WBCC Annual Meeting to be held in Brookfield on November 12

WBCC will hold its annual business meeting and educational event at the Sheraton in Brookfield on Wednesday, November 12, from 6pm to 9pm. This year we will be featuring keynote speaker, Senior Scientist and Lead Environmental Toxicologist, Ruthann A. Rudel of the Silent Spring Institute. We are excited to have Ms. Rudel join us this year and look forward to hearing her presentation.

The event is open to the public and all are welcome. The event begins at 6pm with a short reception including cocktails and hors d’oeuvres. During the annual business meeting we will celebrate a successful year, welcome new directors to our board, and look forward to 2009. Finally, we will hear Ms. Rudel’s presentation, which will be followed by a question and answer session.

WBCC members are free and non-members are $5. Pre-registration is requested. To register please call our office at 414.963.2103 or email wbcc@standupandspeakout.org.

Bosom Buddies Cooking Together Cookbook For Sale

WBCC is proud to have collaborated on a beautiful cookbook called “Bosom Buddies Cooking Together” with ABCD, Inc. and the Wisconsin Breast Cancer Showhouse for a Cure. Recipes were solicited from breast cancer survivors and the members of all three organizations. Who doesn’t love to crack open a new cookbook and dream about all the new recipes you’re going to make? For $20, it’s a great deal and it’s a great way to support Milwaukee area breast cancer organizations. Look for this gorgeous cover art by Fran Rubenstein at area stores, or give us a call if you’d like to purchase a book 414.963.2103.
President’s Letter

Is it October already? This is an exciting time of year for WBCC members. Like every other year, we’re wrapping up our big annual fundraiser, Rare Chair Affair, preparing for our Survivorship Conference and our Annual Business Meeting, attending the latest research conferences, and lining up speaking engagements for local brown bag lunch presentations and corporate and other organizational events.

We have a wonderful issue of Collective Voice as well.

- Breast Cancer Survivor and Honorary Chairperson of this year’s Rare Chair Affair, Jan Hess, has allowed us to print her moving speech from the event.
- WBCC Member and Breast Cancer Survivor Michelle Neustedter writes about an important study about breast cancer in young women that she and her family are participating in.
- We have an update on the success of our efforts this year in getting $150 million for breast cancer research through the Department of Defense Breast Cancer Research Program.
- There is a great wrap up from the Rare Chair Affair event this past September.
- You can read about the special citation WBCC received, signed by Rep. Sheldon Wasserman and Sen. Roberta Darling.
- There are also lots of recent WBCC events and upcoming events that are important to us all.

Yep, it's October and breast cancer is in the media and top of mind for many people. So while you are reminded to get your mammogram and do your self breast exams, remember one more thing to renew or become a new member of WBCC, because the more members we have, the stronger our Collective Voice.

One more thing, WBCC Members, watch your mailboxes for your 2008/2009 ballot to vote for the new WBCC Board Members, and be sure to RSVP for our Annual Business Meeting and Membership Appreciation Reception.

Ellen Vander Heyden

WBCC President

WBCC Receives Honor from State Representative Sheldon Wasserman

WBCC was recently honored for our programs and activities and our hard work toward ending breast cancer in Wisconsin. Citing our success and the need to move to larger offices to better serve our constituency, Rep. Sheldon Wasserman presented us with a beautiful citation, signed by both Wasserman and State Senator Alberta Darling. Wasserman and Darling have both been long-time members and supporters of WBCC. It is a great honor to be recognized for the work we do here in Wisconsin and we thank them both for their continued support of our efforts. If you would like to see the citation, please visit us in our new office at 5630 N. Lake Dr., Whitefish Bay, WI. Rep. Wasserman presented us with the plaque in our new offices on September 18th.
Survivor Spotlight
By Jan Hess, WBCC Member

Jan Hess was this year’s Rare Chair Affair Honorary Chairperson. Her speech was so moving that we wanted to share it with our Collective Voice readers. Jan has graciously allowed us to reprint it here.

Hi, my name is Jan Hess. I’m a teacher of 15 years, a wife of almost 7 years, and I am a breast cancer survivor of almost 4 ½ years. But most notably, I’m a mom of 10 ½ months. This is the third year in a row that I have participated in the Rare Chair Affair; the last two years I painted chairs, but this year, due to the recent birth of my child, after recovery from cancer and chemo-induced menopause, I am here to share my story.

