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for Rare Disorders

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January 19, 2022

The Honorable John Jagler
Wisconsin State Senate
State Capitol, Room 131 South
Madison, WI 53708

Dear Senator Jagler,

On behalf of the 1-in-10 individuals in Wisconsin 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 Wisconsin.

Rare disease patients in Wisconsin 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 Wisconsin 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, the Legislature, and other relevant agencies highlighting the Councils 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 Wisconsin government decisionmakers with one community voice.

In creating this council, Wisconsin would join twenty-one other states (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) that have already enacted similar legislation in support of their rare disease community and proven that an RDAC can be an invaluable resource.

Senator Jagler, we thank you for introducing SB 689 and appreciate your support for this important legislation that will give a voice to Wisconsinites living with a rare disease.

Sincerely,

Alyss Patel

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