



**SB 2302**  
**House Human Services**  
**Wednesday, March 1, 2023**  
**Senator Diane Larson, Chair**

Chair Weisz and Members of the House Human Services Committee:

My name is Roxane Romanick and I am writing as the representative for Designer Genes of ND, Inc., as their Executive Director. Designer Genes' membership represents 230 individuals with Down syndrome that either live in our state or are represented by family members in North Dakota. Designer Genes' mission is to strengthen opportunities for individuals with Down syndrome and those who support them to earn, learn, and belong.

Designer Genes is in support of SB 2302 and asks for a "do pass" consideration from you. We would support an amendment that addresses enforcement and expedited review. The National Down Syndrome Society has possible model language that reads:

(a) An individual with a disability who reasonably believes that a health care provider has violated this section may bring an action for injunctive relief in the appropriate court.

(b) The court shall accord priority on its calendar and expeditiously proceed with an action

Down syndrome occurs from a triplicate copy of the twenty-first chromosome. This genetic phenomenon can bring with it medical complications, one being congenital heart defects (CHD). The reported incidence rate for CHD in persons with Down syndrome is between 40 – 60%. This, of course, puts individuals at a higher risk of potentially needing a heart transplant as some CHD's can be extremely severe. This is why the Down syndrome community has embraced the passage of organ transplant anti-discrimination bills across the country. Thirty-four other states have listened to this request and passed laws to assure fair consideration.

I am not an expert on all that goes into making decisions on who gets a donated organ, but I understand that oftentimes there is a focus on quality of life and the ability to make an informed choice. Speaking to quality of life, studies conducted with individuals with Down syndrome overwhelmingly indicate that there is a high degree of satisfaction with their lives and most individuals have found a way to contribute back to society whether through work, volunteering, or caring for another. Children with Down syndrome are valued members of their homes, schools, and communities. The perception of children with Down syndrome being integrated into our communities' day cares, schools, churches, and community events is now commonplace as they are now longer forced to live in institutions.

Historically it's been assumed that individuals with Down syndrome and other disabilities cannot learn or make informed choices making them poor candidates for organ transplants. Early

intervention starting at birth, special education supports, and access to general education curriculum has debunked this assumption and now you will find individuals with Down syndrome attending high school and college, graduating, and living independently. Tools like supported decision making, limited guardianships, and advanced directives make it possible to achieve informed consent for medical procedures. Providing accommodations improves understanding and follow-through after medical interventions.

Our family faced a serious CHD with our daughter, which required open heart surgery at 5 months. I worried about whether or not we would face any discrimination due to her diagnosis of Down syndrome in getting her adequate care and heart surgery. It was a new journey for us and I had many worries. We had excellent care and coverage and the heart repair has lasted for twenty-three years. I breathe a sigh of relief every time we see the cardiologist, but I know that at any time her cardiac status could change. I personally understand the fear.

Our organization exists to assure that individuals with Down syndrome, no matter what age, get a fair shot to earn, learn, and belong. We see the passage of SB 2302 as furthering that work.

Thank you and I would be willing to answer any questions.

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Executive Director  
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