My breast cancer story starts many years before I was diagnosed. I had an appointment to have a lump checked out. A lump that, over the course of a few years, had been looked at, palpitated, mamagrammed, and ultra sounded many times. Each time I was told it was just a cyst and nothing to worry about. Each time, although I think I knew better inside, I foolishly went away thinking to myself, “Rock On, I’m healthy, and no one has to cut into me or cause me any pain. Thank you, Lord,” I just kept believing that I would be fine. I really should have listened to my inner self; the part of me that was saying, “This just can’t be right. It can’t be just a cyst. If it was, it would have dissipated by now.” Instead, I went to my appointment thinking, “They’re just going to tell me it’s a cyst again, and I can go on living my life as normal.” As it turned out, that was not the case.

At the age of 35, I was diagnosed with stage three, grade three, very aggressive breast cancer. The cancer also had lymph node involvement, meaning that it had spread from the breast to the lymph nodes under my arm. I was only 35, I had only been married a few years, I had just earned my masters degree, and I hadn’t had my children yet. I quickly found out that I was old when it came to fertility, but young when it came to a breast cancer diagnosis. I believe the cancer was missed, brushed off as a cyst, due to my age.

Even so, my first instinct was to try to preserve my fertility because the chemotherapy that could save me would likely strip me of my fertility. I decided to put my cancer treatment on hold while I went through fertility treatments to collect and fertilize eggs in order to freeze embryos; in order to give my husband and I a chance at having children after my cancer recovery. Unfortunately, this did not work. I just don’t know if anyone can truly understand the severity of my disappointment. I fell into a pretty deep depression, but I very quickly decided that that was no way to live. I just couldn’t allow myself to stay in that low, low place. So, although I was just sick about the possibility of not being able to have kids, I picked myself up and decided to get well, to beat the cancer, to kick it’s unwanted butt.

The Center for Breast Care at Waukesha Memorial helped me with my mission. They took care of me as soon as my lump was considered suspicious. They did the diagnostic work. They set me up with my oncologist, Dr LeMarbre, my surgeon, and my radiologyoncologist. They also made sure I was put in contact with cancer support groups, peer mentors, nutritionists, and anyone else I may have needed support from. They even called me from time to time to make sure I was doing okay. In short, they treated the whole me; mind, body, and spirit.

Ultimately, I ended up having a lumpectomy and lymph node dissection, highly aggressive chemotherapy, and a standard course of 6 ½ weeks of radiation which I finished in March of 2005. I had all the medical support I needed to beat the cancer; to be cured. I had the support of family in the hospital for my surgery. I had the support of my friends who rotated weeks to look after me while I was so very tired and sick from the chemotherapy; chemo that did indeed leave me infertile. Of course, my mom was essential in getting me though the roughest of times. She was at my house all the time driving me to appointments, cooking and cleaning for me, and just being there for me whenever I needed anything. I also leaned on many support groups and healing activities.

Now that you know who I am and why I am here, I want to share with you a few things I that have learned throughout this whole ordeal. First and foremost, do not ignore your inner feelings; your gut instinct. If you feel something is wrong, be assertive and get all the care you need until you know exactly what you are dealing with. If I could do it all over again, I would not have stopped at a mammogram and ultrasound so long ago. I would have made sure to have the lump biopsied the first time it was looked at. That is my first piece of advice; get a biopsy. A biopsy can tell you more than a mammogram or an ultrasound ever could, and it’s a very simple procedure with very little pain. If I had known that then, I would have requested a biopsy and been able to catch the cancer before it became so aggressive, so life threatening; requiring the aggressive chemo that robbed me of my precious fertility.

My second piece of advice is to go for what you want in life right away, right now, without worrying about potential obstacles. If
I could have a do over, I would not have put trying to start a family on hold to finish my Master's degree. I just though it would have been better that way. I thought I was building a strong foundation for a new marriage. I thought I was being smart. How very wrong I was! In retrospect, I could have found a way to be a wife, a teacher, a student, and a parent all at once. My hard earned Master's degree no longer seemed important compared to the idea of not being able to raise children.

My last piece of advice is to enjoy each and every day, to be thankful for the time you have on Earth, and to live mindfully; enjoying the small moments in all that you do. Take time for yourself so you can be healthy. Eat well, exercise, rest, and have fun. All those things can help you to relieve stress, a huge factor in all kinds of diseases.

