



BREASTCANCER.ORG

House Committee on Energy and Commerce Health Subcommittee Testimony

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Thank you Chairman Pallone, sub-committee members, and other panelists.

It's a privilege and honor to be here to talk about breast health and breast cancer—issues that have been my core professional focus and driving mission and passion for over 20 years, but more importantly, issues that directly affect about half of the United States population and arguably impact all of us.

My name is Dr. Marisa Weiss. I am a breast oncologist at Lankenau Hospital in the Philadelphia area and founder and president of the nonprofit Breastcancer.org, the world's most utilized online resource for breast health and breast cancer, reaching eight million individuals annually. I am also founder and past president of the nonprofit organization Living Beyond Breast Cancer and author of several books on these subjects. I've had the honor of taking care of thousands of women with breast cancer and have been witness to the profound and devastating effects of this disease. I remain committed to improving the diagnosis and care for every woman and am also dedicated to research and education to improve the long-term breast health of women and girls.

Everyone here knows how much is at stake. The breasts are the favorite places for cancer to occur in women, often in the prime of their lives and when women are indispensable to so many other lives. There are 153 million women and girls in the U.S. today, and one in eight is projected to get breast cancer in the course of her lifetime.



The bills before the committee today represent critical ongoing efforts to improve diagnosis and patient care by promoting education among consumers and health care professionals and holding providers accountable for the quality of their care. The bills are all vitally important, touch on complex health issues, and deserve our full and serious consideration.

EARLY ACT

I would like to start with H.R. 1740, the EARLY Act—a bill that aligns with the results of Breastcancer.org’s recent research in the area of breast health education and breast cancer risk reduction. The EARLY Act seeks to use education and breast health awareness of young women to promote healthy behaviors to modify or reduce established risk factors. I believe this legislation will do much to advance public health efforts and combat the threat of breast cancer and I commend Congresswoman Wasserman Schultz for her leadership.

Concern: Creating Unnecessary Fears

Opponents of the EARLY Act have expressed concerns that outreach to young women will cause more harm than good by creating fear of breast cancer. But that fear already widely exists. Information about breast cancer is pervasive. Young women—like the rest of us—are surrounded by breast cancer messaging aimed at adult women.

To better understand the impact, Breastcancer.org conducted a research project with girls ages eight through 18 across the U.S. and their mothers. Over 3,000 girls have been surveyed. Nearly 30% of girls have already feared that they might have breast cancer—fears triggered by breast pain, diagnosis in someone close to them, or mistaking the changes of normal breast development for signs of breast cancer. Our data also indicate that over 70% of girls have someone close to them who has been diagnosed with breast cancer, such as a mother, grandmother, best friend’s mom, teacher, or neighbor. And when a breast cancer diagnosis hit close to home, fears were greatly magnified. Girls also experienced significant fear by overestimating their mother’s risk of breast cancer.



Many young women respond with fear to breast cancer messages in the media. Although targeted to mature women, younger women think these messages directly apply to them as well. They simply don't have the resources to understand the meaning and relevance of these critical issues, nor do they have the dialogue skills or opportunities to discuss their fears or seek clarification of breast health myths and misinformation. Overall, only 47% of girls have talked to a parent and 40% have talked with a doctor on this subject. African American girls were less likely to get their information from an adult and more likely to get it from a sister or friend.

To resolve unrealistic fears, young women living in the breast cancer-awareness era need accurate information and reassurance that is age-appropriate and scientifically grounded. Education can arm them with the facts, inform them of what's normal and what's not, and empower them to take charge of their breast health future as they build their breast tissue using what they eat and drink, medicines they take, personal products they use, and by how they use their bodies. **At this early point in life, young women are establishing their life-long behavioral patterns.**

Concern: Unsubstantiated Value and Content of Educational Programs

Opponents of the EARLY Act have also expressed concerns about the value of educational outreach to low-risk populations in the absence of modifiable risk factors. I respectfully disagree.

Breast cancer is a complex disease with multiple causes, some proven and others suspect. Most risks for breast cancer don't begin at age 45. Rather, they accumulate over a lifetime, beginning at conception. There are periods when breast cells are hypersensitive to internal and external environmental insults and agents: the first trimester of pregnancy during initial organogenesis, the four to 10 main years of breast organogenesis between adolescence and the twenties, as well as the stretch of time leading up to a woman's first full-term pregnancy, when breast cells are highly active and immature. So, the behaviors of women under age 45 impact not only their own breast health, but the future breast health of their daughters through pregnancy and modeled behaviors.



