

## Senate Bill 2302

Relating to prohibiting discrimination in the organ transplant process.

Chairman Weisz, members of the House Human Services and fellow Citizens of North Dakota. I'm here to speak on behalf of Senate Bill 2302.

My name is Taya Spelhaug and just over a year ago on January 24th, 2022, I heard these words, "I'm sorry but, your baby has a 10% chance of surviving to birth." 14 days prior, we had received our genetic testing results that said our child would likely have Down Syndrome. We then had an ultrasound to look for markers of Down Syndrome, where we were given this devastating news. We were just 16 weeks along. Afterwards, I sat in the car crying and saying, "I don't care what she has, I just want her." Fortunately for us, as our pregnancy progressed, the severity of her heart defect decreased and today our beautiful baby girl, Olive Rae, is a healthy 6-month-old with just a slight heart valve defect. Being told that my child was not going to live was the hardest thing I have ever had to hear. It's a pain that will stick with me forever and a pain that I hope no parent has to ever endure.

I'm here today to lend my support for Senate Bill 2302. I believe, with the passing of this bill, less parents will hear the devastating news that I heard, and the lives of North Dakota's most inspiring individuals will be saved.

Olive smile lights up the room. She literally smiles with her whole tiny, 6-month-old body. I wish you could see her now. One of the fastest ways to get her to smile is to say her favorite word, Love. It's kind of ironic, because when I was pregnant, I told my good friend Heather that my child would likely have Down syndrome. She smiled, grabbed my hand, and said, "Do you know what that extra chromosome is, Taya, it's joy and love." Recently another friend said to me, her name really should be All Love, because that's what she brings to so many.

This quality is not unique to Olive. In college I worked for an organization called CCRI, Creative Care for Reaching Independence, a nonprofit that provides support services to over 450 individuals with disabilities living near Moorhead, MN and currently, I sit on their Board of Directors. Through this work I

have had the pleasure of spending time with many amazing individuals with Down syndrome and my friend Heather is correct, they are the epitome of joy and love. Every day, I was met with a hug, smile and usually a witty joke. I can honestly say, I never had a bad day at work when I was with CCRI. These individuals bless and enrich our lives for the better and they deserve an equal chance to live the life they were called for. By passing this bill, you will be saving the lives of people like my Olive and other joy givers.

Right now, Olive's heart is doing ok, but that could change. It's hard to fathom the fact that my beautiful little Olive with the megawatt smile or anyone else in North Dakota who has Down Syndrome would be placed lower on, or not even placed on, the organ transplant list because of their disability due to a claim that they are unable to follow up with post-op treatment requirements. This is untrue. A 2006 study by Martens, M.A., Jones, L., & Reiss, S.<sup>1</sup> confirms that, provided they receive adequate support with post-operative care, people with developmental or intellectual disabilities have a comparable likelihood of transplant success to people without disabilities. Truly there is no reason for this bill not to pass and as a proud North Dakotan, I implore you to join the other 34 states that have passed this bill. A bill that will give people with Down Syndrome equal rights to life.

On behalf of my Olive, and so many, I respectfully ask the committee to give Senate Bill 2302 a DO PASS recommendation. Thank you for your time, your consideration of SB 2302 and your service to North Dakota. My contact information is provided in my written testimony, and I am happy to answer any questions now, or that you may have later.

Thank you,

Taya Spelhaug

[Taya.Spelhaug@hotmail.com](mailto:Taya.Spelhaug@hotmail.com)

<sup>1</sup> Martens, M.A., Jones, L., & Reiss, S. (2006). *Organ transplantation, organ donation, and mental retardation. Pediatric Transplantation, 10, 658–664 at 661.*