As I reflect upon the journey that has led me here tonight, I realize just how lucky I am that I was led to Dr. LeMarbre, my Earth Angel. While, it's true that he offered me an advanced treatment option that I could find nowhere else, more than that; he treated me, not just my cancer. He believed in me to make choices based on what would make me happy because he knew that my happiness could bring my body back to health faster than any treatment ever could. When I got my menstrual cycle back after chemo induced menopause, Dr. LeMarbre’s belief in me gave me the courage to stop taking tamoxifen early in order to pursue pregnancy. In lieu of tamoxifen, I felt confident in choosing energy healing, acupuncture, and good nutrition as ways to feel that I was taking charge of my health. Just six months after my first cycle, I became pregnant. I believe that having a wonderful, caring doctor like mine is a key factor in a full recovery. His belief in my treatment and in my happiness was instrumental in bringing my husband Joe and I to our little Lila. He was ahead of his time in his treatment of the cancer, and he was ahead of his time in his treatment of the patient as a person, not just a disease.

In closing, I just don't think I could have done so well and come so far without both types of care, both medical curing and supportive healing, and I want to take this opportunity to say thank you to those who donate time, talent, support, resources, and money to Wisconsin Breast Cancer Coalition so that they can keep working to help make great doctors, treatments, and preventative tests available to all; even those without jobs or insurance of their own. Without WBCC working to ensure that everyone has guaranteed access to quality heal care, I’m sure there would be many people who would not be able to receive the great care that I did. I am so thankful to participate in this event knowing that the funds raised here tonight just may help someone else find their happy ending too.

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**Raw Beauty**

November 6, The Institute of Beauty and Wellness will be sponsoring a “Raw Beauty” fashion show at the new Harley Davidson Museum. Proceeds from this event will benefit the WBCC. Tickets are $25 in advance and $35 at the door. Fashions will be presented by Lela, Hers, Fred, Shoo, Stephanie Horne, Miss Groove, Detour, Aala Reed, Yellow Jacket and Three Graces. Call 414-227-2888 to register.

**Neroli Salon & Spa Girls Night Out a Huge Success**

Friday night October 3rd was the Neroli Salon & Spa Bayshore 2nd Annual Girls Night Out event to promote WBCC and raise money for our programs in Wisconsin. Over 60 breast cancer survivors, their families and girlfriends were treated to mini salon and spa treatments, hors d’oeuvres, wine and beverages.

The evening included inspiring conversation with breast cancer survivors and WBCC Member and Volunteer, Linda Weide, shared her encouraging experiences by speaking on how cancer has changed her life and contributed to her being a strong advocate for others battling the illness. We were also able to provide WBCC literature and information in two separate locations in the salon and talk to many individuals. “I talked to lots of survivors about our programs including one who said she saw an ad in the newspaper just by chance and brought her co-worker, also a survivor, along for the treat. By the end of the night they were both new WBCC Members,” stated WBCC President, Ellen Vander Heyden. “I also spoke with a woman who was recently diagnosed with breast cancer and her sister who was
also a survivor. My heart went out to the two of them as we talked about genetic testing and how the results might affect the rest of their family.”

Neroli Salon & Spa Marketing Director, Michael Haessly, said it was important to the company to support a Wisconsin non-profit organization, “When I found out WBCC’s programs helped people in Wisconsin it was a perfect match. It’s important for us to support organizations right here where we live. We’re glad to be able to create and event where breast cancer survivors and their girlfriends can relax and feel good about themselves. To give all the proceeds to WBCC is such and honor.”

Neroli employees are also making a donation to WBCC throughout the month of October and wearing jeans to work and WBCC pins.

We extend our thanks to Neroli Salon & Spa and employees, and to Devon Seafood Grill for providing hors d’oeuvres and Trader Joe’s for donating the wine. Watch for information about next year’s event.

Young Women’s Genetic Breast Cancer Study from a Patient’s Perspective

By Michelle Neustedter, WBCC Member

Many feelings accompanied my breast cancer diagnosis at age thirty-two in 2004. The greatest after fear was frustration. I accepted breast cancer was part of my life but I couldn’t accept that there was seemingly so little I could do. Fear motivated me to educate myself about my disease, learn to take responsibility for my health and volunteer to advocate with others. I acutely understood the pain my family suffered from watching a loved one live with breast cancer when my younger sister Stacey was diagnosed with breast cancer at age thirty-two in 2007. Watching my sister fight this beast was the most heartbreaking experience of my life.

I heard about the Young Women’s Genetic Breast Cancer study at The Washington University in St. Louis through word of mouth. I was glad to find a way for me, my sister and our parents to directly participate in the battle together. The goal of the study is to identify genetic factors that distinguish breast cancer in young women compared to women over forty. Participation was especially rewarding for our parents who felt like they could throw a solid punch at breast cancer after watching Stacey and me battle our illnesses for over three years.

