



## 8th Annual Rare Chair Affair: Bid Farewell to Breast Cancer

**Mark your calendars!** It's time to Bid High, Bid Often, and Bid Farewell to Breast Cancer! This year's Rare Chair Affair is scheduled for Friday, September 28, 2007 beginning at 6:00pm at The Brynwood Country Club. Committee Co-Chairs, Debra Rand Feldman and Linda Weide report that there are some exciting new things happening this year. First, they are very pleased to introduce our Honorary Co-Chairpersons, breast cancer survivor, Robert Cohen, and his wife Karen. Robert is a 6-year survivor of breast cancer and reminds us that this is not exclusively a "woman's disease". New to the silent auction this year will be an "Alumni Section" of chairs painted by Survivor Artists from past years. The silent auction will also feature the return of the always popular "Restaurant Table and sports-related items".

We have a lovely facility in Mequon in which our survivor artists will be able to work on their chairs this summer. We have about 15 survivor artists to date and would love a few more! If you are interested in participating, please contact us soon as space is limited.

Invitations will be in your mailboxes later this summer so watch for them – or register online at [www.rarechairaffair.org](http://www.rarechairaffair.org).

The committee is now organizing volunteers, procuring silent auction items, and assembling our corporate sponsors. If you or your company would like to participate in the event by becoming an event sponsor, contributing an item for the silent auction, or just making a donation to help cover expenses, please contact our office at 414-963-2103. ✕

### in this issue

Rare Chair Affair  
**page 1**

Quality Health Care  
For All  
**page 3**

Complementary and  
Alternative Medicine  
**page 4**

Advocacy Training  
Conference  
**page 6**

Are You at High Risk?  
**page 7**

## Breast Cancer Recovery Foundation to Host First Infinite Boundaries Retreat in Southeast Wisconsin

The Breast Cancer Recovery Foundation (BCRF) has hosted many breast cancer recovery retreats for survivors over the years – in Door County, on Madeline Island, and in Wisconsin Dells to name a few spots. This year they are offering a new location for their November 8-11 retreat – The DeKoven Center in Racine. The DeKoven Center is on 20 wooded acres on the shores of Lake Michigan. Since 1852 it has fulfilled its mission of providing a place for education, spiritual reflection and recreation. All of its beautiful buildings are on the National Register of Historic Places. This will be a very special retreat – call BCRF at 888-821-1140, or register online at [www.bcrf.org](http://www.bcrf.org). Also see [www.dekovencenter.pair.com](http://www.dekovencenter.pair.com) ✕

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## President's Letter

Each time I sit down to write this letter for our "*Collective Voice*" newsletter I'm amazed at all the things this organization has accomplished and the sheer determination of our members and advocates in accomplishing our goals.

Just in the past couple of months we have:

- x Held an educational forum where we brought in top researchers from the Department of Population Health, the Medical College of Wisconsin, and the Milwaukee Breast and Cervical Cancer Program to talk about where we are today on breast cancer issues, specifically, in environmental research and toxicology, disparities in treatment, and challenges in current data and statistics,
- x Represented our constituents on the Wisconsin Cancer Council Public Policy committee,
- x Brought our message of advocacy to several support groups in Wisconsin,
- x Co-sponsored the Wisconsin Comprehensive Cancer Control Plan Summit held in Milwaukee,
- x Attended conferences on the future of healthcare technology, and
- x Brought 31 people to Washington DC to attend the National Breast Cancer Coalition Fund's Annual Advocacy Training and Lobby Day!

This last bullet is one I'm very proud of and consider quite exciting. We were the second largest state delegation at the entire event – second only to California. That is something to cheer about. (I'll even put in a little plug here: if you would like to join us next year, contact the WBCC office for information.)

As you read this issue of *Collective Voice* you will see that we've been busy learning, too. Most of these articles came out of the experiences and education our Wisconsin delegation received on our trip to Washington. We wanted to share as much as we could with you. You will read about interesting facts, notably in the article on Guaranteed Access to Quality Healthcare, the fact that with all the treatments and advances we are making in breast cancer, on average a cancer patient still only lives 10 weeks longer today than she did in 1960. This is a shocking fact to many people, since the positive media sound bytes you hear every day would have you believe we have virtually cured the disease. Other articles are about our first-time Sherry Kohlenberg Scholarship recipients' personal experiences at the conference and the excitement they brought back with them to help make more of a difference here in Wisconsin.

