

Written Testimony of Mary Elizabeth Spreng

Maine HCIFS Committee on LD 1539

February 8, 2022

Members of the Committee, My name is Mary Elizabeth Spreng. I write to you to strongly urge you pass LD 1539. I know that cost is always a factor in bills such as this, however an insurance study only offers a small snapshot as to the cost of the proposed. I am hoping to give you insight as to the cost of what it is like to not have insurances assist with IVF.

My husband and I carry mutations for a very rare autosomal recessive genetic disease, Pierson's Syndrome. To have an autosomal recessive disorder, you inherit two mutated genes, one from each parent. The chances of a child being affected, who was produced from my husband and I, is a 1 in 4 chance. It seems like okay odds doesn't it? That means you have a 75% chance that everything will be okay. Well-what if you have really bad luck? I can tell you.

My husband and I got pregnant in July of 2020 after being told for many years we couldn't. We were scared as any new parents would be, but completely excited with the hopes and dreams ahead of us. It is never a good sign when you are asked to come into a 24 week ultrasound because "they needed clarification from the 20 week appointment" but being naive, we just thought the baby was in a weird position. That was the day our lives changed. That was the day we found out our baby's kidneys were "abnormal".

On comes appointments in Boston, talks about possible dialysis and kidney transplants. At this time we did not know the diagnosis yet, but we knew the treatment. Delivery at Brigham and Woman's hospital in Boston, to be close to Boston Children's. Definite NICU stay... if we make it that far. So much information and not enough information flowing in all at once until we get to the 28 week mark. In four weeks, my amniotic fluid reached a dangerous low and I had to move with my husband to Boston to be close to the hospital. My husband had to leave his job, as an electrician there is no FLMA for him. Luckily I had some benefit but my sister raised money on a GoFundMe campaign to pay our mortgage in Maine and our rent in Boston. Our goal was to grow our baby to full term, which we did. We lived in Boston for 3 months, we made it to 38 weeks, and we gave birth to a beautiful baby girl, Zora Grace, by emergency C-section on March 1, 2021.

The next 9 days were a blur. She was rushed into the NICU, her lungs collapsing from under development. Many nights being woken up to doctors and nurses rushing into our room telling us she could die. Rushing down to the NICU to see our baby girl being handbagged back to stability. Alarms ringing, watching doctors give her blood transfusions, hourly check-ins by the respiratory therapists, and tiny adjustments here and there on her ventilators. There is no way I can possibly describe the amount of stress and trauma we all endured in those nine days, and after...

Zora Grace Spreng passed away on March 10, 2021 in her mommy and daddy's arms on a deck at Brigham and Woman's surrounded by her care team. We had to make the hardest decision we could ever make. We had to take her off of life support.

A week after her passing we got a call from our genetics team, they found a diagnosis... *Pierson's Syndrome*. They discussed our options. 1. IVF, it is the safest way to ensure this doesn't happen again. They would create embryos that they could test for the disease and only implant a non-affected embryo. 2. Get pregnant naturally, get a test at 11 weeks called a Chorionic villus sampling (CVS) and if the baby is affected, then termination. Well at least we knew our options, 1. Another \$30,000 after spending the \$500,000 from Zora's care... or 2. Abortion.

Therapist, trauma groups, and healing happened in the next few months after her death. We had to relearn how to be human. How to put our lives back together after it had broken apart. We thought after many months, well let's try it again. We can't afford the \$30,000 out of pocket, we still owed \$14,000 of out of pocket costs from our deductible for Zora. So we decided to hedge our bets. 75% is good odds in Las Vegas right?

Next, We were pregnant! This time terrified, we make it to 11 weeks, drove down to Boston. We got the CVS which consisted of taking a sample of tissue from the placenta by way of a 6 inch needle the size of a straw being pushed through your abdomen while I am being forced to sit perfectly still for about 10 minutes. It's all worth it though, this time will be different. 75% chance, 3 out of 4, its going to be different....

We get the call a week later. Bad luck again, Baby Two has Pierson's and now we have to plan a D&E. An abortion. October 19, 2021 our baby was terminated. Another baby gone, just like that, and we are back to trying to relearn how to live. Baby-less and empty.

I wish I could tell you that this was it. Hasn't the *cost* been too great for one couple to take? It wasn't. January 6th 2022 I was at work and stood up to go into my boss's office. I started pouring blood onto the floor. Complications from the D&E... I had hemorrhaged. After a second, emergency D&C, I am recovering and hoping that my uterus will heal, but now I am still trying to figure out where we go from here. How do we recover from such heart break?

We are already discussing trying again naturally for a third time in June 2022 because we cannot afford IVF out of pocket. Thankfully we still have this as an option even though it has been so damaging to me emotionally and physically. I am scared because what if my right to abortion is gone too? Then what? These are real possibilities that occurring in our government currently. Please take into account this cost as well. With every positive there is a negative. Yes, you may be saving a few dollars by not paying the \$30,000 IVF fee, but look at what I have had to pay.

If you pass LD 1539, you are not just giving hope to people that have infertility issues, you are giving hope and certainty to couples like Jeremy and I. To get IVF means to have a pregnancy without worry of Pierson's. Without worry of abortion. To have a living child at the end of all of this pain.

Thank you for your time,

Mary Elizabeth Spreng.

Mary Spreng
Bradley
LD 1539

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