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February 15, 2017

**House Committee on Health Care
Testimony of Tobi Rates on HB 2839**

Dear Chair Greenlick and members of the Committee:

My name is Tobi Rates, and I reside at 8306 NE Thompson St, Portland, OR 97220. I am here in my capacity as the Executive Director of the Autism Society of Oregon and as the mother of two children on the autism spectrum, one of whom is nonverbal.

The Autism Society of Oregon is in support of HB 2839 which would prohibit discrimination on the basis of disability in determining recipients of transplants.

The Autism Society of Oregon is the largest autism group in Oregon and the only one that operates state-wide. We represent everyone affected by autism, including individuals on the autism spectrum and their families, across the autism spectrum and throughout the life span. Our mission is to empower these individuals to improve the quality of their lives through resources, education, advocacy and support. Over 9,000 children are identified as having an autism spectrum disorder in Oregon. Their families access ASO as a resource throughout Oregon.

The fact that a need for this bill exists is disheartening and seems to stem from a belief that people who experience disability, particularly those who are nonverbal, are unable to comply with treatment plans. There is no evidence to suggest that is true for these individuals as a group. Nonverbal does not mean unable to communicate. People who are nonverbal or nonspeaking can and do communicate in a variety of ways including sign language, pictures through PECS or computer applications and through receptive language. Receptive language is understanding what is said and is distinct from expressive language, or being able to form words.

There are sound medical bases on which to determine recipients of transplants or

anatomical gifts. Disability is not one of them and should not be used as the basis to deny a life-saving transplant. As the parent of a nonverbal child who is also in contact with many other parents of children with a similar disability, the most common reactions to hearing of this bill is, first, incredulity that it's even necessary and, second, a dawning realization that the policy as it currently stands has determined that the lives of our nonverbal children are not worth living and certainly not worth saving. Nothing could be further from the truth.

Thank you for the opportunity to testify before this Committee.

Very truly yours,

A handwritten signature in black ink, appearing to read "Tobi Rates". The signature is written in a cursive, flowing style.

Tobi Rates
Executive Director