



# MIKE ROHRKASTE

STATE REPRESENTATIVE • 55<sup>TH</sup> ASSEMBLY DISTRICT

## Assembly Bill 653

Relating to: requiring facilities that perform mammography examinations to provide notice to certain patients regarding dense breast tissue and granting rule-making authority.

Testimony of State Representative Mike Rohrkaste

Assembly Committee on Mental Health

December 13, 2017

Thank you, Chair Sanfelippo and members of the Assembly Committee on Health, for holding this public hearing.

As many of you are aware, breast cancer impacts millions of people across the country and thousands of our fellow Wisconsinites each year. Breast cancer is also the most commonly diagnosed cancer in women. In fact, one in eight women in the U.S. will be diagnosed with breast cancer in their lifetime, and it is estimated that over 250,000 American women are diagnosed with breast cancer each year.

Early detection, prevention, and awareness are incredibly important when it comes to diagnosing breast cancer. One obstacle to early detection is dense breast tissue, which can make it harder to detect tumors in a mammogram and is itself a risk factor. This combination is problematic because approximately 40% of women have dense breast tissue. Because of the higher risk factor and more difficult detectability, it is very important to provide women with the information they need concerning their health.

Assembly Bill 653 seeks to provide women with the information they need regarding dense breast tissue. The legislation requires facilities that perform mammograms to provide a notice to women regarding dense breast tissue if they have heterogeneously or extremely dense breast tissue. The notification would be provided on a federally-mandated summary of mammography results which is already sent to women after their mammogram. The goal of the notification is to raise women's awareness regarding breast density and to ensure they have the information necessary to discuss their breast health with health-care providers. Currently, 31 states require some form of reporting to women regarding breast density, and several more are considering legislation.

Thank you for your time and I encourage members of the committee to support Assembly Bill 653.

# Alberta Darling

## Wisconsin State Senator

Co-Chair, Joint Committee on Finance

Testimony before the Assembly Committee on Health  
Assembly Bill 653  
Wednesday, December 13

Thank you Chair Sanfelippo and committee members for holding a public hearing on Assembly Bill 653. This important piece of legislation requires facilities that perform mammograms to provide patients who exhibit dense breast tissue with a breast density notification.

Breast cancer is the most common cancer among women in the US. In fact, it is the 2<sup>nd</sup> leading cause of cancer death in women in the US. In Wisconsin, the Department of Health Services estimated that 4,730 women would be diagnosed with invasive breast cancer in 2016. One risk factor for breast cancer is the presence of dense breast tissue.

Breast density is determined by a mammogram. Breast density is described in one of four categories, ranging from fatty to extremely dense tissue. Nearly 40% of women have dense breast tissue. While dense breast tissue is a normal test result of a mammogram, women with extremely dense tissue are 4 to 6 times more likely to be at risk for breast cancer.

Not only are women with dense breast tissue at higher risk for breast cancer, but the dense tissue actually can hide existing cancers on a mammogram. Much like masses and lumps, dense tissue appears white on a mammogram. Due to this appearance, suspicious lumps may be masked by dense breast tissue and go unnoticed on a mammogram. In these instances, a woman's cancer can progress undetected despite regular mammograms.

Assembly Bill 653 requires facilities who perform mammograms to provide information regarding dense breast tissue to women with dense breast tissue. The statement provides statistics about dense tissue and recommends that the patient discuss the results with their health care professional to further discuss the patient's risk and other potential screening options. Facilities are already required to provide patients with information after their mammogram, and Assembly Bill 653 simply adds a breast density notification for applicable women.

This bill is crucial to ensuring that women in Wisconsin have accurate information about the results of their mammograms. Early detection is key to treating breast cancer, and this bill will help women with dense tissue detect cancer faster. In passing this legislation, Wisconsin will join 30 other states who have instituted a breast density notification.

I'd like to thank Representative Rohrkaste for his leadership on this issue. I would also like to thank the many brave cancer survivors who have shared their stories and reached out in support of this bill. I urge your support on Assembly Bill 653.

**Written Testimony of State Senator Lena C. Taylor**  
**Assembly Committee on Health**  
**Public Hearing RE: AB 653**  
**December 13, 2017**

Chairman Sanfelippo, Vice Chair Bernier, and members of the Assembly Committee on Health, thank you for allowing me the opportunity to submit written testimony for Assembly Bill 653, relating to requiring facilities that perform mammography examinations to provide notice to certain patients regarding dense breast tissue and granting rule-making authority.

In the spring of 2015, Congresswoman Gwen Moore reached out to my office regarding the need for state legislative action in providing information to mammography patients around the issue of breast density. Breast density, which refers to the ratio of fatty tissue to glandular tissue on a mammogram, places women at an increased risk of breast cancer and possible later diagnosis because it is more difficult to accurately read mammography results of women with increased breast density.

