

Are You Dense?

My journey to patient breast health advocacy

BY NANCY M. CAPPELLO, PHD



Nearly 13 years ago, I slipped through a significant and potentially fatal crack in our healthcare system when I was diagnosed with advanced stage breast cancer. Following in the footsteps of my mother's yearly regimen, I never missed my annual mammography exam; however, within weeks of my eleventh normal mammogram, during a routine clinical breast exam, my gynecologist felt a ridge in my right breast. A diagnostic ultrasound illuminated a large lesion, undetectable by mammography, and later determined to be an advanced Stage IIIC breast cancer with metastases to 13 lymph nodes.

A Matter of Density

My new-found team of physicians informed me—after I had to practically arm-wrestle them into explaining why years of mammograms had missed the cancer—that the culprit was my extremely dense breast tissue. This was the first time in a dozen years that I had heard those words. Worse, I learned that the medical community knew about the limitations of mammography for women with dense breasts.

Blindsided and frightened about my late-stage disease, I was outraged that this critical information was unknown to most women. I was also compelled to educate the

public about dense breast tissue—both its significant masking and independent cancer risk. My goal: to help reduce preventable advanced disease and, in turn, reduce mortality from breast cancer.

What the Research Revealed

Knowledge is power. To gain as much information as possible, I went to the literature. I was astonished to discover a decade of scientific studies prior to my diagnosis concluding that 40 percent of women have dense breast tissue and that there are other tests, such as ultrasound and MRI, when added to mammography, that can significantly detect early-stage and node-negative cancers invisible by mammography. Starting in the mid-70s research also concluded that having dense breast tissue is an independent risk factor for breast cancer. I also was confronted with the brutal fact that my advanced-stage breast cancer leaves me at greater risk of dying prematurely from breast cancer despite never missing an annual mammography exam.

After requesting copies of my health records, I discovered 11 mammography reports from the radiologist to my referring physician, that were different from the 11 letters I received. Reading through my records, I was first astonished and later incensed as, year after year, each of the reports contained a sentence that stated, “Patient has extremely dense breast tissue, which could lower the sensitivity of the mammogram.” Since from the time of my first baseline mammogram at 35 years of age up until

weeks before my shocking diagnosis, the information about my dense breast tissue and its impact was known to my doctors, but not revealed to me—the patient with the dense breasts.

Advocating for Change

In 2008 I founded Are You Dense, Inc. (areyoudense.org) and later, in 2011, Are You Dense Advocacy, Inc. (areyoudenseadvocacy.org) with a mission to educate the public about the risks and screening challenges of dense breast tissue to prevent missed, delayed, and advanced-stage cancer, thus reducing mortality. Working tirelessly with advocates in my home state of Connecticut, I began to pursue equal access to an early breast cancer diagnosis for women with dense breast tissue through the state's legislative process. Faced with strong opposition from the Connecticut Society of Radiologists, it took five years for the first-in-the-nation density reporting law to pass in 2009. It was a great victory. Leveraging the accumulating science, our tireless grassroots movement helped make the state of Connecticut a pioneer and subsequent leader in density reporting and breast health.

Since that watershed moment, 31 states have enacted density reporting legislation to give women the same information their healthcare providers have about their dense breast tissue. We continue to work on a national standard, through federal legislation. A bi-partisan proposed federal bill was introduced in the last Congress in both the senate and house, and we are currently advocating for a reintroduction in this current

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Congress. Across the globe, patient advocates, inspired by Connecticut's revolutionary legislative efforts, are exposing the impact of dense breast tissue in their respective countries, including Australia, Canada, Ireland, France, and the United Kingdom.

From Policy to Practice

Immediately upon enactment of the 2009 Connecticut density reporting law, breast radiologist Jean Weigert, MD, who had testified in opposition to the bill, began gathering data to investigate whether screening breast ultrasound improves breast cancer detection in women with dense breast tissue and a recent normal mammogram result. In 2017 she published her third research paper, "The Connecticut Experiment; The Third Installment: 4 Years of Screening Women with Dense Breasts with Bilateral Ultrasound" and shared these findings in a recent OncLive interview.

"I pulled data from my five offices for years one through four [of the study]. I tallied it up, compared it, and found—much to my surprise—we continued to find 3.2 additional cancers per thousand in this cohort of patients with breast tissue density greater than 50 percent."

Additionally, Dr. Weigert's study demonstrated significant progress in reducing the false positive rate of biopsy, often cited as a harm of routine ultrasound screening, where ultrasound now equals the acceptable biopsy rate for mammography.

One of Dr. Weigert's year-four patients with a recent normal mammogram is 48 years old and at average risk of breast cancer. Having dense breasts, the patient underwent a recommended adjunct ultrasound that uncovered a 1.5 cm, triple negative, grade 3, invasive ductal carcinoma with one macro metastasis. If this patient's cancer continued to be missed by mammography and detection was thus delayed, her aggressive cancer most likely would have progressed to a more advanced stage, with fewer treatment options and worse survival outcomes.

The promise of early detection for me and innumerable women with dense breast tissue is vital to surviving the disease. As we look towards potentially changing breast

cancer screening guidelines for women of average risk who have dense breast tissue, Dr. Weigert's Connecticut Experiment reveals that we can significantly improve breast cancer detection by reducing interval cancer and advanced disease.

Randomized controlled trials of mammography conclude that the magnitude of the reduction of advanced stage breast cancer is associated with the magnitude of the reduction of mortality. Dr. Weigert's retrospective study establishes a powerful role for ultrasound in filling in the cracks in breast cancer screening, creating an

opportunity for a reduction in advanced disease and an improvement in survival outcomes—the ultimate goal of any breast cancer screening program. **QI**

Nancy M. Cappello, PhD, is a cancer survivor, and founder and director of Are You Dense, Inc. and Are You Dense Advocacy, Inc.



Nancy M. Cappello, PhD, was honored by UNICO, the largest Italian-American service organization in the United States, with its Americanism-Civis Illustris Award for her outstanding work in communities in the U.S. and around the world. Pictured (L to R) UNICO National President Tom Vaughn, Nancy and Joe Cappello, Francine Nido, UNICO Secretary.

Governor Rell signing the Breast Density Bill into law on May 20, 2010. Pictured (L to R) Cheryl Cepelak and Anne Morris from the Susan G. Komen for the Cure, Connecticut Representative Steve Fontana, Governor M. Jodi Rell, Nancy Cappello, and Connecticut Senator Joseph Crisco.