



## voice

VOLUME 12, NO. 1 Winter 2012

## NBCC's Visionary Leader, Fran Visco, Regularly Takes on Washington – and Wins

Fran Visco will be a featured speaker at the Wisconsin Breast Cancer Symposium.

In September 1987, Fran Visco was 39 years old, a successful attorney in Philadelphia, a local activist for women's rights, a wife and the mother of an 18-month old son. Then she found out she had breast cancer.



Fran had a lumpectomy and radiation, as well as chemotherapy. Little was known then about the disease that threatened her life, and she was not about to just stand by and let breast cancer take over, so she did what she always had done: she educated herself and she fought.

She joined a local advocacy group and was later invited to attend a meeting in Washington with a group of people who wanted to launch an advocacy movement in breast cancer, to increase funding for research, expand access to care and give breast cancer survivors a say in all decisions about the issue. In May 1991, with no expectations Fran traveled to the nation's capital for what was the birth of the National Breast Cancer Coalition. Shortly thereafter, she was elected NBCC's first president, a position she continues to hold.

Fran worked on NBCC's first major campaign directed to Washington—the "Do the Write Thing" letter campaign. The goal was to deliver 175,000 letters to Congress and the President—one for every projected breast cancer diagnosis that year. In an extraordinary demonstration of the power of the grassroots interested in this issue, NBCC delivered more than 600,000 letters to former President Bush and Congress, asking that more tax dollars be spent on breast cancer research. This outpouring of letters, along with hard work by NBCC members, resulted in an appropriation of \$132 million for breast cancer research to the National Cancer Institute (NCI) in fiscal year 1992—a gain of nearly 50 percent over 1991 spending.

NBCC asked this: What funds did the scientific community need, that could be well spent to make a difference in breast cancer. After getting input from scientists and doing

# **Wisconsin Breast Cancer Symposium:**

## A CONVERSATION TO END BREAST CANCER AND WHAT IT WILL TAKE

Wisconsin Breast Cancer Symposium: A Conversation To End Breast Cancer And What It Will Take, will be held on Saturday, June 23, 2012 at the Crowne Plaza Hotel in Wauwatosa, WI., from 9:00am to 2:00pm. The Symposium is a project of the Wisconsin Breast Cancer Coalition.

Though progress has been made regarding treatments and length of survival for breast cancer patients, the mortality rate has not changed significantly in the past twenty years and the rate of incidence has steadily increased.

"Women want to know: what causes breast cancer, how to prevent it and how to end it! " says Kathleen Harris, a member of the symposium planning committee.

Today, scientists, breast cancer advocates and health care professionals are partnering and collaborating in unprecedented ways, in efforts to not only treat breast cancer, but also prevent it and end it. The Wisconsin Breast Cancer Symposium will bring all the stakeholders together, including members of the general public because all women are at risk, to engage in the conversation about ending breast cancer and what it will take to reach that goal.

This half day Symposium will focus on strategies and research that will help us reach our goal of ending this disease. Local and national speakers have been invited to speak on topics

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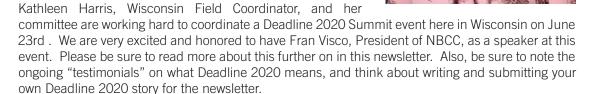
Wisconsin Breast Cancer Coalition P.O. Box 170031 Milwaukee, WI 53217

or email: wbcc@ standupandspeakout.org

### **President's Letter**

Hello all. Even though it's not October, it would have been hard not to notice the spotlight on breast cancer this past week. With the controversies surrounding both the Komen Foundation and Planned Parenthood, I was reminded of the 1950's Civil Rights activist, Alice Ward, who penned the words "...keep your eyes on the prize, hold on!" As members of the National Breast Cancer Coalition (NBCC) and the Wisconsin Breast Cancer Coalition (WBCC), our eyes have always been on ending breast cancer – our prize.

NBCC's Deadline 2020 Campaign is leading the way in helping us to accomplish this goal, and it helps us maintain our focus on what really matters in all this controversy – ending breast cancer. WBCC has answered the "call to action," and we are partnering with NBCC to "change the conversation about breast cancer."



