisconsin Club.

Finally, we thank our silent auction donors, who contributed a variety of fun, beautiful, and memorable items and activity packages to the event: Patricia Skowronski, Laura Acuff of Koss Corporation, Denise Anderson, Roy & Dawn Anderson, Bruce Angeli of Bruce Angeli Artist & Architect, Scott Beck, Peggy Coffey, Diana David of Schlitz Audubon Center, Tom Dixon, Margie Edwards, Peggy Eilers of Harley Davidson Museum, Jim Frutchey of MorningStar Golf Club, Sarah Mayer Gash of Allure, Trish Gillespie, Green Bay Packers, Kristian & Jo Ellen Kay, Patty Lepak, Deb McCarthy of Circus World Museum, Jane Moore, Judy Gahn Murphy, Colleen Moore, Carol & Todd Peterson, Bela Roongta, Linda Setter, Deb Sturdevant, Tabitha Whit, Tara Wilke of McNabb & Risley Fine Furniture and Interior Design, and Melody Williams of Milwaukee Zoological Society.

* We apologize to any contributors were inadvertently left off these lists.
PAULA SCHULZS RECEIVES
WBCC VOLUNTEER OF THE YEAR AWARD

Paula Schulze, a WBCC Communications Committee volunteer, was named the 2016 Volunteer of the Year and presented with a certificate at the committee’s January meeting. When asked about her involvement, Paula said, “I’ve been a volunteer with WBCC since 2009, but I don’t think I’ve actually been on the communications committee that whole time. That’s mainly been in the last couple of years. I’ve worked on the Rare Chair website each year and have assisted with general WBCC website updates, the Collective Voice online e-newsletter, and email alerts.”

It is Paula’s outstanding and dedicated work on the WBCC website that earned her the award. She logged countless hours as she saw the website through a transition to its new WordPress platform and a new host, as well as implementing a new domain name (wibreastcancer.org). This work took her focused attention during 2015, and she continues to tweak and provide maintenance support for the system.

Paula became involved with WBCC because she supports the mission. “I felt that with my background in web design, I had useful skills that could contribute to that mission,” she said. Paula’s background is in the fine arts; she received an MFA from UW-Milwaukee. She currently works in web design and development for a Milwaukee-based association management firm, Executive Director, Inc. “I am also an artist, working mainly in printmaking and drawing. In addition to volunteering for WBCC, I am a mentor for ABCE,” she noted.

Paula will be honored again with a commemorative plaque at the Rare Chair Affair in the fall. The WBCC is grateful to have the generous service of volunteers like Paula!