



Raising Our Voices

NEW HAMPSHIRE BREAST CANCER COALITION

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National Breast Cancer Coalition Launches “Breast Cancer Deadline 2020”

by Nancy Ryan

On September 20, 2010, the National Breast Cancer Coalition (NBCC) announced a bold, new initiative to end breast cancer in ten years. “Breast Cancer Deadline 2020” calls for an unprecedented “no more business as usual” approach to ending breast cancer. Acknowledging that over twenty years of awareness and billions of dollars of public and private investments in research have made scant inroads into preventing or curing breast cancer, NBCC calls on all stakeholders — trained advocates, scientists, economists, policymakers, and researchers — to harness and coordinate the resources we have and focus them in an unprecedented goal: end breast cancer for all women by January 1, 2020.

The National Breast Cancer Coalition is well positioned to lead this effort. NBCC and its network of advocates across the country have surmounted enormous challenges to increase federal funding for breast cancer by \$2.5 billion through the Department

of Defense Breast Cancer Research Program and to enact legislation that guarantees treatment for thousands of low-income and uninsured American women. NBCC has worked for better clinical trial design and has trained hundreds of advocates to participate in breast cancer policy and research decisions. Despite these successes, NBCC knows they are not enough. More awareness and more of the status quo are not enough. NBCC is already organizing catalyst meetings geared to stimulate innovation and creativity in research, and to move beyond incremental changes and the outdated Breast Cancer Awareness Month message that “early detection is your best protection.” Please visit: <http://www.BreastCancerDeadline2020.org>. Download and read the National Breast Cancer Coalition “White Paper” from this website. Then join the New Hampshire Breast Cancer Coalition in supporting “Breast Cancer Deadline 2020.”

NEWS FROM THE CHAIR

Move Over

Breast Cancer Awareness Month
Here Comes Deadline 2020

by Nancy Ryan

On September 20, 2010, just before “Breast Cancer Awareness Month” began, the National Breast Cancer Coalition (NBCC) launched the Breast Cancer Deadline 2020 — “a call to action for policymakers, researchers, breast cancer advocates and other stakeholders to end the disease by 2020.” (See <http://www.breastcancerdeadline2020.org>.) NBCC’s bold, new initiative escalates the breast cancer conversation from “awareness” to “accountability” — and will make Breast Cancer Awareness Month a thing of the past.

Now in its 25th year, National Breast Cancer Awareness Month (BCAM) is hard to miss. You read about it in magazines, newspapers, in blogs, and on Facebook and Twitter, hear about it on the radio, see it on television, and even find jokes about it in the Sunday comics! The symbolic pale pink hue and pink ribbons adorn all manner of merchandise from bras to boxing gloves, from candles to cameras, from personal care products to pistols, and from wristwatches to wine. But if you listened carefully this year, you also heard a loud chorus calling for an end to October’s pink onslaught. Some advocacy organizations, newspaper articles, op-eds and blogs expressed “pink ribbon fatigue,” decried

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NBCCF Annual Conference — “Peel Back the Pink”

by Nancy Ryan

The theme of the 2010 National Breast Cancer Coalition Fund (NBCCF) Annual Advocacy Training Conference was “Peel Back The Pink.” This year the New Hampshire Breast Cancer Coalition received an “Advocacy in Action” grant from the National Breast Cancer Coalition, allowing us to send a total of nine New Hampshire women to the conference. This was an all-time high number of attendees from New Hampshire! In addition to Nancy Ryan, Chair of NHBC, those pictured in the accompanying photograph also attended the conference.

Reprinted here with permission is an edited summary of the NBCCF conference written by Kim Tankersley from the Breast Cancer Care & Research Fund, an education and advocacy organization located in Los Angeles, California. Thank you, Kim, for capturing the energy, excitement, education, and empowerment of the conference!



