



MARK BORN

STATE REPRESENTATIVE • 39TH ASSEMBLY DISTRICT

Testimony on Assembly Bill 539

*Assembly Committee on Health
October 7, 2021*

Chairman Sanfelippo, and members of the Assembly Committee on Health, thank you for allowing me to speak in favor of Assembly Bill 539, which prohibits individuals from being denied an organ transplant on the basis of a disability.

We all know that some of the best pieces of legislation come directly from our constituents. Last year, I was contacted by a constituent of mine from Brownsville who wanted to share his family's story about their youngest son, Malix. Malix was born in 2016 with a major heart defect. Malix also happens to have Down syndrome. When discussing care options with their doctor, they were told that although a heart transplant would be the best option for their son, he was ineligible because of his disability. Malix's parents are here with me today to speak specifically to their story, so I won't go into too much detail. Instead, I would like to talk about the basis of this bill, why it's needed, and why it's important that we follow the lead of states across the country and make it law in Wisconsin.

Current law broadly prohibits individuals with disabilities from being denied an organ transplant. Similar to other areas of the law, vague language allows for these instances to still occur. For example, medical professionals can deny an organ transplant for an individual with a disability if they believe the individual can't comply with postoperative care. These misconceptions can lead to contraindications- which is an indication that a particular candidate for an organ transplant is unsuitable for the procedure.

Assembly Bill 539 clarifies that an individual's ability to comply with postoperative care cannot be considered a reason to deny an organ transplant. It also puts in place a procedure with expedited priority review for these types of situations, considering the timeliness and sense of urgency can be a matter of life and death for these patients. Over half the states across the country have passed very similar legislation, including our Midwestern neighbors of Minnesota, Illinois, Iowa, Missouri, Indiana and Ohio.

Organ transplants save lives- and individuals with disabilities are valuable members of our communities. Their lives are just as valuable to those without disabilities, and they shouldn't be discriminated against when considering these lifesaving procedures. Supporting Assembly Bill 539 clarifies that these individuals should be given an equal opportunity for the transplant process and puts a stop to these devastating situations.

I hope you can join me in supporting this critical piece of legislation.

**AB 539 – Non-Discrimination in Access to
Organ Transplantation and Anatomical Gifts
Assembly Committee on Health
October 7, 2021
POSITION: SUPPORT**

The Down Syndrome Association of Wisconsin, its 5,500 bipartisan stakeholder families across Wisconsin, its 11 Chapter locations across the state, as well as The ARC Wisconsin, Disability Rights Wisconsin, the Wisconsin Board for People with Developmental Disabilities, Survival Coalition, Save IRIS, and with support from national organizations such as the National Down Syndrome Society, Autistic Self Advocacy Network, Autism Speaks, the Autism Society, the National Association of Councils on Developmental Disabilities, the National Down Syndrome Congress, National Fragile X Foundation, TASH, and Transplant Families all **strongly and enthusiastically support the passage of AB 539.**

Problem: Current law broadly prohibits individuals with disabilities from being denied organ transplantation, but various loopholes and vague language in the law allow these instances to still occur. For example, medical professionals can deny organ transplantation for an individual with a disability if they believe the individual can't comply with post-operative care, even if the individual has the necessary family support system to comply. Due to these loopholes, individuals with disabilities who are in dire need of an organ transplant can still be denied organ transplants in Wisconsin. This bill seeks to clarify the law to stop these unfortunate and frustrating situations from happening.


Example: Three-year-old Amelia Rivera of New Jersey went to the Children's Hospital of Philadelphia in critical need of a kidney transplant. Amelia's mother had offered her own kidney to save her daughter's life, and Amelia's treating specialists determined there was no medical reason not to approve the transplant. Nevertheless, Children's Hospital turned Amelia away because she had been diagnosed with Wolf-Hirschhorn syndrome, a genetic condition that causes intellectual disability. Fortunately, in the wake of tremendous public outcry, the hospital reversed its decision. Amelia received a successful kidney transplant and was afterward reported as "thriving and growing."