Following our Annual Meeting, I would like to welcome Marsha Connet from Racine, Chris Krizek from Racine, and Mary Sacia from the LaCrosse area to our Board of Directors. We are looking forward to having their considerable skills and talents working on behalf of the WBCC. I am also saddened to let you know that Ann Aschenbrenner and Hannah Harris have resigned from the Board. We will miss them, we thank them for their many contributions on the Board, and we look forward to their continued involvement as WBCC volunteers.

### Finally, I wanted to encourage you all to Save the Date for the following:

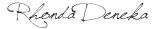
WBCC State Advocacy Day – page 6 Wednesday, 3/7/12 | Madison, WI

### NBCC Advocate Summit - page 4

5/5/12 to 5/8/12 | Arlington, VA The Kick-Off Advocate Rally has returned!

Show your State Pride during this inspiring pre-summit rally.

I encourage you to read more about all of these exciting happenings, as well as other informational articles in this newsletter. Please call the WBCC office at (414) 963-2103 to ask questions, voice concerns or volunteer for any programs that interest you. And please remember, ending breast cancer is within our grasp. Keep your eyes on the prize!



## **2012 Board of Directors Meetings**

Wednesday, January 11 Wednesday, March 14 Wednesday, May 16 Saturday, June 23 – 3pm Holiday Inn Crowne Plaza, Wauwatosa

Wednesday, September 12

**Wednesday, November 14** – Annual Meeting

## What Leaders Are Saying About Breast Cancer Deadline 2020®

Mayor Tom Barrett's response to National Breast Cancer Coalition's Breast Cancer (NBCC) Deadline 2020

Having served at the local, state and federal level, I have seen first-hand how women in the State of Wisconsin are impacted when they have limited access to breast screening programs. Throughout my years in government service, I have supported programs such as the Wisconsin Well Woman Program and the City of Milwaukee Health Department's Milwaukee Breast and Cervical Cancer Awareness Program.

NBCC's Deadline to end breast cancer by January 1, 2020, is an important goal and brings a muchneeded focus to the work to engage leaders, build financial support, encourage education about breast cancer, and most importantly build support in local communities. One agency cannot do this alone, but NBCC's Breast Cancer Deadline 2020 will ensure its objective of ending breast cancer comes one step closer to becoming a reality.



"It is time to change the conversation to ending breast cancer once and for all. The NBCC Deadline 2020 is a terrific way for us all to join and make it happen!"

Susan Love MD MBA President, Dr. Susan Love Research Foundation



## What Breast Cancer Deadline 2020 Means to Me

## **Meredith Rubin**

I was diagnosed with breast cancer 2 years ago at age 34. My husband and I were settling into our new life together, dreaming of starting a family and I had just embarked on a new career. All of our plans went on hold as we focused our energy on my being free of cancer. Now in the aftermath of treatment, planning for the future is still a delicate matter, confronted with a much higher level of uncertainty and health concerns than most thirty-something couples.

Breast cancer research and activism already achieved by those who've come before me have afforded me very good odds. But good odds are not good enough, not for the family I hope to one day have, not for my loving marriage and relationships that I hope will last a long lifetime, not for the contribution I hope to make in the world, and not for the fear of recurrence that still creeps in.

Breast Cancer Deadline 2020 is ACTION. It signifies we have no patience left for a disease that we have the means to stop. It is a RISK, without which change will not come. It is a PROMISE, a promise to all women that we will no longer need to fear this dreadful disease. Deadline 2020 for me personally is a reassurance, a safety net, and a permission to look toward the future with optimism.



## **Judy Mindin**

As a woman who has had three breast tumors (fortunately all benign), in the back of my mind is the question... how many "it's nothings" do I get before it is "something"? I have numerous friends and a family member who are breast cancer survivors and I work as Mission Services Manager for "ABCD: After Breast Cancer Diagnosis". Deadline 2020® for me means that finally we would see the light pour into the tunnel. After countless years of wondering why we weren't at a better place in our battle against breast cancer, and questioning what was being done with all the funding and donations – there would be answers and hope for ALL women!



