

The Best-Kept Secret By Nancy M Cappello, Ph.D. *My Story*

On February 3, 2004, I was diagnosed with stage 3c breast cancer within weeks of a 'normal' mammogram. What I have learned since my diagnosis is that I have dense breast tissue and wasn't aware of its significance as:

- 1) Mammography misses every other cancer in dense breasts as cancer appears white on a mammogram and dense tissue is white-thus there is no contrast to detect the cancer and
- 2) the mammography report that is written by the radiologist to the referring physician, which has detailed information about a woman's breasts, is seldom shared with the patient.

Just seven weeks **prior** to my late stage cancer diagnosis, I had my 11th yearly mammogram & the 'happy gram' report stated that my mammogram was 'normal.' At a subsequent annual exam, my doctor felt a ridge in my breast and ordered a mammogram. The mammogram revealed 'nothing' but that same day the ultrasound detected a quarter-size lesion. The pathology report revealed advanced cancer metastasized to 13 lymph nodes.

What happened to Early Detection?

Because cancer was detected at such an advanced stage, I endured an aggressive treatment consisting of chemotherapy, radiation, numerous surgeries & hormone therapy. Since my diagnosis, I am compelled to expose the BEST-KEPT SECRET about dense breast tissue and its significance as mammography is limited by dense tissue & dense breast tissue is a predictor of breast cancer risk.

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'To withhold a woman's breast tissue composition from her is denying her the right to make an informed decision about her breast health.'

(Cappello, N. J Am Coll Radiol 2013; 10:903-908)

AWARDS AND RECOGNITION

A 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 and for the courage to transform a personal tragedy into a positive force.'

- Parade Magazine-Health Hero**
- Person of the Year-Litchfield County Times**
- Angel Award-American Cancer Society**
- Ruby Award-Soroptimist**
- Health Care Leadership Award-Waterbury Chamber of Commerce**
- Women of Strength Award-Get in Touch Foundation**
- Aixplorer Achievement Award-Supersonic Imagine**
- State Health Advocacy Honoree-St. Vincent's Hospital**
- Making a Difference Award-Safe Haven of Greater Waterbury**
- Pink Pioneer-Pink Paper Publication**
- Women of Innovation-CT Technology Council**
- Women Making a Difference-Griffin Hospital**
- Nancy Pilver Breast Advocacy Award**
Congressman John Larson

MEDIA AND SPEAKING ENGAGEMENTS

Dr. Cappello is a featured speaker across the U.S. & has lectured in Puerto Rico, Canada and Italy. Her message, conveyed with inspiration and humor, speaks of her journey from patient to advocate. Her story inspires others to take challenges and life's lessons to make social change.

Dr. Cappello's tragedy of her advanced breast cancer, resulting in Connecticut's landmark legislation & the national grassroots legislative efforts, are featured in broadcast & print outlets such as ABC, CBS, Fox, Prevention, NY Times, Wall Street Journal, Huffington Post & NPR.

There are too many women who are unaware of their breast density, believe their 'happy gram' when it reports 'normal' and are at risk of a later stage cancer diagnosis. Be informed about your breast density. Cancers detected EARLY have better treatment and survival outcomes.

The **MISSION** of **Are You Dense Inc.** is to educate the public about dense breast tissue and its significance for the prevention of later stage cancers.

Are You
DENSE?
exposing the best-kept secret

- * Forty percent of women have dense breast tissue.
- * Breast density predicts the accuracy of a mammogram at any age.
- * Mammography misses every other cancer in dense breasts.
- * Breast density is a well-established predictor of breast cancer risk.

Are You Dense Inc.
a 501(c)(3) Public Charity
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HOW DO I KNOW IF I HAVE DENSE BREAST TISSUE?

A Radiologist determines the density of a woman's breast by examining a mammogram. Dense Tissue is comprised of less fat & more fibrous & connective tissue & appears white on a mammogram. Cancer also appears white & can be masked by dense tissue. Request a copy of your mammography report from your referring doctor. Make sure it is the report that is generated **by the radiologist** and not a form letter. Read the report carefully. Look for descriptions of your breast tissue.

D.E.N.S.E.®

Connecticut was the first state to mandate that each mammography report provided to a patient includes information about breast density. For information about state, federal & regulatory efforts visit AreYouDenseAdvocacy.org.

WHAT DO I DO IF I HAVE DENSE BREAST TISSUE?

Ask your doctor about having additional screening studies such as an ultrasound or breast MRI. Connecticut General Statutes require insurance coverage for comprehensive ultrasound screening of an entire breasts or breasts if a mammogram demonstrates heterogeneous or dense breast tissue based on 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 and visit AreYouDenseAdvocacy.org.

Remember to:

~Have a Mammogram. A mammogram distinguishes the density of a woman's breasts ~Be breast aware. Look for changes in your breasts ~Have your physician conduct a thorough yearly breast exam.

There are two **BIRADS** (Breast Imaging Reporting and Data System) scales that are used by radiologists to standardize mammography reporting. The following ACR BIRADS® 5th Edition categorizes breast Density.

a	The breasts are almost entirely fatty.
b	There are scattered areas of fibroglandular density.
c	The breasts are heterogeneously dense, which may obscure small masses.
d	The breasts are extremely dense, which lowers the sensitivity of mammography.

Discuss with your doctor your breast tissue composition. Most likely the mammography report that you receive will not contain this information .

The other **BIRADS** scale categorizes the findings that are **seen** on the mammogram. Most mammography reports reference this **BIRADS*** scale.

0	Incomplete Need Additional Imaging Evaluation and/or or Prior Mammograms for comparison
1	Negative
2	Benign
3	Probably Benign
4A,B,C	A: Low suspicion for malignancy B: Moderate suspicion for malignancy C: High suspicion for malignancy
5	Highly Suggestive of Malignancy
6	Known biopsy—Proven Malignancy

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

* Dr. Thomas Kolb's seminal study found that by supplementing mammography with ultrasound markedly increases cancer detection in women with dense breasts. While mammography detected 98% of cancer in women with fatty breasts, it found **only 48%** in women with the **densest breasts**. (American Medical Association: 9/2002 & JAMA Scientific Paper of the Year Award.)

* Mammography misses every other cancer in dense breasts (Berg et al, JAMA: 2012)

* Breast density is consistently associated with breast cancer risk, more strongly than most other risk factors, and extensive breast density may account for a substantial fraction of breast cancer. (Journal of National Cancer Institute, Aug. 2010)

* We're finding small, mammographically occult (not visible) cancers at a significant rate & we're able to do that & still be efficient. (ACR bulletin: Oct., 2012 ; Dr. Regina Hooley, Yale School of Medicine)

* Doctors have spoken to less than one in 10 women about breast density. (Harris Interactive Survey, 2010)



For more information contact:

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Help us in our efforts to prevent later stage cancers.