2023 SENATE JUDICIARY

SB 2302

2023 SENATE STANDING COMMITTEE MINUTES

Judiciary Committee
Peace Garden Room, State Capitol

SB 2302
2/1/2023

A bill relating to prohibiting discrimination in the organ transplant process.

10:29 AM Chairman Larson opened the meeting.

Chairman Larson and Senators Myrdal, Luick, Estenson, Braunberger and Paulson are present.

Discussion Topics:

- Discrimination
- Downs Syndrome
- Organ donors
- Organ recipients

10:30 AM Senator Terry Wanzek introduced the bill and provided written testimony #18497.

10;38 AM Gail Wanzek spoke in favor of the bill.

10:40 AM Jessica Lee spoke in favor of the bill and provided written testimony #18222.

10:43 AM Annalise Duffy spoke in favor of the bill and provided written testimony #18116.

10:49 AM Taya Spelhaug testified in favor of the bill and provided written testimony #18408.

10:54 AM Roxanne Romanick, Executive Director, Designer Genes of North Dakota, testified in favor of the bill and provided written testimony #18389.

10:58 AM Kristen Dvorak, Executive Director of The Arc or North Dakota, testified in favor of the bill and provided written testimony #18346.

11:02 AM Christopher Dodson, Executive Director, North Dakota Catholic Conference, spoke in favor of the bill.

11:07 AM Daniel Gulya Attorney with Protection and Advocacy testified in favor of the bill and provided written testimony #18388.

11:13 AM Donna Wanzek spoke in favor of the bill.

11:15 AM Chairman Larson closed the meeting.

Rick Schuchard, Committee Clerk

2023 SENATE STANDING COMMITTEE MINUTES

Judiciary Committee
Peace Garden Room, State Capitol

SB 2302
2/1/2023

A bill relating to prohibiting discrimination in the organ transplant process.

2:46 PM Chairman Larson opened the meeting.

Chairman Larson and Senators Braunberger, Paulson, Sickler, Luick, Estenson and Myrdal are present.

Discussion Topics:
- Bill status
- Discrimination
- Downs Syndrome
- Organ doners
- Organ recipients

2:46 PM The committee had discussion on the current stratus of the bill.

2:50 PM Chairman Larson closed the meeting.

Rick Schuchard, Committee Clerk

2023 SENATE STANDING COMMITTEE MINUTES

Judiciary Committee
Peace Garden Room, State Capitol

SB 2302
2/7/2023

A bill relating to prohibiting discrimination in the organ transplant process.

10:49 AM Chairman Larson opened the meeting.

Chairman Larson and Senators Myrdal, Luick, Estenson, Sickler, Braunberger and Paulson are present.

Discussion Topics:
- Committee action

10:50 AM Senator Myrdal moved to Do Pass the bill. Motion seconded by Senator Estenson.

10:50 AM Roll call vote was taken.

Senators	Vote
Senator Diane Larson	Y
Senator Bob Paulson	Y
Senator Jonathan Sickler	Y
Senator Ryan Braunberger	Y
Senator Judy Estenson	Y
Senator Larry Luick	Y
Senator Janne Myrdal	Y

Motion passes 7-0-0.

Senator Myrdal will carry the bill.

This bill does not affect workforce development.

10:52 AM Chairman Larson closed the meeting.

Rick Schuchard, Committee Clerk

REPORT OF STANDING COMMITTEE

SB 2302: Judiciary Committee (Sen. Larson, Chairman) recommends **DO PASS** (7 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2302 was placed on the Eleventh order on the calendar. This bill does not affect workforce development.

2023 HOUSE HUMAN SERVICES

SB 2302

2023 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Pioneer Room, State Capitol

HCR 2302
3/1/2023

Relating to prohibiting discrimination in the organ transplant process.

Chairman Weisz called the meeting to order at 3:45 PM.

Chairman Robin Weisz, Vice Chairman Matthew Ruby, Reps. Karen A. Anderson, Mike Beltz, Clayton Fegley, Kathy Frelich, Dawson Holle, Dwight Kiefert, Carrie McLeod, Brandon Prichard, Karen M. Rohr, Jayme Davis, and Gretchen Dobervich. Rep. Todd Porter not present.

Discussion Topics:

- Medical criteria
- Amendment
- Individuals with down syndrome
- Heart transplants
- Limited guardianship

Kirsten Dvorak, Executive Director of the ARC of North Dakota, supportive testimony (#23431).

Additional written testimony:

Annalise Duffy. North Dakota citizen and parent, supportive testimony (#21278) (#21347).

Roxane Romanick, Executive Director for Designer Genes of North Dakota, Inc., supportive testimony (#21425).

Taya Spelhaug, North Dakota citizen and parent, supportive testimony (#21447).

