NORD® National Organization for Rare Disorders
Alone we are rare. Together we are strong.®
ADRENAL INSUFFICIENCY UNITED
AiARTHRITIS INTERNATIONAL FOUNDATION FOR AUTOIMMUNE & AUTOINFLAMMATORY ARTHRITIS
ALS ASSOCIATION
American Cancer Society Cancer Action Network℠
THE BONNELL FOUNDATION: LIVING WITH CYSTIC FIBROSIS
LIVE BREATHE INSPIRE
Roadmap to CF™
thebonnellfoundation.org
CHI Congenital Hyperinsulinism International
When too little sugar hurts, we help.™
CFRI Cystic Fibrosis Research Institute
RESEARCH · EDUCATION · ADVOCACY · SUPPORT
Dravet Syndrome Foundation
FARA Friedreich's Ataxia Research Alliance
GFPD GLOBAL FOUNDATION • for • PEROXISOMAL DISORDERS
FAMILY • RESEARCH • HOPE
HCU NETWORK AMERICA
The Ehlers Danlos Society
FANCONI™ CANCER FOUNDATION
HFA Hemophilia Federation of America™
ippf International Pemphigus & Pemphigoid Foundation
30th ANNIVERSARY
KAI Foundation
LEUKEMIA & LYMPHOMA SOCIETY®
OMS life Foundation
LUPUS and ALLIED DISEASES Association, Inc.
LYMPHEDEMA ADVOCACY GROUP
MELLIE J foundation
MLD foundation We C.A.R.E.
myasthenia gravis association MGA of the heartland
NATIONAL BLEEDING DISORDERS FOUNDATION Formerly NHF
NEC SOCIETY
Building a world without NEC
Neuropathy Action Foundation
Awareness • Education • Empowerment
NEHA NEW ENGLAND HEMOPHILIA ASSOCIATION
nnpdf NATIONAL NIEMANN-PICK DISEASE FOUNDATION, INC.
nmdp FIND CURES. SAVE LIVES.
PROJECT ALIVE
UNITED MSD FOUNDATION MULTIPLE SULFATASE DEFICIENCY

Support for H.5023 (Kennedy)/S474 (Lawson)
Establishing a Rare Disease Advisory Council in the State of Rhode Island

We, the undersigned organizations representing individuals with rare diseases, proudly express our strong support for H.5023, which would establish a Rare Disease Advisory Council (RDAC) in Rhode Island. 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, including thousands of Rhode Islanders. Individuals with rare diseases often face delayed diagnoses, limited treatment options, and barriers to accessing specialized care. H.5023 will establish the Rhode Island 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 Rhode Island'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 streamline feedback, provide data-driven recommendations, and deliver direct solutions to state decision-makers. Without an RDAC, Rhode Island's rare disease

community risks being left out of critical policy discussions, leaving this population more vulnerable to gaps in care, financial hardships, and poor health outcomes
By joining the 30 other states that have created RDACs—including New England neighbors Maine, New Hampshire, and Massachusetts—Rhode Island will become part of a growing national movement to give rare disease patients a stronger voice in state government. Like its regional counterparts, Rhode Island'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 Rhode Island's rare disease community a voice in state government by supporting H.5023. 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 Rhode Island.

Sincerely,

National Organization for Rare Disorders
Adrenal Insufficiency United
AiArthritis
The ALS Association
American Cancer Society Cancer Action Network
The Bonnell Foundation
Congenital Hyperinsulinism International (CHI)
Cystic Fibrosis Research Institute
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 Niemann-Pick Disease Foundation (nnpdf)
NEC Society
Neuropathy Action Foundation (NAF)
New England Hemophilia Association (NEHA)
NMDP (Formerly National Marrow Donor Program)
OMSLife Foundation
Project Alive
United MSD Foundation