February 4, 2022

The Honorable Missy McGee and Chris Johnson

400 High St.

Jackson, MS 39201

RE: Support of Newborn Screening Bills HB 927/SB 2900

Dear Representative McGee and Senator Chris Johnson,

As patient advocacy organizations representing individuals diagnosed with rare diseases and family caregivers in Mississippi and across the United States, we write today to thank you for your leadership on newborn screening and express our support for HB 927 and SB 2900.

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 927 and SB 2900 provide a thoughtful approach to newborn screening in Mississippi 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, evidence-based deliberative review process involving a national committee of experts in newborn screening. This legislation allows Mississippi to efficiently add new conditions by taking advantage of the work done by these medical experts to remove obstacles to needed testing and minimizing the irreversible disease progression and loss of life that comes from untreated diseases.

Mississippi 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 Mississippi newborn screening panel, ALD, was recommended for addition more than six years ago. This legislation would require Mississippi's Department of Health (MSDH) to implement new screening recommendations within **three** years of the RUSP approval, ensuring that babies born in Mississippi 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

Mississippi Metabolics Foundation

T.E.A.M. 4 Travis

Acid Maltase Deficiency Association (AMDA)

Undiagnosed Diseases Network Foundation (UDNF)

International Foundation for CDKL5 Research

ALD Connect, Inc.

SCID Angels for Life Foundation

Batten Disease Support and Research Association (BDSRA)

Organic Acidemia Association

National Ataxia Foundation

Gene Giraffe Project

MTS Sickle Cell Foundation, Inc.

Project Alive

The Akari Foundation

MarylandRARE

HCU Network America

Cure Sanfilippo Foundation

MLD Foundation

Pompe Alliance

Friedreich's Ataxia Research Alliance (FARA)

VHL Alliance

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

Cystic Fibrosis Research Institute

NTM Info & Research

American Behcet's Disease Association (ABDA)

USA- Prader-Willi Syndrome Association (PWSA)

The Oxalosis and Hyperoxaluria Foundation

Sickle Cell Association of Ketuckiana

Histiocytosis Association

STXBP1 Foundation

Remember the Girls

Little Hercules Foundation

Cure MLD

The E.WE Foundation

Hunter Syndrome Foundation

Leukodystrophy Newborn Screening Action Network

Association for Creatine Deficiencies