This time of year we are also well into planning for our annual fundraiser, the Rare Chair Affair. This year it will be held on September 28th from 6 to 10pm at Brynwood Country Club in Milwaukee. There are lots of new and exciting things happening at the event this year. Be sure to register early for the event, as it is sure to be one of the best. Of course we are still looking for volunteers to help with the event, corporate and individual sponsors, and item donor for the silent auction. If you are interested in helping out, please call or email the WBCC office.

Finally, I would like to thank all of you who purchased memberships for friends or family members or renewed your own membership during our recent membership drive. We heard from many people who just couldn't think of a gift to give that hard-to-buy-for-someone and thought a membership with WBCC was the perfect thing. We even had one person who purchased a membership for her sister who celebrated her five-year anniversary of survivorship in May – a terrific reminder of her own personal achievement. Don't forget throughout the year this neat idea for birthdays, anniversaries, holidays, or just because.

Have a safe and healthy summer.

*Ellen Vander Heyden*

WBCC President

## Priority #1: Guaranteed Access to Quality Health Care For All

By Dawn Anderson

The National Breast Cancer Coalition's number one legislative priority is a lofty goal, and not a new one. But with the growing numbers of uninsured and underinsured patients in this country, it certainly is an important one. At the 15th Annual Advocacy Conference held April 28-May 2 in Arlington, VA, the state of our health care system and the funding crisis it presents was a looming issue.

In several of the panel discussions on the topic, it was repeatedly pointed out that the U.S. spends nearly \$2 trillion on healthcare annually – more than any other country in the world, more than the gross national product (GNP) of China. And yet we have huge disparities in health care coverage and the quality of care received. Gail Wilensky, PhD, a senior fellow at Project HOPE (for 50 years Project HOPE has worked to make health care available for people around the globe – especially children), said it very succinctly, “We are absolutely in an unsustainable situation.” Between 1960 and 2004, healthcare costs have grown 2-2.5% faster than the economy – and despite this increasing level of spending, we still have disparity and problems with patient safety. Growth models indicate that if we continue this trend, health care spending will reach a projected \$4 trillion and account for about 20% of our gross domestic product (GDP)\* by 2015. Ironically, for every 1% increase in health care costs over inflation, the number of uninsured increases by 30,000 people – primarily because healthcare plans are becoming prohibitively expensive for employers and are often consequently dropped from employee benefits packages, leaving employees and their families without insurance.

Dr. Zeke Emmanuel of the National Institutes of Health (NIH) pointed to the enormous sums of money we spend and postured that it's not about needing more money, but about needing to reassess how we allocate the money. In his presentation, *Cancer Patients and the Need for Value-Based Rationing*, he discussed the marginal benefits realized in cancer care over time. Since 1960, the average life expectancy in the U.S. has increased by 6.97 years. Despite what we have spent on “the war on cancer,” for cancer patients, that change is only .19 years – the average cancer patient only lives 10 weeks longer today than in 1960! The cost of those 10 weeks of survival amounts to over \$100,000 for a 45 year old and \$150,000 for a 65 year old.

For obvious reasons, patient attitudes are that cost should not matter and that we shouldn't limit expenditures on treatments. This results in a demand for expensive screening and treatment methods that have not been clinically proven to increase survival. As an example, he pointed out that computer-aided mammography (digital mammography)

has not been proven to impact survival rates and he speculates that the same will hold true for MRI screening. Another example, PSA tests routinely used as screening for prostate cancer have not clinically been shown to reduce mortality. Surprised? These are not facts you hear on your evening news or read in newspapers.

Dr. Emmanuel recommends the creation of an independent institute to evaluate treatments and outcomes, to develop a trustworthy process of determining the value of medical interventions, and a systematic evaluation of new technologies. This could lead to a system of tiered coverage in insurance plans where financial incentives would be available only for cost-effective interventions, ie: no co-pays for those services that are proven to be effective. The goal would be to discourage and limit the use of interventions with “low value” and require individuals to pay out of pocket for their preferences for expensive but low value treatments.