Sue Holmes, Elaine Meschino, Heather Merrill, Jeanne Marcoux, Jane Edmunds, Dara Sussman, Lynne Sussman, Elaine Lavallee (From left to right)

National Breast Cancer Coalition Annual Advocacy Training Conference, May 22 – 25, 2010

by Kim Tankersley

We look around us, and sometimes all we see is pink—pink grocery bags, pink spatulas, pink flashlights, pink everything! As breast cancer patients, survivors, loved ones, and advocates, what are we to make of this phenomenon which has pervaded our every corner? The National Breast Cancer Coalition, the premiere organization wholly dedicated to eradicating breast cancer through grassroots advocacy efforts, challenged each one of us attending 2010 Annual Advocacy Training Conference and Lobby Day to “Peel Back the Pink”—this year’s conference theme. Essentially, we need to “peel back,” or uncover what is beneath the surface of breast cancer by continuing to educate ourselves on the latest findings in valid,

evidence-based breast cancer research, and persist in our tenacious efforts to keep policy makers abreast of what we want and need to ultimately eradicate breast cancer.

As our Advocacy Training Conference opened on May 22, it was with a heavy heart that Fran Visco, NBCC President, dedicated the conference to the memory of Carolina Hinestrosa, NBCC Executive Vice President for Programs and Planning, colleague, and dear friend to many, who

passed away on June 21, 2009. Hearing this dedication, and thinking of others close to us whom we have lost, served as a catalyst for the 800 of us advocates to prepare not only to become informed, but to ready ourselves to take action for change.

The conference featured an extraordinary collection of plenary sessions this year—general sessions comprised of panels of experts on topics of importance to the entire breast cancer advocacy community. This year’s plenaries included

“What’s New in Breast Cancer?” featuring esteemed author and breast cancer expert, Dr. Susan Love. Next, Fran Visco set the tone for the remainder of the conference with her presentation, “A Sense of Urgency.” NBCC President Visco talked about how to remain above the fray in the world of breast cancer awareness groups, and definitely got her audience motivated to recapture the sense of urgency and momentum for continued change.

One plenary that particularly showcased the extensive resources of NBCC was “Breast Cancer and the Media: Who Gets It Right?” featuring consummate professionals in their fields, Lisa Schwartz, MD, of Dartmouth (Medical School), Nancy Snyderman, from NBC, and of course, sharing the advocate perspective, Joy Simha, of the Young Survival Coalition. This discussion reminded us again how important education remains for consumers in discerning valid evidence through the pens of the media.

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News from the Chair (Continued from page 1)

the “pink fog,” boldly proclaimed a “pink backlash,” and recognized the pitfalls of “pinkwashing,” a term coined by Breast Cancer Action (BCA) eight years ago denoting the cause-marketing technique of linking pink ribbons to selling merchandise that may actually be harmful to your health. Breast cancer awareness may be at an all-time high, but Breast Cancer Awareness Month may have outlived its usefulness, and here’s why.

Twenty Five Years Ago

When AstraZeneca, manufacturer of the breast cancer drugs Arimidex and Tamoxifen, founded National Breast Cancer Awareness Month, “awareness” seemed a worthy goal. The slogan “Early Detection is Your Best Protection” aligned with an earlier belief that breast cancer arises at a single point and then spreads directly outward into surrounding breast tissue. A public health message of mammography, clinical breast exam, and breast self-examination (BSE) was pounded into the minds, hearts, and souls of American women. If you “caught it early,” you would live.

Today

Some things have improved for women with breast cancer in the past 25 years. Lumpectomy followed by radiation is a viable alternative to mastectomy for some women with early-stage breast cancer. Hospital breast centers have consolidated their services, support groups are plentiful, hotlines and Internet resources are at your fingertips, and new adjuvant, hormonal treatments and targeted treatments are available. According to the National Breast Cancer Coalition, “between 1994 and 2003, the mortality rate for women of all races combined declined by 2.4% annually.” While this is good news, remember that we still lose approximately 40,000 American women every year to breast cancer. There has been little progress in preventing breast cancer, or curing those with metastatic disease.