In addition, a survey of 88 transplant centers conducted by researchers at Stanford University found that 85% of pediatric transplant centers consider intellectual or developmental disability as a factor in their determinations of transplant eligibility at least some of the time. Fully 71% of heart programs surveyed "always" or "usually" considered ID/DD diagnoses when deciding eligibility for transplantation.¹

Solution: AB 539 will:

- **Clarify** that doctors, hospitals, transplant centers, and other health care providers are prohibited from denying access to necessary organ transplants solely on the basis of a qualified individual's disability.
- **Require** that health providers consider, in evaluating the likelihood of a transplant's success, the full range of supports available to help a person with a disability manage their post-operative care;

¹ Richards CT, Crawley La Vera M, Magnus D (2009). Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: Inconsistencies in standards across major pediatric transplant centers. *Pediatric Transplantation* 13:843–850.

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- **Include** a fast-track procedure for challenging discrimination to ensure that people in urgent need of an organ transplant can obtain timely resolutions to their claims.

The proposed legislation would clarify doctors' obligations to avoid discrimination and to consider available supports and services when deciding whether a patient can manage post-operative care. Doctors would still be able to consider a person's ability to follow post-operative care instructions, but would be required take into account supports (such as family help or professional caregivers) that the person can use to help them follow the treatment plan.

The legislation would also create an expedited process for resolving disputes so that people in medical crisis do not languish in the court system.

Over half of the states in the country have already passed very similar legislation, many of those being our Midwestern neighbors including Minnesota, Illinois, Iowa, Missouri, Indiana, and Ohio.

All of the organizations listed strongly support passage of AB 539.

The Down Syndrome Association of Wisconsin

The ARC Wisconsin

Disability Rights Wisconsin

Wisconsin Board for People with Development Disabilities

Survival Coalition

Save IRIS

National Down Syndrome Society

Madison Area Down Syndrome Society

DSAW-Fox Cities

DSAW-La Crosse

DSAW-Central Wisconsin

DSAW-Chippewa Valley

DSAW-Sheboygan Area

DSAW-Southeastern Wisconsin

DSAW-Green Bay

My name is Abby Nuoffer, I am 17 years old and have Down syndrome.

I have a really amazing life. I have tons of friends with and without Down syndrome. I can read, write, do complicated math by hand. I am in Taekwondo, basketball, baseball, bowling, and theater. I love having Down syndrome and I love my life!

Many of my friends with diverse abilities live in their own apartments, have multiple jobs and are valued members of their families and communities.

People with Down syndrome and other diverse abilities have been discriminated against throughout history. Did you know that in 1990 the average life-expectancy was 28 years old for a person with Down syndrome? That was because we weren't given fair and adequate medical treatment. Today our life-expectancy is 60! That's in large part because of people like you advocating for what's right!
Thank you!!

Your support of this bill is very important. If I get sick and need a lifesaving organ transplant, I need to have equal access to the care I deserve. I am very popular and well-loved! People need me!!

I look forward to your support of AB539. Thank you!



October 5, 2021

To the Honorable Members of the Assembly Committee on Health
Representative Sanfelippo (Chair)
Representative Summerfield (Vice-Chair)
Representative Wichgers
Representative VanderMeer
Representative Skowronski
Representative Murphy
Representative Magnafici
Representative Dittrich
Representative Rozar
Representative Moses
Representative Cabral-Guevara
Representative Subeck
Representative Riemer
Representative Anderson
Representative Vining
Representative S. Rodriguez

Re: Assembly Bill 539 relating to: prohibiting discrimination in organ transplantation on the basis of disability

Dear Honorable Members of the Assembly Committee on Health:

The Down Syndrome Association of Wisconsin, our 5,500 plus bipartisan stakeholder families across Wisconsin, and the undersigned organizations are writing to express our strong support for Assembly Bill 539 prohibiting discrimination in organ transplantation on the basis of disability. As organizations who work with people with disabilities who are often discriminated against for organ transplants, we are grateful for your leadership on this important issue.