As others have pointed out, not all risk factors are created equal. Some risks—like being a woman, growing older, having a strong family history, and/or a specific breast cancer gene abnormality—carry more significance than others, such as obesity, physical inactivity, alcohol consumption, smoking, and an unhealthy diet. Some risk factors are modifiable, some are not. But even tiny risks can combine and really add up. Concentrated exposures, combined exposures, regular exposures over time—particularly during sensitive periods—can accumulate and collectively increase risk.

For example, besides being a woman, growing older is the biggest risk factor for breast cancer. And while you can't control *that* you are aging, you can control *how* you age: how your inside environment interacts with the outside environment. **We cannot undo past behaviors, but we can limit the damage by promoting a breast healthy lifestyle and behaviors starting as early as possible.**

Another example of a modifiable risk factor: the rising obesity epidemic across the U.S. in children, adolescents, and adults. This epidemic is associated with unhealthy factors that may increase the risk of breast cancer in adults. Extra fat makes extra hormones that can bring on earlier puberty and over-stimulate breast cell growth. In addition, fat stores hormonally active pollutants such as bisphenol A, atrazine, dioxins, and nonylphenols, which might further stimulate unhealthy breast cell growth and activity. Obesity is also associated with reduced physical activity. Moreover, obesity in childhood predicts for obesity in adults and obese mothers are more likely to raise obese daughters.

Contrary to the claim that proven breast cancer risk factors can't be modified, our obesity epidemic is doing just that by accelerating the age of menarche. In the other direction, early education and behavior modification that increases athletic activity and healthy weight management can postpone the onset of puberty. Lessons learned from EARLY Act programs will benefit current and future generations, since women under the age of 45 are in the prime of their childbearing and parenting years.



Opponents cite the HPV vaccine to help prevent the leading cause of cervical cancer as an ideal and preferred approach to prevention. Relative to what we know about the dominant cause of cervical cancer, this is true; my own daughter was one of the first to be vaccinated. But the reality is that this vaccine is given to millions, yet the annual incidence of cervical cancer in this country is 11,270. There is at least the same opportunity to provide breast cancer reduction strategies in high risk women. With the consumer and healthcare education programs in the Early Act, the 5-10% of breast cancers due to an inherited breast cancer genetic abnormality—over 13,000 per year for women of all ages—would more likely be identified, giving these women a greater chance to reduce their risk of breast cancer by as much as 90% with prophylactic mastectomies or 50% with anti-estrogen therapy. They may even pursue embryo selection to essentially eliminate the risk of transmitting the gene to their offspring.

It's imperative that we impart this knowledge, along with what we, the scientific and medical community, know are NOT risk factors for breast cancer. Fear breeds myths. In our survey, more than 20% of the girls surveyed believe that breast cancer is caused by infection, tanning, drug use, stress, and breast injury or bruising. Many girls also believe that only their mother's family history is important and that breast cancer skips generations. These myths were even more widely held by African American girls. And where mothers affected by breast cancer were close in age to their daughters, the daughters were fearful that they could have caught breast cancer from their mothers during pregnancy and breast feeding.

Education can change attitudes, knowledge, and behaviors. We simply must invest in education—from explaining normal breast development and function and imparting facts about breast cancer and breast cancer risk, to providing evidenced-based behaviors and lifestyles that promote breast health. We do a disservice to this and future generations by neglecting to provide this information and facilitate this dialogue. And what a perfect opportunity to reach younger women while they are students in high school and college. Our ability to reliably reach this population vanishes quickly once they are beyond their years of institutional education. Responsible live and print media outreach is also a critical approach. Both fall within the EARLY Act.



Education is Needed to Avoid Over-Reliance on Any Single Early Detection Tool

I've seen how crucial early detection is to not only "survivorship," but to the quality of life. For many patients, early detection could mean not having to lose a breast with mastectomy or not having to experience aggressive chemotherapy.

But as far as we've come, we still have a long way to go. There is no one or combination of perfect tests that can find all cancers early. Each breast cancer detection tool in the limited arsenal for early detection in the general population is both powerful and flawed: mammography, clinical and self breast examinations. This is particularly true in young women whose background dense breast tissue can easily distract or obscure early breast cancer detection. Yet for most women under 40, the use of breast self exams for breast self awareness and clinical exams are the only detection resources they have. A study from Harvard presented at the April 2009 American Society of Breast Surgeons' annual meeting found that 71% of women diagnosed with breast cancer at 40 or younger discovered their cancers through breast self-exam.

