March 10, 2025

Oregon Legislature Salem, OR

The following recounts part of my breast cancer journey, how being unable to find a skilled surgeon in state impacted me and how bill SB1137 could make this an easier path for women in the future.

I was diagnosed with breast cancer in February of 2021. Being diagnosed with cancer is a whirlwind of appointments, tests and information. It is overwhelming emotionally but also with regards to the amount of information you need to learn quickly and life saving decisions that need to be made quickly, all while under extreme duress. I met with several surgeons and with one of the only plastic surgeons in our area to perform the DIEP flap procedure. Because it is a surgery that can take 10-18 hours, surgeons outside of designated reconstruction clinics often work in tandem with another surgeon. This surgeon had just lost his partner and did not know when he might find another and so counseled me to have the mastectomy with expanders to hold the skin until he might be able to perform the surgery at some unknown date. I learned that there was one other option in an Oregon surgeon for me at OHSU but that she was scheduling out for more than a year. My cancer could not wait and so I moved forward with the mastectomy and no certain plan for reconstruction.

Having the DIEP option for reconstruction was important to me because I had spent the previous decade ill and managing my body's reactivity to my environment. I feared that implants would certainly cause a strong reaction in my compromised system and for that reason, I also chose to not have the expanders (place holders) put in during my mastectomy. My breast surgeon was not comfortable with leaving excess skin and so I was left flat. Flat is a misnomer really. The chest has been completely emptied and the chest wall scraped for cells and so the result is two concave divots with long red scars. It is also painful. So for three and a half years, while I researched and searched for a surgeon who could help me or an insurance plan that would allow me to go to one of the hospitals that perform this regularly, I wore prosthetics that rubbed and slipped and hurt every minute they were on. And I cried every time I changed clothes. Some women take this more in stride, some are even more devastated.

A surgery of this magnitude is hard on anyone. And I knew with my other health concerns that it would be challenging for me. As I researched local doctors and listened to other women speak of their experiences in support groups, I heard so very many stories of women being mangled during this surgery by surgeons who were not specialized and highly experienced. They are doing a tissue transplant and reconnecting blood vessels. And they are also having to arrange that tissue in such a way that resembles the female form. So many surgeons are performing this without a lot of experience or enough skill for a good outcome. The result is a reconstructed breast that dies and has to be removed, or a result that is lumpy and misshapen and scarred, or damage to the body so that women are left with atrophied muscles, incontinence and life long pain. I decided that I would not settle for a surgeon that did this as an occasional side gig between implants.

So for three years I looked for an insurance that would allow me to go out of state to a location where the surgeons specialized in this. Finally in 2024, Pacific Source (as aetna when out of state) allowed the Center for Restorative Breast Surgery in Louisiana to be covered. I signed up for the insurance, paying an additional \$700 per month on top of my regular insurance (which I needed to keep in order to keep my primary, my PT and my oncologist). I had the reconstruction in July of 2024 and had a great result. Not only do I feel whole again, but my pain is better. Cancer already took a lot of me and I will always be numb through much of my torso and covered with many scars but this surgery helped me feel at peace with my body.

If my insurance had allowed me to go to a skilled surgeon out of state in the first place, I would not have had to suffer emotionally and physically for years. I would have been told that having a DIEP at the same time as the mastectomy was possible and I would have had half as many scars on my chest. I would not have had the significant additional expense for a secondary insurance and the second loan on our house to cover that. It has now been almost eight months since my surgery. Aetna approved my surgery, the surgeon and the hospital. Now they have kicked it back twice and still not paid it. It is possible that after all of this I may be hit with a 165,000 dollar bill. This also means that I will continue to pay for two insurances for the foreseeable future.

Many other women will not have the financial option of taking on a second insurance. They may not even learn that autologous surgical options are available because local surgeons typically only perform implants. They may settle for someone who does not do this surgery very often and suffer the terrible outcomes that you will see in hundreds of women in the online support groups. Passing this bill would allow local doctors to present all possible options to their patients and for women to get this care without financial devastation. We all deserve to have good, safe medical care and restoration by skilled surgeons. This bill could allow women who are already going through a devastating experience to receive that great, expert care.

Thank you for your time to read this and your compassionate consideration of what this bill could mean for women in our state.

Sincerely,

Connie Gregor