

Volume 14 - Issue 1, 2014 - Imaging Insights

Breast Density: Why Women Need to Know

Interviewee



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Are You Dense iPhone and iPad App

http://www.areyoudense.org/worxcms_published/resources_page181.shtml

What prompted you to found “Are You Dense”?

I was diagnosed with advanced stage breast cancer in 2004, six weeks after my lab-normal mammogram. My cancer had metastasised to 13 lymph nodes. Being a very faithful patient, who never missed an appointment, had all the mammograms and ate healthy, with no risk factors that I knew of, I was shocked that my cancer was diagnosed at such a late stage. I was 51 when I was diagnosed, that was my 11th yearly mammogram. Knowing that later means a worse prognosis and tougher treatments I went back to my doctors and said, “What happened? I don’t understand this”. Each of my doctors said, “Well, Nancy, as a matter of fact, you have dense breast tissue”. I said “What? Dense tissue?” I ended up doing a literature search. What shocked and outraged me was that there was a lineage of research dating back to 1995 about the masking effect of dense tissue by mammogram, about 40% of women having it, and about added ultrasound or MRI to find cancers the mammogram miss.

I had basically a very slight chance to have my cancer found by mammogram. I had extremely dense breasts. So, what do you do with that information? I went back to my doctors and said, "Shouldn't you start telling these 40% of women just like me that come to your office and they are going to have cancer that was missed by mammogram?" and each of them said, "No, we just don't do that, we can't, it's not the standard of care". When I went back and got my reports from my radiologist that were sent to my referring doctor for 11 years, each of my reports said, "Patient has extremely dense breasts, no change from prior exam". I know my doctors did not have confidence that cancer wasn't lurking within the masking of the dense tissue.

So, working with the Connecticut legislature, we started with insurance coverage for ultrasound screening, and then when doctors still weren't telling women about their dense tissue, ended up with density reporting legislation, which finally passed after lots of drama. We passed the first legislation in the United States, and hence the density movement was formed.

Why do you think you encountered such resistance, particularly from healthcare professionals?

You may wonder why we have to have legislation, shouldn't doctors routinely tell women? Most radiologists report this issue to the referring doctor, but the only person that doesn't see it is the woman who has the dense tissue. Unfortunately, we have to use legislative means, because doctors aren't routinely telling women. The objections run from "we don't like legislation", through unfounded anxiety claims, "there's not enough science", to "mammogram is the only randomised controlled trial test".

It is very frustrating to have to work this diligently and relentlessly to get this information to patients. I was diagnosed 10 years ago, so we are getting more and more focused in understanding the issue, and more and more doctors are supporting our work, but clearly not the majority.

Is the legislation working, to your knowledge, in the 14 states that have passed a law?

In Connecticut we were the first to pass density reporting legislation, in 2009. We have 3½ years' worth of data now. I know from the research from Dr. Hooley (Hooley 2013) and also Dr. Weigert (Weigert 2012) that we are finding more cancers. Dr. Hooley reports a 70% (seventy percent) increase in invasive cancers by adding in the ultrasound. I'm hoping there are more conversations between women and their healthcare providers about the impact of dense tissue on missed cancers by mammography. I do know that our work has absolutely educated so many women and doctors too about this important issue.

Women can ask for copies of the radiologists' reports, which most likely has information about their breast tissue composition. What's the follow-up to receiving the notice that you have dense breasts, are doctors making sure that women have conversations with them? That's the tough one. There is research about those conversations, but it hasn't been published yet.

There is clearly more awareness about the issue, but still many women don't know. In the survey done by Stanford University (Dave 2012), the greater majority of women were still unaware of their own personal density, and what that means for the accuracy of their mammogram.

What would you say to radiologists in Europe about breast density and their responsibility to women?

In October 2013 I was invited to present at the European Society of Breast Imaging congress in Rome about the vast scope of our work. Clearly this crosses any border, state or country. What was remarkable to me was that there was a lot of interest from radiologists in Europe about the issue of density. Many of these radiologists are very much involved with their patients; they know their patients. It seems to be different than what happens in the United States. In Europe it appears that doctors are really hands-on, and many of them acknowledge the fact that they want to tell women about their density. They certainly know as radiologists what density looks like, and they know that they're missing some cancers. In Europe each country's breast screening programme differs, but I know that the Austrian state screening programme is going to tell women about their density, and will also offer the ultrasound to women who have extremely or heterogeneously dense breast tissue.

I would say to doctors that it's critically important that women are aware of the density of their breasts and, when they have their screening mammogram, there should be conversations about what that means, and women should know the risk and the benefit of the screening test. At the same time, physicians and radiologists need to understand the impact of density on the accuracy of the mammogram. We've known for almost two decades now that breast density is the strongest predictor of the failure of the mammogram to see through the density to find the cancer. Most women are totally unaware, and expect if they choose to have screening that if the cancer is there, it's going to be found early. That's not the case, because typically, if it's missed and missed and missed, it's only found by the time it's felt, like in my case, and you can say goodbye to early detection.

What would you advise women in Europe who perhaps have not heard about breast density?

A woman should know about breast tissue composition, whether she has fatty breasts, scattered fibroglandular tissue, or extremely dense tissue, and what it means for her personally. I would suggest that they talk to their doctors about, first of all, what is their breast tissue composition, and then have other conversations about their density, the masking of density by mammogram and also their other risk factors, if they have any.

I thought I was an educated patient and I wasn't. The sad thing is that if women don't even know what to ask, they really can't have informed conversations. If they could only depend upon what their doctor tells them, well, how would they even know about this? I would just say what

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would you want for your sister, mother, daughter or yourself, would you want this information? You can only act on information given to you. If you get this information, and you don't want to do anything about it, that's fine, but it's about informed consent and not withholding information that is very important. If this wasn't a critical risk factor, both the masking and the cause of risk, why would we have folks studying it for nearly 30 years now?

Many companies are now bringing out new tools to assist in imaging dense breast tissue. What role does industry have to play in informing radiologists and women about the issue of screening dense breasts for cancer?

We hear from doctors all the time, so a woman knows she has dense breasts, now what? First of all, a woman has the right to know, it's a basic doctrine of informed consent. Secondly, we know that hand-held ultrasound as a technology has been around for decades, and, we know that ultrasound and MRI will find more cancers certainly than mammography in women with dense breasts. We also know that there are more false positives too. One of the solutions is to find more reliable screening tools that are efficient, with increased specificity and sensitivity, and that's what's happening now.

The responsibility to inform the patient should be between the patient and the doctor through a notice, but clearly industry has a role in educating the physician about what technology they can utilise and how it could actually work in their practice.

Please tell us about the "Are You Dense" app.

It explains the issue of density and also reviews technology, including ultrasound, mammography, molecular breast imaging, tomosynthesis and automated ultrasound.

Published on : Sat, 8 Mar 2014