Science is a Moving Train

Research over the past 25 years suggests that breast cancer is a very complex disease. Breast cancer is no longer seen as one disease that begins in one spot and marches outward in a straightforward fashion. Today researchers categorize breast cancer into different types and subtypes based on the characteristics of the cell such as genetic type, hormonal status and HER2/neu status. Breast cancer may spread from the breast to other organs much earlier in the course of the disease than previously believed. Mammography is one of the most extensively studied cancer screening tools, yet experts remain divided on its role in “saving lives,” par-

ticularly in the 40-49 year old age group. Breast cancer treatment, not the actual time of diagnosis, may be the life-saving factor for many women. The increase in screening mammograms has led to more diagnoses of ductal carcinoma in situ (DCIS), a change in breast tissue that may or may not progress to invasive, life-threatening disease. If you are diagnosed with DCIS and treated, perhaps you will not die of breast cancer, or perhaps we exposed you to unnecessary treatment with significant side effects. Major clinical trials of breast self-examination have been shown not to decrease mortality.

Too Many Breast Cancer Organizations

Dilute The Goal

Breast cancer awareness has inspired a proliferation of new, nonprofit breast cancer organizations. According to Charity Navigator, there are more than 1,000 breast cancer organizations in existence. Some provide services and support. Some focus on one narrow aspect of breast cancer, such as healthy women at high risk for the disease. Many do not concern themselves at all with eradicating the disease. I see little coordination of organizations or their services, little transparency in some organizations that claim to support “research,” and a general public confronted by multiple breast cancer donation requests and left wondering exactly how their donation is being used. I also see a dwindling sense of urgency and a possible waste of resources.

The National Breast Cancer Coalition

Sets a Deadline

The National Breast Cancer Coalition’s Deadline 2020 renews the sense of urgency to end breast cancer by setting a deadline of January 1, 2020, and by focusing all fundraising, research, charitable organizations, and public policies on this goal. You can join this fresh, new conversation by supporting “Breast Cancer Deadline 2020.” Become a member of the National Breast Cancer Coalition (<http://www.stopbreastcancer.org>). Explore opportunities to learn about and share the Deadline 2020 message (<http://www.breastcancerdeadline2020.org>). Explore NBCC’s advocacy training opportunities: The 2011 Annual Advocacy Training Conference set for April 30th to May 3rd, 2011; NBCC’s acclaimed science training course Project LEAD; or NBCC’s Emerging Leaders Program for younger women and men. Speak with policy makers, legislators, scientists, family and friends about ending breast cancer by January 1, 2020. Please learn more, get involved, and add your support. Let’s work together to make Breast Cancer Awareness Month a thing of the past.

Community Fundraisers Support NHBCC

The New Hampshire Breast Cancer Coalition gratefully acknowledges donations from the following individuals and organizations that raised funds this year for our Support Services Fund and advocacy work.

March

Southern New Hampshire Medical Center presented the NH Breast Cancer Coalition (NHBCC) with a check for \$5000 for our Support Services Fund. The money was raised by the annual Medical Center 6K road race and will help provide financial assistance for New Hampshire breast cancer patients who have exhausted all other options.

Ms. Lissa Silk, the current Miss Winnepesaukee, organized two events that raised over \$1,500 to benefit NHBCC: "Passionately Pink on Ice," an ice skating show at the Dover Arena on January 23, 2010 to celebrate National Skating Month, and "Passionately Pink Zumba" at The Works Health and Fitness Center in Somersworth. Thank you, Lissa!

The Portsmouth Lodge of Elks raised over \$1,000 from a meat and lobster raffle to benefit NHBCC. Thank you so much for this donation and for your support over the years.

June

The Wentworth By the Sea Country Club Women's

Golf Association and Wentworth Tennis raised over \$35,000 this year for the NH Breast Cancer Coalition Support Services Fund at the 2010 Sadie Hawkins Golf Tournament and Tennis Clinic. Thank you to the Wentworth By The Sea Women's Golf Association, local businesses and volunteers who worked long and hard to make this event a success. Well done. NHBCC is most grateful for your efforts!

