



The Honorable Doris O. Matsui  
 2311 Rayburn House Office Building  
 House of Representatives United States  
 Washington, DC 20515

The Honorable Neal Dunn  
 466 Canon Office Building United States  
 House of Representatives  
 Washington, DC 20515

The Honorable Mike Kelly  
 1707 Longworth House Office Building  
 United States House of Representatives  
 Washington, DC 20515

The Honorable Mike Thompson  
 268 Cannon House Office Building  
 United States House of Representatives  
 Washington, DC 20515

October 26, 2023

RE: PROTECT Rare Act

Dear Representatives Matsui, Dunn, Thompson, and Kelly:

We are writing to express our appreciation for your leadership in advancing the **Providing Realistic Opportunity to Equal and Comparable Treatment (“PROTECT Rare”) Act**. We stand ready to amplify your work to ensure that individuals with very rare conditions have the same intended benefit of health coverage as individuals with more common conditions – access to treatments our physicians know to be the standard of care for our medical conditions.

The bill will build on existing criteria for medically necessary care so that Medicare and Medicaid will be able to consider clinical guidelines and peer-reviewed literature to assess coverage of rare disease treatments. The bill aligns coverage of rare disease treatments to what Congress previously mandated in terms of Medicare coverage for cancer treatments.

Importantly, the bill does not provide 'special treatment' for rare diseases; rather, it levels the playing field for access to those living with more common conditions.

It will also require private payers to create an expedited review pathway for formulary exception, reconsideration, and/or appeal of any denial of coverage for a drug or biological prescribed for a patient with a rare disorder.

Again, we appreciate your leadership in improving access to the treatments prescribed for rare and ultra-rare patients by their doctors. We appreciate the opportunity to support this important legislation and look forward to working with you to pass the PROTECT Act this year.

Respectfully,

5P Minus Society  
Alpha-1 Foundation  
American Brian Coalition  
Arachnoiditis Chronic Meningitis Research Network  
Association for Creatine Deficiencies  
Autoinflammatory Alliance  
Barth Syndrome Foundation  
Biomarker Collaborative  
Cares Foundation  
Children's PSC Foundation  
Choroideremia Research Foundation  
CLL Society  
CSNK2A1 Foundation  
CRI DU CHAT Research Foundation  
Cutaneous Lymphoma Foundation  
Danny's Dose  
DEE-P Connections  
Desmoid Tumor Research Foundation  
Dup15Q Alliance  
EveryLife Foundation  
FACES The National Craniofacial Association  
Galactosemia Foundation  
Hairy Cell Leukemia Foundation  
Haystack Project  
HCU Network America  
Healthtree Foundation  
Hermansky-Pudlak Syndrome Inc.  
Histiocytosis Association  
Hope for Stomach Cancer  
International Cancer Advocacy Network  
International Fibrodysplasia Ossificans Progressiva Association  
International Foundation for CDKL5 Research  
International Pemphigus Pemphigoid Foundation  
International SCN8A Alliance  
LGS Foundation

MET Crusaders  
MitoAction  
MLD Foundation  
Myasthenia Gravis Foundation of America  
National Ataxia Foundation  
NBIA Disorders Association  
No Stomach for Cancer  
NTM Info & Research  
Organic Acidemia Association  
PDL1 Amplified  
Rare and Black  
SADS Foundation  
Share and Care Cockayne Syndrome Network  
TEAM for Travis  
The Exon 20 Group  
The Foundation for Casey's Cure  
The Global Foundation for Peroxisomal Disorders  
The Mast Cell Disease Society, Inc.  
TSC Alliance  
United Mitochondrial Disease Foundation  
United Porphyrrias Association  
Usher 1F Collaborative  
VHL Alliance