Nick Leto, Manager of State Government Relations with the National Down Syndrome Society, supportive testimony (#21523).

Sierra Heitkamp, Legislative Director for North Dakota Right to Life, supportive testimony (#21555).

Jessica Lee, North Dakota citizen, supportive testimony (#21559).

Chairman Weisz adjourned the meeting at 3:51 PM.

Phillip Jacobs, Committee Clerk

2023 HOUSE STANDING COMMITTEE MINUTES

Human Services Committee
Pioneer Room, State Capitol

HCR 2302
3/1/2023

Relating to prohibiting discrimination in the organ transplant process.

Chairman Weisz called the meeting to order at 4:21 PM.

Chairman Robin Weisz, Vice Chairman Matthew Ruby, Reps. Karen A. Anderson, Mike Beltz, Clayton Fegley, Kathy Frelich, Dawson Holle, Dwight Kiefert, Carrie McLeod, Todd Porter, Brandon Prichard, Karen M. Rohr, Jayme Davis, and Gretchen Dobervich. All present.

Discussion Topics:

- Committee work

Chairman Weisz called for a discussion on SB 2302.

Rep. Frelich moved a do pass on SB 2302.

Seconded by Rep. Dobervich.

Roll Call Vote:

Representatives	Vote
Representative Robin Weisz	Y
Representative Matthew Ruby	Y
Representative Karen A. Anderson	Y
Representative Mike Beltz	Y
Representative Jayme Davis	Y
Representative Gretchen Dobervich	Y
Representative Clayton Fegley	Y
Representative Kathy Frelich	Y
Representative Dawson Holle	Y
Representative Dwight Kiefert	Y
Representative Carrie McLeod	Y
Representative Todd Porter	Y
Representative Brandon Prichard	Y
Representative Karen M. Rohr	Y

Motion carries 14-0-0.

Carried by Rep. Holle.

Chairman Weisz adjourned the meeting at 4:26 PM.

Phillip Jacobs, Committee Clerk

REPORT OF STANDING COMMITTEE

SB 2302: Human Services Committee (Rep. Weisz, Chairman) recommends **DO PASS** (14 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2302 was placed on the Fourteenth order on the calendar.

TESTIMONY

SB 2302

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

annaliseduffy@gmail.com

SB 2303 Re: Organ donation non-discrimination

Chairwoman Larson and members of the Senate Judiciary Committee, my name is Jessica Lee and I am here to speak in support of Senate Bill 2303, which provides protections against discrimination of organ transplants for individuals with disabilities.

The National Center for Disabilities, an independent Federal Agency, reported that 44% of organ transplant centers self-reported that they would not add a child with some level of neurodevelopmental disability to the organ transplant list. Eighty-five percent reported that they would consider the disability as a factor in deciding whether or not to place an individual on the transplant list.

Around the world, Down syndrome, for example, is viewed far different from here in the United States. For anyone that has had the opportunity to experience a friend with Down syndrome, you know they are pure sunshine. Unfortunately, in many Scandinavian countries, very few babies are born with Down syndrome. In Iceland, only 2-3 babies are born each year. After positive pre-natal testing, the pregnancies are terminated. With an increasing number for foreign medical professional in the United States, it is important that we ensure lifesaving treatments are not denied as an option, based on certain diagnoses.

Volunteering at the North Dakota Special Olympics has afforded me the opportunity to meet some of the strongest, bravest and happiest people on earth. I'll never forget the day I met Gail. She was excited to tell me about her competition and got even more excited to learn I worked in Politics. “You must know my brother, TERRY WANZEK!” I smiled and said, “of course, everyone knows Senator Wanzek!” We hugged and took a picture.

Almost a year and a half ago, a friend through CrossFit, Annalise Duffy, whom you'll meet shortly, held a special workout as a fundraiser for a family she met through her network that had lost a baby who desperately needed a transplant, but was denied. I knew if there was anything we could do to prevent a similar situation in North Dakota, Senator Wanzek would be our champion. Of course, without hesitation, he agreed and we'd like to thank both he and Gail for their great work on this bill.

Absent federal legislation, which has been introduced led by Senator Marco Rubio, states are enacting their own non-discrimination laws. North Dakota has the opportunity to join the 34 states that have already provided protection for these great Americans. Thank you all for your service to our state and I hope you will consider a do-pass recommendation for Senate Bill 2303.

Thank you,

Jessica Lee
jessicaleend@gmail.com

The Arc.
North Dakota

Senate
SB 2302
Testimony Kirsten Dvorak
February 1st, 2023

Senator Larson and committee members. I am Kirsten Dvorak, Executive Director of The Arc of North Dakota; we have six chapters throughout the state of North Dakota that advocate on behalf of individuals with intellectual and/or developmental disabilities (IDD) for full inclusion in their community of choice.

