

***Access to Breast Cancer Diagnosis Act***

***HB 7737/SB 2070***

***Written Testimony Supporting Submitted to the Committee on  
House Health and Human Services***

***By***

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***March 19, 2024***

Thank you for the opportunity to provide testimony in support of HB 7737/SB 2070, an act to implement and improve breast cancer equity and early detection.

As stories begin, my story began in 2018, when my sister was diagnosed with extensive Stage 3 breast cancer. We didn't have any family history of breast cancer or the BRCA gene so we were all pretty shocked. I tried to be proactive and began following up by a top breast surgeon since I had breast dense tissue. We established a plan of having a mammogram or a breast ultrasound every 6 months. Both of these imaging exams would require out of pocket expenses, but I was out of work. I was able to get Medicaid to cover all of my breast imaging expenses in full. I was one of the fortunate patients since I didn't have a co-sharing amount or deductible, although it also limited where I could be seen.

It would be an understatement to say that in 2019, my life would be turned upside down. Four months after burying my best friend of 32 years to cancer and the day after visiting her grave, I had this uneasy feeling in my gut, as if it was trying to warn me of something. I chalked it up to grief, and I made an appointment that week for my mammogram. I was only a few weeks late, but I assumed I was safe. After all, I had just had a normal breast ultrasound 6 months prior. I forgot about the results and returned to life until I received a letter in the mail two weeks later, stating I had to return to explore some calcifications found on my diagnostic mammogram ASAP. I didn't even know what calcifications were, nevertheless, that calcifications could coincide with breast cancer. I set up a bilateral biopsy, and on October 31, 2019, I was diagnosed with early stage breast cancer. It was indeed the worst Halloween fright I have ever received.

My procedures and treatment were also during the peak of COVID so I had to face everything alone, due to the lockdown. I had to undergo a partial mastectomy and total

hysterectomy with an oophorectomy (to shut down my estrogen production) just three weeks apart. I was totally devastated. My dreams of becoming a mother were sadly taken from me, due to breast cancer. After giving me a month to recover, I had to undergo daily radiation for 6 weeks, Each day, I had to find transportation, pay for it, and each day required a separate copayment. That was 5 co-payments per week. I was fortunate since I was one of only 25% Rhode Islanders who was on Medicaid, due to the expansion, with COVID, I would not have been able to afford the imaging or treatment otherwise. My heart breaks for those 75 percent with private insurance who literally were putting imaging and treatments on credit cards, just to have a chance to survive.

At one point, I remember laying in preop, crying behind my mask all alone. My amazing breast surgeon held my hand, reassured me that I was going to be ok., and personally wheeled me into the OR. Then more challenges began. Finally, I was cancerfree after a long 7 months. What most don't realize is that all breast cancer patients must have surveillance diagnostic mammograms, to ensure their cancer hasn't come back. Diagnostic mammograms are not covered under ACA so out of pocket expenses is needed for all cancer patients.

.I have gone through many scares. Just last May, the unpredictable happened. A GI test showed lesions on my back, and the thought of my cancer being back crushed me. I had to go for another breast ultrasound where a mass was found. I had to immediately have a follow up diagnostic mammogram, which turned into four diagnostic mammograms and two breast ultrasounds within one year. If I was one of the 75% Rhode Islanders with private insurance, I would have paid thousands of dollars that I didn't have. There are many women who can't afford this and must choose between getting a cancer diagnosis or feeding their children. My own radiologist pays for an insurance plan with a \$10,000 deductible so she ultimately pays for all her medical care.

Along with the overwhelming financial burden, there is also a horrific emotional toll each time you have imaging, You start profusely sweating, your heart is pounding and feels like it's going to explode out of your chest, you start visualizing the treatment memories, until a radiologist gives you your results. Even in just four minutes, it feels like an entire lifetime as you sit alone, waiting for the radiologist to enter the door. Why are we putting Rhode Islanders through these financial and emotional burdens where there are better ways; ways that save more lives?

According to the CDC, in the years 2016-2020, RI had one of the highest rates of new breast cancer cases per 100,000 people in the entire country, at 139.9 new cases per 100,000 people. We know that mammography screening doesn't prevent cancer, but it finds cancer in combination of other imaging. Supplemental imaging is needed if we want to find breast cancer at the earliest stage. An estimated 12-16 percent of women

screened are called back. If we eliminated out of pocket costs for diagnostic and supplemental imaging, it would improve access and likely improve cancer detection at an earlier stage. We know that an average tumor can double in size every 6 months, We can't afford patients to delay imaging. It is estimated that, in 2024, more than 1,090 individuals will be diagnosed with breast cancer and more than 120 will die in Rhode Island alone.

We encourage legislators to support HB 7737/SB 2070, which increases access to medically necessary diagnostic and supplemental breast imaging by eliminating burdensome patient cost sharing. It will be a win-win situation for both individuals and insurance companies. There will be an increase in earlier staged cancers and a significant decrease in advanced stage cancers. Insurance companies would save money on mastectomies, chemotherapy, palliative care, and hospice care.

Currently, Senator Whitehouse is supporting and co-sponsoring this bill at a national level. Twenty states have already passed this legislation, and twenty more states have pending legislation. Rhode Islanders deserve this legislation so we can save so many more lives. No one should have to go broke trying to survive this horrific disease.

I have spoken to many patients, oncologists, breast surgeons, radiologists, members of the Department of Health, and Rhode Island residents. Not one person objected to this bill, and everyone believed it would have a major impact on the lives of Rhode Islanders and cancer patients, My own breast surgeon passed away from this same illness. Her last words to me were to stay determined, be her voice, and stay proactive. We need this legislation passed desperately. So today I stand here, not only as all of our voices, but I stand here for Dr. Marlene Cutitar who believed in RI so passionately. Finally, I stand here as RI's Susan G. Komen Advocate, and a four year breast cancer survivor. Thank you for listening to my testimony and considering this important legislation.