

Enlightening a cause

Are You Dense? organization helps women with dense breasts

BY BRYNN MANDEL REPUBLICAN-AMERICAN

Nancy Cappello wants other women to know about breasts what she did not. The suave education consultant is so adamant about letting other women know what she didn't, she willingly talks to strangers about female anatomy ad nauseam.

On her own time and dime, Cappello formed a nonprofit foundation to expose what she calls a potentially fatal secret. And with a lot of hard work and — hopefully — a famous face, the breast cancer survivor from Woodbury plans to stage a music festival locally this fall that might serve as a megaphone to raise awareness and money for her efforts.

“Certainly I did not think I’d spend the rest of my life talking about breasts,” said Cappello, sharing medical information over tea amid a Waterbury cafe’s bustle. That was before her diagnosis of advanced breast cancer. Before chemotherapy and six surgeries, including a mastectomy. And before she knew she had dense breasts — a condition present in up to 25 percent of postmenopausal women that makes cancer difficult to detect though traditional mammography. “It’s like looking for a polar bear in a snowstorm,” said Cappello, explaining how both cancer and dense breast tissue appear white in mammogram images. “Not only can’t you see it, no one’s telling anyone it’s a risk factor.” The ratio of fatty tissue to fibroglandular tissue in a woman’s chest determines her breast density.

Common in younger women, the prevalence of dense breasts decreases with age. Still, nearly a quarter of older women have dense breasts. Aside from a radiology report, there is no easy way of knowing — whether by touch, feel or appearance — that a woman has dense breasts. Not only can dense tissue hide small abnormalities, research suggests cancer manifests in women with dense breasts at a higher rate — something experts at the Mayo Clinic are trying to further explore through two recent studies. Cappello successfully lobbied lawmakers in 2006 to require insurance companies to cover whole breast ultrasound screening for women with dense breasts.

Earlier this month, Cappello trekked back to the Capitol to testify in favor of a new standard that would inform patients that they have dense breast tissue. A similar effort stalled last legislative session, but seems poised for more promising results this year. It would inform women through their routine mammograms whether they had dense breast tissue and, if so, a note that their doctor might recommend an ultrasound.

Years of routine, clean mammograms gave Cappello, a fitness junkie, a sense of security. That shattered in 2004. Weeks after receiving an “all clear” letter detailing her routine mammogram’s normal results, Cappello’s gynecologist felt a ridge in the her right breast. It turned out to be cancer, a cancer mammography did not detect. Five years later, Cappello is cancer-free. She feels grateful to be alive, but the cancer has taken a lasting toll. But she is frustrated that perhaps she might have been more vigilant with self-exams, or asked for ultrasound scans had she known what her films showed: that she had extremely dense breasts. “I’m just still shocked that I had to have a late-stage diagnosis ... There is no reason I should have had stage three cancer. But what I didn’t know, I didn’t know,” she said, holding meticulously manicured hands palms-up in a small shrug: “I feel like, who’s going to tell other women?”

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CAPPELLO: Sept. 12 concert to raise awareness of issue

Dr. Gary K. Griffin, director of breast imaging at the Charlotte Hungerford Hospital and a Torrington radiologist, routinely informs patients when mammograms show a certain degree of density. Through letters or phone calls, he informs them that it's harder to spot cancer in dense breasts through mammography and that there may be an increased risk of cancer in dense breasts. He offers these women follow up ultrasounds, and gets some takers.

Griffin began this in October 2005, explaining that he felt it important to be proactive and not leave the dissemination of this information to chance, or to busy referring physicians who might not be aware of cancer risks associated with dense breasts. Griffin cited studies that have shown a higher risk of cancer in women with dense breasts, as well as a 30 percent better chance of detecting cancer when ultrasounds are administered in addition to mammography. His practice previously averaged the detection of six cancers per 1,000 patients, he said, and doing ultrasounds upped that rate to between eight and 10 cancers per 1,000 patients. "We're not talking huge numbers here ... We're finding a few more cancers in the most dense breasts," said Griffin. Digital mammography has made it a "little easier" to see cancer in some dense breasts, but not always, said the doctor: "My philosophy is, if I can't see through it, I don't know what's living in there." There is a price for ultrasound screening, but Cappello's earlier legislative push made Connecticut the first believed state where insurers were required to cover it. Griffin dismissed critics who might say he's merely a radiologist looking to pad pockets with additional screening. "My focus is to catch as many cancers as I can, as early as I can. Obviously, better safe than sorry has a price to it, but if it were my wife or my mother ..." he said, voice trailing off.

Dr. Scott Kurtzman, a breast surgeon and Waterbury Hospital chairman of surgery, isn't sold on notifying women about what kind of breast tissue they have. "I think knowledge is always good, but I would suspect most of my patients don't know what (having dense breasts) means," he said. He does not think all women who have dense breast tissue need an ultrasound, noting that the increasing use of digital mammography allows physicians to better see what traditional mammography masked. Even as mammography misses about 10 percent of cancers, he called it still "the best screening test." Ultrasounds are time consuming, presenting an image of the breast "one-millimeter at a time," as opposed to in a larger picture at once, he said. He added ultrasounds have also increased false positives, causing more biopsies for things that proved non-cancerous. Kurtzman advocated women use their annual mammogram to trade information with their doctor: discuss and evaluate all risk factors, get a physical exam and ask that the doctor review your mammography results, since doctors receive reports that have more nuances than the typical two- or three sentence letter many women get.

To know more:

www.areyoudense.org

The daylong Are You Dense Musicfest is slated for Sept. 12, 2009 at Quassy Amusement Park in Middlebury. Planning for the benefit concert to raise awareness and funding for the new, Are You Dense? foundation is under way. Those interested in participating as volunteers, planners and sponsors may contact Cappello or her husband at nancy@areyoudense.org or jcappello@areyoudense.org, respectively.

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