

The Best-Kept Secret

by Nancy M. Cappello, Ph.D. *My Story*

In February 3, 2004, I was diagnosed with Stage 3c breast cancer. Less than 48% of women with Stage 3c breast cancer are alive after five years. What I have learned since my diagnosis is that 1) I have dense breast tissue and wasn't aware of its significance in that tumors in women with dense breast tissue are often not detected by mammography alone (tumors appear white on a mammogram and dense tissue is white-thus no contrast to detect the tumor) and 2) the mammography report that is generated by the radiologist to the referring doctor, which contains more detailed information about a woman's breasts, is not the same report that a woman receives after having a mammogram.

Just two months prior to my late stage cancer diagnosis, I had a mammogram and the "Happy Gram" report that I received gave me the thumbs up. During my annual exam a few months later, my doctor felt a "ridge" in my right breast and ordered a mammogram and an ultrasound. The mammogram revealed "nothing" but that same day the ultrasound detected a large 2.5 cm tumor. Because cancer was detected at an advanced stage, I had a mastectomy and endured an aggressive treatment of chemotherapy and radiation. Since my diagnosis, I am compelled to tell the **BEST-KEPT SECRET** about dense breast tissue and its significance in that mammograms *Are You DENSE?* have limitations and women with dense breast tissue are at a greater risk of getting breast cancer.

AWARDS

A formal **Citation** by the **Connecticut General Assembly** in recognition of "extraordinary commitment to promoting early detection of breast cancer through successful legislative advocacy and public awareness campaign and for the courage to transform a personal tragedy into a positive force."

The **Distinguished Angel Award** from the **American Cancer Society** for advocacy in informing the public about dense tissue and its risk factors.

Falk Foundation for Excellence for informing women of the fatal flaw in the early detection of breast cancer.

There are too many women who are unaware of their breast density, believe their "happy gram" when it reports no significant findings and are at risk of receiving a late stage cancer diagnosis.

Be informed about your breasts.

Early detection is the key to survival.

MEDIA AND SPEAKING ENGAGEMENTS

Dr. Cappello has been a featured speaker at numerous venues throughout the country. Her message, conveyed with humor and motivation, speaks of her journey from patient to advocate. Her story inspires others to take their challenges and lessons learned to make a positive impact in the lives of others. Dr. Cappello's tragedy of her advanced breast cancer, resulting in CT's Landmark legislation, has been featured in many media outlets such as television, print and radio.

The **MISSION** of **Are You Dense, Inc.** is to educate the public about dense breast tissue and its significance for the early detection of breast cancer. Please help us reveal the **best-kept secret** about the limitations of mammography alone to detect cancer in women with dense breast tissue.

Are You DENSE?
exposing the best-kept secret™

www.areyoudense.org

- ◆ Breast density is one of the strongest predictors of the failure of mammography screening to detect cancer.
- ◆ 2/3 of premenopausal women and 1/4 of post menopausal women have dense breast tissue.
- ◆ Women who have extremely dense breast tissue are at a 4 to 6x greater risk of developing breast cancer.

Are You Dense, Inc.

A 501(c)(3) Public Charity



HOW DO I KNOW IF I HAVE DENSE BREAST TISSUE?

A radiologist can determine the density of a woman's breasts by examining a mammogram. Request a copy of your mammography report from your referring doctor. Make sure it is the report that is generated *from the radiologist* and not a form letter. Read the report carefully. Look for descriptions of your breast tissue. Connecticut is the first state to mandate that each mammography report provided to a patient shall include information about breast density.

WHAT DO I DO IF I HAVE DENSE BREAST TISSUE?

Talk to your doctor about having an ultrasound or breast MRI. Connecticut General Statutes Sections **38a-503** and **38a-530** require insurance companies to provide coverage for comprehensive ultrasound screening of an entire breast or breasts if a mammogram demonstrates heterogeneous or dense breast tissue based on the BIRADS (Breast Imaging Reporting and Data System) established by the American College of Radiology (ACR). To determine the insurance laws in your state contact your state representative or public health department.

Remember to:

- ◆ Conduct monthly breast exams and have your physician conduct a thorough yearly breast exam.
- ◆ Have a mammogram. A mammogram distinguishes the density of a woman's breasts.

There are two **BIRADS** (Breast Imaging Reporting and Data System) scales that are used by radiologists to standardize mammography reporting.

The following (ACR) **BIRADS** scale categorizes breast density:

1	ALMOST ENTIRELY FATTY: <i>mammogram very effective, sensitive to even small tumors</i>
2	SCATTERED FIBROGLANDULAR TISSUE: <i>minor decrease in sensitivity</i>
3	HETEROGENEOUSLY DENSE TISSUE PRESENT: <i>moderate decrease in sensitivity</i>
4	EXTREMELY DENSE TISSUE PRESENT: <i>marked decrease in sensitivity</i>

Ask your doctor which category of breast density you have. Most likely the mammography report that you will receive will not contain this information.

The other BIRADS scale characterizes the findings that are seen on the mammogram. Currently, most mammography reports reference this BIRADS* scale:

0	ASSESSMENT IS INCOMPLETE; <i>additional imaging is needed</i>
1	NEGATIVE
2	BENIGN FINDING
3	PROBABLY BENIGN FINDING; <i>short interval follow-up suggested</i>
4	SUSPICIOUS ABNORMALITY; <i>biopsy should be considered</i>
5	HIGHLY SUSPICIOUS OF MALIGNANCY; <i>biopsy should be perform</i>

A woman with dense breast tissue cannot rely solely on the above BIRADS* scale to determine findings of breast cancer.

Thomas Kolb, M.D. in his research on 11,130 women found that supplementing mammography with ultrasound markedly increases cancer detection in women with dense breasts. The additional ultrasound screening increased the number of women diagnosed with non-palpable invasive cancers by 42%. While mammography detected 98% of cancer in women with fatty breasts, it found **only** 48% in women with the densest breasts.

(American Medical Association: September 19, 2002)

"I've seen over and over cancer cases in which ultrasound has picked up what mammogram has missed in women who were not at risk, and who had dense breasts." Wendie Berg, M.D., Radiologist and Principal Investigator of large-scale study to examine benefits of ultrasound screening.

(Marnell Jameson, Los Angeles Times: June 14, 2004. pg. F.1.)

Cancer turns up five times more often in women with extremely dense breasts than in those with the most fatty tissue, a study shows, signaling the importance of a risk factor rarely discussed with patients. "It's been ignored to an absolutely unbelievable degree," said study leader Dr. Norman Boyd at Princess Margaret Hospital in Toronto. He believes that breast density is equally as important as advanced age and dangerous mutations of cancer genes in raising a woman's breast cancer risk.

(Jeff Donn, The Associated Press: 2007)

The addition of a single screening ultrasound to mammography increased detection of breast cancers that are small and node negative.

(Berg et al, JAMA: 2008)

A 2010 Harris Interactive Poll revealed that 95% of women do not know their breast density despite increased cancer risk and that doctors have spoken to less than one in 10 women ages 40+ about breast density.

(U-Systems Survey: 2010)

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