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 Porphyrias Association
Usher 1F Collaborative
VHL Alliance