



February 8, 2023

The Honorable Brad Barrett
Chair
House Committee on Public Health
200 W. Washington Street
Indianapolis, IN 46204

The Honorable Julie Olthoff
Vice Chair
House Committee on Public Health
200 W. Washington Street
Indianapolis, IN 46204

Re: Support for House Bill 1201: Establishing a Rare Disease Advisory Council

Dear Chair Barrett, Vice Chair Olthoff, and Members of the House Committee on Public Health:

On behalf of the 12 undersigned organizations representing individuals with rare diseases, we urge you to add House Bill 1201 (HB 1201) to the House Committee on Public Health’s next meeting agenda. If enacted, HB 1201 would establish a Rare Disease Advisory Council (RDAC) in Indiana 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 more than 25 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 wide variety of rare diseases, it can be difficult for 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 compile and publish resources related to rare diseases.

In creating this council, Indiana would join twenty-four 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, Colorado, Connecticut, Florida, Georgia, Illinois, Kentucky, Louisiana, Maine, Massachusetts, Minnesota, Missouri, New Hampshire, New Jersey, New York, Nevada, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, and West Virginia.

Once again, we urge you to add HB 1201 to the Committee on Public Health's next meeting agenda and help give a voice to all Indiana residents living with rare diseases. For any questions, please contact Annissa Reed with the National Organization for Rare Disorders via email at areed@rarediseases.org. Thank you for your consideration.

Sincerely,

National Organization for Rare Disorders
The ALS Association
American Cancer Society Cancer Action Network
Best Day Ever Foundation
Epilepsy Foundation
HCU Network America
Immune Deficiency Foundation
International Foundation For AiArthritis
International Pemphigus Pemphigoid Foundation
The Myositis Association
National Niemann-Pick Disease Foundation
National Scleroderma Foundation