The Arc of North Dakota Supports SB 2302 for the following,

1. It upholds the principles of equality and non-discrimination: Everyone, regardless of their disabilities, should have equal access to medical procedures such as organ transplantation.

2. It is based on medical criteria: The provision of an anatomical gift should only be based on medical considerations, not the individual's disability.

3. It promotes the well-being of individuals with disabilities: By removing discrimination in the organ transplant process, individuals with disabilities will have equal access to life-saving procedures, improving their quality of life and overall well-being.

4. It aligns with the Americans with Disabilities Act (ADA): This statement supports the principles of the ADA, which prohibits discrimination against individuals with disabilities in all areas of life, including medical procedures.

However, The Arc of North Dakota asks that North Dakota adopt a nondiscrimination health coverage such as that of Oklahoma’s Nondiscrimination in Health Care Coverage Act for disabilities for the following:

1. Promotes Equality and Fairness: The act promotes equality and fairness in health care by ensuring that people with disabilities are not discriminated against regarding access to health care coverage. This means that people with disabilities have the same opportunities as others to receive the care they need, regardless of their disability.

2. Reduces Health Disparities: People with disabilities often face healthcare barriers, leading to health outcomes disparities. The Nondiscrimination in Health Care Coverage Act for disabilities addresses these disparities by ensuring that people with disabilities receive equal coverage for their health care needs.

3. Protects Health and Well-being: People with disabilities often require more specialized healthcare services and treatment than those without disabilities. The Nondiscrimination in Health Care Coverage Act for disabilities ensures that people with disabilities have access to the care they need to maintain their health and well-being.

4. Protects the Rights of People with Disabilities: People with disabilities have the right to be treated with dignity and respect. The Nondiscrimination in Health Care Coverage Act for disabilities helps to protect these rights by ensuring equal access to health care coverage.

5. Supports Independent Living: Accessing comprehensive and appropriate health care can help people with disabilities live independently and participate in their communities. The Nondiscrimination in Health Care Coverage Act for disabilities supports independent living by providing equal access to health care.

Overall, the Nondiscrimination in Health Care Coverage Act for disabilities is a positive step towards promoting equality, reducing health disparities, protecting the health and well-being of people with disabilities, and supporting independent living. North Dakota should adopt this act to ensure that people with disabilities receive the care they need to lead healthy and fulfilling lives.

Kirsten Dvorak
701-222-1854

PROTECTION & ADVOCACY PROJECT
400 EAST BROADWAY, SUITE 409
BISMARCK, ND 58501-4071
701.328.2950

Senate Judiciary Committee
Senate Bill 2302 – February 1, 2023
Testimony of Daniel Gulya, P&A Attorney

The North Dakota Protection and Advocacy Project (P&A) protects the human, civil and legal rights of people with disabilities. The agency's programs and services seek to make positive changes for people with disabilities where we live, learn, work and play.

P&A supports SB 2302 as a civil rights protection in the organ transplantation process. The entities that organize organ transplantation explicitly bar discrimination on the basis of political influence, national origin, ethnicity, sex, religion, or financial status. Disability, however, is not included in that list.

Transplant programs often use additional nonmedical evaluation of patients for transplantation. This allows subjective metrics that treat people with disabilities as less desirable transplant recipients. Because people with disabilities have continued to face discrimination in the allocation of organs for transplantation, over 20 other states including South Dakota and Montana have adopted additional protections in their state laws.

P&A's belief is that a person's disability should only be considered to the extent it expressly impairs a successful transplantation. Medical decisions should be made on a medical basis.

As this bill ensures that North Dakota will remain at the forefront of those states that treat each citizen as equal under the law, P&A requests your DO PASS vote for this bill.

Thank you.

DESIGNER GENES
A·DOWN·SYNDROME·SUPPORT·NETWORK

SB 2302

Senate Judiciary
Wednesday, February 1, 2023
Senator Diane Larson, Chair

Chair Larson and Members of the Senate Judiciary 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.

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.

Roxane Romanick 701-391-7421
Executive Director roxane@designergenesnd.com
Designer Genes of ND, Inc.

Senate Bill 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.

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 makers 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.[1] 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

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

Testimony on Senate Bill 2302

Good morning Madam Chair Senator Larson and members of the Senate Judiciary Committee. My name is Terry Wanzek, State Senator representing District 29 in ND. Im here today to introduce SB 2302 to your committee. It is a simple, concise, self-explanatory bill, and only one page long. It simply states that no one can discriminate, at any point in an organ transplant process, against a recipient of an organ transplant based solely on a mental or physical disability that they may have. I am not aware that this is an issue in our state or that there are cases where this happens. But I am aware of the fact, that all our surrounding states have similar language protecting against discrimination in an anatomical gift situation. Matter of fact this language is almost identical to SD's language. We are taking a proactive approach with this bill, in clarifying that our law, will not allow this type of discrimination.

