

March 8, 2018

Chairman Burke, Vice-Chair Beagle, Ranking Member Tavares, and Members of the Health, Human Services and Medicaid Committee:

Thank you for allowing me to provide proponent testimony on House Bill 332, which would ensure that individuals with disabilities will not be banned from an organ transplant waitlist solely based on their disability.

My name is Courtney Hansen. I'm a private citizen from the 42nd district and a disability advocate. I approached my representative, Niraj Antani, earlier this year after learning that individuals with disabilities face significant barriers to accessing life-saving organ transplants. The Americans with Disability Act provides broad protections against discrimination for people with disabilities, but often families don't realize they have recourse or the federal courts system takes too long for their loved one who may need a life-saving transplant urgently. During these distressing times, families often don't know how to navigate the health system and advocate for their child.

H.B. 332 would address two problems. First it would set clear rules that organ transplants cannot be denied purely on the basis of disability, unless there's something about the disability that would make the transplant unsuccessful. Second, although the law has no penalty clause, the patient or their family can seek legal recourse to ensure their right to an organ transplant is secured.

Organ transplant discrimination is often hard to prove. Medical staff may decide not to refer a person with a disability to an organ transplant center. Other times they argue the individual would not be able to follow post-transplant medical regimen, even if they have a support team in place. In fact, studies show that individuals with intellectual disabilities often do as good or better than typical patients with post-transplant care because of their support system.

A 2008 survey conducted by researchers at Stanford University found that 85% of pediatric transplant centers consider neuro-developmental status as a factor in their eligibility process at least some of the time. In the same study, 62% of the centers stated that their decisions for eligibility based on disability was informal, making discrimination hard to prove.

Some transplant centers may not deny anyone based on a disability, but instead the denial came earlier on from nurses or doctors. This bill would address a collective system starting at the hospital where the patient is first seen. The legislation would make it clear that no one should be denied life-saving transplants based solely on their disability.

Sometimes discrimination is overt. At a couple months old, **Ellie Ward, from Sidney, Ohio** needed a heart transplant to save her life. When her mother, Jackie Ward, inquired about the procedure, her doctor at Cincinnati Children's said she wouldn't qualify for an organ transplant because she has Down syndrome. Jackie Ward understood that other medical factors may prohibit her daughter from the procedure, but Down syndrome shouldn't be part of the equation. The medical staff at Cincinnati Children's released Ellie to live out what was left of her potentially short life. Still, Jackie Ward refused to go home and watch her daughter die. She searched the country for the top cardio-thoracic surgeons and found one at

Boston Children's, who offered to treat her daughter. Today, Ellie is a thriving 3-year-old preschooler. Her family says "she loves openly and brings joy to each day."

Ohio is not alone in this type of discrimination. In fact, H.B. 332 is based on legislation that has passed unanimously in seven other states (Kansas, Pennsylvania, Oregon, Maryland, California, New Jersey, and Massachusetts). Delaware currently has a bill working its way through the state legislature. Most of these states had little opposition from transplant centers after the bill was explained to them.

Ohio H.B. 332 is modeled after Maryland's law. After helping Rep. Antani draft Ohio's bill, I realized that Oregon's legislation (passed in 2017) actually has stronger language for timely recourse for patients. I encourage the committee to amend H.B. 332 to include more specific language on legal recourse. Oregon's bill states the following: ***The circuit court shall give priority on its docket and expedited review to a claim brought under this section.*** Often patients that need life-saving organs face a short timeline. This stronger language would ensure their right to an organ transplant is secured in a timely manner. Remember, patients cannot sue for punitive damages under this bill.

As a mother to twins, one with Down syndrome, I could never imagine being faced with the sort of discrimination the Ward family endured. H.B. 332 clearly defines a human right, and ensures that families like the Ward's and my own can advocate for their child with a disability when they need it the most. A disability should not define a person's access to life-saving care. Adults and children with disabilities in need of an organ transplant should be afforded greater legal protection. Their lives are inherently worth saving. Thank you for your support of H.B. 332.

With High Regards,

Courtney Hansen
Miami Valley Down Syndrome Association
Advocacy Liaison
1100 Quail Run Drive
Dayton, Ohio 45458
courtneyj.hansen@gmail.com
(801) 641-6825

"Nondiscrimination in Organ Transplantation Laws and Toolkit." *NDSS*, 4 May 2017, www.ndss.org/Advocacy/Legislative-Agenda/Health-Care-Research/Nondiscrimination-in-Organ-Transplantation-Laws-Toolkit/.

Ne'eman, Ari, et al. "Organ Transplantation and People with I/DD: A Review of Research, Policy and Next Steps." *Autistic Self Advocacy Network*, ASAN, Mar. 2013, autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-Transplantation-Policy-Brief_3.18.13.pdf.

U.S. Rep. Michael, Honda. "2016 10 12 Members Letter-HHS OCR Organ Transplant Discrimination." Received by Jocelyn Samuels, 12 Oct. 2016. 30 Members of the U.S. House of Representatives sent a letter to the Department of Health and Human Services requesting the department issue guidance on organ transplantation discrimination as it relates to a protection under ADA. The department has yet to issue further guidance related to this problem.