



January 24, 2025

The Honorable Rob Nosse  
 Chair  
 Oregon House Committee on Behavioral Health and Health Care  
 900 Court St NE  
 Salem, Oregon 97301

**Re: Support for House Bill 2457**

Dear Chair Nosse and Members of the Committee on Behavioral Health and Health Care:

On behalf of the undersigned organizations representing individuals with rare diseases in Oregon, we urge your support of House Bill 2457 (Pham). HB 2457 establishes a Rare Disease Advisory Council (RDAC) within the state, which if passed, would help to give a voice to the estimated 1-in-10 individuals living with a rare disease in Oregon.

Rare diseases are present across a broad spectrum of medical conditions. For patients living with one of the over 10,000 known rare conditions, it can take several years to receive an accurate diagnosis and effective treatment. Further, only a handful of rare diseases are well understood, with most not receiving sufficient attention or funding for research. This lack of awareness often contributes to the obstacles to timely treatment and care faced by many rare disease patients.

Creating an RDAC in Oregon will give rare disease patients a unified voice in state government to help address challenges that are faced by the rare disease community by serving as the advisory body on rare diseases to the Legislature and state departments. Additionally, the RDAC will be tasked with: 1) Developing policy recommendations to improve the continuum of care, services, and resources for persons impacted by a rare disease; 2) Advising the Governor, state agencies, and the Legislative Assembly on research, diagnoses, treatment, and education related to rare diseases; 3) Providing information and support to persons with rare disease, families of persons with a rare disease, health care providers serving persons with a rare disease, and entities paying for health care services for persons with a rare disease, such as health insurance companies and coordinated care organizations; 4) Making publicly available on the council's

website a list of existing resources on research, diagnoses, treatment and education related to rare diseases; and 5) Developing effective strategies to raise public awareness of rare diseases in Oregon.

The RDAC represents enormous value to our organizations and the communities we serve 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. In addition, the RDAC would help relieve some of the burden on the state by expeditiously delivering direct feedback, solutions, and resources to Oregon government decisionmakers with one community voice.

In creating this council, Oregon will join thirty other states that have proven that the RDAC can be an invaluable resource. Those states are Alabama, California, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Hampshire, New Jersey, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

Once again, on behalf of the undersigned organizations, we urge your support of HB 2457 and ask that you push for swift passage of the bill. For any questions, please feel free to contact Lindsey Viscarra with the National Organization for Rare Disorders via email at [lviscarra@rarediseases.org](mailto:lviscarra@rarediseases.org). Thank you for your consideration.

Sincerely,

National Organization for Rare Disorders  
Parent Project Muscular Dystrophy  
Dravet Syndrome Foundation  
Cystic Fibrosis Research Institute  
ALS Northwest  
Mellie J Foundation  
Vestibular Disorders Association  
Pacific Northwest Bleeding Disorders  
Project Alive  
AiArthritis  
Neuropathy Action Foundation  
International Pemphigus & Pemphigoid Foundation  
Adrenal Insufficiency United  
Chronic Disease Coalition  
HCU Network America  
ACT Now  
NEC Society  
The Bonnell Foundation: Living with Cystic Fibrosis  
Myasthenia Gravis Association  
Little Hercules Foundation