

Submitter: Jessica Adams

On Behalf Of:

Committee: Senate Committee On Early Childhood and Behavioral Health

Measure, Appointment or Topic: HB2741

Testimony in Support of House Bill 2741

Chair Nosse, Vice-Chair Javadi, and Members of the House Committee on Behavioral Health and Health Care,

I write to support House Bill 2741 as a loving auntie to a six-year-old niece with a recently diagnosed terminal rare disease. Had her disease been identified with a newborn blood test, she may have started treatment earlier and prevented years of frustrating and ultimately harmful misdiagnoses. Earlier treatment could have greatly improved both the quantity and quality of her short years. Because of my niece's late diagnosis (which was confirmed with a blood test), she did not receive timely intervention, and the neurodegenerative cascade could not be inhibited or reversed. In addition to the devastating news, her parents are wading through information regarding what care and services are available and helpful to my niece. My brother and sister-in-law bravely fight through waves of hope and despair as they piece together resources to help their daughter.

While there is no cure for my niece's disease, an early diagnosis with a newborn bloodspot accompanied by education, support, and community resources to families like mine would help quell "what if" and help direct "what now."

I strongly support HB 2741.

Sincerely,
Jessica Adams
Sherwood, Oregon