



April 1, 2021

The Honorable Jaime Herrera Beutler
2352 Rayburn HOB
Washington, DC 20515

The Honorable Katie Porter
1117 Longworth HOB
Washington, DC 20515

Dear Congresswoman Herrera Beutler and Congresswoman Porter:

The National Down Syndrome Society (NDSS) and the undersigned organizations are writing to express our strong support for the *Charlotte Woodward Organ Transplant Discrimination Prevention Act (HR 1235)*. 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.

Despite federal protections, such as the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973, people with disabilities still face discrimination determining eligibility to receive organ transplants. Providers often have a misconception that people with disabilities, especially those with intellectual and developmental disabilities (ID/DD), are unable to manage complicated post-operative treatment. Providers may also assume that people with disabilities have a lower quality of life than those without disabilities and would not benefit from life-saving transplants.

This legislation is named for Charlotte Woodward, NDSS community outreach associate, who has Down syndrome and received a heart transplant in 2012. Since then, she has advocated tirelessly to ensure others with disabilities have the same access to organ transplants. 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

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

to help a person with a disability manage their post-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 the states of California, Delaware, Florida, Indiana, Iowa, Kansas, Louisiana, Maryland, Massachusetts, Missouri, New Jersey, Ohio, Oregon, Pennsylvania, Virginia and Washington.

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.

Thank you again for your leadership.

Sincerely,

Autism Self Advocacy Network

Autism Society of America

Autism Speaks

National Association of Councils on Developmental Disabilities

National Down Syndrome Congress

National Down Syndrome Society

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