### Visco: continued from page

independent research and analysis, NBCC recognized that number was an additional \$300 million.

Under Fran's leadership, the women who made up NBCC arrived in Washington by the busloads and flooded their members of Congress with calls, faxes, telegrams and constituent visits demanding \$300 million more for breast cancer research. NBCC's demands were met. The additional \$300 million, for a total of more than \$400 million was appropriated for breast cancer research with \$225 million to NCI and, from the defense budget, \$210 million to establish the Department of Defense (DOD) Breast Cancer Research Program (BCRP) at the Department of the Army. Fran and NBCC members continue to fight for government funding to be appropriated to this program. As a result, the worldwide scientific community has received more than \$2.8 billion in federal appropriations for innovative breast cancer research. Fran knew more money for research was not the whole answer. NBCC needed to be at the table to set priorities and oversee how those dollars were spent.

NBCC's next big push was to secure 2.6 million letters, postcards, signatures, faxes and mailgrams directed to President Clinton, asking that he develop a national strategy to end the epidemic of breast cancer. Wherever they could get signatures and raise awareness about the issue, NBCC members and volunteers gathered signatures. In October, 1993, Fran accompanied by more than 200 Coalition members met with President Clinton, Hillary Rodham Clinton and Secretary Donna Shalala in the East Room of the White House to present the signatures.

Again, NBCC's demands were met and President Clinton asked Secretary Shalala to host a conference to begin the design of a national action plan for breast cancer, an innovative collaboration of government, science, private industry and consumers. Fran was appointed the public Co-Chair. In 1993 President Clinton appointed Fran as one of three members of the President's Cancer Panel; she was re-appointed to successive terms in 1996 and 1999\*.

Labeled a true visionary, Fran knew from the very first meeting of the National Breast Cancer Coalition that breast cancer survivors should have a seat at the table where decisions about the disease were taking place. But she also agreed with other NBCC Board

members that if these advocates were to be taken seriously, they would need to be educated in , the language, concepts and process of research and the structure of breast cancer research decision making. So Project LEAD® was established. Project LEAD is designed to push breast cancer advocates outside their experience, beyond their cancer to focus on the intersection where science and policy meet. Graduates of Project LEAD are well respected in the scientific community. In his recently released book, Dr. Otis Brawley, chief medical and scientific officer of The American Cancer Society, said "a Project LEAD credential means that you are dealing with someone who understands the fundamentals" of breast cancer. With these credentials, many Project LEAD graduates go on to work side-by-side with scientists reviewing grants for NIH and DOD. They often sit on institutional review boards, monitoring the ethics of clinical trials and safetymonitoring boards that decide whether clinical trials have met their objectives.

NBCC has played a key role in other legislative successes that benefit women. For example, NBCC framed the problem and designed the legislation that was passed to ensure that uninsured women diagnosed through the CDC Breast and Cervical Cancer Screening Act have access to treatment. For more than a decade, the National Breast Cancer Coalition (NBCC) has made access to quality health care for all a top legislative priority.

But for Fran Visco, the most important year in the history of the National Breast Cancer Coalition was 2010—the year NBCC set a deadline to end breast cancer by January 1, 2020—Breast Cancer Deadline 2020®. Backed by a coalition of hundreds of organizations and tens of thousands of individuals, Breast Cancer Deadline 2020® focuses resources and efforts to the areas that will end breast cancer:

Primary Prevention: How do we stop people from getting breast cancer in the first place?

The Causes & Prevention of Metastasis: How do we stop people from dying of breast cancer?

Ending breast cancer requires a paradigm shift in the way we approach research and advocacy. The National Breast Cancer Coalition and Fran Visco are leading that change.

## What Breast Cancer Deadline 2020 Means to Me

We want to hear from our readers. What does changing the conversation to ending breast cancer mean to you? Please send us your thoughts, in 150 words or less. We will print your comments along with a photo, if you care to include one.

Your stories are compelling.

Your stories inspire us to continue the work we do, every day, every week, every month and every year, until we end this disease!

## REGISTER NOW for the NBCC Annual Advocate Summit!

Saturday May 5-8, 2012. Hyatt Regency Crystal City, Arlington VA.



