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Senator Vicki Schmidt,
Chair of the Public Health and Welfare Committee

Individuals with Down syndrome have an extra copy of the 21st chromosome. This extra genetic material causes them to be more prone to a host of medical issues. Fifty percent of individuals with Down syndrome will have a genetic heart defect requiring open heart surgery before their first birthday. Many experience lifelong medical issues including respiratory, gastrointestinal, thyroid, and vision or hearing issues. In some more extreme instances, people with Down syndrome may require an organ transplant.

I strongly agree with the findings in the legislation: "state residents in need of organ transplants are entitled to assurances that they will not encounter discrimination on the basis of a disability. (b) A covered entity may not solely on the basis of an individual's disability: (1) Consider a qualified individual ineligible to receive an anatomical gift or organ transplant; (2) deny medical and other services related to organ transplantation, including evaluation, surgery, counseling and post-transplantation treatment and services; (3) refuse to refer the individual to a transplant center or a related specialist for the purpose of evaluation or receipt of an organ transplant; (4) refuse to place a qualified individual on an organ transplant waiting list; or (5) place a qualified individual at a lower-priority position on an organ transplant waiting list than the position at which the qualified individual would have been placed if not for the disability".

I also feel the unfounded claims that disabled people cannot themselves maintain or have support systems maintain post-transplant care regimens are false. In fact, the opposite may be true as a person with an intellectual disability may have several care providers assisting them with post-transplant care.

In the past, Stereotypes about patient's quality of life and outdated actuary charts have been used to screen out individuals with Down syndrome or intellectual disabilities. HB 2343's provisions will ensure that Kansas residents living with intellectual disability are given proper consideration when an organ transplant may be beneficial. We know that individuals with Down syndrome can live well into their 50's or 60's now with proper medical care and screening

On behalf of our patient's, Children's Mercy Down Syndrome Clinic asks that you support the passage of HB 2343. If you have any additional question please contact me at 816-960-2856. You can learn more about the Down Syndrome Clinic and the services we provide by visiting our website at www.childrensmercy.org/downsyndrome.

Sincerely

A handwritten signature in black ink, appearing to read "Nasreen Talib".

Nasreen Talib, MD
Medical Director, Down Syndrome Clinic
Children's Mercy Hospital
Professor of Pediatrics
University of Missouri-Kansas City School of Medicine