

January 29, 2025

House Committee on Behavioral Health and Health Care

Attn: The Honorable Rob Nosse, Chair

900 Court St. NE,

Salem, Oregon 97301

Chair Nosse and Members of the Committee,

On behalf of NMDP (formerly National Marrow Donor Program)—the nonprofit organization operating the national registry of volunteer bone marrow and blood cell donors—thank you for the opportunity to submit written testimony in support of HB 2457, legislation that would establish a Rare Disease Advisory Council (RDAC) to amplify the voices of rare disease patients within state government.

Rare diseases are more common than many realize. Any disease affecting fewer than 200,000 people in the United States is considered rare and 30 million Americans are living with a rare disease.<sup>1</sup> There are 75 blood cancers and disorders that can be treated with a bone marrow or blood cell transplant, all of which fall under the category of rare diseases.

Rare diseases are often under supported, underfunded, and under researched. Individuals with rare diseases face unique challenges, such as difficulties accessing specialized medical care, obtaining an accurate diagnosis, and securing appropriate treatment options. There are currently 30 other states that have an RDAC. Establishing this dedicated advisory council in Oregon will be instrumental in providing critical guidance to policymakers on how to better support rare disease patients in the state.

On behalf of NMDP, we ask that the committee support the passage of H.B. 2457 to help address the unique needs of individuals with transplant-treatable diseases and all rare diseases in Oregon.

Thank you for your consideration.



Anne Simaytis

Senior National Advocacy Manager, Government Affairs and Public Policy

NMDP

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<sup>1</sup> National Organization on Rare Disorders