# Extended Environmental Exposures Annual Meeting November 16-18, 2011, Cincinnati Ohio

Dawn Anderson, WBCC Executive Director

The Breast Cancer and the Environment Research Program (BCERP) is a national program to identify potential environmental causes of breast cancer. The annual conference is an opportunity for participating researchers, community partners and advocates to hear results from studies that have been published.

Since 2003 participating researchers have been looking specifically at predictors of early age at onset of puberty, which is associated with an increased risk of breast cancer. These "Puberty Studies" were epidemiologic studies in which cohorts of young girls (6-8 years of age) were enrolled and followed as they approached and entered puberty. Biomarkers for chemicals of interest were tracked in blood and urine samples, as was their development in areas considered hallmarks of the onset of puberty.

The second round of funding and research was begun in 2010. University of Wisconsin - Madison researchers, Dr.'s Michael Gould and Amy Trentham Dietz, received a grant as part of the "Windows of Susceptibility" studies that are looking at times in a woman's life cycle during which it appears she is more vulnerable to environmental 'hits' that would make her more susceptible to the development of breast cancer later in life. This research is ongoing and findings have yet to be released.

The grants that are funding the research, from the National Cancer Institute (NCI) and the National Institute of Environmental Health Sciences (NIEHS), require that all institutions participating have Community Partners to help translate and disseminate research findings to the public. These public health messages will be key to changing behaviors and policy that could mediate the risk of breast cancer. WBCC serves as a Community Partner on Dr.'s Gould and Trentham-Dietz's grant.

Published findings from the Puberty Studies seem to indicate an association between exposures to certain chemicals in our food, water, personal care and cleaning products and early onset puberty. This is considered a risk factor - the longer a women is exposed to estrogen (early menarche/late menopause) the higher the risk. Since these suspect chemicals are often endocrine disrupters that mimic estrogen in the body, the exposure is increased.

In the conference keynote address from Dr. Bruce Blumberg of the University of California - Irvine, an association was also indicated between body fat and earlier onset puberty. "Obesogens" are chemicals that inappropriately stimulate fat cell formation and fat storage. Emerging evidence suggests that some of these chemicals can alter gene expressions in fat cells - causing them to be bigger, and perhaps even promoting the development of fat at the expense of bone. The research pointed out that 90% of obese people regain lost weight within a year, suggesting that perhaps chemical exposures result in programming a "set point" weight during development. These exposures could be important very early in life - even prenatally.

The implications proposed in this line of research are that diet and (lack of) exercise are insufficient to explain obesity - particularly in young persons.

Dr. Jose Russo, of Fox Chase Medical Center, is widely thought to be the "father" of the concept of "Windows of Susceptibility" (WOS). In his address to the conference, he indicated his belief that puberty is perhaps the most critical window, because it is a time of high activity in cellular differentiation and sensitivity. He noted that in animal studies, pre-pubertal exposures increased susceptibility in younger animals (this could correlate to pre-menopausal breast cancer in humans), and pre-natal exposures increased susceptibility in older animals (this could correlate to post-menopausal breast cancer in humans).

Dr. Michele Forman of the University of Texas at Austin shared results from an epidemiologic study that showed that mothers who were highly active during pregnancy resulted in a 3 month delay in the onset of menarche in their daughters. This is thought to have a protective effect. With regard to pregnancy weight gain, mothers who gained less than 10 pounds or more than 40 pounds had daughters who reached puberty 30% earlier than others.

Dr. Susan Teitelbaum from the Mr. Sinai School of Medicine in New York spoke about the combined effects of multiple exposures, noting the difficulty of looking at individual agents in the lab and pointing out that we live in a sort of toxic "soup" in which our genes get bathed. The agents she is looking at with regard to puberty are methyl parabens, phthalates, and triclosan – all commonly found in personal care products. Her initial study results showed increased paraben urinary concentrations (in girls) with the frequency of product use per week and the number of products used in combination.

As part of the program, Community Partners for the research sites around the country are now working with consultants to help develop and then disseminate public health messages based on agreed upon findings from the Puberty Studies. WBCC looks forward to this continued collaboration on a topic we believe will move us towards prevention of breast cancer.

