

Testimony before the House Energy & Commerce Committee
Subcommittee on Health
October 7, 2009
Rep. Debbie Wasserman Schultz

Thank you, Chairman Pallone, Ranking Member Deal, and distinguished Members of the Subcommittee, for inviting me to testify today. It is an honor to appear before this Committee. It is fitting that you are holding this hearing as we begin Breast Cancer Awareness Month and that we review what is needed in the fight against this terrible disease.

Before I go further, I give my deepest gratitude to the efforts of three of my colleagues: Sue Myrick, Rosa DeLauro, and Donna Christensen, who embraced this legislation months ago, before I publicly shared my own battle with breast cancer. Rosa, it's an honor to testify at your side. Sue, I'm so grateful for all you have done to advance this legislation as the lead Republican co-sponsor. All three of you have been an incredible source of support.

Breast cancer strikes women from all backgrounds, all races, all ages, and all ethnicities. It strikes black and white, rich and poor, those with access to quality health care and those without. But many women -- too many women -- do not know their specific risk factors or their family history. This is especially true with young women who see breast cancer as an older women's disease. Many young women think breast cancer will never happen before they turn 40, but we know that young women can and do get breast cancer.

In fact, each year, nearly 24,000 women under 45 are diagnosed with breast cancer in the United States. While incidence rates of breast cancer are much lower in young women than older women, young women's breast cancers are generally more aggressive, are diagnosed at a later stage, and result in higher mortality rates.

After talking with many health care professionals, advocates in the breast cancer community, and the Centers for Disease Control and Prevention, it became clear that there was an urgent need to help build awareness among this often overlooked group. These conversations led to H.R. 1740 -- the Breast Health Education and Awareness Requires Learning Young Act, or "EARLY Act." This bill will empower young women to learn the facts, know their bodies, speak up for their health, and embrace support.

The truth is -- we all need to be better informed about our own health. We must empower each other to know and reduce our risks. Recently, I learned I had more personal risk than I was aware of. Almost two years ago -- only six weeks after a clean mammogram -- I found a lump in my breast while doing a routine self-exam. My doctor diagnosed me with breast cancer. I had just turned 41.

As a legislator, I've been in the fight against breast cancer for a long time. In Florida, I was the lead sponsor of the Drive Thru Mastectomy law, the focus of Rosa's bill. I never dreamed I would need its protection myself. I thought I knew all of my risk factors. That's why I chose to perform self-exams and saw my doctor regularly.

But after I was diagnosed, I learned I had more risk factors than I was aware of. I had no idea that, as an Ashkenazi Jewish woman, I was five times more likely than the general population to have a BRCA 1/BRCA 2 genetic mutation. I did not know the mutation gave me as much as an 85

percent chance of developing breast cancer during my lifetime. Too many young women are unaware of their risk.

The EARLY Act will give ALL young women the tools and information they need to take more control of their health. It will raise awareness of their personal risks and the importance of paying attention to their breast health. It will encourage young women to be familiar with the look and feel of their breasts. By knowing what feels normal, a young woman has a better chance of knowing when something feels different and knowing when to see her doctor.

The EARLY Act will teach young women and medical professionals about the importance of family history, warning signs of breast cancer, and predictive tools such as genetic testing that can help some high-risk women make informed decisions about their health. It will also provide grants to organizations dedicated to supporting young women diagnosed with breast cancer. These grants will help young women tackle the unique challenges, such as fertility preservation, body image and self esteem they face as well as help them manage and understand their risks.

With 369 cosponsors in the House -- including nearly all Members of this subcommittee -- and 34 cosponsors in the Senate, the EARLY Act has also garnered broad public support from more than 40 advocacy and health organizations. I cannot thank these groups enough for their support, their expertise, and their guidance in helping to craft this legislation.

Some say this legislation will detract from other important health care efforts or siphon funding away from the important National Breast and Cervical Cancer Early Detection Program. That's wrong. As a long-time advocate of breast cancer awareness, and as an Appropriator, I have fought for, and will continue to fight for a multi-faceted approach to combating breast cancer.

Others say we shouldn't be talking to young women about breast cancer at all-- because it will scare them. Well, I find this, quite simply, patronizing. Young women and providers can handle the truth. They can and should be empowered with the knowledge that while only 15 percent of breast cancer cases are in women under 45, eight of these women die every day here in America. Having no information when you are 35 and find a lump in your breast, that is what is really scary.

Over the past year I have met with oncologists and other health care professionals that work with breast cancer patients. Whether at the M.D. Anderson Cancer Center in Houston, the Dana-Farber Cancer Institute at Harvard, or the cancer center at Memorial Hospital in my District in Florida -- the message is clear: too often a diagnosis of breast cancer is delayed or missed in young women. A Harvard study of young women with breast cancer found 26 percent delayed seeking medical attention and 27 percent experienced a delay in diagnosis after seeking medical attention. This means more than half of young women are not receiving the timely treatment they need! We must do better!

By encouraging young women to know their bodies and their family history, and by teaching young women how to effectively talk with their doctors, and their doctors with them, we can transform how we approach the fight against breast cancer.

Every young woman I know has the goal of becoming an older woman! With passage of the EARLY Act, we can help more young women in America reach that goal and give them powerful tools to take control of their own health for a lifetime.

Thank you.