



October 18, 2024

The Honorable Bernie Sanders
332 Dirksen Senate Office Building
U.S. Senate
Washington, DC 20510

The Honorable Bill Cassidy
455 Dirksen Senate Office Building
U.S. Senate
Washington, DC 20510

Dear Chairman Sanders and Ranking Member Cassidy,

On behalf of the National Down Syndrome Society (NDSS) and the undersigned organizations, we write to urge you to support a path forward in the United States Senate for the *Charlotte Woodward Organ Transplant Discrimination Prevention Act* (S. 1183 / H.R. 2706). This bipartisan piece of legislation passed the House of Representatives unanimously on September 23, 2024. This legislation is named for Charlotte Woodward, NDSS 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 transplant.

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.

The Charlotte Woodward Organ Transplant Discrimination Prevention Act, which is named after an adult woman with Down syndrome and transplant recipient, Charlotte Woodward, 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 postoperative 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.

To date, 40 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.

We strongly support this bipartisan legislation seeking to prevent organ transplant discrimination and urge you to support a path forward in the United States Senate before the end of this Congress.

Sincerely,

American Academy of Developmental Medicine & Dentistry (AADMD)

American Association of People with Disabilities (AAPD)

American Association of Kidney Patients (AAKP)

Association of Organ Procurement Organizations (AOPO)

Autism Society

Autism Speaks

Communication First

Conquering CHD

Cure SMA

Disability Rights Education and Defense Fund (DREDF)

Down Syndrome Affiliates in Action (DSAIA)

Family Voices

GiGi's Playhouse Down Syndrome Achievement Centers (GiGi's)

Global Down Syndrome Foundation (GLOBAL)

Global Liver Institute (GLI)

LuMind IDSC Foundation

National Association of Councils on Developmental Disabilities (NACDD)

National Down Syndrome Congress (NDSC)

National Fragile X Foundation

Northwest Kidney Kids

The Arc of the US

Transplant Families

United Network for Organ Sharing (UNOS)