Now, I have a special person to introduce to you. I'd like you to meet my sister Gail, who has Down syndrome. Gail is the baby in our family. She has been a family member for 52 years. She came to us when she was 9 months old, from Grafton, when Judge Van Sickle ordered the Grafton state school to find families for their population. She has been with us ever since, growing up on the farm.

I cannot express it enough; how much love Gail has given to our family. Gail is a highly valued person in our family. Of all my 5 siblings, Gail is the one who never forgets birthdays, anniversaries, her niece and nephews' birthdays and other special events. She taught us about her disability, she opened our eyes, and helped us understand the struggles with living a life with disability. She has shown us that she is a person, with feelings and love for others. She has also shown our family that people like her have value and purpose in life, when given opportunities and loved. We, my parents, siblings and spouses, nieces and nephews, treat her no differently than any of the other family members. Today Gail lives on her own in an apartment in Jamestown, with family nearby, and is employed at UJ.

SB 2302

Relating to prohibiting discrimination in the organ transplant process.

Chairwoman Lee, members of the House Committee and fellow Citizens of North Dakota. I'm writing to speak in support 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.

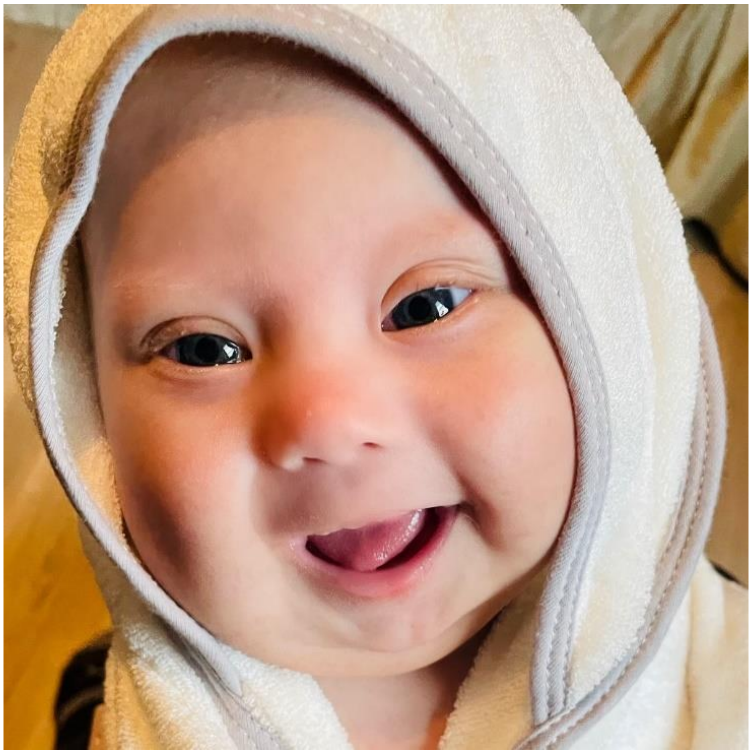
I thank you for all your time and service you dedicate to the State of North Dakota and its people. My contact information provided in this written testimony, and I am more than happy to answer any questions you have now, or that surface later.

Thank you.

