

January 17, 2018

Kansas State Legislature

Committee on Public Health & Welfare

Regarding HB 2343 Ensuring nondiscrimination of organ transplants on the basis of disability

Position: SUPPORT

Dear Chairman Schmidt and Committee Members,

Thank you for giving me the opportunity to submit testimony in support of HB 2343, Ensuring nondiscrimination of organ transplants on the basis of disability. My name is Jawanda Mast. I am a disability rights advocate and host of an online advocacy group, #321Advocate. More importantly, I am mom to an 18-year-old daughter with Down syndrome named Rachel.

As you may know, five states have already passed similar legislation: California, New Jersey, Maryland, Massachusetts and Delaware. I have worked with people in several of these states and others to promote the passage of organ transplant bills because I 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 people without disabilities must 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. I have heard many anecdotes from friends and parents 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.

Every parent’s nightmare is 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 will graduate from Olathe South High School in May where she was volleyball manager for four years, is a Thespian, part of STUCO and a member of National Honor Society. 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 Kansas House Children and Seniors Committee in support of the ABLE Act and last January 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

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Rachel all smiles as she comments on opening the 1st Kansas ABLE Savings Account (January 2018)