Think BEYOND Pink

By Bethany Zell
November 2015

Every year, as Breast Cancer Awareness Month begins and the wave of pink floods my inbox, mailbox, TV screen, Facebook wall and store shelves, I cringe. This year, I have lost six friends to breast cancer. In the past three weeks, I have received more than a dozen resource requests from women newly diagnosed with breast cancer in the rural county I serve in northern Maine. What is going on? How can this be happening? Haven't all of these pink ribbons fixed this problem yet? On the contrary, breast cancer incidence is increasing and, despite small adjustments to treatment regimens, years of campaigns to raise awareness, ever-expanding screening programs, increased fundraising efforts and research, incidence and mortality have not changed significantly.

In the United States, breast cancer is the second leading cause of cancer death for women, after lung cancer. The chance of a woman developing breast cancer during her lifetime has increased from about 1 in 11 in 1975 to 1 in 8 today. Approximately 40,290 women and 440 men will die from the disease in the US in 2015, and it is estimated that 231,840 new cases of invasive breast cancer will be diagnosed in United States women, and approximately 2,350 among the men. (ACS, 2015)

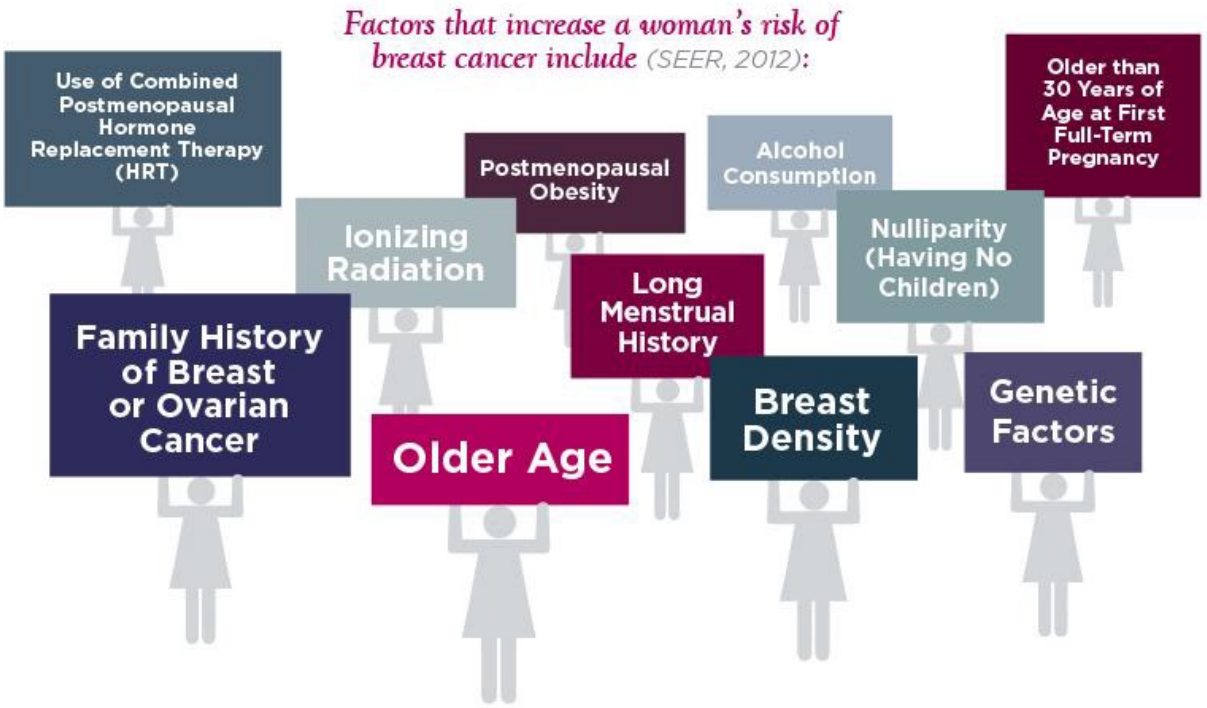
Worldwide, breast cancer is the most frequently diagnosed cancer in women and the leading cause of cancer death among women. In 2012, we lost more than 522,000 women worldwide to breast cancer. That's more than 1,400 women each day. (GloboCan, 2012)

The lack of progress is not due to insufficient resources for research.

- Since 2001, the National Institute of Health has spent roughly a $2.8 billion on breast cancer research.
- The Department of Defense Breast Cancer Research Program (DOD BCRP) has allocated over $3 billion to peer-reviewed breast cancer research since 1992.
- Susan G. Komen for the Cure has spent close to $2.5 billion on research since 1982.
- The American Cancer Society has funded $86 million of breast cancer research in their multi-year portfolio.
- Since 1999, the Avon Foundation for Women provided more than $175 million to breast cancer research programs.
- Since 1993, the Breast Cancer Research Foundation has funded more than 9.5 million hours of breast cancer research.

