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Rep. Robin Weisz, Chairman
ND Human Services Committee
2639 First Street SE
Hurdsfield, ND 58451-9029

RE: House Bill No. 1370 – Mammography Result Notices

Dear Rep. Weisz:

Thank you for allowing me to testify at the hearing on House Bill No. 1370 on Wednesday, Jan. 28, 2015. My name is Cynthia J. Eggl and I reside in Fargo, ND. I am the author of a book entitled, "Boundless Blessings and God's Grace: My Journey through Breast Cancer." I am testifying in support of the proposed North Dakota legislation. 21 states in the U.S., including North Dakota's border state Minnesota, have legislated density reporting to women, starting in Connecticut in 2009 - a testament that there is no shortage of women harmed by their dense breast tissue with missed, delayed and late stage breast cancer.

I want to share my personal experience with you. I completed monthly self-breast exams, a baseline mammogram at age 35, annual mammograms starting at age 40, and annual physicals, all with no indication of breast cancer – all my exams and reports were "normal." From January, 2011 to April, 2011, I experienced excruciating breast pain in my lower left breast which radiated out under my left arm. The pain finally forced me to my doctor's office on April 5th, 2011 for an exam.

On that day, a physician's assistant at Sanford SouthPointe Family Practice completed my exam and marked three areas of concern on or near my left breast which she felt needed to have further testing. She left the exam room, returning about 10 minutes later to tell me I was not going back to work that day, and that I was to proceed immediately to the Breast Imaging Clinic at downtown Sanford Clinic. She indicated the staff at the Breast Imaging Clinic would be working me into their schedule for a breast ultrasound. I remember thinking to myself that I should not be afraid because I had done everything I possibly could to try to catch potential breast cancer at its earliest stage.

Three hours after I arrived at the Breast Imaging Clinic, I was called back for the test. It took the technician about 20 minutes to complete my breast ultrasound. She indicated she would be showing the scans to Dr. Janine Carson, the Radiologist on call at the Breast Imaging Clinic, to see if there was anything further she needed to see before letting me leave the clinic. About 10 minutes later, both the technician and Dr. Carson came back in the room. Dr. Carson stood by my bed and said, "Cynthia, looking at your breast scans is like looking through mud. Your breast tissue is so dense, I cannot see what I am looking for on the scans." She indicated she was in the room to help guide the technician as they did a second breast ultrasound. Following the second ultrasound, she turned back to me and said, "We need to schedule three needle biopsies as soon as possible." I got dressed and proceeded to the scheduling office, where I made appointments for my biopsies the following Monday.

I endured three needle biopsies on April 11, 2011. Dr. Carson indicated I should know my biopsy results in the next day or two. The following day, April 12, 2011, at 2:30 p.m., Dr. Carson called to confirm I had breast cancer in all three of the biopsied locations. She told me I had ½ hour to call my family and my

employer, and then I needed to be off the phone so I could receive a call from the Sanford Roger Maris Cancer Center regarding appointments they were already scheduling with a medical oncologist, radiation oncologist, a breast surgeon, and for other tests. I have survived a 9+ month breast cancer battle.

Breast cancer doesn't run in my family – I'm the first to be diagnosed with this disease. I was stunned to learn I had Stage 2b breast cancer which had moved into my lymphatic system. Several of my physicians told me my breast cancer had most likely been growing undetected for a period of 2-4 years.

I also discovered additional information regarding dense breast tissue after my journal was published as a book in December, 2012. From the www.areyoudense.org website, I learned that nearly half of our population worldwide has dense breast tissue. Two-thirds of women pre-menopausal and one-third of the women post-menopausal have dense breast tissue. Breast density is one of the strongest predictors of the failure of mammography screening to detect cancer. If you have dense breast tissue, there is a much greater risk of having breast cancer which will go undetected, even within months of undergoing a normal mammogram. Knowledge about your breast tissue composition is an important part of your breast health records. The more "dense" tissue a woman has, the higher the chance that cancer might be missed and that cancer might develop in the first place. While mammogram detects 98% of cancers in women with fatty breasts, it finds ONLY 48% in women with the densest breasts. Cancer turns up 5 times more often in women with extremely dense breasts than those with the most fatty tissue.

Dense breast tissue is comprised of less fat and more connective tissue which appears white on a mammogram. Cancer also appears white on a mammogram thus tumors are often hidden behind the dense tissue. As a woman ages, her breasts usually become more fatty. A radiologist determines the density of a woman's breasts by examining a mammogram.

