



Testimony in support of HB 2343:

Chairman Alford and members of the Committee:

My name is Sarah Long. I am a wife, photographer, and mother to six unique children. Unfortunately, I am here in front of you today to try and convince you that one of my children has a right to life. I am here today to ask you to support HB 2343.

Almost four years ago, I gave birth to a beautiful baby girl. She surprised us with red hair, piercing blue eyes, and an extra chromosome. I saw right away that she had Down syndrome. We were starting to wrap our minds around her diagnosis, when we were told that she had a congenital heart defect, and would need open heart surgery to correct it. Willow went on to have not one, but two open heart surgeries. Due to some rare complications, she is monitored closely by her cardiologist though she is currently doing quite well.

I would like to believe, that the world values my daughter enough that if her condition worsened and there was need for a heart transplant, that she would not be discriminated against because she happens to have an extra chromosome. Unfortunately, this isn't the case for many families. Other advocates today are sharing horrible and horrific statistics, like the study from Stanford University which found that 71% of heart programs surveyed always or usually utilized neurodevelopmental status, such as Down syndrome, in determining eligibility for transplantation. Please don't let my Willow become a statistic by being denied a heart transplant because of her disability, if she should ever need one. Willow is just as deserving as any other human, and is just as God made her.

Willow's extra chromosome makes some things more difficult for her, like running and speech. The same extra chromosome also makes some things easier for my daughter. She's skilled at bringing down barriers, has an amazing aptitude for sign language, and radiates love and authenticity. Her disability is a part of who she is--though it does not define WHO she is. Other parts of Willow include a major sweet tooth, a dry sense of humor, and a strange love of mascots, including our very own Washburn Ichabod.

Willow and people like her are not less than. Different than? Perhaps, in some ways. But I assure you that she is more like you than different, and she deserves non-discriminatory health care. Her life is not less than yours or mine. Please hear me when I say that her worth is immeasurable. Unquantifiable. Boundless. As is yours. Hopefully no one will argue that point. Such an argument is indefensible.

Thank you. I would stand for questions.