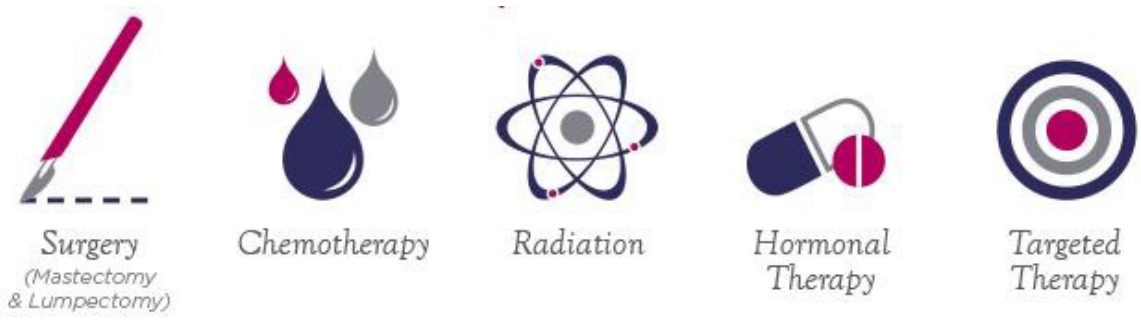
More than 40 years and billions of dollars have not ended breast cancer. It has, however, created a robust cancer industry that thrives on raising awareness and producing drugs, screening devices and genetic tests. That's not to say that all of the research has been fruitless. We have gained a new understanding of basic biological processes important in breast cancer. We now know that breast cancer is not one disease, but many. We know that breast tumors do

not all grow at the same rate or spread in the same way, and it is not the size that determines the aggressiveness of breast cancer but the tumor biology and microenvironment. Some breast cancers are small, found early, and yet are deadly. Some are fast growing. Some grow slowly, are found by mammograms and are treated, but would never have been life threatening. Each subtype of breast cancer has distinct biological features and responses to therapies. Most scientists believe that breast cancer is caused by both inherited and somatic mutations in a specific subset of genes. There is also a growing recognition that cancer does not grow in isolation but is impacted by its immediate environment. Through research we have been able to identify risk factors impacting women, which may affect cancer growth and the body's response to treatment. Some of these are environmental factors, factors that affect energy balance and obesity, and factors that influence immunity and the tumor's environment within the body.



(Graphic from National Breast Cancer Coalition Facts and Figures 2015)

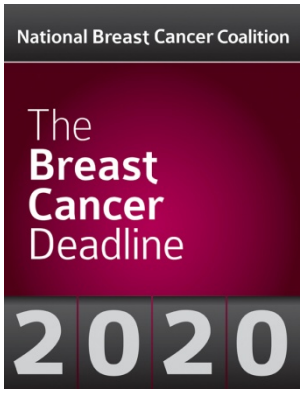
One of the more popular options for women with breast cancer is breast-conserving surgery (lumpectomy) followed by local radiation therapy. Most women diagnosed with breast cancer, and many diagnosed with precancerous ductal carcinoma in situ (DCIS), still have some kind of surgery, regardless of whether their particular situation was life threatening. Although growing evidence shows that many drugs benefit only a small group of breast cancer subtypes, they are given to all. Chemotherapy drugs, for example, are often added to treatment regimens without a great deal of evidence of benefit.



(*Graphic from National Breast Cancer Coalition Facts and Figures 2015*)

The goal should not be more treatment; the goal should be to make treatment unnecessary. How can we prevent breast cancer altogether and avoid the treatments that themselves can lead to morbidity and mortality? While the list of therapeutics continues to lengthen, there is little emphasis on prevention of the disease and strategies for understanding how to intervene in a high risk or healthy population, including the role of the environment in the development of breast cancer.

To renew the sense of urgency for its mission and to refocus global efforts on ending breast cancer and saving lives, the National Breast Cancer Coalition has set a deadline:



With their mission focused on knowing how to end to breast cancer by 2020, the NBCC is calling for an end to the status quo. Increasing awareness of breast cancer and continually funding research is not part of their mission. The three focus areas of the National Breast Cancer Coalition's Breast Cancer Deadline 2020® are:

RESEARCH - Utilizing their advocate-led, innovative, mission-driven research arm, the Artemis Project®, the National Breast Cancer Coalition facilitates collaborations that involve researchers, advocates and other key stakeholders. Artemis Project® participants design and implement research plans focused on two areas: Primary Prevention - stopping people from getting breast cancer in the first place, and Preventing Metastasis - stopping people from dying of breast cancer.