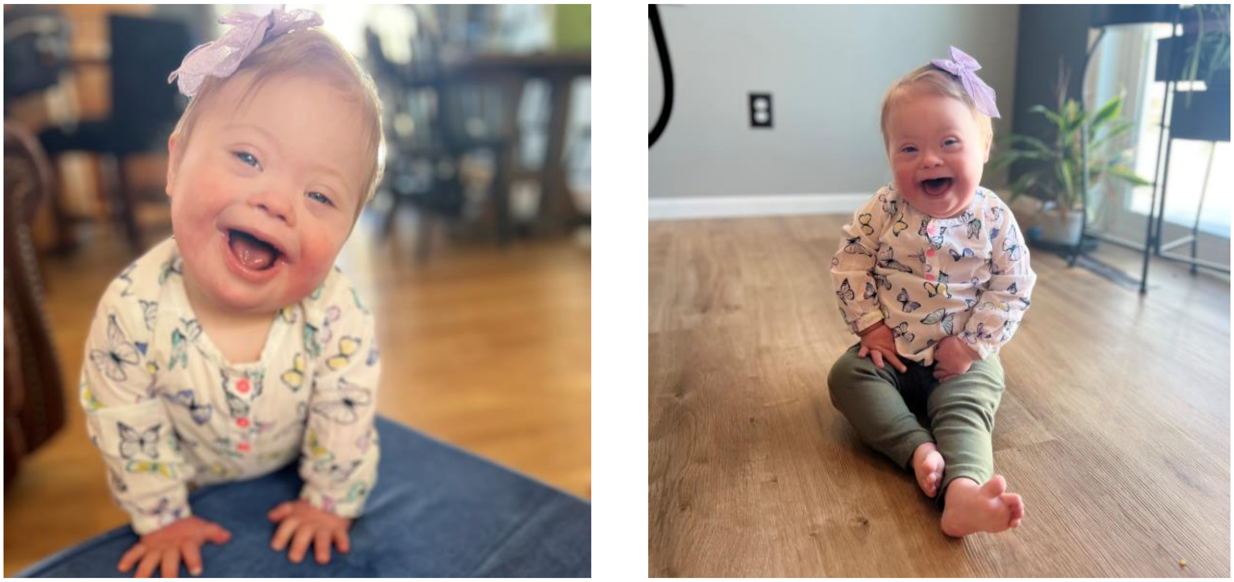
Annalise Duffy

annaliseduffy@gmail.com

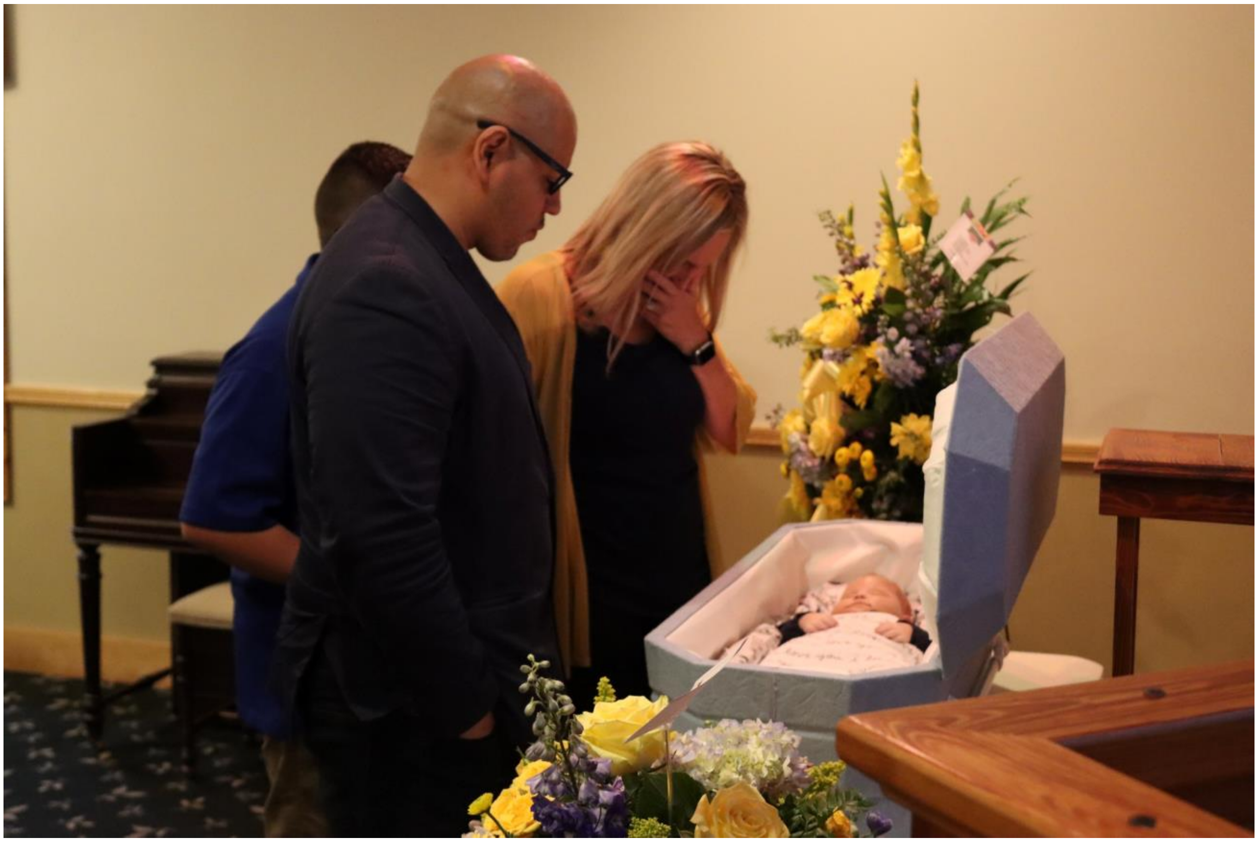
Lakyn at 3 months



Zion at 3 months



Lakyn now, at 20 months



Zion, and his family, at his Funeral (10/8/21)

SB 2302

Relating to prohibiting discrimination in the organ transplant process.

Chairwoman Lee, members of the House Committee and fellow Citizens of North Dakota. I'm writing to speak in support 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.