Personally impacted, Moore was interested in making sure that Wisconsin women were receiving the best available information during their mammograms. With the goal of helping both doctors and patients respond to results that found "dense" breast tissue and in particular understanding that breast density was found to be higher in African-American/black women, I drafted legislation in June 2015 requiring mammography facilities to report breast density information to patients.

To my surprise, I was contacted by Wisconsin breast cancer and women's health advocacy groups who believed that the Breast Density Notification law should be placed on hold. Stating at the time that they felt there was not enough data to "improve the understanding of breast cancer risk, the limitations of mammography as a screening test, and the diagnosis or patient outcomes" or that additional testing might not prove any better for women, I reluctantly relented to their request. I will never know if that was the best decision at the time, given that by April 2015, 22 states have already enacted breast density notification laws. Today there are 31 states, but according to [breast360.org](http://breast360.org), only 4 states have laws requiring insurance coverage for additional imaging for women with this condition.

I am pleased that legislators on both side of the aisle, are at the table on this critical issue impacting the health of Wisconsin residents. Although mammography remains one of our most effective tools for screening for breast cancer, we know that there are women who require additional measures to assist more accurate testing. AB 653 brings us in line with the majority of other states who make this notification available to women and can lead to better informed healthcare decisions and outcomes. I encourage your support for this proposed legislation.

Senator Lena C. Taylor  
4<sup>th</sup> Senate District



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IRB00003490 approved 4/28/2016

## Assembly Bill 653

The testimony of Michele Goodweiler MSHSA RTR (MR) (QM) relating to: requiring facilities that perform mammography examinations to provide notice to certain patients regarding dense breast tissue and granting rule-making authority.

I would like to thank the Assembly Committee on Health for their time today and holding this public hearing today.

I am very passionate about this topic and thankful that my voice can be heard in this setting. I would also like to thank Gail for sharing her touching story.

I will make this brief so that I can allow time for questions from the audience. I will pass out some educational materials about the different density categories. (General physics provided here).

Over the last year, I have been researching dense breast tissue in a breast center. As a part of data collection, we ask them if they knew if they had breast dense tissue and how anxious they are about having dense breast tissue.

- A 75% of women do not know they are dense. Across the State of Wisconsin, many breast centers offer 3d mammograms to women with dense breast and their annual screening appointment. All too often, people decline the 3d mammo since they do not know sensitivity of mammo is lowered in areas of dense fibro glandular tissue.
- What is more concerning is when they know have dense tissue; they are not at all concerned or anxious. They saw that their mammograms have always been "normal". After hearing about Gail's story, it is important to know that normal may be not necessary be normal.
- I believe that this bill will allow the women of Wisconsin make informed health care decisions about their breast health.
- I thank you for your consideration and possible support on this bill.

**Breast Density Notification Bill (LRB-3518)**

**December 13, 2017**

**Testimony of Anne M. Zellner**

Thank you for being here today to discuss this important issue and hear our stories.

My name is Anne Zellner and I'm a resident of Wauwatosa, Wisconsin.

My story began just over two years ago, when I felt a lump in my right breast. I saw my doctor on November 11, 2015, and she immediately sent me for imaging. After an ultrasound, the radiologist recommended a biopsy, which was done a few days later, and shortly thereafter I received my diagnosis - a phone call while at work. I had invasive lobular carcinoma. An MRI and more biopsies eventually revealed not one, but two tumors in my breast and cancer in my lymph nodes. Just like that, at age 50, I had Stage 3 breast cancer.

The surgery to remove my cancer was on December 15. Of the 20 lymph nodes removed, 6 had cancer - a very high number according to my surgeon, a specialist in surgical oncology and breast surgery.

At the same time, I underwent step one of breast reconstruction and had an expander implanted. I was able to start walking after a couple of weeks, and was diligent in getting in at least 10,000 steps everyday, and began physical therapy to regain range of motion in my right arm.

Because my lymph nodes were involved, it was important to begin chemotherapy as soon as possible, and I had four rounds of chemotherapy during January, February and March.

In April I had another procedure to complete breast reconstruction - removing the expander and placing an implant. My ovaries were also removed, as my cancer was estrogen positive.

After healing from that procedure, and having completed months of physical therapy to be able to lay with my right arm high over my head, I began 38 rounds of radiation treatment. By mid-July my radiation treatment was complete.

When all of this happened I was fortunate to have been in otherwise good health. A lifelong runner, 10 year member of a masters swim team, and triathlete, I'd been careful to make wise choices for my health and well being. My primary care physician always said I'd live forever, I was the model patient he said. My sister, a nurse practitioner, urged me to get a baseline mammogram at age 35, and at age 40 I began getting annual mammograms. Genetic testing showed no mutations indicating a genetic cause for my cancer.

