May 11, 2021

The Honorable William Brisson
300 N. Salisbury Street
Raleigh, NC 27603

RE: HB 736 – Newborn Screening

Dear Representative Brisson,

As patient organizations representing the rare disease community in North Carolina and across the United States, we write today to thank you for your leadership on newborn screening issues and to express our support for HB 736, Timely Updates to Newborn Screening Program.

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 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 736 provides a thoughtful approach to expanding newborn screening in North Carolina that ensures that all federal Recommended Uniform Screening Panel (RUSP) conditions 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. By allowing North Carolina to take advantage of the work done by these medical experts at the federal level, we can remove the obstacles to needed for this testing and minimize the irreversible disease progression and loss of life that comes from untreated diseases.

North Carolina passed legislation in 2018 that required the state to screen for all conditions on the RUSP and identified a funding source that enables the state's newborn screen program to pay for the additional conditions. This impactful legislation ensures that North Carolina can utilize the work done by medical experts, however multiple conditions on the RUSP still remain off the North Carolina newborn screening panel even after being on the RUSP for as long as seven years.

<u>This legislation would require the North Carolina Department of Health and Human Services (NCHHS) to implement new screening recommendations within **three** years of the RUSP approval, ensuring that babies born in North Carolina have the same opportunity for diagnoses and treatments as babies born across state lines. In addition, it will require the NCHHS to report to the Joint Legislative Oversight Committee on Health and Human Services on the status of efforts to add a condition 18 months after RUSP addition and every 6 months if it misses the three-year deadline. These additional reporting</u>

requirements provide important transparency of processes and will help facilitate opportunities to work through screening implementation challenges.

For these reasons, we are proud to support HB 736. We are grateful for your leadership on this issue and look forward to working with you and your senate colleagues to ensure this bill becomes law.

Sincerely,

EveryLife Foundation for Rare Diseases