



February 24, 2022

The Honorable Stephen Fenberg
President of the Senate
200 East Colfax
Denver, Colorado 80203

The Honorable Dominick Moreno
Senate Majority Leader
200 East Colfax
Denver, Colorado 80203

Re: Support for Establishing a Rare Disease Advisory Council

Dear President Fenberg and Majority Leader Moreno,

On behalf of the 17 undersigned organizations representing individuals with rare diseases in Colorado, we ask that you approve the bill draft language by Senator Joann Ginal which would establish a Rare Disease Advisory Council (RDAC) in Colorado. This legislation would 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 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 and rare disease 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, Colorado 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, we ask that you approve Senator Joann Ginal's bill request to give a voice to all Colorado 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
American Partnership for Eosinophilic Disorders
Be The Match/ National Marrow Donor Program
Chronic Care Collaborative
Cystic Fibrosis Research Institute (CFRI)
IGA Nephropathy Foundation
Immune Deficiency Foundation
International Pemphigus Pemphigoid Foundation
Intermountain PKU & Allied Disorders
Lymphedema Advocacy Group
Mila's Miracle Foundation
Sick Cells
SLC6A1 Connect
The Homocystinuria Network of America
The Independence Center
The Leukemia & Lymphoma Society