

Jan. 10, 2018

Kansas State Legislature Committee on Public Health and 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 allowing me the opportunity to testify in support of HB 2343: Ensuring nondiscrimination of organ transplants on the basis of disability. My name is Sarah Meitner and I'm a resident of Hays. My husband, Chad, and I have five children, including an almost 4-year-old named Abraham who has Down syndrome. I am here to support HB 2343 in honor of Abe and on behalf of the three dozen families who belong to the Northwest Kansas Down Syndrome Society. Our group represents families from more than 10 counties in Northwest Kansas. I am also a Western Kansas parent ambassador with the National Down Syndrome Society.

My family is only 4 years into our journey as advocates for persons with Down syndrome and other disabilities. Our son, Abe, is a bright, valuable, and contributing member of our family. He – like all people with Down syndrome -- deserves to live in a world that is supportive of his differences and accepting of his unique gifts. He is no less deserving of life than any of my other children.

It is because of Abe and all Kansans with Down syndrome that I strongly support HB 2343. With its passage, we have the opportunity to right an injustice. Many individuals with disabilities still experience discrimination in accessing critical health care services. Historically, in Kansas and elsewhere, patients with cognitive delays or other mental and physical disabilities have been denied life-saving organ transplants based on unfounded assumptions that their lives are less worthy or because they cannot independently provide post-operative care. I understand that sometimes there is a legitimate medical reason that would make an individual with a disability ineligible for an organ transplant, just as there are medical reasons why individuals without disabilities might also be ineligible. But all people – disabled or not disabled -- deserve the chance to undergo a medical evaluation and earn a spot on an organ transplant waiting list. A patient's mental or physical disability should have no bearing on a physician's decision to authorize a transplant and perform the surgery. Likewise, a patient's support system for post-transplant care should be considered.

Kansans in need of organ transplants are entitled to quality, life-saving health care and access to providers who will not discriminate on the basis of a disability. Please pass HB 2343 out of committee. It would provide necessary reassurance to people with disabilities and sends a strong message that all lives are equal and valuable.

Thank you for your time.

Respectfully,

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