



May 12, 2022

The Honorable Jared Polis  
Governor of Colorado  
200 E. Colfax Avenue  
Room 136  
Denver, Colorado 80203

**Re: Support for Senate Bill 186 - Colorado Rare Disease Advisory Council**

Dear Governor Polis:

On behalf of the 15 undersigned organizations representing individuals with rare diseases in Colorado, we urge you to sign Senate Bill 186 (SB 186) into law. SB 186, which passed the House by 45-17 and Senate by 27-8, would establish a Rare Disease Advisory Council (RDAC) to help give a voice to the estimated 1-in-10 individuals living with a rare disease in Colorado.

Any condition that affects fewer than 200,000 Americans is considered rare. 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, caregivers, 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. The RDAC members will include a variety of rare disease stakeholders, including patients, caregivers, health care providers, health insurers, biotech industry, researchers, and patient advocacy organizations. The

council will conduct surveys to better understand common challenges rare disease patients or caregivers face, consult with experts to improve access to quality health care, and compile resources related to rare diseases.

In creating this council, Colorado will join twenty-three 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, 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 ask that you sign SB 186 into law to help give a voice to all Colorado 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](mailto:areed@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  
Lymphedema Advocacy Group  
Sick Cells  
SLC6A1 Connect  
The Homocystinuria Network of America  
The Independence Center  
The Leukemia & Lymphoma Society