## Senate Judiciary Committee Senate Bill 2150 January 16, 2023

Good afternoon Chairperson Larson and members of the Committee. My name is Mandy Dendy and I come before you today to share my personal story with you.

Twenty years ago this week my husband and I began living our worst nightmare. We were expecting our first child and an ultrasound had revealed some abnormalities. We were sent for a higher level ultrasound which revealed our baby did not have kidneys. It is a condition called Potter's Syndrome named after Dr. Edith Potter who discovered it in the 1940s. It is almost universally fatal with only one known survivor that I can find since that time. The abnormality was not discovered until our first routine ultrasound at the halfway point of my pregnancy. This particular abnormality cannot be found until at least the second trimester as what happens is the mother's body provides amniotic fluid for the baby in the developing first trimester and then the baby's boy, specifically the baby's kidneys, take over in the second trimester. Wyatt didn't have kidneys and so he could not produce amniotic fluid. Amniotic fluid is critical for development of the fetal lungs. Wyatt died from underdeveloped lungs, not his missing kidneys. Medically, this is known as bilateral renal agenesis.

We were told that he could die at any time and if by some miracle he was born alive he would die shortly after. There were no treatments, only planning for

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the inevitable worst. We were given a choice - continue to carry a child that was given no chance of survival with, at that time, no known survivors, or terminate the pregnancy. My husband placed the decision in my hands because it was my body that would house this child and it was my vigilance day and night that would monitor his continued survival in utero. I was the one who would deliver him, dead or alive.

I chose to take a chance that the doctors were somehow mistaken or that my baby would somehow defy the overwhelming odds. I am the patient that Drs. Boe, Tobiasz, and Lessard referred to in their testimony, the patient who is given a fetal diagnosis incompatible with life. They have given you the medical perspective of that diagnosis and I am here to give you the human patient perspective. There is more to my story that I haven't told you yet.

I have made this decision twice and carried two babies to term, both with the same fetal anomaly. Our first and our fifth children, and our only sons. There is an emotional cost that cannot be accurately measured. I carried my sons each for four months of pregnancy, knowing they could die in utero at any moment. I obsessed over their every moment, fearing what stillness could mean. I delivered them by scheduled c-sections around the 37th week of pregnancy, still knowing that a moving baby prior to that first incision did not guarantee anything. We arranged for photographers to be in the delivery room, along with a priest, to baptize our sons as soon as possible and to capture every fleeting moment of

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their brief lives. I arranged for funerals and burials before ever entering the operating room.

I delivered my babies on the maternity floor just like any other expectant mother. Except my room had a butterfly on the door to signify the emptiness. I listened to the cries of babies in rooms around me and left the hospital with empty arms and milk-filling breasts with no child to feed. I attended the funerals of my sons just five days after giving birth, watching their tiny coffins lower into the ground of the double grave plot we had purchased, one at the foot of our graves and one at the head.

I went home after the birth of our second son, but fifth child, Eli, to three young daughters who needed their mother. Their mother needed to grieve. I can tell you those experiences profoundly changed me as a person and as a parent.

Those are the emotional costs. There are also financial costs. Going to a hospital and having a baby is expensive. Tack on the cost of a funeral and burial right on the heels of that and it can be financially overwhelming. Even with my husband lovingly crafting our babies' coffins himself and already having a headstone and grave plot, Eli's funeral cost thousands of dollars. Whether a child is buried or cremated, there is a cost, a heavy financial burden to sit alongside the steep emotional price of choosing to carry and deliver a child with a fatal fetal abnormality.

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I am asking you to consider our story when deciding whether there should be an exception for pregnancies diagnosed with lethal fetal abnormalities. We don't regret the choices we made in carrying our sons to term despite both of them dying within hours of their births. Having a choice in a situation where you have such little control is important.