



October 21, 2021

Wisconsin State Legislature
2 Main Street
Madison, Wisconsin 53703

Re: Co-Sponsorship of LRB-5036/1: Rare Disease Advisory Council

Dear Members of the Wisconsin Legislature,

On behalf of the undersigned organizations representing individuals with rare diseases in Wisconsin, we encourage you to co-sponsor LRB 5036/1 to establish a rare disease advisory council (RDAC). If passed, LRB 5036/1 would help to give a voice to the estimated 1-in-10 individuals living with a rare disease in the state of Wisconsin.

Any conditions that affect fewer than 200,000 American are considered rare. Rare diseases are present across a broad spectrum of medical conditions. Creating an RDAC in Wisconsin will give rare disease patients a unified voice in Wisconsin's state government. Additionally, 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 Council's findings, activities, and recommendations for addressing the needs of rare disease patients in the state.

The RDAC represents enormous value to our organizations and the communities we serve by allowing them to directly engage with a diverse group of stakeholders interested in identifying and solving pressing challenges. In addition, 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, seven within the past year, 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 include: 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 undersigned organizations, we urge your support for LRB 5036/1 and ask that you consider co-sponsoring this legislation to give a voice to all Wisconsin residents living with rare diseases. 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,

National Organization for Rare Disorders
American Kidney Fund
Be The Match/ National Marrow Donor Program
Cystic Fibrosis Research Institute (CFRI)
CFC International
Epilepsy Foundation of Wisconsin
IGA Nephropathy Foundation
Immune Deficiency Foundation
International Pemphigus and Pemphigoid Foundation
The Leukemia & Lymphoma Society
National Niemann Pick Disease Foundation
National PKU Alliance
Neuropathy Action Foundation