



Alone we are rare. Together we are strong.®

January 22, 2025

The Honorable Rob Nosse, Chair
House Committee on Behavioral Health and Health Care
Oregon State House of Representatives
900 Court Street, NE H-282
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 1-in-10 individuals in Oregon with one of the more than 10,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges your support of HB 2457, legislation to establish a Rare Disease Advisory Council (RDAC), when it comes before your Committee for consideration on January 30.

Rare disease patients in Oregon face unique challenges every day, from obtaining an accurate diagnosis and accessing medical specialists with knowledge of their condition, to battling for fair insurance coverage of their treatment and care. The Oregon RDAC would help address these issues by providing a forum for stakeholders knowledgeable about the needs of rare disease patients to make recommendations on how to improve public policy that impacts the community.

The RDAC will be a valuable advisory body to elected officials and other state leaders on rare disease research, education, diagnosis, and treatment for the care of those with rare diseases. It will be tasked with developing policy recommendations to improve the care, services, and resources for persons impacted by rare disease, providing information to stakeholders in the rare disease community, publishing a list of publicly available resources on rare disease, and developing effective strategies to raise public awareness of rare diseases in Oregon. The RDAC would help relieve some of the burden on the state by expeditiously delivering direct feedback, solutions, and resources to Oregon policy decisionmakers with one community voice.

In creating this council, Oregon would join thirty other states (Alabama, California, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland,

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Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nevada, New Hampshire, New Jersey, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia) that have established an RDAC in support of their rare disease community and proven that an RDAC can be an invaluable resource.

Chair Nosse, NORD thanks you for scheduling a hearing on HB2457 in your committee so quickly into the legislative year. We appreciate your support of this important legislation that will help give a voice to those living with a rare disease in Oregon. Please feel free to contact me at lviscarra@rarediseases.org for any questions or assistance.

Sincerely,



Lindsey Viscarra
State Policy Manager, Western Region
National Organization for Rare Disorders

CC: Leah Barber, Director of Grassroots Advocacy, NORD



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