



Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 1520)

Legislative Request

Please cosponsor the Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 1520).

Background

Despite existing civil rights protections, individuals with Down syndrome and other disabilities continue to face both willful and unintended discrimination in organ transplantation which 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 which 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.

Bill Summary

Introduced by Representatives Kat Cammack (R – FL) and Debbie Dingell (D – MI), the Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 1520) 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. The bill prohibits 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.

The 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.

Impact

There have been several instances in which members of the Down syndrome community were unable to get the lifesaving transplants they needed and tragically passed away. This bill would ensure that individuals with disabilities have access to an organ transplant system free from discrimination. Furthermore, the bill provides those that feel they have been discriminated against the recourse they need to seek life-saving relief in a timely manner.

Important Information

- The bill passed the House of Representatives with unanimous bipartisan support in the 118th Congress.
- This bill has the support of a growing list of disability and medical organizations.
- 40 states have passed state-level legislation prohibiting discrimination based solely on disability in the organ transplant system.
- The bill is named after Charlotte Woodward, an advocate with Down syndrome who received a life-saving heart transplant over a decade ago.

For more information, please contact Anna Fedewa, National Down Syndrome Society Senior Manager of Government Relations at afedewa@ndss.org