

Madam Chair and Committee Members,

I am writing this letter to express my support in passing HB 21-1169- Pruitt's Law.

I am the mother to two daughters, Emma and Abby. Both of my daughters are diagnosed with an ultra-rare genetic condition resulting in epilepsy and developmental delays. But even through their struggles, both girls are happy and giggly and are bright lights in the world. Emma recently started pre-school and loves spending time around her peers. She teaches her classmates about different abilities and kindness towards others. Abby loves listening to music, spending time in her sensory room, and brings smiles to the faces of all that meet her. As a mom to two very special children, I can't imagine a situation where my daughters were discriminated against because of their unique abilities and were not given access to a medical transplant that could save their lives.

In addition to my advocacy for my daughters, I also started a non-profit foundation called The Lightning and Love Foundation that aims to drive scientific research and awareness for all ultra-rare diseases. My goal is a world where all children living with disabilities and rare diseases have the chance to live the healthiest and happiest lives possible, now and in the future. I aim to help this goal become a reality through my work with our foundation.

Pruitt's Law is immensely important for families like mine who depend on equality of services to ensure our children are healthy and safe and can thrive in their own unique ways. Children should be treated as what they are...simply children, and should not be discriminated against on the basis of their abilities. Please pass Pruitt's Law so that in critical medical situations, all children are treated equally and fairly.

Sincerely,
Mariah Gillapsie

The Honorable Susan Lontine
House Health & Insurance Committee
200 E Colfax, RM 307
Denver, CO 80203

March 22, 2021

RE: HB21-1169, Prohibit Discrimination Organ Transplant Recipient -- Support

Chair Lontine, Vice Chair Caraveo and House Health and Insurance Committee Members:

On behalf of all the people we serve in Colorado, I am writing to ask for your support for [HB21-1169](#), known as Pruitt's Law, which would prohibit discrimination against a potential organ transplant recipient based solely on their physical, developmental or intellectual disability.

The American Kidney Fund (AKF) is the nation's leading nonprofit organization working on behalf of the 37 million Americans living with kidney disease, and the millions more at risk, with an unmatched scope of programs that support people wherever they are in their fight against kidney disease, from prevention through transplant. With programs that address early detection, disease management, financial assistance, clinical research, innovation and advocacy, no kidney organization impacts more lives than AKF. We are also one of the nation's top-rated nonprofits, investing 97 cents of every donated dollar in programs, AKF has also received the highest [4-Star rating from Charity Navigator](#) for 19 consecutive years, as well as the Platinum Seal of Transparency from Guidestar.

People with disabilities may face discrimination when seeking potentially life-saving organ transplants. While there are federal protections in place from the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973, people with disabilities are still discriminated against when their eligibility for an organ transplant is being determined. Discrimination often happens at the point where someone is referred for evaluation by a transplant center and before they are placed on the official transplant waiting list. For example, there is a Stanford University study showing that 85 percent of pediatric transplant centers consider intellectual and/or developmental disabilities when determining eligibility for transplants.¹

Additionally, some providers have a misconception that people with disabilities are unable to manage post-operative treatment or would benefit from a live-saving transplant. It is also assumed that people with disabilities have a lower quality of life than those without disabilities. This is simply not true.

This bill would prohibit denials for the sole reason of disability. Mental or physical disability could not be used as a reason to deny transplant eligibility, surgery, medical care, or insurance coverage. Disability also could not be used as the sole reason for moving an individual to a lower-priority position on a transplant waiting list. Nor could an individual's inability to comply with post-transplant medical requirements be used as a reason for denial, if he or she has support from others who can assist in that process.

¹ Richards CT, Crawley La Vera M, Magnus D (2009). Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: Inconsistencies in standards across major pediatric transplant centers. *Pediatric Transplantation* 13:843–850.

At the American Kidney Fund, we believe that no transplant should be denied on the grounds of disability alone. All patients who need to receive a kidney transplant, regardless if they have a disability or not, should be eligible and get the same treatment to receive a transplant as someone who does not have a disability. For these reasons, we are hopeful for your support of this and any future legislation that could help improve the lives of those fighting kidney disease.

Thank you again for your leadership and for your consideration of this important issue. If you have any questions, please feel free to contact me directly at any time.

