

Testimony on Behalf of HB 1888

Dr. E. Goldblatt Hyatt

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My spouse and I had been married a little over a year when we learned we were expecting a child. We celebrated the news with our friends and family, and I excitedly went into each prenatal appointment with hopes and dreams for my little one. I imagined myself swaddling a tender newborn, rocking my future child in my arms as he drifted into a peaceful sleep. I pictured him as a chubby-cheeked toddler running faster than his legs would carry him. I thought of him growing and thriving, one day with siblings, under our loving care.

My hopes and dreams came to a screeching halt when, at 20 weeks pregnant, I learned that our son had a rare and deadly fetal anomaly, appropriately named CHAOS: Congenital High Airway Obstruction Syndrome. While prior ultrasounds revealed a healthy and active fetus, this anatomy scan was the first time doctors could see accurately what was happening inside our baby's body. Many parents refer to this screening as "gender scan", a time when they excitedly learn the sex of the fetus. We were, too. However, hours after the technician gently wiped the gel from my growing belly and my husband Will and I sat awaiting news in a dimly-lit consult room, we were given the devastating diagnosis: our son never developed an airway. The anatomy where the airway should have been was only a sealed stump. Fluid that should have been expelled through that airway back into the womb was building up inside of his tiny lungs, stretching them to maximum capacity, squeezing his heart into failure. His diaphragm, because of the pressure from the fluid in the lungs, was inverted. We were told that our dearly beloved, badly wanted little boy, was going to die, and it was only a question of when.

We were given three options. The first: wait for him to go into heart failure in the womb, a process that could take weeks, and may have an impact on my own health as I carried him. The second: continue the pregnancy if he didn't go into heart failure and give birth through a procedure that would also risk my health, to a baby that would be born brain-dead due to where his anomaly was: they wouldn't be able to create an airway in time for him to breathe on his own. In this situation, our sweet little boy would never be conscious, would spend his life in a neonatal intensive care unit, likely to die of a secondary infection or be removed from life support at a time we would need to choose. He would never fall asleep in my arms, never run faster than his legs could carry him, never bounce on my knee. He would be suspended in darkness until his life ended. Our third option was to end the pregnancy, but if we did so, we needed to do this quickly, because of Pennsylvania gestational age limits.

We were lucky enough to be able to be seen nearly immediately for a second opinion at a world-class Center for Fetal Diagnosis and Treatment, where they confirmed that there was no fetal surgery option that would be able to save our boy's airway. We underwent fetal MRI, echocardiogram, and genetic testing that also revealed an extremely rare chromosomal anomaly that is usually responsible for miscarriages in the first trimester, and likely meant that the CHAOS was part of a large array of anomalies that were soon to develop. It became clear that Darby was not meant for this world.

Will and I were plunged into a world of decision-making we never imagined having to go through when we first saw those two lines appear on the pregnancy test. We did this all while our child simultaneously lived and died inside of me. We were making end of life decisions at the beginning of life, a time that was supposed to be filled with joy marred with tragedy. This was truly the first parenting decision we ever had to make. We consulted with our spiritual community, communed with our family and friends, and I cried and cried. I couldn't believe it was happening to me; I couldn't believe how naïve I was to all that could go wrong with a pregnancy. After extensive, gut-wrenching, deeply honest conversations, we ultimately decided that ending the pregnancy was the best decision for our family and on August 3rd, 2012, two days before my birthday, I went from pregnant to grieving in a matter of hours.

As heartbreaking as our experience was, I was so grateful to have the choice: the option for my bodily autonomy and the future of my family, to make my decision to have an abortion. Now, as a researcher and clinician specializing in experiences like my own, I am only too painfully aware of the experiences of parents in other states where they are not allowed to make the choice that I did. The fact is that any reason for an abortion is a valid reason, and for those who undergo fetal anomaly diagnoses and choose to end the pregnancy: about 1% of the population—the decision is one made with extensive care and never lightly. There is no other way to find out about a fetal anomaly other than through prenatal testing, and the anatomy scan happens in the second trimester, where time is of the essence here in Pennsylvania. And yet when we make these choices, it is because we would rather suffer than allow our children to suffer.

Still: accessing an abortion, especially if your state forbids it, requires resources: having the funds to travel, for childcare—as many people seeking abortion already have living children—for lodging, permission to take time off work, and more. It requires resources that many people do not have, yet if they are determined to end a pregnancy, they will find a way. This may even result in seeking abortions in an unsafe way. I know that I was determined not to let Darby suffer one minute more while I, as his loving parent, could prevent it. I would have done anything humanly possible to release him from his broken body.

In my private practice, I work with expecting families who, too, have received heartbreaking information about their pregnancies. Some of these families have spent years, great expense, and, some with assisted reproductive technology, trying to get pregnant, only to learn that their fetus is not developing as they had expected. They, too, face heartbreaking choices. It is never my position to judge or force them into any particular course of action as every family has their own unique circumstances and calculus that they use as they walk this painful path. I honor the principle of choice in their lives and abide with them as they make the choice that is right for them. Some choose to continue to term and engage perinatal hospice, giving birth to babies that die in their arms. Others choose to end the pregnancy. Again, key to all of these circumstances is the element of *reproductive choice*. We know that people who are not granted choice and autonomy over their own bodily decision-making choices experience disastrous emotional and psychological, as well as potentially physical, consequences. I have seen this both in research as well as in communication with colleagues who work in anti-choice

states, where they are unable to guide their clients in making the best possible decisions for themselves and their families. I have vowed, since my experience, to support as many people facing these heartbreaking choices as possible, in whatever way I can. I have vowed to uphold the principle of reproductive choice.

Every day when I wake up, I think of my first son Darby. When I'm anxious, I whisper his name. Some of his ashes sit inside a necklace that hangs over the doorframe of one of my living children, and the remaining ashes sit in an urn with a figurine of a small boy embracing a dog sitting atop. Would he have loved animals? I know he would have loved his four healthy siblings, the ones who came after him, who entered this world because he could not be here. I like to think he is our guardian and protector, and I know one day I will meet him and kiss those beautiful cheeks, stare into those deep blue eyes, and tell him how much I have longed for him. Until that day, it is my duty to speak about the choice that I was privileged to have, the choice that every person deserves to make on behalf of themselves and their family. I will fight for this choice until the day I die.