The conference program and slides / abstracts from a number of speakers may be found at:

http://www.bcerc.org/2011mtg/program.htm





## 6th Annual State Advocacy Day State Capitol, Rm. 415 NW Wednesday, March 7 8:30am-5pm

Join WBCC as we take important information and policy priorities to key legislators. Training and materials are provided in the morning. Small groups, led by experienced WBCC volunteers, will make legislative visits throughout the afternoon. Lunch is provided.

**Register online** now or contact our office for more information. wbcc@standupandspeakout.org/ 414-963-2103

Our Collective Voice makes a difference!

## **State Policy Update**

2011 was a challenging year for organizations concerned with access to healthcare for Wisconsin citizens. The WBCC has been tracking and responding to a number of bills, but it is YOUR voice that policy makers need to hear. Please consider joining us as we discuss these and other priorities with legislators on our State Advocacy Day.

(AB = Assembly Bill, SB = Senate Bill)

### AB151/SB101 - The Oral Chemotherapy Access Act

This bi-partisan bill has strong support and Governor Scott Walker has indicated he is inclined to sign it if it passes. It will ensure that insurance companies classify oral chemotherapy drugs (such as tamoxifen) the same as intravenous chemotherapy infusions. Currently they are often classified as pharmaceuticals and patients are subjected to very high and often prohibitive out of pocket costs. WBCC SUPPORTS THIS BILL

### SB206/AB312 - The Wisconsin Patients' Bill of Rights

This bill will make the patient protections in the Federal Patient Protection and Affordable Care Act (PPACA) the law in Wisconsin. These protections - vital to many breast cancer patients and survivors - include protection from being denied coverage due to a pre-existing condition, elimination of annual and lifetime caps, free coverage of preventive screening services and more. WBCC SUPPORTS THIS BILL

### **AB210**

This bill formally incorporates regulations and requirements found in the PPACA (health care reform law) into Wisconsin statutes, UNLESS PPACA is found unconstitutional in a federal court. The bill also give the appointed Commissioner of Insurance emergency rule making authority without legislative oversight or public hearings. WBCC IS OPPOSED TO THIS BILL

### AB242/SB321

The goal of this bill is to limit the number of charitable donation check off boxes on the Wisconsin State Income Tax Form, and, by amendment, combines all cancer research into one check off box. This eliminates the WI Breast Cancer Research Fund, which WBCC helped to establish in 2003 and which has raised \$1.6 million to date. On the grounds that it removes the choice of breast cancer advocates to direct dedicated funding to new breast cancer research. WBCC IS OPPOSED TO THIS BILL

### AB386/SB331

Currently, the Department of Health Services administers the WI Well Woman Program, under which service providers are reimbursed for providing preventive health care services for un-insured and under-insured women. Thousands of women rely on Well Woman Program for their mammograms. Under this bill, Well Woman Program would not be permitted to reimburse for services provided by any entity that provides abortions, makes referrals for abortion services, or has an affiliate that provides or refers for abortions. On the grounds that this bill disqualifies health care providers that offer comprehensive women's health care from participating as service partners in the Well Woman Program. WBCC IS OPPOSED TO THIS BILL

## "Beyond the Pink Ribbon Volunteer Award" to Lauren Roberts

At its November meeting, the WBCC Board of Directors selected Lauren Roberts to receive the 2011 "Beyond the Pink Ribbon Volunteer Award". Lauren came to the WBCC through her employer and quickly became involved in the logistics committee for the Rare Chair Affair. She has worked hundreds of hours streamlining our check in and check out processes, cleaning and improving the functionality of our databases and recently became a member of the WBCC Administration Committee as our "go to" information technology person. Lauren has been a Manufacturing Engineer for Harley-Davidson for four years, lives in Glendale with her significant other Kyle (also a Rare Chair Affair volunteer), and a houseful of lucky rescue animals - pups Chloe and Jack and cat, Baby. Congratulations and thank you Lauren!



