February 1, 2022

The Honorable Emily Shetty and Stephen Hershey

100 State Circle

Annapolis, MD 21401

RE: HB 109 and SB 242- System for Newborn Screening- Requirements

Dear Delegate Shetty and Senator Hershey,

As patient advocacy organizations representing individuals diagnosed with rare diseases and family caregivers in Maryland and across the United States, we write today to thank you for your leadership on newborn screening and express our support for HB 109 and SB 242.

Every year, millions of babies born in the US are screened for a variety of devastating and often fatal diseases and conditions that might otherwise go undetected. These simple screens help provide lifesaving early identification, allowing for the earliest possible diagnosis and immediate access to potentially life-saving treatments for babies. In many cases, early detection can avert costly and risky medical procedures later in life.

HB 109 and SB 242 provide a thoughtful approach to expanding newborn screening in Maryland that ensures that all conditions on the federal Recommended Uniform Screening Panel (RUSP) are added to the screening panel in a reasonable amount of time. The RUSP is periodically updated using a thorough, science and evidence-based deliberative review process involving a national committee of experts in newborn screening. This legislation allows Maryland to efficiently add new conditions by taking advantage of the work done by these medical experts at the federal level to remove obstacles to needed testing and minimizing the irreversible disease progression and loss of life that comes from untreated diseases. States like Georgia, North Carolina, Arizona, and California have passed similar legislation and each time it has had overwhelming bipartisan support.

Maryland is a leader in the field of newborn screening, screening for 34 of 35 conditions currently on the RUSP. However, one of the conditions not currently on the Maryland newborn screening panel, ALD, was recommended for addition more than six years ago. This legislation would require Maryland's Department of Health (MDH) to implement new screening recommendations within **two** years of the RUSP approval, ensuring that babies born in Maryland have the same opportunity for diagnosis and treatments as babies born across state lines.

For these reasons, we are proud to support the newborn screening language. We are grateful for your leadership on this issue and look forward to working with you and your office to ensure this language becomes law.

Sincerely,

EveryLife Foundation for Rare Diseases

MarylandRARE

Duplication Cares

TSC Alliance

Batten Disease Support and Research Association (BDSRA)

Gene Giraffe Project

MTS Sickle Cell Foundation, Inc.

The Akari Foundation

MitoAction

T.E.A.M. 4 Travis

Leukodystrophy Newborn Screening Action Network

United MSD Foundation

International Foundation for CDKL5 Research

Organic Acidemia Association

Project Alive

Acid Maltase Deficiency Association (AMDA)

SCID Angels for Life Foundation

SSADH Association

Undiagnosed Diseases Network Foundation (UDNF)

The Jansen's Foundation

Association for Creatine Deficiencies

HCU Network America

Parent Project Muscular Dystrophy (PPMD)

USA- Prader-Willi Syndrome Association (PWSA)

The Oxalosis and Hyperoxaluria Foundation

Children's PKU Network

Myositis Support and Understanding Association (MSU)

Brian's Hope

International Pemphigus Pemphigoid Foundation

Lymphatic Malformation Institute

National Ataxia Foundation

VHL Alliance

Stronger Than Sarcoidosis

MLD Foundation

STXBP1 Foundation

Histiocytosis Association

Cure GM1 Foundation

Jack McGovern Coats' Disease Foundation

Cure SMA

Cystic Fibrosis Research Institute (CFRI)

ALD Alliance

SYNGAP1 Foundation

Friedreich's Ataxia Research Alliance (FARA)

Pompe Alliance

National PKU Alliance

The E.WE Foundation

Ryker's Foundation for Pompe Disease

Rare Disease Innovations Institute, Inc.

Little Hercules Foundation

Cure Sanfilippo Foundation

Rare and Undiagnosed Network (RUN)

SLC6A1 Connect

The Global Foundation for Peroxisomal Disorders

Fibromuscular Dysplasia Society of America

ADNP Kids Research Foundation

Syngap Research Fund (SRF)

Alport Syndrome Foundation

NTM Info & Research

Remember the Girls

Cure MLD

Hunter Syndrome Foundation