I had a few questions prior to participation so I contacted Jennifer Ivanovich, who leads The Young Women’s Breast Cancer Program at The Washington University in St. Louis. Jennifer answered my questions thoroughly and thoughtfully. I learned my negative results of BRAC1 and BRAC2 testing is not a factor for participation. She also told me this is a study that does not involve the use of animals which is extremely important to me. I have great respect and admiration for the phenomenal Young Women’s Breast Cancer Program Jennifer has created.

Enrollment for new participants is still open. The individual study packets my family received made participation very easy. Following is an overview of the study and requirements Jennifer sent to me and a link to the program: http://ywbcp.wustl.edu/.

The specific title of our study is, Identification of Novel Genetic Factors that Contribute to the Risk for Breast Cancer. The goal of the program is to identify the genetic factors which distinguish breast cancer in younger women compared to older women. The study has been approved by the Human Studies Committee at Washington University School of Medicine.

Women who were diagnosed with invasive breast cancer over 40 years of age are invited to participate. The age at diagnosis is used to determine eligibility, not their current age. Women who have undergone genetic testing are eligible to participate, regardless of the test results. Women who have not had testing are also eligible to participate.

Women are asked to:
× Sign a consent form,
× Submit a sample of blood,
× Release their cancer related records, and
× Allow researchers to ask them about their family history.

A woman’s parents and sisters are also invited to participate as controls. They are asked to simply sign a consent form, and submit a sample of blood. A woman may still participate if her parents or sisters are not living or are not interested in participating.

Study materials are mailed directly to individual. The blood sample can be drawn at the next doctor’s appointment and shipped via federal express. All the study materials and shipping supplies are provided. There is no expense to the woman, her parents, sisters or her physician. If participants are charged to have their blood drawn, they are reimbursed for the expense.

After researchers receive the materials, they contact participants in the future to obtain family history information.

My family’s blood work, medical records and family history interviews are all complete and we greatly appreciate the development of this study. I am hopeful the dedicated team at Washington University in St Louis will help uncover some of the mystery about breast cancer in young women.
WBCC Sherry Kohlenberg Scholarship Program
Seeking Applicants for 2009

By Rhonda Deneka, WBCC Vice President, Membership Committee Chairperson

Sherry Kohlenberg was a young mother who died of breast cancer at age 37. She spoke out in Washington, DC about the need for more research and she also co-founded the Virginia Breast Cancer Coalition. Her sister, Linda, helped co-found WBCC in Sherry’s honor, and we continue to honor her spirit and courage with this scholarship.

Like Sherry, WBCC members and supporters stand up and speak out about breast cancer, funding for innovative research, and quality care for all women and men. From experience, we know it only takes one voice to make a difference. Imagine the effect of 700+ voices bringing attention to breast cancer in our nation’s capital and yours being one of them! Our Sherry Kohlenberg Scholarship can provide you with this opportunity.

Each year a group of WBCC constituents travels to Washington, DC to attend the National Breast Cancer Coalition Fund’s Annual Advocacy Conference and Lobby Day to learn the latest information on breast cancer research, quality care and access, the politics of healthcare, the nuts and bolts of the political process, and the nuanced strategy necessary to achieve our goal of ending breast cancer. We wrap up the conference with a trip to Capitol Hill where we and some 700 other advocates have meetings with our Congressional Representatives to talk about legislation affecting breast cancer we would like them to support. The next conference will be held on May 2 through May 5, 2009, in Washington, DC. The scholarship helps with the expenses. We are looking for advocates who are: dedicated to helping end breast cancer, willing to continue their volunteer efforts with WBCC after the conference, and willing to help us widen our influence by enlisting others in our grassroots efforts in Wisconsin.

If you are ready to become more involved in our efforts or if you just have questions about the scholarship, about WBCC or about the conference, please call our office for a scholarship application. We need YOU to bring your voice along with the Wisconsin delegation to Washington, DC to help end breast cancer. We are accepting applications for the Sherry Kohlenberg Scholarship now, and the deadline for submission is December 31, 2008.

Success in Innovative Breast Cancer Research Funding through the Department of Defense

By Bonnie Anderson, WBCC Board Director, Policy Committee Chairperson

Did you know there is important and innovative breast cancer research done through the Department of Defense? The Department of Defense Breast Cancer Research Program (DOD BCRP) began as a result of the National Breast Cancer Coalition’s 1992 campaign to dramatically increase federal funding for breast cancer research. Since the inception of this program the National Breast Cancer Coalition (NBCC), including WBCC, has been successful in adding more than 1.7 billion dollars, in this fight against breast cancer. This unique program makes consumer activists equal partners in the peer-review research, meaning research dollars aren’t just handed out to any researcher who applies. The grant applications are scrutinized by both the applicant’s peers as well as by consumer advocates. WBCC members have been consumer reviewers in this program almost every year since it began.

