Senator Susan Collins
United States Senate
413 Dirksen Building
Washington, DC 20510-1904

Senator Mark Kelly
United States Senate
516 Hart Building
Washington, DC 20510-0303

Senator Bob Menendez
United States Senate
528 Hart Building
Washington, DC 20510-3004

January 7, 2022

Dear Senators Collins, Menendez, and Kelly,

We are writing to thank you for introducing S.2022, the "Ending the Diagnostic Odyssey Act of 2021." 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 the 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 is 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, preventing additional unnecessary testing, and helping 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,

Sharon F Terry, CEO, Genetic Alliance, on behalf of all the undersigned organizations

22Q Texas
Ago2 Association
Alagille Syndrome Alliance
AliveAndKickn
Alstrom Syndrome International
American Behcet's Disease Association
Amyloidosis Support Groups
Angioma Alliance
APBD Research Foundation
APS Foundation of America, Inc
Arachnoiditis & Chronic Meningitis Collaborative Research Network
ARPKD/CHF Alliance
Asante Mariamu Foundation
Association for X and Y Variations
Asthma and Allergy Foundation of America
Barth Syndrome Foundation
Batten Disease Support and Research Association
Blue Faery: The Adrienne Wilson Liver Cancer Association
Bobby Jones Chiari & Syringomyelia Foundation
Botany for Kids
BPAN Warriors
CACNA1A Foundation
Canavan Foundation
CFC International
Children's Cardiomyopathy Foundation
ClinWiki
Coalition to Cure CHD2
Cockayne Syndrome Network - Share & Care
Colon Cancer Alliance for Research & Education for Lynch Syndrome
Colorectal Cancer Alliance
Columbia University Medical Center
Congenital Adrenal Hyperplasia Research, Education & Support Foundation
Congenital Hyperinsulinism International
Costello Syndrome Family Network
CSNK2A1 Foundation
Cure CMD
Cure HHT
Cure Sanfilippo Foundation
CURED Foundation
CureSHANK
Cutis Laxa International
Dravet Syndrome Foundation
Dup15q Alliance
Epilepsy Foundation
Fabry Support & Information Group
Fellman Studio Inc.
Fibromuscular Dysplasia Society of America
FND Hope
FOD Family Support Group
FORCE: Facing Our Risk of Cancer Empowered
Foundation for Prader-Willi Research
Friedreich's Ataxia Research Alliance

Gaucher Community Alliance
Genetic Alliance
Georgian Foundation for Genetic and Rare Diseases
Global Genes
Glut1 Deficiency Foundation
GRIN2B Foundation
Guide Genetics Inc.
HCU Network America
Hemophilia Federation of America
Hermansky-Pudlak Syndrome Network
Histiocytosis Association
Hope for HIE
Hope For Hypothalamic Hamartomas
Hydrocephalus Association
Hypertrophic Cardiomyopathy Association
Idaho Parents Unlimited
Inflammatory Breast Cancer Research Foundation
International Foundation for CDKL5 Research
International Pemphigus Pemphigoid Foundation
Kabuki Syndrome Foundation
KCNT1 Epilepsy Foundation
Laboratory Corporation of America Holdings
Lennox-Gastaut Syndrome Foundation
Lupus and Allied Diseases Association, Inc.
Lymphangiomatosis & Gorham's Disease Alliance
MEPAN Foundation
Mississippi Metabolics Foundation
MitoAction
MLD Foundation
Mowat-Wilson Syndrome Foundation
National Ataxia Foundation
National Fabry Disease Foundation
National Foundation for Ectodermal Dysplasias
National Neutropenia Network
National Tay-Sachs & Allied Diseases Association
National Urea Cycle Disorders Foundation
NBIA Disorders Association
Neurofibromatosis Midwest
No Stomach For Cancer
Noah's Hope - Hope4Bridget Foundation
NYU Clinical Genetic Services, Dept Pediatrics, NYU Grossman School of Medicine
Organic Acidemia Association
Pachyonychia Congenita Project
Parent to Parent USA
Parents and Researchers Interested in Smith-Magenis Syndrome
Pathways for Rare and Orphan Studies
Phelan-McDermid Syndrome Foundation
Precision Healthcare Ecosystem
Propionic Acidemia Foundation
PSC Partners Seeking a Cure
PTEN World
PXE International
Rare Chromosome Disorder Support Group

Rare Epilepsy Network
Rare New England
Rare Trait Hope Fund
RASopathies Network
Ring14 USA
Saint Peter's University Hospital
SATB2 Gene Foundation
SCID Angels for Life Foundation
Shwachman-Diamond Syndrome Alliance Inc
Sickle Cell Thalassemia Patients Network
SLC6A1 Connect
SPAN Parent Advocacy Network
Spastic Paraplegia Foundation
Stickler Involved People
Strategic Consulting Partners
STXBP1 Foundation
SYNGAP1 Foundation
Team Sanfilippo Foundation
Team Titin
The 40 Percent Inc.
The Ehlers-Danlos Society
The Life Raft Group
The Marfan Foundation
The Oxalosis and Hyperoxaluria Foundation
The Sudden Arrhythmia Death Syndromes Foundation
Timothy Syndrome Alliance
TSC Alliance
Turner Syndrome Foundation
United Leukodystrophy Foundation
United Mitochondrial Disease Foundation
United MSD Foundation, Inc
US COPD Coalition
Usher 1F Collaborative
Usher Syndrome Coalition
VHL Alliance
WAGR Syndrome Association
Wilson Disease Association
Wiskott-Aldrich Foundation