The problem of course is how does the average person know what a high value vs. low value screening or treatment option is? As consumers, we are bombarded with news stories and advertising for new drugs, screening and treatment options. If it's on TV, there is a sense of credibility that the average person buys into – and healthcare providers, perhaps because of our system of fees for service, often concede to the demands for these new interventions. Carolina Hinestrosa, of the National Breast Cancer Coalition Fund (NBCCF), noted that the health of our population is not the cause of our high costs – the problem is OVERUSE of the system and procedures.

Musa Mayer, MA, is the author of three books on breast cancer and has developed an online consumer course on evidence-based medicine for the U.S. Cochrane Center. She pointed out in her presentation that American breast cancer patients may be the most over-treated in the world and that 60% used the internet to search for information on treatments. Kay Dickersin, PhD, from Johns Hopkins University explained the problem with consumers' views of evidence-based health care: they don't understand it and think more is better.

So, how do consumers know when a healthcare claim is true? Dr. Dickersin outlined a continuum from evidence to practice, of what should be done.

- ✗ Conduct individual studies on each research question.
- ✗ Perform a formal synthesis of high quality studies regarding a similar question (systematic review)
- ✗ Develop practice guidelines based on all high quality evidence and systematic reviews.

It certainly puts an unrealistic burden on consumers to educate themselves on the scientific method and to research

## Evidence Based Complementary and Alternative Medicine (CAM)

By Karen Nelson

I recently had the most wonderful opportunity to attend and participate in the National Breast Cancer Coalition (NBCC) Advocacy Training Conference in Washington DC. I was blessed with a scholarship from both the Wisconsin Breast Cancer Coalition (WBCC) and NBCC. Without these scholarships, I would not have been able to attend. It is my intention here to expound upon one of the many seminars I attended.

Since I am a three year survivor of Stage IV metastatic breast cancer, I felt it imperative that I attend the seminar on Evidence-Based Complementary and Alternative Medicine. I was drawn to this subject because this was a portion of my treatment, in addition to “normal” chemo and radiation therapy.

Lisa Corbin, MD, Medical Director of Integrative Medicine at the University of Colorado Hospital and Health Sciences Center facilitated this workshop. Dr. Corbin first defined “CAM”:

- C** = Complimentary, meaning in addition to conventional medicine
- A** = Alternative, meaning instead of conventional medicine
- M** = Medicine

CAM therapies are those not usually associated with hospitals or medical schools - such as acupuncture, massage therapy, or chiropractic work.

Integrative Medicine involves CAM therapies that are coordinated with conventional medicine. This is the route I chose to take.

It is important to note in this discussion the importance of ethical principals in coordination of treatments. Dr. Corbin outlined four important principals:

**1) Respect for Persons:** (Autonomy) – a health care provider must value patients as individuals and respect their personal freedom, respect cultural diversity, acknowledge a patient’s control over their life/body, and emphasize respect in treatment. Communication must be completely honest. For instance distinctions must be made between “best possible evidence” vs. “best available evidence”, what’s known vs. what is theory.

Informed consent/refusal and conventional standards must be discussed and explained, and finally, confidences must be honored.

**2) Nonmaleficence:** (First Do No Harm). All patients should be asked about CAM use and dissuaded from harmful practices. Patients should be referred only to trained and licensed CAM providers.

Risks to be avoided include anything being used in place of proven, curative, conventional treatments; financial risks because many treatments may not be covered by insurance and can be costly; and spending money on unproven lab tests or other studies.

CAM therapies that were noted include colonic enemas, chelation therapy, intravenous therapies, restrictive diets, megavitamins, and some supplements. Supplements she recommended are selenium, omega3 fatty acids (fish oil), CoQ10 in patients taking doxorubicin, and glutamine in patients at risk for chemotherapy or radiation GI side-effects. Supplements that were condoned were MVI (multi - vitamin infusion) up to the RDA, CoQ10 in other patients and shark cartilage.

There are three types of medicines: prescriptions, over-the-counter (OTC), and dietary supplements. It’s important to note that unlike prescriptions and OTC’s, dietary supplements are not required to prove safety or effectiveness. They are not required to enforce quality control and vary tremendously in concentration of ingredients, so it is critical to not only look for quality brands, but to discuss their use with your physician

**3) Beneficence:** (Promote health and alleviate suffering). Following are some of the benefits of the more widely known and used CAM therapies.