### Symposium: continued from page 1

related to preventing and ending breast cancer. The two main categories to be addressed are:

- Primary prevention-(prevent getting breast cancer in the first place) such as preventive vaccines, lifestyle approaches and windows of susceptibility- stages in life when girls and women might be most vulnerable to internal and external environmental influences.
- Preventing or delaying metastasis (cancer spreading to other parts of the body)

### Confirmed speakers to date include:

Fran Visco, President of the National Breast Cancer Coalition, will speak about the Breast Cancer Deadline 2020 campaign, a national strategic plan to end breast cancer by January 1, 2020.

Brunhilde Felding-Habermann, PhD, Associate Professor, Department of Molecular and Experimental Medicine, Scripps Research Institute, La Jolla, CA. Dr. Felding-Habermann will speak on the topic of prevention or delay of breast cancer metastasis.

Shirley Mertz, MA, JD, a national voice/advocate for women and men living with metastatic breast cancer, will speak on the role metastatic breast cancer patients can play to help end breast cancer for all women.

Attendees will have the opportunity at the event to become engaged in the conversation to END breast cancer, to network and to take action to help reach our goal and learn new strategies to improve their health and the health of future generations. Whether you come as a survivor or someone seeking knowledge on how we might prevent getting the disease ourselves or for our loved ones and friends, you will leave this Symposium energized and empowered to act in some way to make a real difference in ending this disease.

We want to hear your voice and your story- what you are doing to help end this disease and what changing the conversation to ending breast cancer means to you.

End breast cancer. It's time! Please join us, Saturday, June 23, 2012, Crowne Plaza Hotel, Wauwatosa, WI, corner of Highway 100 and Watertown Plank Road, near the Medical College of Wisconsin campus and Mayfair Mall. For updates and information regarding registration, please go to: www.standupandspeakout.org.

Wisconsin Breast Cancer Symposium 2012 is dedicated to the thousands of women and men living with metastatic breast cancer.

## **Snowmobilers Raise over \$2600 for WBCC**

Many thanks to Chris Fabich of the Steven's Point area for organizing a very successful snowmobile "Poker Run" on our behalf. Over thirty area businesses and snowmobile clubs participated. Fortunately the weather cooperated at the last minute! After weeks without enough snow to open the trails, snow finally arrived the week of the event.





## Roadhouse Pizza in Ripon hosts WBCC Fundraiser

Ripon area WBCC volunteer, Mandi Teerbest, recently organized a fundraising event at Roadhouse Pizza raising over \$1500. Many thanks to Mandi, the owners of Roadhouse Pizza, and the participants who made this fun event so successful!







standupandspeakout.org / po box 170031 milwaukee wi 53217-0031

### **WBCC MISSION**

The Wisconsin Breast Cancer Coalition brings Wisconsin voices together to Stand Up and Speak Out about breast cancer with: Education – spotlighting critical breast cancer issues Collaboration – empowering through strategic alliances Legislation – influencing policy making.

### TO CONTACT WBCC

414.963.2103 888.295.2622 wbcc@standupandspeakout.org

## SAVE THE DATE - Rare Chair Affair 2012

## Friday, September 21 Hyatt Hotel - Downtown Milwaukee

### Sponsorship Opportunities for Wisconsin Breast Cancer Symposium - June 23, 2012

We are currently seeking sponsors for the Wisconsin Breast Cancer Symposium. There are a number of sponsorship opportunities available that will help make the Symposium possible and affordable to attend. For example, you could sponsor a speaker for \$1000.

Visit www.standupandspeakout.org (click the Education tab) for information on additional Symposium sponsorship opportunities and benefits. Donations in any amount are greatly appreciated. Please make your check payable to Wisconsin Breast Cancer Coalition or WBCC and <u>designate Symposium on the memo line</u>. WBCC is a 501(c)(3) non-profit organization. All donations are tax deductible to the extent allowed by law.

Thank you. Your donation/sponsorship will help make our Symposium a success!

Checks can be mailed to:

WBCC Attn: Symposium PO Box 170031 Milwaukee, WI 53217

### **Please Donate!**

As you plan your end of year giving, please consider a donation to the WBCC. Your generosity helps us continue our work. Scan or click on this code to go directly to our secure donation site. Thank you!

