Senator Susan Collins
413 Dirksen Senate Office Building
Washington, DC 20510

Senator Mark Kelly
516 Hart Senate Office Building
Washington, DC 20510

Senator Bob Menendez
528 Hart Senate Office Building
Washington, DC 20510

August 4, 2021

Dear Senators Collins, Menendez, and Kelly,

We are writing to thank you for introducing S.2022, the "Ending the Diagnostic Odyssey Act of 2021." We, the undersigned organizations, know well how critical a diagnosis is to a family. A correct diagnosis empowers parents to find support, participate in research, and ultimately get the right care. We have a strong passion to see that every child with a rare disease receives a diagnosis in a timely manner.

Should you want to know more clearly and personally how important it is to stop the terrible suffering of families when there is no diagnosis, please reach out. We are happy to share our stories. All of the undersigned organizations have members, patients, in your state.

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 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 promises to 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 benefits 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 pilot programs via an increase in the Medicaid 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 these services can be offered to families, regardless of income.

This legislation has the potential to further the emerging field of precision medicine, lower health care costs by facilitating better diagnoses, and improve the lives of every family affected by rare genetic conditions.

Thank you again for your leadership on this important legislation.

Sincerely,

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

Ago2 Association
AliveAndKickn
Alstrom Syndrome International
American Behcet's Disease Association
Amyloidosis Support Groups
Angioma Alliance
APBD Research Foundation
APS Foundation of America, Inc
ARPKD/CHF Alliance
Association for X and Y Variations (AXYS)
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
BPAN Warriors
CACNA1A Foundation
Canavan Foundation
CFC International
Children's Cardiomyopathy Foundation
ClinWiki
Coalition to Cure CHD2
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 Nfp
CureSHANK
Cutis Laxa International
Dravet Syndrome Foundation
Dravet Syndrome Foundation Spain
Dup15q Alliance
Epilepsy Foundation
Fabry Support & Information Group
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 (FARA)
Gaucher Community Alliance
Genetic Alliance
Georgian Foundation for Genetic and Rare Diseases
Glut1 Deficiency Foundation
HCU Network America
Hemophilia Federation of America
Hermansky-Pudlak Syndrome Network

Histiocytosis Association
Hope for HIE
Hydrocephalus Association
Hypertrophic Cardiomyopathy Association
Idaho Parents Unlimited
International Foundation for CDKL5 Research
International Pemphigus Pemphigoid Foundation
Kabuki Syndrome Foundation
KCNT1 Epilepsy Foundation
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
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
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
PSC Partners Seeking a Cure
PTEN World
PXE International
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
SLC6A1 Connect
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 Sudden Arrhythmia Death Syndromes (SADS) Foundation
Timothy Syndrome Alliance
TSC Alliance
Unique
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