



**Preserve Ohio's Rare Disease Advisory Council (RDAC)
Opposition to Sub. H.B. No.96 §105.40**

We, the undersigned organizations representing individuals with rare diseases, write today with genuine concern about Sub. H.B. No. 96 §105.40, which would repeal Ohio's Rare Disease Advisory Council (RDAC). We respectfully ask for the Committee's reconsideration and urge you to preserve this vital voice for Ohio's rare disease community by striking this provision.

A rare disease is defined federally as any condition affecting 200,000 or fewer Americans. While each disease is rare, collectively, rare diseases affect an estimated 1 in 10 Ohioans. These individuals often face delayed diagnoses, limited treatment options, and significant barriers to accessing specialized care. Ohio's RDAC has been addressing these challenges since 2020 through collaboration and practical policy recommendations.

The council brings together Ohio-based stakeholders from across the rare disease ecosystem—patients, caregivers, healthcare providers, academic researchers, industry representatives, health plan representatives, and lawmakers. This diverse group provides essential infrastructure that connects rare disease patients and families directly with the providers, researchers, and policymakers working to address their challenges. The council creates efficient communication between the community and state government, delivering practical solutions through one coordinated voice.

The RDAC operates within existing state administrative structures without requiring dedicated funding. Eliminating the council would produce only nominal savings while removing important infrastructure that benefits Ohio's substantial rare disease population.

On behalf of the undersigned organizations, we respectfully ask to strike the language eliminating the Ohio Rare Disease Advisory Council from Sub. H.B. No. 96 §105.40 and preserve this vital voice for Ohio's rare disease community. For any questions, please contact Carolyn Sheridan with the National Organization for Rare Disorders (NORD) via email at csheridan@rarediseases.org.

Thank you for your service to Ohio.

Sincerely,

National Organization for Rare Disorders®
Adrenal Insufficiency United
Advocates for Compassionate Therapy Now (ACTnow)
AiArthritis
APS Type 1 Foundation, Inc.
BDSRA Foundation
The Bonnell Foundation
Congenital Hyperinsulinism International (CHI)
Cure CMD
Cure Sanfilippo Foundation
Cystic Fibrosis United
Dravet Syndrome Foundation
The Ehlers-Danlos Society
Fanconi Cancer Foundation
Fibromuscular Dysplasia Society of America (FMDSA)
The Global Foundation for Peroxisomal Disorders
HCU Network America
International Pemphigus & Pemphigoid Foundation
KAT6 Foundation
Little Hercules Foundation
Lupus & Allied Diseases Association Inc.
Lymphedema Advocacy Group
Mellie J Foundation
MLD Foundation
MSUD Family Support Group
Myasthenia Gravis Association

National Bleeding Disorders Foundation (NBDF)
National Fragile X Foundation
National Niemann-Pick Disease Foundation (nnpdf)
NEC Society
Ohio Bleeding Disorders Council (OBDC)
Platelet Disorder Support Association (PDSA)
Project Alive
United MSD Foundation
US Hereditary Angioedema Association