Acupuncture has been used to reduce nausea/vomiting due to chemotherapy, reduce hot flashes, and decrease peripheral neuropathy. It is said to have a calming and relaxing effect, help with other pain control, and may help your immune system.

Massage Therapy can be helpful for depression, anxiety, sleep disorders, and muscular pain, and may speed postoperative healing, be helpful in reducing lymphedema, and also may boost your immune system. Two important points to remember – appropriate touch is important and massage therapy will NOT “spread” a tumor.

Diet is important all along the breast cancer continuum, but particularly it is important to ensure good nutrition during treatment. Increasing consumption of fruits and vegetables may be helpful, as it is with the general population and minding fat intake (ie: keeping it at about 20% as opposed to 40%) is a good idea for all of us, but especially for those at high risk or risk of recurrence.

Mind-Body Therapies are generally safe however costs may vary and practitioners should have training. Some of the benefits include a decrease in stress (helping patients regain control), a sense of identity and connectedness through spirituality, and better sleep. Support groups have been shown to help improve outcomes and exercise has shown to reduce risk of recurrence.

**4) Justice:** Patients should not only have fair access to CAM therapies but should have access to a good practitioner consisting of the following traits. They should:

- ✗ Be trained and licensed
- ✗ Have experience with cancer risks
- ✗ Be willing and able to work with conventional providers
- ✗ Provide and time frame to assess your progress

Finally, patients should watch out for unethical examples of CAM or CAM practitioners such as

- ✗ Aggressive marketing to patients by the industry
- ✗ Conflicts of interest; are they selling supplements from the doctor’s office?
- ✗ Over-representation of the virtues of CAM
- ✗ Ignoring or downplaying the benefits of conventional treatments, or falsely elevating the risk. ✗



article continued from page 3

treatment and screening options. But just having the confidence to question their healthcare provider about the clinical value of a treatment, for example, is a step in the right direction. Patients should be comfortable asking their doctors “where’s the proof that this is going to work?”

The issues that confront us are enormous in trying to fix our broken system and ensuring that everyone who needs care receives good care. It will require a lot of thoughtful consideration of issues, collaboration between advocacy groups, governmental agencies and healthcare providers, and certainly some hard decisions will have to be made. But, as NBCC President Fran Visco said to attendees during the

NBCCF annual meeting luncheon, “The most important thing a state can do is work to expand access to quality care for everyone.” In our role as patient advocates and educating patients to be advocates for themselves, WBCC will continue to look for ways to collaborate with other groups, and to work with policy makers, to move us closer to that goal.

\*The GNP and GDP are measures of the total economic output of a country in one year. GNP measures output by the country’s citizens both at home and abroad. GDP measures the output of the country as a physical entity. ✕

## An Advocate’s Unique Experience on Capitol Hill

By Galina Tash

I attended the recent Annual Advocacy Training Conference and Lobby Day, given by the National Breast Cancer Coalition (NBCC) in Washington, DC. This was my 5th time attending the conference and I would say my first trip and most recent trip have, by far, been the best.

My first trip to DC was in 2002 and I felt as if I was back in first grade learning the alphabet. I didn’t know anything about Lobby Day or what to expect. I quickly studied NBCC’s Legislative Priorities prior to the trip. I attended workshops at the conference and learned a lot of new and useful information. Prior to us visiting offices of our WI Representatives in the Senate and the House of Representatives there was a Rally on the steps of the Capitol. There were speeches, singing, and fun. Then with signs and banners, we went on to do our job: convince our representatives to support, and sign on to co-sponsor our priorities. It was great feeling I was part of something big, making changes in breast cancer treatment/research. It was no longer my own fight against breast cancer; it was OUR fight against breast cancer.

Now that I have been a member and advocate with WBCC for some years, the 2007 conference brought new workshops, new knowledge, new friends, and fun – it also gave me a new unique experience. This year my daughter attended the conference with me. On Lobby Day, between meetings with WI Representatives my daughter, another member of the Wisconsin delegation and I were able to attend hearings of the House Appropriations Defense Subcommittee on Preventative Medicine and Cancers Programs (DOD Breast Cancer Research).

