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Committee: Senate Committee on Health Care

Measure: SB1137

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Testimony In Support of Measure SB1137

Submitted by, Kristin Villavicencio of Brookings, OR

My name is Kristin Villavicencio, and I am testifying in favor of measure SB1137. I am writing to you to share my personal experience and advocate for improved access to specialized medical procedures for individuals facing reconstructive autologous breast surgery.

In January 2024, I received a diagnosis of Li-Fraumeni Syndrome, a genetic condition that carries a 90% chance of developing breast cancer by the age of 50, and multiple cancers in your lifetime. As a 41-year-old, this diagnosis was life-altering. Before this, I had already struggled with numerous benign breast issues, which caused considerable stress and pain.

Following my diagnosis, I consulted with an oncology team in March in Portland, OR. They strongly recommended preventative mastectomy surgery, with the DIEP flap procedure being their preferred method of reconstruction. DIEP flap breast reconstruction is a surgical procedure that uses the patient's abdominal tissue to reconstruct a natural-looking breast after a mastectomy. This method avoids the need for breast implants. Which was necessary for me as my body rejects all foreign bodies.

However, my research revealed a disheartening reality: only two surgeons in Oregon were currently performing the DIEP flap procedure. One of the hospitals performing the surgery had suspended the procedure indefinitely due to nursing shortages, and the other surgeon was fresh out of school, performing this procedure for less than a year. My high-risk breast doctor emphasized that this is a specialized surgery that should be performed by a surgeon with extensive experience in the procedure.

This situation severely limited my options and introduced significant logistical and financial challenges. As a resident of rural Oregon, accessing the necessary medical expertise would require extensive travel. The surgical team my doctor highly recommended is in New Orleans. This meant incurring substantial out-of-network costs, as well as covering the expenses of hotels, flights, and much more.

In June of 2024, my husband and I traveled to New Orleans where I underwent my Phase I surgery for DIEP flap reconstruction, and in June, we traveled back to New Orleans for Phase II. This was not only a difficult process physically, but financially, and emotionally as well. It was a hardship for our family to pay for many of the costs upfront due to being out-of-network with our insurance, which is a much higher rate than if we were in-network.

We have come to realize that although this was a hardship for us, we were one of the lucky ones who had insurance that paid at an out-of-network rate. Looking back at the care I received, and the stories of the thousands of women that I hear from regularly who didn't have a choice, I am so glad that I was able to make the best choice for me based on the sound advice of some of the top medical professionals in our state- get care from the best of the best. I was able to choose! It should be that way for everyone!

As someone who is struggling with a genetic condition that predisposes them to multiple cancers, the last thing I want to be worried about is access to care and how to afford it. I urge you to consider and approve Measure SB1137 – no one should be denied the right to choose the best care for them, especially when their life depends on it.

Thank you for your time and consideration,

Kristin Villavicencio