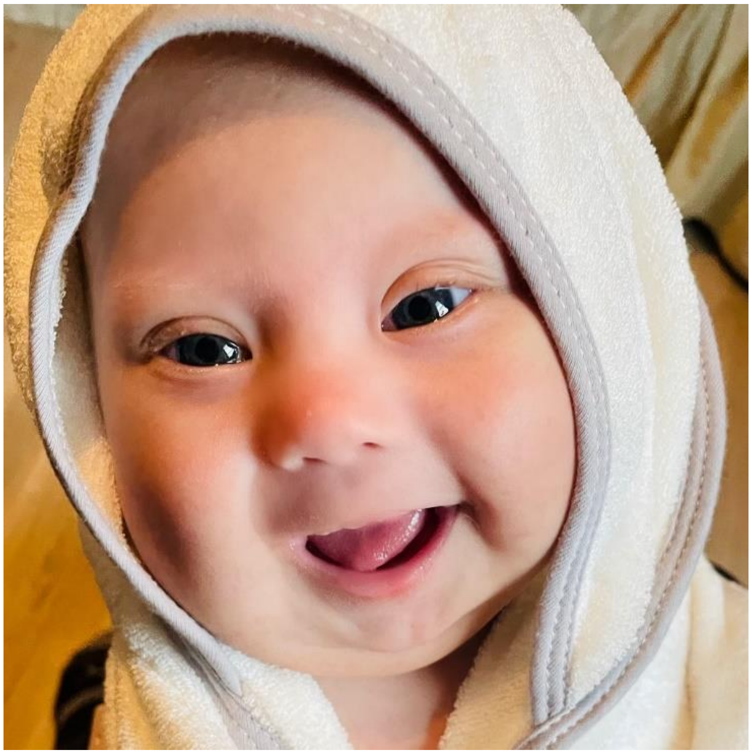
I thank you for all your time and service you dedicate to the State of North Dakota and its people. My contact information provided in this written testimony, and I am more than happy to answer any questions you have now, or that surface later.

Thank you.

