



July 6, 2023

The Honorable Margaret Hassan
324 Hart Senate Office Building
Washington, DC 20510

The Honorable Marco Rubio
284 Russell Senate Office Building
Washington, DC 20510

The Honorable Kat Cammack
2421 Rayburn House Office Building
Washington, DC 20515

The Honorable Debbie Dingell
102 Cannon House Office Building
Washington, DC 20515

Dear Senator Hassan, Senator Rubio, Congresswoman Cammack, and Congresswoman Dingell:

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* (H.R. 2706/S. 1183). This legislation is named for Charlotte Woodward, NDSS education programs associate and an adult woman with Down syndrome who received a heart transplant in 2012. For more than a decade, she has advocated tirelessly to ensure others with disabilities have the same access to organ transplants. 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 existing civil rights protections, individuals with disabilities continue to face both willful and unintended discrimination in organ transplantation that threatens their ability to access health care when they need it most. A 2019 report from the National Council on Disability (NCD), an independent federal agency that advises Congress and the executive branch on disability policy issues, found that people with disabilities, especially intellectual disabilities, have been denied access to organs because of subjective judgements about the value of a life with a disability, assumptions about their quality of life, and misconceptions about their ability to comply with post-operative care. Furthermore, the report found that some organ transplant programs have policies that exclude people with disabilities as candidates for a transplant – some with categorical exclusions based on disability, refusing to even evaluate a person’s medical suitability for an organ transplant because of their disability.¹

The Charlotte Woodward Organ Transplant Discrimination Prevention Act upholds, clarifies, and builds upon rights established in the Americans with Disabilities Act of 1990, Sec. 504 of the Rehab Act, and Sec. 1557 of the Affordable Care Act to prohibit covered entities from determining that an individual is ineligible to receive a transplant, deny an organ transplant or related service, refuse to refer the individual to an organ transplant center, refuse to place an individual on a waiting list or decline insurance coverage for a transplant or related service based solely on the fact that the individual has a disability. This crucial bill also recognizes the importance of auxiliary aids and services, the ability of an individual’s support network to help with post-operative care, and the need for reasonable modifications to policies and procedures to make organ transplant systems and facilities more accessible to people with disabilities. At the same time, the bill respects the professional judgment of health care providers by clarifying how disability should properly be considered in an individualized treatment plan. Finally, this bill provides access to expedited review through the Office of Civil Rights at the Department of Health and Human Services and in a federal district court.

¹ National Council on Disability. (2019). *Organ Transplant Discrimination Against People with Disabilities*.
https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf



To date, 38 states have passed state-level legislation prohibiting discrimination based solely on disability in the organ transplant system; however, this patchwork system of protections leaves those in states without legislation vulnerable to discrimination and denial of lifesaving care. Federal action is needed to ensure that individuals with disabilities have access to an organ transplant system free from discrimination.

Thank you for your leadership on this critical issue. Our organizations look forward to working with your offices to ensure the passage of this bill and the saving of countless lives.

Sincerely,

American Academy of Developmental Medicine & Dentistry (AADMD)
Association of Organ Procurement Organizations (AOPO)
Autism Speaks
Conquering CHD
Down Syndrome Affiliates in Action
Family Voices
GiGi's Playhouse Down Syndrome Achievement Centers
Global Down Syndrome Foundation
LuMind IDSC Foundation
National Association of Councils on Developmental Disabilities
National Down Syndrome Congress
National Fragile X Foundation
The Arc of the US
Transplant Families