

SB 2302

Relating to prohibiting discrimination in the organ transplant process.

Chairwoman Larson, members of the Senate Judiciary Committee and fellow Citizens of North Dakota. I'm here to speak on behalf of Senate Bill 2302.

I'm Annalise Duffy, and I'm mother to Lakyn, who has Down Syndrome. She is the absolute best thing that has ever happened to me and my family. Before her, I'd say I was your average participant in everyday life. I went through the motions, did what was expected of me, and didn't step outside my comfort zone much. I can't say that's true anymore.

Life changes when you find out you're going to have a child with Down Syndrome. I could go into specific detail about the roller coaster of emotions you are forced to ride. The long list of questions, unknown, indescribable fear & worry. No one has it in their plans to have a child with Down Syndrome or a disability. And that is exactly why I'm here. You don't think about having a child with a disability until you're actually the one having a child with a disability. We become the people in the trenches, climbing the mountains of inequity. We become the advocates for those who can't always advocate for themselves. Whether it be education, healthcare, or quality of life, it's us, the warriors of our kids' lives, that become the change makers. I'm no longer average and going through the motions, but a soldier for equity and life of all human beings, especially those with disabilities.

I want to tell you about Baby Zion. Zion was born June 15th, 2021, with Down Syndrome. He also had and a heart condition, which isn't a surprise as 50% of individuals with Down Syndrome have some sort of heart condition. Zion was born just 9 days before Lakyn actually. Zion & Lakyn would spend a sometime in the NICU and Both Zion and Lakyn would go home just 1 day a part. Zion went home July 25th and Lakyn went home July 26th.

Zion would have 5 open heart surgeries those first few months and Lakyn would have 3 abdominal surgeries. Zion's parents we were navigating the same emotional rollercoaster ride that My husband and I were navigating. The hills and valleys of the NICU, multiple surgeries, Down Syndrome. It was comforting knowing we weren't alone in our journeys and connected through it all.

Our journeys quickly went different directions though. Zion needed a heart transplant. At 3.5 months old, doctors would deny him being put on a transplant list. They would even go as far to say, "it would be a waste of a heart." Why? Because he had Down Syndrome. Zion wouldn't be given the opportunity to show the world what his abilities would be, what milestones he would crush, and what he had to offer the world because of his disability. On October 8th, 2021, Zion would lose his life at the hands of discrimination.

I can't quite describe the feelings and confusion that surface when learning this news. I didn't understand how a baby could be denied the opportunity for continued life. I didn't even realize this was possible. Imagine the feeling of learning that your child isn't protected against this type of discrimination in the State you live, North Dakota. I can tell you, it's gut wrenching. But there is power in knowing and as a warrior for Lakyn and others with varying disabilities, that knowledge allows us to make a difference, so here I am. Here we are. The opportunity to be difference makers. To save lives of the people of North Dakota.

If we can have a divided country over abortion rights, and life in the womb, then there shouldn't even be a question or debate on protecting the lives of those who we already have living and breathing amongst us. I believe in North Dakota, and I believe in you all. On behalf of my sweet, beautiful Lakyn, her would have been buddy, Zion, and other individuals with varying disabilities and Down Syndrome, I ask you, the committee, to give SB 2302 a DO PASS recommendation.

I thank you for all your time and service you dedicate to the State of North Dakota and its people. My contact information provided in this written testimony, and I am more than happy to answer any questions you have now, or that surface later.

Thank you.

Annalise Duffy

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