ACCESS - Making sure that people with, and at risk of, breast cancer have access to information, quality care and scientific advances.
INFLUENCE - Educating media, advocates, researchers, policy makers and others to change the conversation about breast cancer from awareness and screening to prevention and saving lives.

Don't just buy another pink ribbon product and think you have done your part. Pink ribbons make us feel good, but they don't get the job done. Pink ribbon cause marketing has become big business and many organizations have profited significantly by aligning themselves with the fight to end breast cancer. Unfortunately, many pink ribbon promotions benefit the corporation more than they do people at risk of — and living with — breast cancer.

In response, a non-profit group called Breast Cancer Action launched their Think Before You Pink© campaign in 2002. The campaign calls for transparency and accountability from companies and organizations that take part in breast cancer fundraising and pink ribbon cause marketing. Most of us see a pink ribbon and understandably assume something good for breast cancer patients is happening with the money, but that's not always the case. Many of you may be surprised to realize that some companies put pink ribbons on products simply to "spread awareness" and make no donation at all. Because the pink ribbon is completely unregulated, any company can put the pink ribbon on any product. Consumers who expect their purchase to generate needed money for breast cancer organizations should look more closely to see if any breast cancer organization or patient group is actually benefitting from the purchase.

Breast Cancer Action recommends asking the following questions BEFORE you purchase a pink ribbon product:
1. Does *any* money from this purchase go to support breast cancer programs? If so, how much? If you can't tell how much money from your purchase will go to support breast cancer programs, consider giving directly to the charity of your choice instead.
2. *Which* organization will get the money? What will they do with the funds, and how do these programs help turn the tide of the breast cancer epidemic? Before donating, check the recipient organization's website to make sure that its mission and activities are in line with your personal values. If you can't tell, or you don't know what the organization does, reconsider your purchase.
3. Is there a cap on the amount the company will donate? Has this maximum donation already been met? Can you tell?
4. Does this purchase put you or someone you love at risk for exposure to toxins linked to breast cancer? What is the company doing to ensure that its products are not contributing to the breast cancer epidemic?

If you aren't satisfied with the answers, give directly to a breast cancer organization doing work that matters to you - research into the causes of the disease, transportation vouchers for low-income women, support groups or policy work - there is a lot of work that needs to be done to address and end the breast cancer epidemic.

Awareness of breast cancer is at an all-time high. Yet breast cancer still kills almost as many Americans each year as it did 24 years ago. Awareness isn't working! Only ACTION will end breast cancer. Organizations like the National Breast Cancer Coalition and Breast Cancer Action are taking the action needed to end breast cancer – and breast cancer awareness month - forever. It is time to Think BEYOND Pink…BEYOND awareness. Help us change the conversation about breast cancer.

JOIN THE NATIONAL ACTION NETWORK OF THE NATIONAL BREAST CANCER COALITION: You will receive occasional mailings with practical actions that you can take to help in the mission to achieve Breast Cancer Deadline 2020®. Calls to action could be as simple as posting something on Facebook or Twitter or making a phone call in order to reach out to your state's legislators.

ENDORSE THE DEADLINE: To reach the goal of knowing how to end breast cancer by 2020, NBCC needs endorsements from a diversity of businesses, groups, public officials and organizations—not just those focused on breast cancer but all who care about and understand the importance of this issue—to help create the required sense of urgency to meet our mission. An endorsement of Breast Cancer Deadline 2020® publicly acknowledges your support for knowing how to end breast cancer by January 1, 2020, and it may inspire others to support our efforts.

As the wave of pink ebbs at the end of October, we can continue to affect change right where we are, one person at a time. Think BEYOND Pink when you talk about breast cancer. More importantly, tell other people why THEY should and how they can also affect change. More than awareness, we need action and advocacy. Are you with us?

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Bethany Zell has been the Program Director for Pink Aroostook, a breast health program designed for support, advocacy, education and awareness of breast health issues in northern Maine, since 2011. Recently, she started in an additional role with Cary Medical Center as the Program Director of Healthy You, a program dedicated to providing accessible, affordable wellness and health education opportunities to local communities through a unique combination of events addressing overall wellbeing including physical, mental, spiritual, and social health. Currently, she also serves as the President of the Maine Breast Cancer Coalition, Aroostook's Coordinator of the American Cancer Society's Reach to Recovery program and Maine's Field Coordinator for the National Breast Cancer Coalition. Bethany has lobbied in Washington, DC, on multiple occasions for the National Breast Cancer Coalition and in July of 2015 completed their prestigious Project LEAD course for breast cancer advocates, which covers the biology of cancer, genetics, epidemiology, research design and advocacy.