

Dear Chair Nosse, Vice Chairs Nelson and Javadi, and Members of the Committee,

On behalf of the estimated 10% of women of reproductive age who suffer from endometriosis, I write to thank you for hearing **HB 2959** in the House Committee on Behavioral Health and Health Care. I also want to take this opportunity to share my endometriosis journey with you and explain the heartbreaking choice I made between motherhood and living with constant and debilitating pain. I might have made a very different choice if I had been able to consider infertility treatments covered through insurance.

As a brief overview for those unfamiliar with endometriosis, it is one of the leading causes of female infertility and affects up to 50% of infertile women. The disease causes tissue similar to the lining of the uterus (endometrium) to grow outside the uterus. The tissue may develop on your ovaries, fallopian tubes, and even your bladder or intestines. The tissue can irritate the structures it touches, causing pain and adhesions (scar tissue) on these organs. It is a chronic disease that can cause severe, life-impacting, and debilitating pain, nausea, and even depression. There is currently no known cure for endometriosis, and treatment is only aimed at controlling symptoms.

My endometriosis symptoms developed as a teenager, but it took until I was 31 years old to finally see a doctor who took my debilitating pelvic pain seriously. This is not an uncommon experience as, on average, there is a 7-10-year delay in diagnosis for women with this disease. When I was officially diagnosed through laparoscopy, my endometriosis had already progressed to Stage 4, or the most severe stage, and my ovaries were covered in endometriomas and scar tissue, and more scar tissue had glued the back of my uterus to my colon. As a young woman in my early 30s, having just finished graduate school, I was not prepared to decide whether I wanted to have children - I thought I had more time for this conversation. However, my diagnosis and the severity of the disease forced me to consider whether I would have a hysterectomy to alleviate the constant pain or if I would try and preserve my fertility. I chose to fight for my fertility for the next eight years. I had two surgeries to remove as much of the endometriosis as possible, and another surgery to remove my right ovary when it came to the point that it could no longer function properly. I spent years on intensive hormone therapies, including three years on Depo Lupron, which put me into synthetic menopause. Yet, through all of this, my pain persisted. The tissue that had grown between and connected the back of my uterus to my colon caused me to often have the sensation that something was ripping apart in my body every time my colon was active. At age 39, I had spent almost a decade desperately trying to save my fertility and the pain had only gotten worse. It was at this age that I made the incredibly difficult decision to have a hysterectomy with bilateral salpingo-oophorectomy or the removal of my uterus, remaining ovary, and fallopian tubes. This surgical method has the highest success rate with endometriosis, but it also put me into immediate menopause.

I didn't have another option - the pain was simply too much to handle, and there was no other reasonable choice. I believe that the most significant decision that a woman can make is whether to have a child, and I felt that I was robbed of that choice. I'd often wished I could freeze my eggs so that I could still have the ability to have a child if I wanted, but it was an option that was out of reach for me because of the prohibitive cost. For the most significant decision of my life, the reality was that there was no choice at all because infertility treatment was never an option for me. **If HB 2959 had been law when I was going through all of this, there is no doubt in my mind that I would have chosen to freeze my eggs.**

I ask you to consider my story, which is not uncommon when you vote on HB 2959. Please vote to provide real choices to all women who want to have a child.

Sincerely,

Carolyn Lee
Albany, Oregon