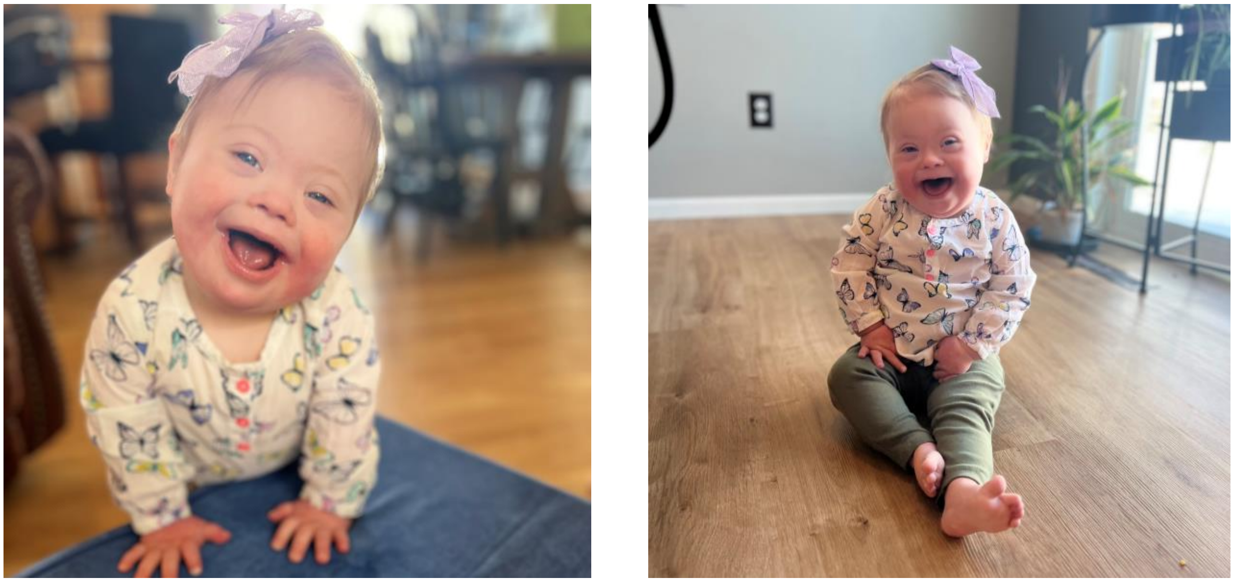
Annalise Duffy

annaliseduffy@gmail.com

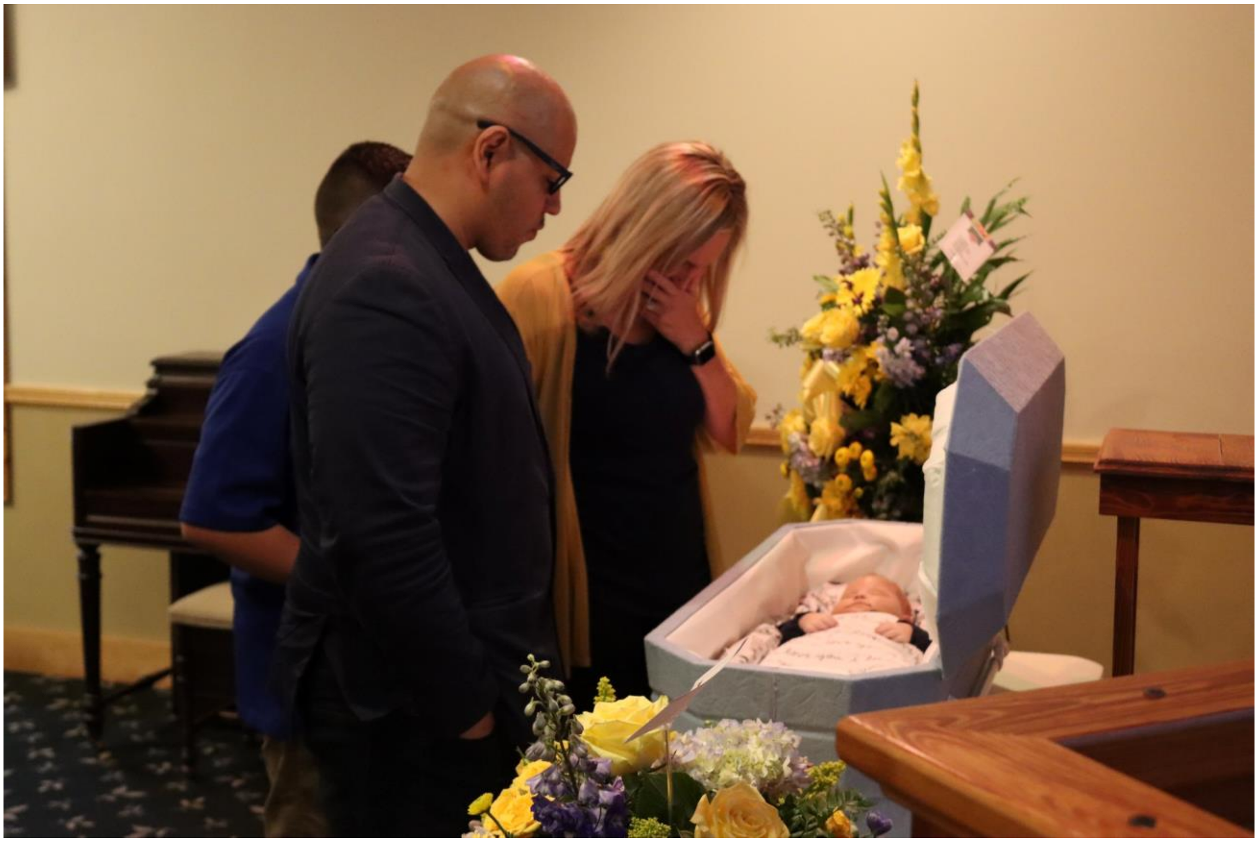
Lakyn at 3 months



Zion at 3 months



Lakyn now, at 20 months



Zion, and his family, at his Funeral (10/8/21)

DESIGNER GENES
A·DOWN·SYNDROME·SUPPORT·NETWORK

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.

Roxane Romanick 701-391-7421
Executive Director roxane@designergenesnd.com
Designer Genes of ND, Inc.

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 makers 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.[1] 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

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

national down syndrome society
ndss

March 1, 2023
Re: SB 2302
Dear Members of the House Human Services Committee,

As the leading human rights organization for all individuals with Down syndrome, the National Down Syndrome Society (NDSS) supports the passage of SB 2302, which will promote health equity throughout the organ transplant system for people with disabilities.

NDSS also strongly encourages adding an enforcement and expedited review section to SB 2302. An enforcement section will guarantee that an individual who feels they are being discriminated against has a legal course of action to correct the situation. An expedited review section would direct a court to give priority to those affected on the docket and an expedited review. Organ transplantation is a very time sensitive process, and this wording is necessary to ensure individuals receive the care they need.

Despite existing civil rights protections, individuals with Down syndrome and other disabilities continue to face both willful and unintended discrimination in organ transplantation, limiting their access to health care when they need it most. At the same time, healthcare providers need clarity and guidance about how to account for and accommodate disability in their practice.

There are currently laws against organ transplant discrimination in 36 states. It is time for the state of North Dakota to follow suit.