I've learned that this is not unusual. More than half of all women who develop breast cancer have no known risk factors other than being female and aging. The risk for developing breast cancer is influenced by many factors, and there is currently no reliable means for fully accounting for the interplay of these factors in determining overall risk.<sup>1</sup>

So my diagnosis was shocking, both for me and for all who knew me. I had never missed a mammogram, and had had a 'clear' mammogram just four months before my diagnosis. Significantly, I was told that mine was a slow-growing type of cancer. So my cancer must have been present for some time, not seen in the imaging I had been so dutiful to undergo every year.

I now know that 40% of women over age 40 have dense breasts, myself included, and that 95% of them don't know it – myself also included. My doctors knew, the radiologists knew, but I didn't know. Withholding that information denied me the right to make an informed decision about my own health. I also now know that for women with dense breasts, different types of imaging may be more appropriate, and women with dense breasts are more likely to develop breast cancer.

Women in Wisconsin deserve to be given information about their breast density and the implications of breast density; they deserve to have equal access to early detection of cancer – which is what we're talking about here, to be able to have a conversation with their care providers regarding their body makeup, their risk factors, the types of imaging available... so that they can make an informed choice regarding the type of imaging they receive.

Women know about, and in some cases, can impact, other risk factors for breast cancer, such as lifestyle choices and heredity. But breast density, which has a more significant risk factor associated with it, is the one thing others know, but the patient does not. Without this

information, the patient has no power to choose whether to pursue a different type of imaging, based upon her risk factors.

To make matters worse, studies confirm that high breast density is in itself an risk factor for developing breast cancer.<sup>2</sup> Seventy-one percent of all breast cancers occur in women with dense breasts.<sup>3</sup> And, the data shows that mammography misses as many as half of the cancers in women with dense breasts.<sup>4</sup>

What this means is that the women who are most likely to get breast cancer (those with dense breasts) are also the women whose cancer is most likely to be missed on a mammogram.

To quote a study published in the American Journal of Roentgenology, women with dense breasts have the perfect storm: decreased mammographic sensitivity and increased risk of breast cancer.<sup>5</sup>

There is good news, however. In addition to mammography, other types of screening tests substantially increase detection of early stage breast cancers in dense breasts. Ultrasound, Tomosynthesis and MRI, for example, have been available for years and have been shown to improve cancer detection in women with dense breasts.<sup>6</sup> So we have the means to detect breast cancer earlier and reduce morbidity and mortality rates in women with dense breasts, with no new medical breakthroughs or inventions! By informing women who have dense breasts, they will have the opportunity to choose different imaging modalities that have a higher likelihood of finding cancer at an earlier stage, greatly improving survival outcomes.<sup>7</sup>

In addition to these compelling reasons to inform women with dense breasts, earlier detection can impact treatment cost. We are all familiar with statistics on the rising costs of healthcare – health spending in the U.S. is expected to grow at a rate of 5.6% per year between now and 2025, a rate higher than the GDP.<sup>8</sup> Studies show that treatment costs are significantly higher for advanced-stage breast cancer than for early-stage disease.<sup>9</sup> These findings strongly suggest that earlier detection of breast cancer... leads not only to reduced morbidity and mortality, but also to lower treatment costs. This fact supports pursuing actions that can shift breast cancer diagnosis to earlier stages.<sup>10</sup>



So today I'm asking you to support the Breast Density Notification bill to ensure that the 40% of Wisconsin women – wives, daughters, mothers, neighbors - with dense breasts have equal access to early detection of breast cancer, to improve survival rates, and to reduce the costs associated with cancer treatment.

You know, as I've talked to people about this issue, and shared with them our hope that this notification legislation gets approved, they've applauded me for choosing to get involved in this. But I have to tell you what I tell them, this is not a choice for me. And I think I can speak for others here, every time I hear of another story like mine or Gail's, I feel a sense of responsibility. Our stories did not need to happen. This was completely preventable. I would give anything for a Stage 1 diagnosis rather than Stage 3. We can make that a reality and save other women from going through what we've been through simply by arming them with information about their breast density.

Thank you again for your time, for listening to my story and for your thoughtful consideration of this important bill.

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Assembly Bill 653

Relating to: Requiring facilities that perform mammography examinations to provide notice to certain patients regarding dense breast tissue and granting rule-making authority.

Testimony of Gail Zeamer  
Assembly Committee on Health  
December 13th, 2017

Thank you, Chair Sanfelippo and members of the Assembly Committee on Health, for holding this public hearing on Assembly Bill 653.

My name is Gail Zeamer, and I am a resident of Neenah, Wisconsin. I have always been proactive in my healthcare. My healthcare provider informed me that as I get older, having a mammogram every year, plus a clinic visit spaced out within the year would ensure that my breasts were being examined every 6 months. This seemed like a great plan in theory. Nothing could possibly be missed if someone was checking me for anything unusual twice per year, right? As it turns out, there was an enormous piece missing in my preventative care, and I wish, more than anything, that I could go back in time and change it. That missing piece was the fact that I had never been informed that I had dense breasts.

