



January 19, 2023

The Honorable Rob Nosse
Chair, House Committee on Behavioral Health and Health Care
900 Court St. NE, H-472
Salem, OR 97301

Dear Chairman Nosse,

On behalf of all individuals in Oregon with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) commends your leadership and willingness to sponsor legislation to establish a Rare Disease Advisory Council (RDAC) in Oregon.

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 across our state knowledgeable about the needs of rare disease patients to make recommendations on how to improve public policy that impacts our 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 also be tasked with providing a report to the Governor and the Legislature, highlighting the Council's findings, activities, and recommendations for addressing the needs of rare disease patients in the state. 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 would join twenty-four other states (Alabama, Colorado, Connecticut, Florida, Georgia, Illinois, Kentucky, Louisiana, Maine, Massachusetts, Minnesota, Missouri, New Hampshire, New Jersey, New York, Nevada, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia) that have already enacted similar legislation in support of their rare disease community and proven that an RDAC can be an invaluable resource.

Representative Nosse, we thank you for introducing HB 2047 and appreciate your support for this important legislation that will give a voice to Oregonians living with a rare disease.

Sincerely,

A handwritten signature in black ink that reads "Alyss Patel".

Alyss Patel
State Policy Manager, Western Region
National Organization for Rare Disorders