



Alone we are rare. Together we are strong.®

January 17, 2025

The Honorable Annette Cleveland
Senate Health & Long-Term Care Committee
Washington State Senate
110 Legislative Building
Olympia, WA 98504

Re: Support for Senate Bill 5064

Dear Chair Cleveland and Members of the Health & Long-Term Care Committee,

On behalf of the 1-in-10 individuals in Washington with one of the more than 10,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges your support of Senate Bill 5064, legislation to establish a Rare Disease Advisory Council (RDAC) in Washington, when it is heard in your committee on January 23.

Rare disease patients in Washington 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 Washington RDAC would help address these issues by providing a forum for stakeholders across your state 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 also be tasked with advising and coordinating efforts for the study of incidence and prevalence of rare disease in Washington, identifying effective research-based strategies to help diagnose, treat, and prevent rare disease, and developing effective strategies to raise public awareness of rare diseases in Washington. The RDAC would help relieve some of the burden on the state by expeditiously delivering direct feedback, solutions, and resources to Washington government decisionmakers with one community voice.

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

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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) that have established councils in support of their rare disease community and proven that an RDAC can be an invaluable resource.

Chair Cleveland, NORD thanks you for swiftly scheduling a hearing on Senate Bill 5064 in your Committee. We appreciate your support of this important legislation that will help give a voice to those living with a rare disease in Washington. 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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