

Submitter: Caroline Cook
On Behalf Of:
Committee: Senate Committee On Health Care
Measure, Appointment or Topic: SB1137

To whom it may concern,

Thank you for your attention to this matter

I am a 38 yo woman living in Sisters, OR diagnosed with breast cancer at 37. I was in peak health, athletic, focussed on nutrition, and working full time as a board certified emergency physician at that time. I have been a physician for 12 years. I had no family history or high risk features. Since starting treatment in Dec 2022 I have only been able to work 30 shifts. Generally I work 144 a year. Treatment involves injection medications to put me into menopause (and associated health risks), a total of 20 rounds of chemotherapy (one every 3 weeks) and 2 immune therapy infusions as well as infusions to boost my bone strength every 6 months. I also take a daily oral chemo drug and many meds to manage side effects. However the mainstay of breast cancer treatment is surgical. I chose to have a bilateral mastectomy with immediate autologous reconstruction. This means I had both breasts removed and had them rebuilt with my own tissue. DIEP flap transfer occurs immediately at the time of mastectomy. I still have at least one surgery to complete this process scheduled for April of 2025. The long delay due to needing to attend more chemotherapy. And thus carrying my surgeries in to a new calendar year and new deductibles.

I chose to have breast reconstruction as I am young, I am a woman, and I could not fathom the loss of that aspect of my femininity. Though going in I knew I'd likely not have sensation in my breasts afterward. I chose an autologous reconstruction to avoid implants and associated need to change out surgeries, expanders for months and the discomfort that comes with them, breast implant syndrome (an autoimmune like syndrome), risk of capsular contraction, risk of a secondary related cancer to the implant, and a general lack of natural feel to the tissue. In order to obtain this surgery I had to go out of the region and out of network. I saw surgery groups at three hospital systems in Oregon: St. Charles, OHSU, and Legacy. I also called Providence and UW in Seattle and was told there were months long waits for an appointment let alone surgery. In addition I called plastics offices in Eugene and Medford but the procedure was not offered there.

The only surgeons I spoke with who were confident in offering me a DIEP flap were out of network in Los Angeles (the Institute for Advanced Breast Reconstruction) or in New Orleans (Center for Breast Reconstruction). There was an understanding that I may also need additional more skilled flap transfer of a PAP flap for a second

surgery. My bill to the surgeons themselves was around \$20,000 out of pocket as network agreements / single case agreements were not able to be made. This was both locations. My insurance, Regence BCBS has told me they do not offer single case agreements outside of the trip state area. And they also told me the doctors I saw locally "know what's best for me" They could not explain where I was meant to find care in network and in the region despite that I had a nursing navigator assisting me to navigate insurance.

I ultimately chose to see the surgeon in Los Angeles as her skills for managing a second flap were superior. She also offered the option for a chance at nerve grafting to preserve sensation. Ultimately this is something that I was not able to consider secondary to cost. My insurance would not agree to an agreement and I could not afford more out of pocket. Instead I will, for the rest of what I hope is a very long life, have entirely insensate breasts to any touch or pressure.

In addition to the fees to the surgeon, I also spent money traveling to Los Angeles as well as paying for housing for an over three week stay. To add to this the breast surgeon my plastic surgeon works with is also out of network and I had to pay nearly \$10,000 out of pocket to her that was not reimbursed by insurance. I did not have another bre