NDSS envisions a world in which all people with Down syndrome could enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities. We hope that the North Dakota State Legislature shares our commitment to eliminating discrimination based on disability. Thank you for your leadership on this important piece of legislation.

Sincerely,

Nick Leto
National Down Syndrome Society
Manager of State Government Relations
nleto@ndss.org

#21555

North Dakota
Right to LIFE

Chairman Weisz and Members of the House Human Services Committee –

My name is Sierra Heitkamp and I am the Legislative Director for North Dakota Right to Life. I am here today to represent the interests and legislative initiatives of our thousands of members across the state of North Dakota.

Today we have before us SB 2302 which is intended to protect those most vulnerable in the state of North Dakota from discrimination. The bill is simple and it states, “[a] person may not discriminate against a recipient at any point in the organ transplant process, solely on the basis of the recipient's mental or physical disability, unless the disability has been adequately determined to be medically significant to the provision of an anatomical gift.”

At NDRL, our mission is to protect those most vulnerable from conception to natural death. Those diagnosed with physical or mental disability should be allowed the same opportunity as someone without a similar diagnosis when it comes to a life saving organ transplant.

Today, I ask this committee to stand with those most vulnerable and I ask for a **Do Pass Recommendation on SB 2302** in order to solidify the values of North Dakotans.

Thank you for your time today and I am available by phone or email to answer any questions you may have.

Sincerely,

Sierra M Heitkamp

Sierra M Heitkamp
NDRL Legislative Director

☎ (701) 955-8239 ✉ office@ndrl.org P.O. Box 1325, Williston, ND 58801

SB 230 Re: Organ donation non-discrimination

Chairman Weisz and members of the House Human Services Committee, my name is Jessica Lee and I am here to speak in support of Senate Bill 2303, which provides protections against discrimination of organ transplants for individuals with disabilities.

The National Center for Disabilities, an independent Federal Agency, reported that 44% of organ transplant centers self-reported that they would not add a child with some level of neurodevelopmental disability to the organ transplant list. Eighty-five percent reported that they would consider the disability as a factor in deciding whether or not to place an individual on the transplant list.

Around the world, Down syndrome, for example, is viewed far different from here in the United States. For anyone that has had the opportunity to experience a friend with Down syndrome, you know they are pure sunshine. Unfortunately, in many Scandinavian countries, very few babies are born with Down syndrome. In Iceland, only 2-3 babies are born each year. After positive pre-natal testing, the pregnancies are terminated. With an increasing number for foreign medical professional in the United States, it is important that we ensure lifesaving treatments are not denied as an option, based on certain diagnoses.

Volunteering at the North Dakota Special Olympics has afforded me the opportunity to meet some of the strongest, bravest and happiest people on earth. I'll never forget the day I met Gail. She was excited about her competition and got even more excited to learn I worked in Politics. "You must know my brother, TERRY WANZEK!" I smiled and said, "of course, everyone knows Senator Wanzek!" We hugged and took a picture.

Almost a year and a half ago, a friend through CrossFit, Annalise Duffy, whom you'll meet shortly, held a special workout as a fundraiser for a family she met through her network that had lost a baby who desperately needed a transplant, but was denied. I knew if there was anything we could do to prevent a similar situation in North Dakota, Senator Wanzek would be our champion. Of course, without hesitation, he agreed and we'd like to thank both he and Gail for their great work on this bill.

Absent federal legislation, which has been introduced led by Senator Marco Rubio, states are enacting their own non-discrimination laws. North Dakota has the opportunity to join the 34 states that have already provided protection for these great Americans. Thank you all for your service to our state and I hope you will consider a do-pass recommendation for Senate Bill 2302.

Thank you,

Jessica Lee
jessicaleend@gmail.com

The Arc.
North Dakota

House Human Services
SB 2302
Testimony Kirsten Dvorak
February 1st, 2023

Rep. Weiz and committee members. I am Kirsten Dvorak, Executive Director of The Arc of North Dakota; we have six chapters throughout the state of North Dakota that advocate on behalf of individuals with intellectual and/or developmental disabilities (IDD) for full inclusion in their community of choice.

The Arc of North Dakota Supports SB 2302 for the following,

1. It upholds the principles of equality and non-discrimination: Everyone, regardless of their disabilities, should have equal access to medical procedures such as organ transplantation.

2. It is based on medical criteria: The provision of an anatomical gift should only be based on medical considerations, not the individual's disability.

3. It promotes the well-being of individuals with disabilities: By removing discrimination in the organ transplant process, individuals with disabilities will have equal access to life-saving procedures, improving their quality of life and overall well-being.

4. It aligns with the Americans with Disabilities Act (ADA): This statement supports the principles of the ADA, which prohibits discrimination against individuals with disabilities in all areas of life, including medical procedures.

Kirsten Dvorak
701-222-1854