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January 31, 2022

The Honorable Annette Cleveland
Chair
Senate Health & Long-Term Care Committee
416 Sid Snyder Ave SW
Olympia, WA 98501

The Honorable Ron Muzzall
Ranking Member
Senate Health & Long-Term Care Committee
416 Sid Snyder Ave SW
Olympia, WA 98501

Re: Support for SB 5886: Rare Disease Advisory Council

Dear Chair Cleveland and Ranking Member Muzzall,

On behalf of the 1-in-10 individuals living in Washington with a rare disease, the National Organization for Rare Disorders (NORD) thanks you for holding a hearing on Senate Bill 5886 (SB 5886). If passed and signed into law, SB 5886 would establish a Rare Disease Advisory Council (RDAC) in Washington and give a voice to all Washingtonians who are part of the rare disease community. We urge you to support this important legislation and swiftly advance it out of your Committee.

Any condition that affects fewer than 200,000 Americans is considered rare. Overall, there are more than 7,000 known rare diseases, affecting 25-30 million Americans across a broad spectrum of medical conditions. Rare disease patients face many 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. However, due to small patient populations and the variety of rare diseases, it can be difficult for state government officials to have an in-depth understanding of the rare disease community’s needs. This lack of awareness often contributes to the obstacles faced by rare disease patients and their loved ones.

While RDACs are organized differently in each state, they provide a forum for patients, families, and experts across the state to analyze the needs of the community and make recommendations on how to improve public policy related to rare diseases. RDAC members typically include a variety of rare disease stakeholders, including patients, caregivers, health care providers, health insurers, biotech industry, researchers, patient advocacy organizations, and state government officials. The council may conduct surveys to better understand common challenges rare disease patients or caregivers face, consult with experts to improve access to quality health care, or publish and compile resources related to rare diseases.

In creating this council, Washington will join twenty-one other states that have already enacted similar legislation in support of their rare disease community and proven that an RDAC can be an invaluable resource. Those states are Alabama, Connecticut, Florida, Illinois, Kentucky, Louisiana, Massachusetts, Minnesota, Missouri, New Hampshire, New Jersey, New York, Nevada, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

Once again, on behalf of the Washington rare disease community, we thank you for putting SB 5886 on the Senate Health & Long-Term Care Committee's agenda and urge its swift passage. For any questions, please contact Alyss Patel with the National Organization for Rare Disorders via email at apatel@rarediseases.org. Thank you for your consideration.

Sincerely,

Alyss Patel

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

CC: Members of the Senate Health & Long-Term Care Committee