

January 14, 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

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

SCID Angels for Life Foundation

SSADH Association

Undiagnosed Diseases Network Foundation (UDNF)

The Jansen's Foundation

Association for Creatine Deficiencies

HCU Network America

MarylandRARE