

Push is on for national law similar to Connecticut breast density notification

By Liz Seegert, Conn. Health I-Team Writer

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Nancy Cappello wants all women to receive the same opportunities for breast cancer screening that women in Connecticut have had for years.

Cappello, who worked for passage of the state's 2009 breast density notification law, has taken her cause nationally — advocating for similar legislation in every state and lobbying policy-makers in Washington, D.C.

Connecticut's law — the first of its kind in the country — requires radiologists to inform women who undergo mammography if they are diagnosed with dense breast tissue, a condition known to obscure cancer detection. These “inform” reports must reference potential benefits of supplemental screening such as an MRI or ultrasound. So far, 11 states have followed Connecticut's lead by passing similar laws.

Ninety five percent of women with dense breast tissue — approximately two-thirds of premenopausal women and one-quarter of post-menopausal — don't know if they have dense breast tissue, experts say.

“They have a right to know this — it's informed decision-making,” said Cappello, a former state education official from Woodbury, breast cancer survivor and founder of Are You Dense, a breast health advocacy group.

U.S. Rep. Rosa DeLauro, a Democrat from the 3rd Congressional District, will introduce a breast density inform bill modeled on Connecticut's law in the House later this month. The U.S. Food and Drug Administration is also considering modifications to national mammography reporting guidelines to include breast density notification.

Opponents of the legislation, including some national radiologist organizations, say the law is intrusive and leads to too many false positives. However, some previously skeptical clinicians now support the policy.

In separate reviews, Dr. Regina Hooley, assistant professor of Diagnostic Radiology at Yale School of Medicine, tracked 935 women and Dr. Jean Weigert, director of mammography, Hospital of Central Connecticut, collected data on 8,000 women who received additional post-mammography screening in 2010, the year after Connecticut's law was implemented. Equivalent results showed 3.2 additional cancers per thousand detected through screening ultrasound, a rate comparable to that of mammography for women with normal tissue density. Other recently published studies had similar findings.

“I think the law is working very well. Patients understand the value of additional testing and advantages for cancer screening,” said Hooley. She said that as technicians' expertise improves, the false positive rate is decreasing.

Weigert also tracked 10,000 high-risk Connecticut women in 2011, the second year of the law. There was additional improvement in cancer detection and a decrease in false positive rates,

according to preliminary data. “We’re biopsying fewer lesions but finding more abnormalities. It’s working,” she said.

Hooley is now analyzing year three data from 2012, comparing ultrasound results of 1,046 women from her practice at the Smilow Breast Cancer Center with tomosynthesis — 3D mammography images. “We’re looking at our data and it looks like both screening ultrasound and tomosynthesis can pick up additional cancers compared to conventional mammography alone,” she said. Her study will be published in mid-2014.

The law has prompted women and physicians to discuss supplemental screening, said Cappello. “It doesn’t matter how the cancer is found, as long as it’s found early.”

Still, not all providers think the law is necessary. “I think we’re opening a Pandora’s box,” said Dr. Mary Pronovost, a breast surgeon and medical director of the Norma F. Pfriem Breast Care Center at Bridgeport Hospital.

“While we’re finding a few more cancers, there’s no definitive data that says we’re saving more lives.” She said that available research doesn’t justify the increased number of biopsies performed; nor should advocates at the state level be directing medical policy.

Dr. David Gruen, director of Women’s Imaging and co-director of the Women’s Breast Center at Stamford Hospital, said notifying women is not a bad thing. “There’s always push back to change. We’ve seen some real success, with fewer false positives after a year of tracking. It works.”

Despite regular annual mammograms with “normal” reports, Cappello’s cancer was not caught until stage III. That was when she learned about breast density, and that breast ultrasound likely would have found the disease sooner.

“I was outraged that women were not being told about something that could save their lives,” she said.

After several years of intense lobbying, former Gov. M. Jodi Rell, herself a breast cancer survivor, signed the notification bill into law in 2009.

Some state radiology groups initially opposed the mandate. “There was almost no data to go on,” said Weigert. “Many of us thought that the rate of false positives and potential for unnecessary biopsies was too great.”

Cappello argued that patients should know about all their options, including the 40 percent of mammography-age women with dense breasts. “Women need to have this conversation with their doctors. They need to know how important this test is.”

State efforts are vital, but national legislation would standardize language and make requirements less ambiguous, according to Cappello. “On the other hand, passing a national law is very challenging and there’s a risk of the bill being watered down,” she said.

In a statement, DeLauro said, “By providing this important piece of information, we can identify women who are at higher risk for developing breast cancer— and help to improve their chances for early detection and survival. As a survivor of ovarian cancer, who is only here today because my cancer was caught early, I know how important it is to be aware of your risks. Increased awareness

means earlier detection, and that means more women will have a fighting chance against this terrible disease.”

Including breast tissue density information in the FDA Mammography Quality Standards Act would provide the necessary strong universal reporting and language guidelines, said Cappello.

Six states — Massachusetts, New Jersey, Pennsylvania, Michigan, Ohio, and Indiana have introduced density inform bills. Eight others are drafting legislation. Cappello said she would attend as many state hearings as possible, armed with the latest data that shows Connecticut’s law works.

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