Each year, along with NBCC and through our WBCC Alert Network we ask our Congressional Representatives to support this program by helping to make sure funding continues. To date the DOD BCRP has attracted more than 18,000 research proposals and has funded many promising new approaches. This year we have great news: Congress has passed a continuing resolution that includes as part of it, a Defense Appropriations bill for FY 2009 providing $150 million for the BCRP! As many of you know, this is a $12 million increase over last year and the exact appropriation WBCC and NBCC advocates have been working to realize. Great work and thanks to all of you who helped make this a reality.
Rare Chair Affair: Our 9th Year of Success
By Dawn Anderson, 2008 Rare Chair Affair Chairperson

The 9th Annual Rare Chair Affair: Bid Farewell to Breast Cancer was held on Friday, September 26 at Brynwood Country Club in Glendale, WI, and the funds we raised that night will go a long way to supporting our programs in Wisconsin. Thanks to our 2008 event sponsors Northwestern Mutual Life, Wheaton Franciscan Healthcare, Johnson Bank, Dr. Thomas & Linda Zukowski, Grant Chamberlain, AstraZeneca, Herbert H. Kohl Charities, and Genentech, all the money we raised that evening will go directly toward our programming.

Thanks also goes to our in-kind donors:
- Robbie Geboy and Avante Florist for her centerpiece artistry.
- Meg Stoddard Messerschmidt for designing our beautiful invitations and posters.
- Musicians Mike and Kathy Gallenberger, for lending their support and beautiful music to our event.
- Erin Calfa-Weide for providing photography services for the event.
- Space for our Survivor Artists to work this summer, in honor of Terry Kivley, Survivor.
- Harris Marketing for helping us with public relations and event promotion.
- M Milwaukee's Lifestyle Magazine, for media sponsorship.
- Jeffrey Schrab, Tom Swoboda, Brett Dangott, Doug Luedtke, and Ellen Vander Heyden for providing printers, lap tops, and other equipment for the event.
- George Fitzwilliams for transporting our Survivor Chairs.
- Village Ace Hardware and Mark Meinecke for providing several gallons of paint for our Survivor Artists.

We had an amazing group of Survivor Artists this year who, along with our tremendous Artist Advisors, Eriks Johnson, Lisa Balistreri-Geib, and Kellie Krawczyk, created some very unique chairs for the live auction. We also had a very nice offering of silent auction items including chairs created by local artists, jewelry, Packers and Brewers memorabilia, and a Nintendo Wii and Wii Fit that brought in a significant amount of donations.

We are now looking for volunteers to help on the committee plan for next year’s 10th Year Anniversary Event and Survivors who would like to create a chair of their own. Breast cancer survivor Jan Hess, the 2008 event’s Honorary Chairperson created a chair last year while she was pregnant with her first child recalled her own Rare Chair Affair Survivor Artist experience, “I joined several other women each week painting and sharing our personal stories. It was an amazing experience. It brought me such courage and enthusiasm and I was so proud of myself and my fellow artists for the beautiful chairs we created.”

If you would like to volunteer to help plan the 10th Anniversary Rare Chair Affair or if you are a Breast Cancer Survivor who would like to create a chair with fellow survivors, please contact the WBCC office by calling 414.963.2103 or email info@rarechairaffair.org.

Holly Jones’ Bowling Themed Chair
Linda Weide’s Election Themed Chair
Collaborative Chair from 2008 Survivor Artists
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
414.963.2103
888.295.2622
wbcc@standupandspeakout.org

STAND UP
and speak out

Up Coming Events
For more information on these events, please contact the WBCC office at 414.963.2103.

Breast Cancer Awareness Month, October

WBCC Moving Forward Breast Cancer Survivorship Conference – October 11
Italian Community Center, Milwaukee

Sister’s Network Gift for Life Event – October 18
Park Lawn YMCA, Milwaukee

UWCCC Annual Cancer Symposium – October 24
Monona Terrace, Madison

Institute of Beauty and Wellness, Raw Beauty Fashion Show – November 6
Harley Davidson Museum, Milwaukee

Breast Cancer Recovery’s Sharing the Knowledge – November 8
Alliant Energy Center, Madison

WBCC Annual Meeting – November 12
Sheraton, Brookfield

WBCC Beyond the pink ribbon.™ Training – December 13
Sheraton on John Nolen Dr., Madison