Although federal and state laws prohibit organ transplant discrimination, people with disabilities are often denied equal access to organ transplants because of discriminatory assumptions that their lives are of poorer quality than those of people without disabilities, in addition to misconceptions about the ability of people with disabilities to comply with post-operative care. A study by Stanford University showed that 85 percent of pediatric transplant centers consider intellectual or developmental disabilities when determining eligibility for transplants. Additionally, 71 percent of heart programs also consider disabilities as a factor.¹

This crucial legislation clarifies that doctors, hospitals, transplant centers and other health care providers are prohibited from denying access to necessary organ transplants solely on the basis of a qualified individual's disability. Additionally, this bill requires that, when evaluating the likelihood of a transplant's success, health providers consider the full range of supports available to help a person with a disability manage their post-

¹ Richards CT, Crawley La Vera M, Magnus D. Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: Inconsistencies in standards across major pediatric transplant centers. *Pediatric Transplantation* 2009;13:843-850

operative care. The bill also includes a fast-track procedure for challenging discrimination to ensure that people in urgent need of an organ transplant obtain timely resolutions to their claims.

There are currently laws against organ transplant discrimination in at least 29 other states including our neighbors in Minnesota, Illinois, and Indiana. We encourage you to access the wide array of materials, research and support available at a national level for similar organ transplant discrimination bills by visiting the National Down Syndrome Society's resource page for this work: <https://www.ndss.org/programs/ndss-legislative-agenda/healthcare-research/nondiscrimination-in-organ-transplantation-laws-toolkit/>

Our organizations look forward to working with your offices to ensure the passage of this bill so people with disabilities across the country can have equal access to organ transplants and no longer face discrimination. This bill will save lives.

We want to express our sincerest gratitude and appreciation to those Representatives and Senators who have already signed on in support of this very important bill.

Thank you again for your leadership.

The Down Syndrome Association of Wisconsin
The ARC Wisconsin
Disability Rights Wisconsin
Wisconsin Board for People with Development Disabilities
Survival Coalition
Save IRIS
National Down Syndrome Society
Madison Area Down Syndrome Society
DSAW-Fox Cities
DSAW-La Crosse
DSAW-Central Wisconsin
DSAW-Chippewa Valley
DSAW-Sheboygan Area
DSAW-Southeastern Wisconsin
DSAW-Green Bay



Assembly Committee on Health
Wisconsin State Legislature
Binsfeld Office Building
2 East Main Street
Madison, WI 53703

Re: AB 539/ SB 538

Dear Chair Sanfelippo, Chair Summerfield and Members of the Assembly Committee on Health:

The National Down Syndrome Society supports and endorses the passage of AB 539/ SB 538, which prohibits discrimination against organ transplant recipient based on physical or mental disability.

NDSS is the largest nonprofit representing and advocating for people with Down syndrome and their families. With over 375 affiliate groups spanning across all 50 states, NDSS has worked tirelessly on the federal, state and local levels to break down barriers and create opportunities for individuals with Down syndrome to be included in all aspects of society and fulfill their hopes and dreams.

This bill will seek to affirm that the Wisconsin Legislature is committed to eliminating discrimination by ensuring that individuals with disabilities are not denied access to organ transplants based solely on their disability. A study by Stanford University showed that 85 percent of pediatric transplant centers consider intellectual or developmental disabilities when determining eligibility for transplants. Additionally, 71 percent of heart programs also consider disabilities as a factor.¹

There are currently laws prohibiting organ transplant discrimination in 29 states, with legislation currently pending in one state. Advancing science and medicine has changed the life expectancy of an individual with Down syndrome from 25 years old in 1983 to 60 years old today. Individuals with Down syndrome are living longer, healthier lives, attending postsecondary education programs, obtaining employment, getting married, living independently and are productive members of their local communities.

We hope that Wisconsin will pass this legislation to eliminate discrimination for organ

transplants on the basis of disability. This bill will save lives. Thank you for your leadership with regard to this important piece of legislation.

Sincerely,

Nicole Patton
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National Down Syndrome Society
646-797-6855
npatton@ndss.org

¹Richards CT, Crawley La Vera M, Magnus D. Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: Inconsistencies in standards across major pediatric transplant centers. *Pediatric Transplantation* 2009;13:843–850