Sincerely,



Lindsay Gill

Associate Director, State Policy and Advocacy

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House Health & Insurance							
03/23/2021 Upon Adjournment							
Testimony - HB21-1169 Prohibit Discrimination Organ Transplant Recipient							
Title	First Name	Last Name	Position	Representing	Testifying	Text of Testimony	Registered
Mrs.	Sherri	Ball	Neutral	Self	Submitted text	<p>_x000D_</p> <p>_x000D_</p> <p>March 9, 2021_x000D_</p> <p>_x000D_</p> <p>To Whom It May Concern;_x000D_</p> <p>_x000D_</p> <p>I am writing this letter in support of HB 21-1169, Pruitt's Law. I am sharing my wishes in hopes that this bill will be considered going forward. _x000D_</p> <p>_x000D_</p> <p>As a 13-year elementary school classroom teacher, I have worked with hundreds of children over the course of my career. In those years I have worked with children with a variety of abilities and never once have I thought to discriminate against them based on their abilities, physical, mental or otherwise. It seems asinine to do so in regards to organ donations. Should a child or person, any person, have a need for a lifesaving organ transplant, there should be no considerations other than the fact that if the organ transplant could better the quality of life for the recipient. In choosing to discriminate against those with disabilities, we run the risk of playing with the fragility of life._x000D_</p> <p>_x000D_</p> <p>It is my opinion that ALL lives should be given equal opportunities when it comes to life-saving organ transplants and regardless of abilities, all people deserve the chance to be considered and to live to their fullest potential.</p> <p>_x000D_</p> <p>_x000D_</p> <p>Please consider passing HB 21-1169, Pruitt's Law to give all children the opportunity for the life they so deserve. _x000D_</p> <p>_x000D_</p> <p>Sherri Ball_x000D_</p> <p>Elementary Classroom Teacher_x000D_</p> <p>_x000D_</p>	3/18/2021 10:29

	Kristen	Brainard	For	Self	Submitted text	<p>March 8, 2021 _x000D_ _x000D_ To whom it may concern,_x000D_ _x000D_ I am writing to express my overwhelming support for HB 21-1169 (Pruitt's Law). I have been a practicing pediatric Occupational Therapist for 21 years. All of my work experience has been solely with children with different types of developmental disabilities. I support this law as it requires equal treatment for those with disabilities, by ensuring that access to life saving organs will not be restricted because of developmental disabilities. _x000D_ _x000D_ Through my profession, I have seen firsthand the fulfillment that people with disabilities have in their lives and the joy they bring to the lives of their loved ones. The part that people with disabilities play in their family is as valuable as that of their siblings without developmental disabilities. I support the families of people with disabilities by teaching them how to empower their child to be the absolute best they can be. Parents of children with disabilities pour into their children every day to help them thrive. To imagine that access to life saving organs would be limited or refused because of a developmental disability is heartbreaking, inhumane, and short sided. I believe that all people deserve to be treated fairly across all areas of life, including their access to medical care. _x000D_ _x000D_ Please join me in supporting equal treatment for people with developmental disabilities by voting in support of Pruitt's Law. _x000D_ _x000D_ Sincerely,_x000D_ _x000D_ _x000D_ _x000D_ Kristen Brainard, OTR/L _x000D_</p>	3/18/2021 10:32
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	Peter	Sgro	For	Self	Submitted text <p>Madam Chair and Committee Members,_x000D_ _x000D_ I am writing in support of HB21-1169_x000D_ _x000D_ I have two siblings with special needs. My sister has Down Syndrome and my brother was brain-damaged at birth. I cannot imagine that they would be passed over or turned down for a potential organ transplant, based on their disability. _x000D_ _x000D_ Their influence on my life has been the greatest gift to my development as a person. On the outside-looking in, it might appear that I have mostly helped teach and take care of them. The truth is that by their genuine selflessness, forgiving example, endless love and tireless humility, they have been my example, teachers and mentors throughout my life. I am 62 years old and I still say that someday when I grow up, I want to be just like them!_x000D_ _x000D_ I could never imagine that anyone might consider them less-than in a decision that could positively alter their lives. _x000D_ _x000D_ Thank you for seeing people with special needs as the important and wonderful people that they are._x000D_ _x000D_ Sincerely,_x000D_ _x000D_ Peter M. Sgro _x000D_</p>	3/18/2021 10:35
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UCHEALTH Transplant Center Letter of Support for HB 21-1169

As a member of the UCHealth team and of our national organ transplant community, I firmly support HB21-1169 in its intent to eliminate any potential discrimination of Colorado residents seeking a solid organ transplant. Candidacy for organ transplantation should always be determined by a multidisciplinary team of licensed professionals who together have weighed all factors applicable to an individual patient's case. No potential candidate for organ transplantation should be excluded for reasons outside sound evidenced-based clinical criteria and psychosocial determinates that ensures the benefit outweighs the risk of such a high risk procedure. I ask that you support this bill to protect the rights of all Coloradans and ensure equitable access to the gift of life. Thank you.

-John Gutowski, Executive Director of the University of Colorado Hospital Transplantr Center