

Support for H.46 (Stone)
Establishing a Rare Disease Advisory Council in the State of Vermont

We, the undersigned organizations representing individuals with chronic, complex, and rare diseases, are proud to express our strong support for H.46, which would establish a Rare Disease Advisory Council (RDAC) in Vermont. This legislation is a critical step toward addressing the complex and often unmet needs of the rare disease community by creating a dedicated platform to ensure their voices are heard and their challenges addressed by state decision-makers.

A rare disease, as defined by the Orphan Drug Act, is any condition affecting fewer than 200,000 Americans. While each disease is rare, collectively, rare diseases affect an estimated 1 in 10 Americans. Individuals with rare diseases often face delayed diagnoses, limited treatment options, and barriers to accessing specialized care. H.46 will establish the Vermont RDAC within the Department of Health to tackle these challenges through collaboration, public engagement, and actionable policy recommendations.

The RDAC will bring together a diverse membership of patients, caregivers, healthcare providers, researchers, and industry representatives, along with designees from key state agencies. This council will be tasked with identifying best practices, addressing systemic barriers, and ensuring that rare disease stakeholders are involved in shaping Vermont's healthcare policies. Public engagement, such as surveys and open forums, will ensure the council remains responsive to the needs of this vulnerable population. A strong RDAC can help relieve burdens on the state by expeditiously delivering direct feedback, solutions, and resources to Vermont government decision makers with one community voice. Without an RDAC, Vermont laws and regulations that affect the rare community will be developed without the

consultation of rare disease stakeholders, leaving this vulnerable population at greater risk for poor health and economic outcomes.

By joining the 33 other states that have created RDACs—including all of VT's regional New England neighbors, Vermont will become part of a growing national movement to give rare disease patients a stronger voice in state government. Like its regional counterparts, Vermont's RDAC will align with established best practices, focusing on improving healthcare access, raising awareness, and addressing barriers to care and treatment.

On behalf of the undersigned organizations, we respectfully ask for your support in giving Vermont's rare disease community a voice in state government. For any questions, please feel free to contact Carolyn Sheridan with the National Organization for Rare Disorders (NORD) via email at csheridan@rarediseases.org. Thank you for your service to Vermont.

Sincerely,

National Organization for Rare Disorders
AiArthritis
Adrenal Insufficiency United
ALS Association
American Cancer Society Cancer Action Network
The Bonnell Foundation
Congenital Hyperinsulinism International (CHI)
Cystic Fibrosis Research Institute
Cystic Fibrosis United
Dravet Syndrome Foundation
The Ehlers-Danlos Society
Fanconi Cancer Foundation
Friedreich's Ataxia Research Alliance (FARA)
The Global Foundation for Peroxisomal Disorders
HCU Network America
Hemophilia Federation of America
International Pemphigus & Pemphigoid Foundation
KAT6 Foundation
Leukemia & Lymphoma Society (LLS)
Lupus & Allied Diseases Association Inc.
Lymphedema Advocacy Group
Mellie J Foundation
MLD Foundation
Myasthenia Gravis Association
National Bleeding Disorders Foundation
National Fragile X Foundation (NFXF)
National Niemann-Pick Disease Foundation (nnpdf)
NEC Society
Neuropathy Action Foundation
OMSLife Foundation
Project Alive
United MSD Foundation