

Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 1235/S. 3301)

What it is:

Introduced by Congresswomen Jaime Herrera Beutler (R-WA) and Katie Porter (D-CA) in the House and Senators Marco Rubio (R-FL) and Maggie Hassan (D-NH) in the Senate, the Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R. 1235 / S. 3301) 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 discrimination against people with disabilities in the organ transplant system.

The bill is named for Charlotte Woodward, an adult with Down syndrome and member of the NDSS staff who received a life-saving heart transplant a decade ago. Since then, she has advocated tirelessly to ensure individuals with Down syndrome and other disabilities have the same access to life-saving care that she did.

What it does:

The Charlotte Woodward Organ Transplant Discrimination Act 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, 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. 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 both the Office of Civil Rights at the Department of Health and Human Services and in a federal district court.

Why it is important:

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. At the same time, health care providers need clarity and guidance about how to account for and accommodate disability in their practice. Charlotte's bill addresses both issues by spelling out what is and isn't allowed and providing new avenues for families to seek timely relief, a critical consideration due to the urgency of these situations.

Because there are not transplant centers in every state, both organs and families travel across state lines to access the transplant system. Some states have passed legislation prohibiting organ transplant discrimination based solely on disability, but many have not. Federal action is the clearest way to make sure everyone can avail themselves of these protections and understand their rights.

Other important details:

- This bill has no fiscal impact.
- This bill is bipartisan in both chambers.
- This bill has the support of a growing list of disability and medical organizations for a current list, please visit <u>https://www.ndss.org/programs/ndss-legislative-agenda/healthcare-</u> research/nondiscrimination-in-organ-transplantation-laws-toolkit/.

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