



HOUSE OF REPRESENTATIVES

Testimony in Support of HB 2457

Good afternoon Chair Nosse, Vice Chairs Nelson, and Javadi, and Members of the House Behavioral Health and Healthcare Committee.

For the record, my name is Hai Pham and I am the State Representative for House District 36. As a long-time community health advocate, it is important to me that we as a state better understand the impact of rare diseases that are often overlooked, especially when our current system leaves patients feeling invisible and lost as they often have to navigate our complex healthcare system alone.

According to the National Human Genome Institute, there are nearly 10,000 rare diseases that impact 1 in 10 Americans. 50% affected by rare diseases are children and 30% of individuals will not live to see their 5th birthday¹. Getting an accurate diagnosis for a rare disease can take years and people living with rare diseases face social and psychological challenges like isolation, structural and societal stigma, and inequities. It's especially important to note that only 5% of rare diseases have FDA approved treatment².

The collective information of most rare diseases is so insufficient that they are also known as orphan diseases because researchers, drug manufacturers, medical specialists, and policy makers fail to fully understand diseases and its impact. We need to break through these barriers and create a shared space to share more education about rare diseases, increase accessibility across all domains of our society, and set tables to have conversations that will bring experts, advocates, and patients together.

HB 2457 will give Oregon's rare disease community a vital voice in guiding state policy that will help transform and save lives. A Rare Disease Advisory Council is an advisory body that gives the rare disease community an opportunity to develop policy recommendations to strengthen our continuum of care, include outreach and help provide information to families and providers, and be a central place to share resources, research, and education related materials. With HB 2457, Oregon would be joining 30 other states that have enacted legislation establishing an RDAC, supporting the rare disease community, and proving that these councils are an invaluable resource.

Committee members, thank you for your time today, I urge your support in passage of HB 2457.

Hai Pham, DMD
State Representative HD 36

¹ [Rare Disease Facts — Rare Genomics Institute](#)

² [Rare Disease Drugs: FDA Has Steps Underway to Strengthen Coordination of Activities Supporting Drug Development | U.S. GAO](#)