NORD® National Organization for Rare Disorders
Alone we are rare. Together we are strong.®
Adrenal Insufficiency United
AiArthritis International Foundation for Autoimmune & Autoinflammatory Arthritis
APS1 The APS Type 1 Foundation Inc.
CHI Congenital Hyperinsulinism International
When too little sugar hurts, we help.™
Dravet Syndrome Foundation
Fanconi™ Cancer Foundation
The Ehlers Danlos Society
The Bonnell Foundation: Living with Cystic Fibrosis
Live Breathe Inspire
Roadmap to CF™
thebonnellfoundation.org
FARA Friedreich's Ataxia Research Alliance
nfxf National Fragile X Foundation
GFPD Global Foundation for Peroxisomal Disorders
Family • Research • Hope
KAT6 Foundation
HCU Network America
ippf International Pemphigus & Pemphigoid Foundation 30th Anniversary
Lupus and Allied Diseases Association, Inc.
Lymphedema Advocacy Group
United MSD Foundation Multiple Sulfatase Deficiency
Mellie J foundation
NEC Society®
Building a world without NEC
nnpdf National Niemann-Pick Disease Foundation, Inc.
MLD foundation We C.A.R.E.
myasthenia gravis association MGA of the heartland
Project Alive

Support for HB943 (Tuss)
Establishing the Montana Rare Disease Advisory Council

We, the undersigned organizations representing individuals with rare diseases, are proud to express our strong support for HB943, which would establish a Montana Rare Disease Advisory Council (RDAC). 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 Montana residents. Individuals with rare diseases often face delayed diagnoses, limited treatment options, and barriers to accessing specialized care. HB943 will establish the Montana RDAC within the Department of Public Health and Human Services to tackle these challenges through collaboration, public engagement, and actionable policy recommendations.

The RDAC will bring together a diverse 17-member council that importantly includes two individuals living with rare diseases and a caregiver, alongside healthcare providers, researchers, and industry representatives. Montana would be the first state to explicitly include a representative of the state's public health laboratory, recognizing the critical role of newborn screening programs in early identification of rare diseases. This council will be tasked with developing policy recommendations, conducting needs assessments, and ensuring that rare disease stakeholders are involved in shaping Montana's healthcare policies. Public engagement through hearings 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 Montana government decision makers with one community voice. Without an RDAC, Montana 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 30 other states that have created RDACs, Montana will demonstrate regional leadership in the Northwest, where neighboring states like Idaho, Wyoming, and North Dakota have yet to establish similar councils. Montana's proactive approach, including a dedicated appropriation of $16,000 to support the council's work from the outset, positions the state as a pioneer in addressing the needs of the rare disease community in this region. Like other successful RDACs across the country, Montana's council will focus 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 Montana'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 Montana.

Sincerely,

National Organization for Rare Disorders
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