



February 15, 2017

Representative Steve Alford
Chair of the Children and Seniors Committee

The Down Syndrome Guild of Greater Kansas City (DSG) strongly supports the passage of HB 2343 Organ Transplant Nondiscrimination legislation. DSG currently serves over 700 families in Kansas who have a loved one with Down syndrome. We provide support across the lifespan and we welcome approximately 50 new families who give birth to a baby with the condition each year.

Individuals with Down syndrome have an extra copy of their 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.

DSG agrees strongly 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".

We 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In the past, stereotypes about patient quality of life and outdated actuary charts have been used to screen out individuals with Down syndrome or intellectual disabilities.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 an 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 members, DSG asks that you support the passage of HB 2343. If you have any additional questions please contact me at 913-384-4848. You can learn more about the DSG and the services we provide by visiting our website at www.kcdsg.org.

Sincerely,

Amy Allison
Executive Director

5960 Dearborn Street
Suite 100
Mission, KS 66202
Tel 913-384-4848
Fax 913-384-4949
www.kcdsg.org
info@kcdsg.org