I use every opportunity to encourage women to request a copy of their mammography report from their doctor - to make sure it is the report that is generated from the radiologist and not a form letter. I ask them to read the report carefully, looking for descriptions of their breast tissue. If they do have dense breast tissue, I strongly encourage them to talk to their doctor about having a breast ultrasound, breast MRI, 3-D imaging or whatever additional testing options that may be available to them to find potential breast cancer at its earliest stage.

I have gained knowledge about the risks associated with dense breast tissue while battling for my life after no one told me about my dense breast tissue. Knowing would have afforded me a chance to find my breast cancer at an earlier stage by undergoing additional testing. I know personally how profoundly my breast cancer battle has affected my quality of life for the long-term.

Prior to my breast cancer battle, I was diagnosed with Hashimoto's Disease, an autoimmune disease of the thyroid, which in and of itself, is difficult to manage. Following a double lumpectomy, removal of 9 lymph nodes from beneath my left arm, 16 chemotherapy treatments using three different chemotherapy drugs, and 33 radiation treatments, I have now been diagnosed with a total of five (5) autoimmune diseases – Hashimoto's Disease, Rheumatoid Arthritis, Fibromyalgia, Pre-Diabetes bordering on full blown Diabetes, and a rare autoimmune disease of the skin recently diagnosed by The Mayo Clinic.

Additionally I have peripheral neuropathy (nerve damage) which has affected my ability to drive – I have driven only three times in the past year because of disorientation and dizziness. I cannot feel the bottom of my feet and my little toes are numb. I cannot sit in a darkened room because it feels like I am going to fall right out of my chair. I have lymph edema throughout my left breast, degeneration of bones in my knees, feet, and shoulders, severe disabling muscle spasms, and swollen ankles if I sit for periods longer than several hours. My fatigue is overwhelming and I have overall body aches each day. Because I have a suppressed immune system following my formal breast cancer treatments, there are limitations to what type of prescribed drugs I can use to help manage my autoimmune diseases and other health issues. I

make each day that I have been granted the best it can be, regardless of my health issues, because I am quite simply grateful to be alive. Prior to my breast cancer diagnosis, I was working 50-60 hour work weeks for Dakota Medical and Impact Foundations as the Executive Assistant to the President, boards, committees and members. I was also managing a home-based business and teaching private voice lessons, where I drove to the homes of my voice students for their lessons.

During my 9+ months of formal breast cancer treatments, surgery, and for one year following those treatments, I worked 40-hour work weeks for my employer. On January 9, 2013, I filed for personal long-term disability, and was forced by our private insurance carrier to file for Social Security Disability Insurance (SSDI) so they could offset their payments to me. After being denied twice by SSDI in a written application and an appeal, I appeared at a formal hearing in front of an Administrative Law Judge on Sept. 13, 2013. Five days later, Sept. 18, 2013, the judge ruled I was permanently disabled for a period of 5-7 years.

My physical health has been diminished, but my mental health, thank God, has remained intact. I was encouraged by many people and finally published my personal journal written while I underwent my formal treatments and recovered from my breast cancer battle into a book entitled, "Boundless Blessings and God's Grace: My Journey through Breast Cancer" by Cynthia J. Eggl. My book is available worldwide, and is a positive, uplifting journal from my perspective as a patient, encouraging others should they ever be diagnosed with cancer or another challenging medical condition. I promised myself that I would make the path for individuals diagnosed with breast cancer in the future smoother than my journey.

This legislation, through education alone, could help save lives, save trauma to future breast cancer patients, and could save millions of healthcare dollars because breast cancer is diagnosed at its earliest stage. Passing this legislation and having it signed into law will be the most important thing I do in my life to positively impact others.

I have felt a sense of betrayal being diagnosed with a later stage breast cancer following 12 years of supposed "normal" mammograms and yearly exams by my family physician. It is especially troubling knowing that some of the very medical doctors who purport to have the best interests of their patients in mind, who fail to disclose that your dense breast tissue could prevent your mammogram from finding your breast cancer situation at its earliest stage, and who fail to even discuss additional testing with you, are the same physicians who think that how they are fulfilling their medical oaths today is perfectly fine when it comes to this medical issue.

Beyond my personal goal of wanting to do better for future patients lies my hope that North Dakota's legislators would have the best interests of their constituents at heart - affording them every opportunity to survive a breast cancer battle. Since we do not have a cure for breast cancer, the most obvious way we can affect breast cancer's grip is to find it at its earliest stage. But that is not possible unless your medical doctor discloses to you that your breast tissue is dense and the associated risks of dense breast tissue. Education and additional testing are key, and you could help affect change and educate North Dakotans through this specific legislation. I ask for your support in recommending passage of House Bill No. 1370 so that it can be signed into law in North Dakota as soon as possible. Thank you!

Sincerely,



Cynthia J. Eggl

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