

Submitter: Rachel Peterson

On Behalf Of:

Committee: House Committee On Behavioral Health and Health Care

Measure, Appointment or Topic: HB2457

Re: Support for House Bill 2457 (Pham)

Dear Chair Nosse, Vice-Chairs Javadi and Nelson, and Members of the Committee on Behavioral Health and Health Care:

As a rare disease caregiver in Oregon, I urge your support of House Bill 2457. HB 2457 establishes a Rare Disease Advisory Council (RDAC) within the state, which if signed into law, would help to give a voice to the estimated 1-in-10 individuals living with a rare disease in Oregon.

My son lives with Hemophilia B. It is a lifelong genetic condition that we have learned to care for. With years of research and advancement in medicine in addition to a quick diagnosis and access to care, he is able to live a full life as any kid should. This has required visits with a specialist and specialized medication in addition to his regular pedestrian's care. Many rare diseases are not well understood and don't receive the attention or funding for research that is needed to overcome the obstacles people living with those conditions face. The lack of awareness can contribute to barriers patients face to receiving timely care that they need to live full lives.

The council will be able to raise awareness about rare disorders, provide valuable knowledge and information to policymakers, and be a resource to individuals and families throughout their journey with a rare disease, as well as to medical providers who are working to support a patient in their diagnosis. The RDAC will provide a benefit to the state legislature and other departments by allowing them to directly engage with a diverse group of stakeholders interested in identifying and solving pressing challenges that Oregon's rare disease community faces.

Once again, I urge your support of HB2457. It is essential that the rare disease community have a voice in state government. Thank you for your consideration.

Sincerely,
Rachel Peterson