national down syndrome society
ndss®

May 15, 2025

The Honorable Ashley Moody
SR-387 Russell Senate Office Building
Washington, DC 20510

The Honorable Maggie Hassan
324 Hart 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 Senators Moody and Hassan and Representatives Cammack and Dingell:

The National Down Syndrome Society (NDSS) empowers individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions. Today we write in strong support of the *Charlotte Woodward Organ Transplant Discrimination Prevention Act* (S. 1782/H.R. 1520), which seeks to prevent discrimination based solely on disability in the organ transplantation process and provides additional legal recourse to people with Down syndrome and other disabilities should they experience discrimination. The legislation is named for Charlotte Woodward, NDSS Programs Associate and a woman with Down syndrome who received a lifesaving 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.

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 healthcare 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 those with intellectual and developmental disabilities—have been denied access to organs because of subjective judgments 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 upholds, clarifies, and builds upon existing civil rights protections 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, or refuse to place an individual on a waiting list based solely on the fact that the individual has a disability. This 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 healthcare 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.

The *Charlotte Woodward Organ Transplant Discrimination Prevention Act* passed the United States House of Representatives with widespread bipartisan support in the 118th Congress. We urge the United States Congress to take swift action to pass this bill into law this year. Thank you for your continued leadership on this critical issue.

Sincerely,

Kandi Pick

Kandi Pickard
President and CEO
National Down Syndrome Society