Congressman Peters
US House of Representatives
Rayburn House Office Building, 2338
Washington, DC 20515

Congressman Shimkus
US House of Representatives
Rayburn House Office Building, 2217
Washington, DC 20515

October 1, 2019

Dear Congressmen Peters and Shimkus,

We are writing to thank you for introducing H.R.4144, the "Ending the Diagnostic Odyssey Act of 2019." As all of us know well, and often personally, a diagnosis means a great deal to a family. Just having that information empowers parents to find support, participate in research, and ultimately get the right care. We have a strong passion to see that all children receive a diagnosis in a timely manner.

As you know, nearly 80% of all rare diseases have a genetic cause, and half of rare disease cases impact children. The average diagnostic odyssey can last from anywhere from five to seven years. You can imagine the anguish of parents watching their children suffer, watching them endure one test after another. The toll this takes on the family, emotionally and financially, is a great travesty in an age where comprehensive genetic screening available and affordable. Whole Genome Sequencing will alleviate an enormous part of a huge burden these families carry.

Knowing the genetic cause of a disease can mean an actionable diagnosis – leading to changes in treatment and management of the condition, prevent additional unnecessary testing, and help families find a support structure via other families and organizations. This has utility and benefits for the child, the family, and society at large. And when there is no treatment at the ready, just having multiple kids diagnosed early on, with the hope of gathering data on their condition and those of other kids like them, accelerates treatment development.

The "Ending the Diagnostic Odyssey Act" would allow states to conduct a pilot program to increase the Federal Medical Assistance Percentage rate (FMAP) to provide Whole Genome Sequencing clinical services for children on Medicaid with a disease that is suspected to have a genetic cause. We are eager to see this bill signed into law so this first-line test can be offered to families, regardless of income.

This legislation has the potential to build upon the promises of the "21st Century Cures Act," furthering the emerging field of precision medicine, and lowering health care costs by facilitating better diagnoses, and the consideration of preventive measures.

Thank you again for your leadership on this important legislation.

Sincerely,

22Q Texas
5p- Society
Adult Polyglucosan Body Disease (APBD) Research Foundation

AliveAndKickn
All Things Kabuki
Alstrom Syndrome International
American Lyme Disease Foundation
American Multiple Endocrine Neoplasia Support
American Porphyria Foundation
APS Foundation of America, Inc.
Asthma and Allergy Foundation of America
AXYS
Bale Genetic Consulting LLC
Barth Syndrome Foundation
Batten Disease Support and Research Association
Beyond Celiac
Bridge the Gap – SYNGAP Education and Research Foundation
CARES Foundation
CCARE Lynch Syndrome
Children's Tumor Foundation
Children’s Cardiomyopathy Foundation
Cholangiocarcinoma Foundation
Colorectal Cancer Alliance
Columbia University Irving Medical Center
Congenital Hyperinsulinism International
Cure CMD
Cure HHT
Cure Sanfilippo Foundation
CURED Nfp
CureSHANK
Cutaneous Lymphoma Foundation
Dandy-Walker Alliance
Debra of America
Dravet Syndrome Foundation
Dup15q Alliance
EB Research Partnership
Epilepsy Foundation
Epilepsy Leadership Council
Familial Hypercholesterolemia Foundation
Family Voices-NJ
FOD Family Support Group

Foundation for Prader-Willi Research
Foundation for Sarcoidosis Research
Foundation to Eradicate Duchenne
FOXG1 Research Foundation
Genetic Alliance
Glut1 Deficiency Foundation
Hannah’s Hope Fund
Hope for Hypothalamic Hamartomas
Hunter's Hope Foundation
Hydrocephalus Association
Hypertrophic Cardiomyopathy Association
Idaho Parents Unlimited
International FOP Association
International Foundation for CDKL5 Research
International Pemphigus and Pemphigoid Foundation
International WAGR Syndrome Association
Kabuki Syndrome Foundation
LGS Foundation
Lipodystrophy United
LunaPBC
Lupus and Allied Diseases Association, Inc.
Lymphangiomatosis & Gorham's Disease Alliance
MitoAction
MLD Foundation
Myocarditis Foundation
National Blood Clot Alliance
National Eosinophilia Myalgia Syndrome Network
National Foundation for Ectodermal Dysplasias
National Neutropenia Network
National Psoriasis Foundation (NPF)
National Urea Cycle Disorders Foundation
NBIA Disorders Association
No Stomach For Cancer
Organic Acidemia Association
Parent Project Muscular Dystrophy
Pathways for Rare and Orphan Studies
Phelan-McDermid Syndrome
PTEN World

PXE International
RASopathies Network
Rett Syndrome Research Trust
Ring14 USA
RUNX1 Research Program
SCID Angels For Life Foundation
Sickle Cell Thalassemia Patients Network (SCTPN)
SPAN Parent Advocacy Network (SPAN)
Spastic Paraplegia Foundation
Spina Bifida Resource
Stickler Involved People
Sudden Arrhythmia Death Syndromes (SADS) Foundation
SWAN USA (Syndromes Without A Name)
Team Titin
The FH Foundation
The Global Foundation for Peroxisomal Disorders
The International 22q11.2 Foundation, Inc.
The Life Raft Group
The Mastocytosis Society, Inc
The Transverse Myelitis Association
The XXYY Project
Tuberous Sclerosis Alliance
United Mitochondrial Disease Foundation
Usher 1F Collaborative
Usher Syndrome Coalition
WE ACT for Environmental Justice
Williams Syndrome Association
Wilson Disease Association
Wishes for Elliott: Advancing SCN8A Research
X4 Health

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