On February 2, 2016, at the age of 47, I answered a phone call that forever changed my life. It was a phone call from my doctor informing me that I had Stage 3 Invasive Ductal Carcinoma. I had breast cancer. Just 7 days earlier, I had a 3D mammogram, which did not detect any abnormality in my breast. Nothing. NO tumor showed using the BEST technology that we currently have to detect breast cancer. It did show an enlarged lymph node on the left side, however, and so for the FIRST time, I was offered a breast ultrasound. 3D mammography is widely available in breast screening centers in Wisconsin. It is currently the Gold Standard for screening and diagnosing breast abnormalities. However, even this 3D mammogram missed my tumor, which was nearly 4 cm in size. I could feel it, but it never showed up on these diagnostic tests. The cancer was not detected until it had moved to my lymph nodes. Later, halfway through my cancer treatment, I would finally be told by a radiologist that finding my tumor was like "finding a polar bear in a snowstorm". You see, dense breasts show up as white on a regular or 3D mammogram, and so do tumors. It was, quite frankly, impossible to see my tumor, without an ultrasound or breast MRI. Once I was diagnosed, I received life-saving treatment in the form of 6 rounds of intense chemotherapy, a double mastectomy, three reconstructive surgeries, 30 rounds of radiation, and additional targeted chemotherapy for 1 year. I am also currently taking a daily course of medication to attempt to keep the cancer away, for the next 5 or possibly more years.

As I was receiving treatment, I read everything I could about breast cancer, and I began to wonder why, with all the preventative mammograms I received in the past, did my cancerous tumor get missed? It turns out, everyone knew about my dense breasts: my doctors, the radiologist, the breast diagnostic clinic. Everyone knew, but ME. My breast density information was hidden deep in my medical records, which is difficult to access as a patient, and nearly impossible to read. I was unable to ask the right questions, get a second opinion, or advocate for myself because I simply DID NOT KNOW THAT BREAST DENSITY WAS A RISK FACTOR FOR BREAST CANCER. I was unaware that I had dense breasts and I was unaware of how they affected my risk of getting breast cancer. And that is why I am here. Let me explain

what dense breasts are and how important it is for every woman to understand her density, and more importantly, be notified when she is determined to have dense breasts.

Nearly 40% of women have dense breasts. This is a normal occurrence. Higher breast density is common in women under 50. Some breasts have more fatty tissue, which show up dark on a mammogram. The rest of us have either heterogeneously dense or extremely dense breasts, based on traditional BiRads classifications consistently used by radiologists. This tissue shows up as white on a mammogram. Dense breasts are correlated with a higher risk of breast cancer. The reason for this is not yet known, but recent research has now determined that dense breasts are an important risk factor, surpassing family history and genetic disposition. Women with dense breasts are often diagnosed with later stage cancer because it is so difficult to detect the cancer early. In addition, our outcomes and survivorship are poorer. For many women with dense breasts, even a 3D mammogram is simple NOT ENOUGH. In my case, a simple ultrasound 18 months earlier, when I first felt a lump, would have detected my cancerous tumor at an EARLIER STAGE, with less rigorous treatment, and ultimately, less burden on my insurance company for the hundreds of thousands of dollars it took to save my life. Women in Wisconsin are NOT routinely informed of their breast density, nor are we allowed EQUAL access to breast density information to make informed, educated choices about our breast health. Not every woman with dense breasts needs additional screening procedures, but information is POWERFUL, and the best decisions are made when we are fully INFORMED. This is why I am asking you to please support this very important breast density notification legislation, which allows women with dense breasts to be fully informed about their breast health and their risk factor for breast cancer. Currently, there are 31 states that have breast density notification laws helping women be advocates of their healthcare. These states include our Midwest neighbors Michigan, Minnesota, Iowa and Ohio. The women of Wisconsin also deserve to be notified at the point of their mammogram about their breast density, so that we can make INFORMED, EDUCATED decisions about our health care needs. I feel it is important to clarify that the legislation does NOT mandate additional screening, or impose additional screenings, but rather brings awareness to a woman, so that she can consult with her health care provider about what, if any, additional screening may be needed. Notification would open up the discussion between women and their healthcare providers. I dream of a day when women enter a breast screening facility, and ask "what is my breast density?" as routinely as we now ask "what is my blood pressure?" Breast density notification will surely lead to earlier diagnoses, lower treatment costs, and most importantly, more lives saved!

Thank you, sincerely, for listening to the story of my personal cancer journey, and for your time and attention to this most important legislation for the women of Wisconsin.