



January 11, 2022

The Honorable Joe Sanfelippo
 Chair
 Assembly Committee on Health
 State Capitol, Room 412 East
 Madison, Wisconsin 53703

Re: Support for Assembly Bill 744: Rare Disease Advisory Council

Dear Chairman Joe Sanfelippo,

On behalf of the 13 undersigned organizations representing individuals with rare diseases in Wisconsin, we thank you for placing Assembly Bill 744 (AB 744) on the Assembly Committee on Health’s agenda for consideration. If passed, AB 744 would establish a Rare Disease Advisory Council (RDAC) in Wisconsin and help to give a voice to the estimated 1-in-10 individuals living with a rare disease in our state.

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 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, RDACs 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, Wisconsin would join twenty-one other states, seven within the past year, that have enacted similar legislation in support of their rare disease community. 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. While many of these councils are still in their infancy, already RDACs are showing enormous promise in each of these states in addressing the barriers that prevent individuals living with rare diseases from obtaining proper treatment and care for their conditions.

Once again, we urge your swift consideration of AB 744 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 Cancer Society Cancer Action Network
American Kidney Fund
CFC International
Cystic Fibrosis Research Institute (CFRI)
Epilepsy Foundation of Wisconsin
IGA Nephropathy Foundation
International Pemphigus and Pemphigoid Foundation
The Leukemia & Lymphoma Society
National Niemann Pick Disease Foundation
National PKU Alliance
Neuropathy Action Foundation
Sick Cells