July

The Halcyon Club of Dover, New Hampshire chose NHBCC to benefit from a donation from club members.

Paul and Barbara Watson of **Rocky Knoll Photography** donated partial proceeds from the sale of Paul's 2010 Breast Cancer Awareness Calendar to NHBCC. Thank you, Paul!

August

Laurie's Ride 7, an annual motorcycle ride to benefit the New Hampshire Breast Cancer Coalition Support Services Fund, raised an incredible \$4,000 in 2010. Mid-ride, participants were treated to several laps around the New Hampshire Motor Speedway in Loudon. This ride, with full police escort, culminates with a celebration, BBQ, raffles, and live music by Brickyard Blues. Plan now for Laurie's Ride 8, scheduled for Sunday, August 7, 2011. Our sincere thanks to Laurie Thiboutot and friends!

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NHBCC Unveils New Mission Statement

The New Hampshire Breast Cancer Coalition Steering Committee held a strategic planning session early this year. We reviewed how NHBCC began, what NHBCC has accomplished, and how NHBCC fits into the world of breast cancer today. After careful discussion, the committee (now termed a Board of Directors) voted unanimously to rewrite the NHBCC mission statement as follows:

The mission of the New Hampshire Breast Cancer Coalition is to advocate for and provide assistance to New Hampshire residents with breast cancer.

The revised New Hampshire Breast Cancer Coalition mission statement reflects our commitment to advocate for the change necessary to end breast cancer and our dedication to helping New Hampshire women and families through our Support Services Fund. NHBCC's Board wants the Coalition to play a key role in the national fight against breast cancer. NHBCC continues to do this as a member organization of the National Breast Cancer Coalition (NBCC). The Board also wants to help New Hampshire residents with breast cancer meet needs that are not covered by other means. Increasingly, New Hampshire residents need help covering medical expenses and expenses of daily living related to a breast cancer diagnosis. NHBCC can now respond through our Support Services Fund, established in 2006. With the help of several highly successful fundraisers this year, the Support Services Fund is positioned to continue addressing this critical need. For information about the fund, please visit <http://www.nhbcc.org> and click on Support Services Fund on the Home Page navigation bar. As always, thank you all for supporting the New Hampshire Breast Cancer Coalition.

Peel Back the Pink (continued from page 2)

Lastly, and particularly meaningful prior to Lobby Day, was “Politics and Health Care Reform,” featuring political strategist Chris Jennings, and Julie Rovner, from NPR. This was an informative discussion about some of the changes we can expect from the new legislation, how it came to be, and what it will mean to us. It is particularly important to understand the ins and outs of this legislation, as this issue has been a number one priority for NBCC from day one.

Equally impressive in topic offerings and expert presenters were the workshop sessions—there were scientific seminars available, as well as legislative education. As always, there were meetings geared towards first timers to explain the workings of Congress, beginning steps in advocacy, and some basics [of] the science of breast cancer. The workshops that I attended were geared toward Project LEAD graduates, as they focused on ongoing scientific research. Dr. Muller Fabbri, from Ohio State University, discussed the possibility of utilizing MicroRNAs (MiRNA) in the arena of early breast cancer detection, and targeted treatment in his talk “MicroRNA: New Research Avenues in Early Detection and Treatment.” This area is a hot topic, and was also discussed in detail by several researchers at the most recent San Antonio Breast Cancer Symposium.

Additionally, Dr. Patricia Steeg, a researcher from the National Cancer Institute (NCI) and National Institutes of Health (NIH) gave a captivating lecture giving an update on PARP Inhibitors and their potential in treatment in some previously difficult-to-treat breast cancer subtypes. Dr. Steeg has a way of engaging her audience, and making even the most esoteric subject matter accessible to nearly everyone. All told, there was a first-rate variety of offerings for all, from the neophyte advocate to the seasoned alumnus.

