



March 22, 2022

The Honorable Cathy Breen
 Chair
 Committee on Appropriations and Financial Affairs
 15 Falmouth Ridges Drive
 Falmouth, ME 04105

The Honorable Teresa Pierce
 Chair
 Committee on Appropriations and Financial Affairs
 6 Waites Landing Road
 Falmouth, ME 04105

RE: Support for LD 972 - Maine Rare Disease Advisory Council

Dear Chair Breen, Chair Pierce, and Members of the Committee on Appropriations and Financial Affairs:

The 15 undersigned organizations, who represent Mainers living with rare diseases, urge you to include LD 972 in the supplemental budget as unanimously recommended by the Joint Health and Human Services Committee. LD 972 creates a Rare Disease Advisory Council (RDAC) within the state, which if passed, would help to give a voice to the estimated 1-in-10 individuals living with a rare disease in Maine.

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, 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, Maine 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, on behalf of the Maine rare disease community, we thank you for considering the addition of LD 972 to the supplemental budget and urge its swift passage with adequate appropriations. For any questions, please feel free to contact Annissa Reed via email at areed@rarediseases.org.

Sincerely,

National Organization for Rare Disorders
APS Foundation of America, Inc
Be The Match/National Marrow Donor Program
CFC International
Children's Cardiomyopathy Foundation
Cure SMA
Cystic Fibrosis Research Institute
Epilepsy Foundation New England
HCU Network America
International Pemphigus Pemphigoid Foundation
The Leukemia & Lymphoma Society
Lymphedema Advocacy Group
National Scleroderma Foundation
Sick Cells
United MSD Foundation