

February 23, 2021

The Honorable Zack Stephenson
509 Rev. Dr. Martin Luther King Jr. Blvd.
St Paul, MN 55155

RE: HF 1080 Letter of Support

Dear Chair Stephenson, Vice Chair Kotyza-Witthuhn, and members of the House Commerce Finance and Policy Committee:

On behalf of all the people we serve in Minnesota, I am writing to ask for your support for [HF 1080](#), known as Jonny's Law, which would prohibit discrimination against a potential organ transplant recipient based solely on their physical, developmental or intellectual disability.

The American Kidney Fund (AKF), based in Rockville, Maryland is the nation's leading nonprofit organization working on behalf of the 37 million Americans living with kidney disease, and the millions more at risk, with an unmatched scope of programs that support people wherever they are in their fight against kidney disease, from prevention through transplant. With programs that address early detection, disease management, financial assistance, clinical research, innovation and advocacy, no kidney organization impacts more lives than AKF. We are also one of the nation's top-rated nonprofits, investing 97 cents of every donated dollar in programs, AKF has also received the highest 4-Star rating from Charity Navigator for 19 consecutive years, as well as the Platinum Seal of Transparency from Guidestar.

People with disabilities may face discrimination when seeking potentially life-saving organ transplants. While there are federal protections in place from the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973, people with disabilities are still discriminated against when their eligibility for an organ transplant is being determined. Discrimination often happens at the point where someone is referred for evaluation by a transplant center and before they are placed on the official transplant waiting list. For example, there is a Stanford University study showing that 85 percent of pediatric transplant centers consider intellectual and/or developmental disabilities when determining eligibility for transplants.¹

Additionally, some providers have a misconception that people with disabilities are unable to manage post-operative treatment or would benefit from a live-saving transplant. It is also assumed that people with disabilities have a lower quality of life than those without disabilities. This is simply not true.

This bill would prohibit denials for the sole reason of disability. Mental or physical disability could not be used as a reason to deny transplant eligibility, surgery, medical care, or insurance coverage. Disability also could not be used as the sole reason for moving an individual to a lower-priority position on a transplant waiting list. Nor could an individual's inability to comply with post-transplant medical requirements be used as a reason for denial, if he or she has support from others who can assist in that process.

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.

At the American Kidney Fund, we believe that no transplant should be denied on the grounds of disability alone. All patients who need to receive a kidney transplant, regardless if they have a disability or not, should be eligible and get the same treatment to receive a transplant as someone who does not have a disability. For these reasons, we are hopeful for your support of this and any future legislation that could help improve the lives of those fighting kidney disease.

Thank you again for your leadership and for your consideration of this important issue. If you have any questions, please feel free to contact me directly at any time.

Sincerely,



Lindsay Gill

Associate Director, State Policy and Advocacy

(240) 292-7062 direct | (210) 860-7407 cell

lgill@kidneyfund.org
