February 22, 2021

The Honorable Sharon Cooper
436 State Capitol
Atlanta, GA 30334

RE: HB 567 – Newborn Screening

Dear Representative Sharon Cooper,

As patient advocacy organizations representing individuals diagnosed with rare diseases and family caregivers in Georgia and across the United States, we write today to thank you for your leadership on newborn screening and express our support for HB 567. In 2020, your leadership was integral to the unanimous passage in the House of Representatives of similar legislation. We thank you for your continued leadership on this issue through the introduction of HB 567.

Every year, millions of babies born in the U.S. 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 567provides a thoughtful approach to expanding newborn screening in Georgia that ensures that all federal Recommended Uniform Screening Panel (RUSP) conditions are added to the screening panel in a reasonable amount of time with the appropriate funding. The RUSP is periodically updated using a thorough, science and evidence-based deliberative review process involving a national committee of experts in newborn screening. By allowing Georgia to implement work done by these medical experts at the federal level, we can remove the obstacles to needed testing and minimize the irreversible disease progression and loss of life that comes from untreated diseases.

Georgia passed much needed funding in 2019 to add four new diseases to its newborn screening panel. While securing this funding was a great achievement, it also highlighted the inconsistency in Georgia's newborn screening program with one of the four additions having been recommended seven years ago. This legislation would empower the Georgia Department of Public Health (DPH) to ensure that the state implements new screening recommendations within two and a half years. It would also codify the existing DPH Advisory Committee and require it to consider new diseases added to the federal Recommended Uniform Screening Panel (RUSP) within one year, ensuring babies born in Georgia have the same opportunity for diagnosis and treatments as babies born across state lines.

For these reasons, we are proud to support HB 567. We are grateful for your leadership on this issue and look forward to working with you and your offices to ensure these bills become law.

Sincerely,

EveryLife Foundation for Rare Diseases
Cure GM1 Foundation
Prader Willi Syndrome Association | USA
Tuberous Sclerosis Alliance
National MPS Society
Global Genes
Boomer Esiason Foundation
Friedreich's Ataxia Research Alliance (FARA)
Minutes Matter - MCADD
Newborn Foundation
Phoenix Fox Foundation
Cure Sanfilippo Foundation
Pompe Alliance
Bridge the Gap - SYNGAP Education and Research Foundation
Association for Creatine Deficiencies
National PKU Alliance
Answer Cancer Foundation d/b/a AnCan
Cure VCP Disease, Inc.
Bridge the Gap - SYNGAP Education and Research Foundation
M-CM Network
Dreamsickle Kids Fdn
RASopathies Network
Children's PKU Network/ NPKUA
International Pemphigus and Pemphigoid Foundation
Noah's Hope - Hope4Bridget Foundation
Lennox-Gastaut Syndrome (LGS) Foundation
MTS Sickle Cell Foundation, Inc.
Rare New England
The E.WE Foundation
Usher Syndrome Coalition
KrabbeConnect
HCU Network America
Gene Giraffe Project
Rare and Undiagnosed Network (RUN)
National Ataxia Foundation
Parent Project Muscular Dystrophy
Lupus and Allied Diseases Association, Inc.
Avery's Hope
Fabry Support & Information Group
Lymphatic Malformation Institute
MLD Foundation
Organic Acidemia Association
T.E.A.M. 4 Travis (Together Ending Asplenia Mortality)
The Global Foundation for Peroxisomal Disorders.
Angelman Syndrome Foundation
Project Alive
Congenital Adrenal hyperplasia Research, Education & Support Foundation, Inc. DBA: CARES Foundation, Inc.
Batten Disease Support and Research Association
MitoAction