



February 16, 2023

Re: HB 238

Dear Members of the Kentucky Legislature,

As the leading human rights organization for all individuals with Down syndrome, the National Down Syndrome Society (NDSS) strongly supports the passage of HB 238, which will promote health equity throughout the organ transplant system for people with disabilities.

The bill prohibits discrimination based solely on disability before, during, and after an organ transplant procedure. This legislation reinforces and supplements rights established or supported by existing civil rights laws, most notably the Americans with Disabilities Act, Sec. 504 of the Rehabilitation Act of 1973 and Sec. 1557 of the Patient Protection and Affordable Care Act.

HB 238 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. This bill also directs a court to give priority to those affected by discrimination on the docket and an expedited review.

Despite existing civil rights protections, individuals with Down syndrome and other disabilities continue to face both willful and unintended discrimination in organ transplantation, limiting their access to health care when they need it most. At the same time, healthcare providers need clarity and guidance about how to account for and accommodate disability in their practice. This legislation addresses both issues by spelling out what is and is not allowed and providing new avenues for families to seek timely relief, a critical consideration due to the urgency of these situations.

There are currently laws against organ transplant discrimination in 36 states. It is time for the state of Kentucky to follow suit.

NDSS envisions a world in which all people with Down syndrome could enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities. We hope that the Kentucky state legislature shares our commitment to eliminating discrimination based on disability. Thank you for your leadership on this important piece of legislation.

Sincerely,

Nick Leto
National Down Syndrome Society
Manager of State Government Relations
nleto@ndss.org