

March 12, 2018

Chairman Burke, Vice-Chair Beagle, Ranking Member Tavares, and Members of the Health, Human Services and Medicaid Committee:

Thank you for allowing me to provide proponent testimony on House Bill 332, which would ensure that individuals with disabilities will not be banned from an organ transplant waitlist solely based on their disability.

I was approached by Courtney Hansen after hearing of the proposal of Ohio House Bill 332 and wanted to share our story and put a face with the impact of this bill. We found out that our unborn child would have Down syndrome in the spring of 2014. Suddenly, the hopes and dreams I had for my child came crashing down around me. I hadn't had much interaction with individuals with Down syndrome in my personal life and honestly didn't see past that diagnosis at all. A month later, we found out that our daughter, Ellie, also had a severe heart defect that would require at least one open heart surgery to repair. I knew from the day of our diagnosis that I'd have to become an advocate for our child – I had no idea that I would have to advocate to show the world that her life was worth living.

Ellie arrived that September and was out to show the world that impossible was nothing. She was closely monitored from day one by her pediatrician and cardiologist. When Ellie was just two weeks old, she went into heart failure. At one month old, she was admitted for failure to thrive and congestive heart failure. Her battle had begun – as had ours. At two months old, we found out that Ellie's heart defects were more complex than we'd imagined and we tossed around the idea of three surgeries now and a possible heart transplant in her future. The next month brought a trach and g tube, several more tests, and a heart cath. By Christmas, Ellie was spending her days in the Cardiac ICU and was only awake for a few hours each day. She was in the depths of heart failure. We prayed over her every night, begging her to be here in the morning. She'd get another pep talk each morning, begging her to power through so that Daddy could see her when he came back after work. Every day was spent fighting for her – making sure that there was a future for our daughter.

She was scheduled for her first open heart surgery on December 31st. On the 28th, I came into a meeting with her surgeon prepared with notes and questions and a plan. He told me that she was extraordinary, but in the worst ways. Her little body likely wouldn't make it out of the OR. His words were, "the risks here are steep – the chance of mortality is quite high for her". He explained the surgery and what he'd be doing. He'd be placing a band around her pulmonary arteries to try to prevent permanent damage to her lungs. He wouldn't be able to do more at that time because of the risks revealed in her heart cath. I looked down at my list of questions... none of which were relevant anymore. I asked about future surgeries, he said that unless this first surgery

was wildly successful, which was doubtful, he wouldn't be able to do step 2 or step 3 in her repair. I said, "Okay, then she can have a transplant."

"No," he said, "she wouldn't be eligible for a transplant, because she has Trisomy 21 (the clinical term for Down syndrome) and a host of other complications." She would likely be sent home to live out the remainder of her short life with the broken heart she had.

The depths of my soul pooled out of me and gathered like a puddle on the floor. How could her life not be worth saving? How could her future not be worth exploring every option? What in the world does having Down syndrome have to do with access to a transplant?

To his surprise, Ellie pulled through her first heart surgery like a champ. She was given a few months of extra time. It was now up to us to figure out a way to get Ellie the surgery that she needed to move forward – a surgery with a future and a life. We looked into pediatric cardiothoracic programs across the country. We'd heard great things about Boston.

When we were finally discharged after four months inpatient, we went to see our cardiologist right away. She helped us gather our files and test results and she got her foot in the door at Boston Children's Hospital. Ellie would undergo her second open heart surgery just two months later. At the time of her second heart surgery, Ellie was again in the hollows of heart failure – ventilator dependent, fed strictly by her g tube, and spending her days sleeping and sweating. The surgeon went in and used part of her pericardium (the sack around her heart) to build a septum in her heart and construct a mitral and tricuspid valve. He removed her PA band that was placed in her first heart surgery. In six hours, our daughter had a whole heart. She came through her second heart surgery and had pink little lips for the first time in her life. Ellie didn't end up needing a transplant then, but congenital heart defects are never gone. They can be repaired, but her heart will never be like mine. There is always a chance that she will need additional surgeries in the future – always a chance that a transplant will again be on the table. While we don't have to think about a transplant today, so many of the other families we met in hospitals are looking at that option. Some of them have been told by multiple hospitals across the country that their child was not eligible for the transplant list because of their disability. If we have to face this again down the road, I'm counting on you to make sure that her disability will not stand in the way of her getting the treatment she deserves.

I don't think her first surgeon had any discriminatory feelings towards her. I think his advice was given with integrity and based on what the medical community believes to be true. But let me tell you this, if Ellie was my age, she wouldn't have survived to see her first birthday. The treatments and options we had for Ellie simply weren't options thirty years ago. Ask any of Ellie's specialists and they'll all tell you that she breaks the mold. That what the textbook says she'll do is rarely the case. In this regard, Ellie is in good company. See, the medical world is just now seeing exactly what people like Ellie

are capable of because of parents and advocates before us who have broken down barriers. Barriers were broken to allow her to get equal medical treatment. Access to organ transplants belongs on the short list of medical barriers that still need to be broken down.

Ellie is now three and a half years old. She is in preschool and loves to dance and color. She's been in fashion shows and on billboards. She knows about 150 words in sign language and is learning more and more verbal words every day. Her brothers adore her and we cannot imagine our lives without the joy she brings to our days.

I'm asking you to make sure that other families have this same opportunity. We all deserve the watch our children grow up. We all deserve the right to equal medical care and opportunities for all treatments. Denying a transplant to someone because their life is deemed less valuable is absolutely unacceptable.

As Courtney reminded you, seven states (Pennsylvania, Oregon, Maryland, California, New Jersey, Massachusetts, and Kansas) have unanimously passed similar bipartisan legislation to prevent organ transplant waitlist discrimination. Delaware currently has a bill working its way through their state legislature, as well. Let Ohio be next.

I know that you are faced with difficult decisions on a daily basis. Someone asked me if I was surprised that this bill passed unanimously in the Ohio House. I said, "No. This is an easy decision. This is a decision that feels right and makes sense." Adults and children with disabilities in need of an organ transplant should be afforded greater legal protection. Their lives are inherently worth saving. Thank you for your support of H.B. 332.

Warm Regards,

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