This form is for patient ORGANIZATIONS based in the United States to sign-on to a letter to support the addition of appropriations language, that will offer the funding in order for every state to test for MPS1, Pompe, ALD and SMA - to become RUSP compliant:

May 13, 2021

Dear Members of Congress:

As an organization focused on rare disease, I am signing on to support appropriations for Fiscal Year 2022 Labor, Health, Human Services, Education and Related Agencies to ensure every state has fully implemented all Recommended Uniform Screening Panel (RUSP) conditions.

While the federal government makes recommendations on diseases for newborn screening, it is implemented on a state by state basis. Every year, thousands of children die or become permanently disabled simply because they are not screened at birth for many known genetic diseases that have a treatment, resulting in something known as "Death by Zip Code" -- infants in one state are identified with a debilitating disease but those in another are not. This doesn't have to happen.

In 2019 the Secretary of HHS's Advisory Committee on Heritable Disorders in Newborns and Children received the results of the New STEPs New Disorders study which identified the two greatest barriers to implementation of RUSP newborn screening to be state staffing needs and equipment procurement. Currently, only 15 states are implementing newborn screening for all RUSP conditions. A number of states have not yet begun to screen newborns for these rare diseases even though in several instances they were added by the RUSP more than 6 years ago.

As we move forward at the appropriate time with the Fiscal Year 2022 Labor, Health, Human Services, Education and Related Agencies bill, we urge you to ensure every state has fully implemented newborn screening for all Recommended Uniform Screening Panel (RUSP) conditions. Specifically, we ask you to direct the Centers for Disease Control (CDC) to provide $15 million for timely implementation of newborn screening conditions with a goal of complete RUSP implementation in all 50 states by 2025.

At present rates, it will take states more than a decade to implement newborn screening for RUSP approved diseases for which treatment options are available to families, resulting in preventable deaths and disability. The Centers for Disease Control and Prevention has existing legislative authority and direct experience working with states to implement RUSP recommendations for enhanced newborn screening. The House of Representatives also recently demonstrated strong, bipartisan support for advancing newborn screening with the passage of H.R. 2507, the Newborn Screening Saves Lives Reauthorization Act of 2019.

In closing, we request that you ensure that children in all 50 U.S. states have a fair chance at life. We know from experience that early diagnosis will save countless children from death or paralysis. This is a life-and-death issue. To end "Death by Zip Code," we must prioritize complete RUSP implementation by all 50 states by 2025. Accordingly, we encourage you to

include both funding and report language in the Fiscal Year 2022 Labor HHS appropriations bill mandating such implementation. With your leadership and support, we can save lives and improve the health of newborns in all 50 U.S. states.

Sincerely,

Acid Maltase Deficiency Association
Adrenal Insufficiency United
Aidan Jack Seeger Foundation
Alabama Rare
ALD Alliance
ALD Connect
Alexander Matthew Foundation
Arrivederci ALD
Association for Creatine Deficiencies
Believing for Bryleigh
Benji Strong
Beyond the Diagnosis Organization
Brian's Hope
Bridge the Gap - SYNGAP Education and Research
Calliope Joy Foundation
Center for Independence of the Disabled NY
Children's Hospital of Pennsylvania
Children's Healthcare of Atlanta
Cure AHC
Friedreich's Ataxia Research Alliance (FARA)
Cure San Filippo
Cure VCP Disease
Cutaneous Lymphoma Foundation
Dalton's New World Order
Dysautonomia Determination
Ehlers Danos Hypermobility
Ethan Zakes Foundation
Fight ALD
Foundation to Fight H-abc
Gene Giraffe Project
Gene Spotlight Charity
Global Foundation Peroxisomal Diseases
Global Genes
Global Leukodystrophy Initiative
Hope for Dante
Hunter's Hope
Hydrocephalus Kids
Icahn School of Medicine at Mount Sinai
Jonah's Just Begun

Judson's Legacy
Kennedy Krieger Institute
Krabbe Connect
Little Hercules Foundation
Little Zebra Fund
Lurie Children's Hospital
Lupus & Allied Diseases Association
Memorial Sloan Kettering Cancer Center
MORGAN Project
MPS Society
Navigating Life with Genetic Mutations
National Adrenal Disease Foundation
National MPS Society
National Tay-Sachs & Allied Diseases Association
Partners for Krabbe Research
Pathways for Rare and Orphan Studies
PMD Foundation
Probably Genetic
Project Alive
Project 8p Foundation
PTEN Foundation
Rare New England
RDLA
Remember the Girls
Sarcoidosis of Long Island
Save BabiesThrough Screening Foundation
Sickle Cell Thalassemia Patients Network
Sisterlink Collaborative, Inc
SLC6a1 Connect
Stop ALD
Taylor's Tale
Team 4 Travis
Titus Tough
The Firefly Fund
The Mount Sinai Hospital
The Myelin Project
The Jackson Project
University of California Davis Health
United Leukodystrophy Foundation
University of Minnesota Masonic Children's
UNTOLD Story
Weill Cornell Medical Center
Wynne Mattefy Research Foundation
Yaya Foundation for 4H Leukodystrophy