

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.

HOW DO I KNOW IF I HAVE DENSE BREAST TISSUE?

A Radiologist determines the density of a woman's breasts by examining a mammogram. Dense tissue is comprised of less fat & more fibrous & connective tissue & appears white on a mammogram. Cancer also appears white thus cancer 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 and 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 breast exam.

There are two ACR **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:

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 Prior Mammograms for comparison
1	Negative
2	Benign Findings
3	Probably Benign
4 A,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.

Are You Dense Inc.

a 501(c)(3) Public Charity

AreYouDense.org

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Please support our efforts to prevent later stage cancers.

The Best-Kept Secret

By Nancy M Cappello, Ph.D.

My Story

On February 3, 2004, I was diagnosed with advanced stage breast cancer within weeks of a 'normal' mammogram. It was at this time that I learned that I had 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 see the cancer and 2) the mammography report, written by a radiologist to the referring physician, has detailed information about a woman's breasts BUT that report is typically not shared with the patient.

Just 6 weeks **prior** to my late stage cancer diagnosis, I had my 11th yearly mammogram and the 'happy gram' report that I received reported 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 stage breast 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 and hormone therapy. Since my diagnosis, I am compelled to tell the **BEST-KEPT SECRET** about dense breast tissue and its significance as mammograms have limited sensitivity in dense breasts and women with dense breast tissue have a greater risk of breast cancer.

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 options and survival outcomes.*

For more information contact:



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'To withhold a woman's breast density 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)

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- Dr. Thomas Kolb's seminal study found that by adding ultrasound to mammography 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 & AMA 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)

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

Health Advocacy Honoree-St. Vincent's Hospital

Making a Difference Award-Safe Haven of Greater Waterbury

Pink Pioneer-The Pink Paper Publication

Women of Innovation-CT Technology Council

Women Making a Difference - Griffin Hospital

Nancy Pilver Breast Advocacy Award- Congressman John Larson

Susan G. Komen Promise Award- Presented by Joan Lunden

Health & Wellness Advocacy- CT Women's Hall of Fame

MEDIA AND SPEAKING ENGAGEMENTS

Dr. Cappello is a sought after speaker across the U.S & has lectured in Puerto Rico, Canada, Japan, France and Italy. Her message, conveyed with inspiration and humor, tells her journey from patient to advocate & inspires others to make a difference. Dr. Cappello's tragedy of advanced breast cancer, resulting in Connecticut's landmark legislation & *the national grassroots density reporting efforts*, have been featured in broadcast & print media such as ABC, CBS, Fox, Prevention, NY Times, Wall Street Journal, & NPR. Her Blog, Nancy's Chalkboard, is published by The Huffington Post & other outlets.

The **MISSION** of Are You Dense Inc. is to educate the public about the impact of dense breast tissue on missed, delayed and advanced breast cancer.