Education can help clarify the strengths, weaknesses and complementary properties of each detection method. The ability of "breast awareness" to detect breast cancer early is severely limited by the frequent absence of signs or symptoms. By the time cancers make their presence known through "breast awareness," they are usually later in stage and the opportunity for early detection has passed. The value of mammography in young women with dense breasts is limited by the thick curtain of breast tissue that may block a mammographer's ability to find the relatively infrequent number of breast cancers observed in young women. Prescribed to women age 40 and above and to women 10 years younger than their earliest affected family member, mammography might have to pull in other tests for backup. MRI is a powerful example. With sensitivity as its greatest strength—it's the best at finding invasive breast cancers in their earliest form—and the most guilty of ringing too many false alarms. Comparing and correlating findings of all detection methods require a significant investment of attention and time but will yield the best overall interpretation.



The EARLY Act addresses these complex issues by promoting education—not only to consumers, but among health care professionals who may dismiss early breast cancer signs and symptoms under the premise that breast cancer is rare in women under age 45.

But 24,000 annual cases of breast cancer in women under age 45 does not make it rare. It is just relatively uncommon compared to the much higher incidence in women over 45 (since a woman's risk increases with age). Compared with other cancers, that incidence is not considered rare. When we factor in that breast cancer survival rates are lower for women under 45, we must be realistic about how vitally important the tenets of the EARLY Act are.

Unique Concerns of Young Women with Breast cancer

Special issues that uniquely affect young women with breast cancer will also be included in the EARLY Act. Beyond issues of quality of life and ability to fully function like fertility and cognition, there are issues that affect risk of recurrence and survival, such as, knowing how to get the full benefit of Tamoxifen without major interference from commonly used medicines that might be taken at the same time, like anti-depressants, Benadryl, and Lamisil.

There are many issues to address with regard to the EARLY Act and I look forward to your questions.

Breast Cancer Patient Protection Act of 2009

I've been a long-time champion for Congresswoman DeLauro's bill — H.R. 1691, the Breast Cancer Patient Protection Act of 2009. Mandatory "drive-through mastectomies" are an unconscionable practice that can endanger a woman's recovery and lead to avoidable complications.

A mastectomy and lymph node dissections are serious, invasive surgeries with profound physical and emotional impact. While many women are ready to go home after 24 hours, some need more time. They may experience unexpected complications or have no support at home,



and therefore they may require a longer stay to manage bleeding, pain, drains, and the risk of infection. When patients are turned out of the hospital because insurance refuses to cover necessary post-operative care, their physical and emotional health is further endangered by this unnecessary practice.

There is no "one size fits all" solution. The decision about the length of needed in-hospital recovery time following breast surgery must be made within the sacred relationship between a woman and her doctor, not reduced to a business decision that overrides a doctor's best judgment and the patient's best interest.

Breast cancer is a serious condition that requires serious—and sensitive—attention to the physical and emotional needs of each patient. As someone who has treated thousands of women, I know that the care of these women at this most vulnerable and high-risk time must be individualized. To suggest otherwise demeans the challenge these women face in their fight against breast cancer. I urge this committee to support this bill. It will not only improve patient lives, but potentially save them from preventable serious complications.

Mammogram and MRI Availability Act of 2009

I am also highly supportive of Congressman Nadler's H.R. 995, the Mammogram and MRI Availability Act of 2009, which further requires providers to cover annual screening mammography for women 40 and older and diagnostic mammography, annual screening mammography, and annual magnetic resonance imaging for high risk women. Again, my support stems from the demonstrated survival and quality of life benefits of early detection—particularly for young, high-risk women for whom more sensitive tests may be necessary to find the most life-threatening types of cancer that can hide from standard imaging procedures.



Eliminating Disparities in Breast Cancer Treatment Act

H.R. 2279, the Eliminating Disparities in Breast Cancer Treatment Act, sponsored by Congresswoman Castor, addresses a critical gap in the quality of medical care for all Americans. I've witnessed this on a daily basis in my clinical practice in the Philadelphia area. Sadly, African American women continue to have worse outcomes than Caucasian women: they tend to utilize mammography less, get diagnosed with more aggressive types and stages of cancer, and their treatment outcomes and survival are also significantly worse. These disparities are absolutely unacceptable and have persisted for far too long. I commend Congresswoman Castor for her efforts to improve a situation that will not otherwise resolve itself.

In conclusion, I would like to thank the Chairman, the Subcommittee, and the panel for giving me the time to speak with you today. I applaud the efforts of the sponsors and supporters of these bills and am grateful for the platform to openly discuss these vitally important issues affecting so many precious Americans lives.