## Dear Friend,

I am so very lucky to be alive to write to you today and I apologize if you have heard my story before. But I am a twenty-eight year educator and have never been so passionate about teaching a lesson as I am about my personal lesson in breast density. I have attached a photo of me in Butte Falls this winter so that you can place a name with a face. Here's my story!

My doctors failed to inform me of my breast density during ANY of the thirteen years that I had mammograms (which were all reports with a two-line "happy letter" stating that my breasts were NORMAL). Had I been informed of my breast density, I would have quickly paid out-of-pocket for an ultrasound is necessary, as I have heard medical professionals state that the combination of mammography and ultrasound is 96-98% in regard to early detection. Just prior to my 49th birthday, I was diagnosed with invasive cancer in both breasts, one tumor being 6.5 cm. long (nearly three inches) which been inhabiting my body for eight to ten years. I was (lymph) node-negative, but my story is not yet finished which is why I can not stand before you today, as I so wish that I could.

I was invited by Senator Dingfelder to testify, but unfortunately my daily trips to the Ashland Wound Clinic and hyperbaric oxygen chamber to heal a horrific undermining radiation wound (where first my breast then various implants once resided) do not allow me to travel. But I will be there in spirit, if you will. If you'd like to talk about my story, please feel free to call me at <u>541-878-3315</u> or cell <u>650-868-0160</u>. I will be home from the clinic by 1:30 each day. If it will serve your purposes at all, I am happy to meet with any member of the press at Ashland Community Hospital. I am certainly well enough to talk to you or any member of the press and will do anything to spare other women a replica of the last sixteen months of my life and with that being said- I am lucky to be alive. So I speak for my fallen sisters as well. Thank you, in advance, for your support of this lifesaving bill for the women of Oregon. Feel free to visit me at caringbridge/kathy parara or "like' my Facebook pages Know Your Own Breast Density KYOBD and Survivor Sisters. Thank you, Kathy Parara 205 Rene Drive, Shady Cove, Oregon

HAD MY INITIAL TUMOR BEEN DIAGNOSED BY ULTRASOUND WHEN IT WAS 1 CM, I WOULD HAVE HAD A SIMPLE LUMPECTOMY AND RADIATION AND ALREADY RETURNED TO THE WORK OF EDUCATING FUTURE EDUCATORS- WITH A MUCH BETTER OPPORTUNITY OF HAVING A "LONG LIFE."

## BACKGROUND STORY

On September 19, 2011, I was called back for a diagnostic mammogram. Calcifications were noted on my left breast with a 30-40% chance of breast cancer. On September 29th, a biopsy revealed Stage 0, DCIS (ductal carcinoma in situ), non-invasive, pre-cancer. Because of the size and location of the tumor, a mastectomy was the only option. My horrendous family history, the fact that I am Ashkenazi Jew and have no children led me to have a bilateral mastectomy. This proved to be a wise decision as a pre-surgery MRI showed three additional tumors in the OTHER breast. These three life-threatening tumors were not noted on the brand new digital mammography machine because of my breast density.

On 11-1-11, I had a four-hour bilateral mastectomy with immediate reconstruction. The pathology report indicatedh invasive ductal carcinoma. The surgeon was unable to get clear margins on either breast. I began tissue expansion (a painful process of enlarging the saline expanders in my breasts) immediately, then started chest wall radiation on December 5, 2011. An oncotype score of 9 dictated that chemotherapy was not needed as I did not score in the 18-31 range. However, my new oncologist in Medford last week asked why I was not offered chemotherapy, which was a terrifying question indeed.

On Christmas 2011, a blister appeared on the incision of my right breast. This breast was receiving the most radiation for my heart would be compromised if the same was delivered to the left side. I ended up with third-degree radiation burns on my right breast and under my right arm-unimaginable pain. My ribs ached from a co-morbid condition called costochondritis as my ribs and lungs were radiated as well. I completed radiation on January 23, 2012 and nursed my burned body for five weeks.

I had my "exchange" surgery on May 22, 2012 whereby the saline implants were exchanged with silicone implants. Healing was progressing until early July when I noticed that my right incision was leaking. There began two and a half months of back and forth travel from Redwood City, CA to Shady Cove, OR (800 miles) every week or two to see my plastic surgeon so he could stitch and re-stitch and observe the wound which never closed. While we had moved to Oregon, my employer, thus health insurance opportunities remained in California.

On October 5th, I had emergency surgery to resection my breast and at that time three infections (including MRSA-methicillin resistant staphylococcus aureus) were diagnosed at treated.

On the Sunday after Thanksgiving, once again the newest incision began to leak. My doctor ordered me to the nearest ER to have the implant removed entirely-the implant that I had battled for over a year to maintain so that I could have a semblance of physically being a whole woman. The ER staff was preparing for my transport back to CA because they said that nobody here would take such a complicated wound and infection. At that time, Dr. Robert Jensen called the hospital and said he would do the surgery; he removed the implant entirely.

Today is February 16, 2013. For the past month, I have been treated at the Ashland Wound Clinic for a one-inch surface wound and an undermining wound encompassing the entire chest cavity. It is a burned, charred, horrific mass of nerve endings the size of a russet potato as a result of poor care by an unnamed radiation oncologist. I have been wearing a Wound Vac 24/7 for the last month and started hyperbaric oxygen therapy last week. I am scheduled for thirty treatments, two hours a day, five days a week. My arm is immobilized in a sling as they do not want any movement of my chest muscle. Unfortunately, I injured my eardrums last Friday in the oxygen chamber and had emergency surgery three days ago to place tubes in my ears for the duration of the oxygen therapy.

I pray every day that these two treatments work for if they do not, my last chance for survival is a very complex, risky free flap surgery. HAD MY INITIAL TUMOR BEEN DIAGNOSED BY ULTRASOUND MUCH EARLIER, I WOULD HAVE HAD A SIMPLE LUMPECTOMY AND POSSIBLY RADIATION AND HAVE BEEN BACK EDUCATING THE YOUTH OF OUR STATE WITH A MUCH BETTER OPPORTUNITY OF HAVING A "LONG LIFE." I know my wound clinic treatments will work, for I must spend my better days educating future educators in Oregon and informing the women of Oregon about breast density! Thank you for your time. Kathy Parara 205 Rene Drive, Shady Cove, OR 97539 541-878-3315