Among the many unique facets of the Conference are the NBCC Member events, and this year was no exception. Fran Visco, the President of the National Breast Cancer, is ever present—she is not an absent figure-head. Our Annual Membership Meeting Luncheon was touching, as we began with a Moment of Silence—the traditional commencement for all NBCC activities—a celebration of the lives of advocates whose dedication to ending breast cancer will not be forgotten. This year, we were also joined by a group of Emerging Leaders—younger people whose interest in advocacy has led them to the Training Conference to learn and lobby.

In addition to the Emerging Leaders group, in attendance were a group of women, many of whom had traveled half-

way around the world to experience the Annual Advocacy Conference and learn strategies to take back to their respective countries. The women, most of whom were graduates of a recent NBCC International Project LEAD Institute held in Buenos Aires, Argentina, represented South Africa, India, Japan, and Nigeria, and to name a few. As I stood by, Ms. Kenny Gbelee, a LEAD grad from Nigeria, told a reporter that it was her “dream” to bring such levels of advocacy to her country as she had experienced at the conference. Ms. Molebatsi Pooe-Shongwe, has started a foundation in Johannesburg, Breastsens, to increase breast cancer awareness among black women in South Africa. Each woman, as all of us do, had her own story, and I was amazed to see how far the hand of NBCC actually reaches, and it was an honor to have them there to celebrate with the rest of us LEAD grads at a dinner held in celebration of the 15th Anniversary of the NBCC Project LEAD advocacy education programs.

For those who have never attended the National Advocacy Conference, the day prior to Lobby Day is tense, exciting, and simultaneously nerve-wracking—a mad rush to secure appointments with our representatives, meet with our advocacy delegation, prepare materials, and review the NBCC Priorities for the next day. This year, we had two “Priorities,” or two main issues which were of primary importance for us in our meetings with legislators.

A continuing Priority of NBCC, since the time of the Coalition’s inception, is commitment to guaranteed access to quality health care for all. According to NBCC, this is the only way to achieve our mission to eradicate breast cancer; additionally, we believe that “patient advocates will play a key role in achieving this goal and in reforming our health care system.” Therefore, not only do we want health care reform, but we want seats for advocates at every table, at every level of decision making in the process of such reform. Is that too much to ask? I think not when each of us is touched by this disease or another in some manner or fashion.

Priority number two remains continuing to ask for support for the Department of Defense Breast Cancer Research Program (DoD BCRP). Since its initiation in 1993, the groundbreaking program has invested \$2 billion in breast cancer research—research in which educated advocates have had a say. Through lobbying efforts, NBCC members have continued to garner support for \$150 million, level funding compared to last year, of the Defense Appropriations bill. California, with our population, has received over \$306 million over the life of the program; these dollars have

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Peel Back the Pink (continued from page 5)

funded investigations that have thus far yielded stunning discoveries such as that of Dr. Dennis Slamon's Herceptin research. With continued funding of this program, who knows what will be next?

The morning of Lobby Day, hundreds of us, representing states from Alaska to Florida, along with our international friends, loaded onto buses and made our way to Capitol Hill Annual Lobby Day.

Our long day on The Hill culminated with a reception in the Russell Senate Office Building—this was not only to celebrate our successes, but to honor legislators who support our grassroots efforts in achieving our goals of quality health care for all and continued funding for the Department of Defense Breast Cancer Research Program (DoD BCRP). A special honoree at the Congressional Awards Reception was Speaker of the House, Nancy Pelosi, who was presented with the Public Policy Leadership Award.

The Honorable Speaker Pelosi delivered a speech recognizing NBCC's immense contribution to health care reform as she relayed to us, "because of your advocacy, your organization, your number one legislative priority is now the law of the land."

Ms. Pelosi reminded us that, "We'll never stop fighting until we eradicate this disease, and create a healthier America for all." She's right: We have come a long way, but we are not there yet. It's incumbent upon us to continue, alongside Ms. Pelosi, and our other legislative allies, to maintain our strength in this battle until the day we win.

As Dr. Susan Love signs a book, "To the end of breast cancer!" To that, Dr. Love, I say, "Cheers!"