For those who may not be familiar, the Appropriations Committee is a committee of the United States House of Representatives in charge of setting the specific expenditures by the government of the United States. Basically, it holds the purse. The current Chairman of the Appropriations Committee is David R. Obey from Wisconsin.

The hearing lasted approximately about one hour and began with the testimony of Colonel Harris (Director of DOD research program) on behalf of the Cancer Research Programs. Her speech was short, smooth, and to the point. She gave an overview of the Cancer Programs, how the money has been spent, and an indication/request regarding how much money is needed to fund next year’s research projects.

I had the privilege of meeting Colonel Harris three years ago, when I was part of the DOD Peer-Reviewed Breast Cancer Research Program (BCRP) panel in Washington DC. She was newly appointed to this position.

After Colonel Harris finished her testimony, the DOD Scientific Research Program Panel took their places. Fran Visco, President of NBCC, is one of the panelists and she provided testimony recognizing the progress that has been made in breast cancer research through the DOD BCRP and the affect the program has had on other programs that now use it as a model. She also reminded the committee that research conducted through this program has led to many significant advances in breast cancer research, such as the drug Herceptin®. Ms. Visco then appealed to the committee to maintain the \$150 million level of funding required to continue this important and innovative research.

Other points that were made during this testimony were that cancer survivors were a highly effective part of the grant approval process in this program, research into other cancers, such as ovarian, cervical, and uterine as well as prostate was also being conducted.

While I listened to the testimony of the panel and the subcommittee, I realized how both far we have come and how far we have yet to go in breast cancer research. I am thrilled to have had this unique opportunity to witness the activities of our government and how it directly relates to my own personal war with breast cancer. This was definitely a significant experience in my life and I’m happy to be able to share it with my daughter and others. ✕

## 2007 National Breast Cancer Coalition Advocacy Training Conference

By Kim Daniels

As a 2007 WBCC Sherry Kohlenberg Scholarship recipient, I was able to attend my first National Breast Cancer Coalition (NBCC) Advocacy Training Conference in Crystal City, VA, April 28- May 1, 2007. These four days were literally packed with a wealth of information about breast cancer.

The plenary sessions, whose panelists consisted of physicians, scientists, foundation and health network leaders, covered topics such as “15 Years of Breast Cancer Advocacy: Did it Matter?“, “The True Costs Of Healthcare” and “Evidenced-Based Healthcare.”

Each attendee was able to participate in workshops that covered a wide spectrum of topics. Some discussed breast cancer research and treatment such as “Breast Cancer Treatment: New and Emerging Therapies”, “The Carolina Breast Cancer Study”, “Stem Cell Research in Breast Cancer”, “Diet and Breast Cancer”, and “Evidenced-Based Complimentary and Alternative Medicine”. Other workshops focused on the NBCC’s 2007 Legislative Priorities, “The Nuts and Bolts of Congress” and “The Role of Consumer Advocates in Health System Change”.

On Monday evening, everyone danced to music played by a great DJ and celebrated being together and being alive.

Tuesday was spent in Washington D.C. on Capital Hill, visiting our Wisconsin Senators and Congressmen. We thanked those who have supported the NBCC’s legislative priorities in the past and urged them to continue their commitment. The NBCC’s legislative priorities for 2007 are:

- ✗ *Guaranteed access to quality healthcare for all*
- ✗ *\$150 million for Department of Defense Peer-Reviewed Breast Cancer Research Program*
- ✗ *Enactment of legislation to study links between breast cancer and the environment*
- ✗ *Preservation of The Medicaid Breast and Cervical Cancer Treatment Program*

The NBCC Conference was an extraordinary experience for me. I learned so much about what is being done with research and what we are accomplishing as an organization in Congress. My head is still spinning from all of the knowledge I gained. The most meaningful experience I gained, though, was meeting all of the wonderful women (and man) from the WBCC. I am in awe of how generous you all are with your time and commitment to fighting and finding a cure for breast cancer. You all made me feel very welcome from the moment I met you. I am honored to be a member of such an important organization. I look forward to meeting more members, and working with everyone for our cause, TO END BREAST CANCER. ✗



*Wisconsin advocates at the National Breast Cancer Coalition's Annual Advocacy Training Conference.*



*Wisconsin Advocates with Dr. Susan Love.*



*Wisconsin advocates at the National Breast Cancer Coalition's Annual Advocacy Training Conference.*



*Wisconsin Advocates with Senator Feingold.*



*2007 Sherry Kohlenberg Scholarship Recipients.*



*Wisconsin Advocates with Rep. Gwenn Moore.*

## MRI Screening and High Risk

By Karen Maynard

Knowing your risk for a breast cancer diagnosis could be a valuable tool for most people. Scary, yes, and full of drama to decide what steps to take. But what about your other alternatives? Wouldn't it be in your best interest to "catch" it early rather than down "invasive lane"?

