



February 14, 2017

Kansas State Legislature
Committee on Children and Seniors Committee
Regarding HB 2343 Ensuring nondiscrimination of organ transplants on the basis of disability
Position: SUPPORT

Dear Chairman Alford and Committee Members,

Thank you for giving me the opportunity to speak in support of HB 2343, Ensuring nondiscrimination of organ transplants on the basis of disability. My name is Jawanda Mast, and I am the Manager of Grassroots Advocacy for the National Down Syndrome Society (NDSS), which is the largest nonprofit representing and advocating for people with Down syndrome and their families, with over 375 affiliate groups spanning all 50 states including Kansas. I am also a resident of Olathe and have a 17-year-old daughter with Down syndrome named Rachel.

As you may know, four states have already passed similar legislation: California, New Jersey, Maryland and Massachusetts, and Delaware has a bill pending. NDSS has actively advocated for the passage of these bills because we recognize that people with Down syndrome and other disabilities routinely face discrimination in health care, from consultations to referrals all the way to determination of eligibility and placement on waiting lists. Many times this discrimination is subtle and based upon prejudicial assumptions that people with Down syndrome have a lower quality of life than nondisabled people, so that people without disabilities may be more “deserving” of the organ. Healthcare providers also sometimes falsely assume that people with Down syndrome and other disabilities are not able to understand directions or adhere to a post-transplant treatment regime – without even considering the vast support network of family and caregivers that the patient has in place. We have heard many anecdotes from our members across the country who have had firsthand experience with these forms of discrimination by health care providers.

This bill does not tell health care providers that they are not allowed to consider the patient’s disability as a factor at all in making a determination of eligibility for an organ transplant. Rather, it emphasizes that disability should only be considered if it has been found to be *medically significant* to the provision of an organ. The bill also requires a health care provider to consider the patient’s support network for post-transplant care, and to make reasonable modifications to policies and procedures to allow the patient to access all services relating to the transplant, including information and counseling.

On a personal note, it is every parent's nightmare that his or her child would be sick enough to require an organ transplant. Our daughter is truly amazing, and she has touched so many people in our community in positive ways. She often speaks publicly about the experience of having Down syndrome, and always says "I love my life." In fact, three years ago, Rachel testified before this committee in support of the ABLE Act and recently became the first Kansan to open a Kansas ABLE Savings Account (picture below.) This bill would go a long way to ensure that Rachel would receive equal treatment and consideration, just like her friends without disabilities, should she ever need a life-saving transplant procedure. I urge you to pass this bill and send the message that the Kansas state legislature values ALL lives equally, regardless of disability.

Respectfully submitted

Jawanda Barnett Mast
Manager of Grassroots Advocacy
National Down Syndrome Society
Mom to Rachel
1389 E. 154th Terrace
Olathe, KS 66062
913.940.4199
Jmast3@earthlink.net



Rachel Mast speaking at the launch of the Kansas ABLE Savings Plan