

March 16, 2021

RE: HF 1080 Written Testimony

Chair Stephenson, Vice Chair Kotyza-Witthuhn, and members of the House Commerce Finance and Policy Committee:

During our routine 20 week ultrasound, we were given the unexpected news that our son had Down syndrome and a Congenital Heart Defect. The following several hours and days turned into a blur of appointments. We were informed of all of the things that our child wouldn't be able to do in life, the health complications that can come with Down syndrome, the hardships we would face. We were asked about termination on more than one occasion. My Obstetrician flat out informed me that all of the patients that she cared for with a prenatal Down syndrome and Congenital Heart Defect diagnosis had chosen to terminate their pregnancies. Half of all babies born with Down syndrome have a congenital heart defect.

As we sat down with the Cardiologist, he carefully crafted a picture that showed the anatomy of our son's heart. He explained to us that his dual diagnosis of Complete Atrial Ventricular Canal Defect and Tetralogy of Fallot could lead to a succession of multiple open heart surgeries throughout childhood until he grew into an adult sized heart. The open heart surgeries would be needed to repair and accommodate his growing heart and valves. The image of our innocent child repeatedly on the operating table seemed unbearable. What was impossible to swallow was the information we received next. I questioned how many surgeries his heart could withstand before he would need a transplant? I will never forget the matter of fact tone of voice when the Cardiologist informed us that he may be able to get through 5 surgeries, but ultimately would not qualify for a transplant because he had Down syndrome.

My mind was trying to sort and digest all of the information that we were just given. With his dual diagnosis, our son could have 5 surgeries by his elementary years. That was it. We were looking at a possible life expectancy of elementary school because he did not qualify for a transplant. We hadn't even met him yet or seen his incredible capabilities, and medical professionals were pointing out the value of his life, and that his life was not worthy of being extended by an organ transplant simply because he had Down syndrome. The picture that was being painted certainly was not a hopeful one.

Jack was born full term with an onslaught of extra doctors present. The Echocardiogram at birth revealed that Jack did not have Tetralogy of Fallot, the condition that would have required so many additional surgeries. Jack went into unexpected heart failure at 4 weeks old. He was admitted into the Pediatric Cardiology Intensive Care Unit, where we would spend the next month of our lives. The first time the surgeon met Jack he told us that he looked terrible and was not strong enough to withstand a surgery. Yet, one week later that same surgeon performed a life-saving operation on our new baby.

The skill, the care, and the expertise we received from the surgeon, doctors, and nurses was absolutely phenomenal. When we were discharged from that hospital stay, they expected Jack would need another open heart surgery within a year. As he was allowed to grow and heal he began to astonish his doctors. Further testing revealed that not only was his heart miraculously healing, at this rate he may never need another heart surgery.

Just recently we were at a 2 year post operation check-up. His doctors said that they could not be more pleased with how things looked. They said his heart looked and functioned basically like that of a normal heart. There were doctors requesting pictures with him and much celebration. Coincidentally that same doctor who had first educated us and shared the unbelievable fact that in this day and age, Jack would still be denied an organ transplant, was there for the celebration. I had not seen him for two and a half years. With an enormous smile etched across his face, he exclaimed that Jack's heart looked incredible. And, that if we are seeing this much progress after only 2 years, Jack is going to thrive for a very long time! For some reason, hearing this news from his mouth was even more important to me. When given the chance, Jack has always risen to exceed expectations.

There is no doubt that the surgeon deserves our utmost gratitude for the incredible work he performed on Jack's heart. But, Jack has proved that he is no less capable of undergoing a procedure, healing from it, or thriving in its aftermath than anyone else. Down syndrome or not.

On behalf of my son with Down syndrome and my family, I am requesting your support of SF875. Please do not allow a disability diagnosis to delay or deny a life-saving transplant. My son's life could depend on it.

Thank you,

Carolyn Petree