Unfortunately, your options for a definitive result are limited. The basics include a breast self exam (BSE) or a clinical breast exam (CBE). Although helpful, these can only indicate an area of suspicion, which is already felt as a palpable lump or an actual tumor...personally, I prefer a microscopic finding, something on the nano level would be even better. Next, there's your yearly mammogram if you're 40 of course, unless you have been deemed high risk and begin screenings earlier. We know the yearly mammogram is especially helpful if you have less dense or non-fibrocystic breasts. Also on the list of options is the ultrasound to detect variances in breast density, but not useful for detecting the very early cancers which we would love to find at that golden "curable stage". Finally, and most recently added to the approved and recommended list, there is the Magnetic Resonance Imaging (MRI).

Recent chit chat about MRI is based on studies of individuals with a personal history of breast cancer. The MRI was used in this study as part of follow-up routine to locate new or secondary cancers in the opposite breast at time of diagnosis of the first or primary cancer in the opposite breast. Statistics show that approximately 1 in 10 women who have a primary cancer in one breast will be diagnosed with another cancer in the other breast at some point in their lifetime. A bit of unsettling news for me, having been diagnosed in one breast at age 33. I hopefully have many years of waited anticipation for this to occur.

Due to the lack of conclusive imaging or detection methodologies, detection methodology studies are constantly being conducted for more effective methods to detect cancer. In the March 29, 2007 issue of the New England Journal of Medicine, The American College of Radiology Imaging Network (ACRIN) study, which is supported by the National Cancer Institute (NCI), disclosed results from a study using MRI to detect cancers in those with a prior diagnosis.

Wow! The study was impressive or scary depending upon how you look at it. The report by NCI stated "The study

recruited 1,007 women from 25 institutions who had a recent diagnosis of cancer in one breast. Of these, 969 women completed the study, which began in April 2003. All of the women enrolled had a negative mammogram and negative clinical breast exam of the opposite breast within 90 days prior to the MRI. After receiving an MRI, 33 contra-lateral breast cancers were diagnosed. Thirty of these tumors, or 91 percent, were diagnosed as a result of MRI. The other three cancers were detected due to subsequent mastectomies. The best news of the day for me as young survivor and advocate was that researchers found that the 'added benefit of MRI was consistent, regardless of a woman's cancer type, age, or breast density'."

Sounds unbelievable doesn't it? It would be great to find these cancers at an earlier stage upon initial diagnosis of the contra-lateral breast so that both breasts could be treated at the same time rather than having a repeat performance months or years later. Better yet, breast conservation for those women opting for surgical removal of the healthy breast due to the possibility of a hidden cancer.

Wouldn't it be great to find cancers earlier and someday, possibly find them before they occur and have a way to prevent them from ever occurring? Don't get too excited. With the good always comes some bad - or let's say questionable. What we need to do is look at the high possibility of false negatives. For those of us with a declaration of high risk or personal risk I am all for chop-chop-zip-zap. Anything to eliminate the dreaded waiting game or the "come back in 6 months" approach - which is not only frustrating but scary for all cancer patients. But how about the use of MRIs for the average woman? Other issues can mimic or confuse the results of the MRI that might be interpreted as the big-C. Then what do physicians do with this information?

Although this study presents new and exciting news for the breast cancer patient at initial diagnosis, those without a personal history are just going to have to wait for the results of other studies determining if MRI can be used as a screening tool. If you fall into this high risk category why not find out if there is a study that you can participate in? It is true that prevention or surveillance studies often have difficulty recruiting healthy and willing participants. As a biased cancer survivor, I prefer to call it a form of life insurance. ✕

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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.

### TO CONTACT WBCC

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