New Hampshire Breast Cancer Coalition

SUPPORT SERVICES FUND

Have you or someone you know recently been diagnosed with breast cancer?

Are you a breast cancer patient or do you know a breast cancer patient who needs financial assistance?

The New Hampshire Breast Cancer Coalition Support Services Fund is a resource for patients who have exhausted all other options for financial assistance.

- Anyone with a diagnosis of breast cancer living or being treated in New Hampshire is eligible to apply to the New Hampshire Breast Cancer Coalition Support Services Fund.
- Typical requests for help include breast imaging or diagnostic services, cost of treatments (including prescriptions), transportation, childcare, or household expenses.
- Access the NHBCC Support Services Fund in collaboration with your health care provider (social worker, oncologist, nurse, surgeon), through your hospital or clinic Social Services or Financial Department, by calling 1-800-930-8410, or by visiting the NHBCC Web Site: <http://www.nhbcc.org>

The New Hampshire
Breast Cancer Coalition
may be able to help!



Raising Our Voices

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Raising Our Voices is a newsletter of the New Hampshire Breast Coalition. Contributions of ideas, articles, or art are welcome for consideration.

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Community Fundraisers (continued from page 4)

September

The New Hampshire Roller Derby is the original women's flat track roller derby league in New Hampshire. The group promotes women's athleticism while giving back to the local community! Thank you for your \$150 donation!

FM Radio Station 95.7 WZID spearheaded an historic event called **Bras Across The River** to benefit NHBCC. With support from many sponsors, the city of Manchester, and countless volunteers, the Notre Dame Bridge was transformed on September 11th into a celebration of life, education and action. Attendees donated \$10 and a bra to string along the bridge, raising over \$20,000, of which over \$10,000 was donated to the NHBCC Support Services Fund to continue its direct financial assistance for New Hampshire

women with breast cancer. Terrific!

October

Members of the **City of Manchester Fire Department** wore pink t-shirts and sold the t-shirt to the general public for \$10 each as a fundraiser for families fighting the disease. NHBCC received \$5,000 for its Support Services Fund, and the remaining profits generated from sales are helping two New Hampshire fire fighters currently battling breast cancer. Thank you to the Manchester Professional Firefighters Association for initiating this campaign!

Londonderry Women's Softball chose NHBCC for a \$900 donation! This most welcome donation will be put to good use! Many thanks.

BOLP, LLC Paintball in Lee, New Hampshire, included fundraising

for NHBCC during its October 16th paintball activities! This single-day event raised \$675 for the NHBCC Support Services Fund. A great effort!

The Anjoli Salon and Spa Open House in Amherst, New Hampshire, hosted by co-owners Johnna Gendron and Angie DeLaMota, raised \$2,528.00 for the NHBCC Support Services Fund. Our thanks to Johnna, Angie, and all the staff and clients who supported this outstanding effort!

The New Hampshire State Association of Emblem Clubs sent a gift of \$50.00 to NHBCC. Thank you for supporting our work!

Several other exciting fundraisers for NHBCC occurred in 2010, with benefits soon to be received. We will report them in our next newsletter. Thank you to all.

SUPPORT THE NEW HAMPSHIRE BREAST CANCER COALITION TODAY

Your contribution supports NHBCC advocacy and provides direct financial help for New Hampshire residents with breast cancer.

Thank You!

I would like to be on your mailing list to receive NHBCC newsletters, updates and alerts.

I am willing to help on NHBCC projects or committees.

Enclosed is: _____ \$25 _____ \$50 _____ \$100
 _____ \$250 _____ OTHER

Make checks payable to: NH Breast Cancer Coalition.

Send to: NHBCC, c/o Nancy Ryan,
 18 Belle Ln, Lee NH 03861-6438.

NHBCC is a non-profit, tax exempt organization.
 All donations are tax deductible.

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“Let’s work together to make Breast Cancer Awareness Month a thing of the past.”

Nancy Ryan
Chair, NHBCC
