

March 8, 2023

The Honorable Stephanie Klick
P.O. Box 2910
Austin, TX 78768

The Honorable César Blanco
P.O. Box 12068
Capitol Station
Austin, TX 78711

RE: H.B. 2478 and S.B. 1697: Relating to an annual report regarding certain newborn screening tests

Dear Representative Klick and Senator Blanco,

As patient advocacy organizations representing individuals diagnosed with rare diseases and family caregivers in Texas and across the United States, we write today to thank you for your leadership on newborn screening and express our support for H.B. 2478 and S.B. 1697.

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.

H.B. 2478 and S.B. 1697 provide a thoughtful approach to expanding newborn screening in Texas 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 Texas 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.

Texas is a leader in the field of newborn screening, screening for 33 of 37 conditions currently on the RUSP. Texas passed legislation in 2013 and 2019 that required the state to screen for all conditions on the RUSP as funding allowed and identified a funding source that enables the state's newborn screen program to pay for the additional conditions. This impactful legislation ensures that Texas can utilize the work done by medical experts, however multiple conditions on the RUSP still remain off the Texas newborn screening panel even after being on the RUSP for as long as eight years.

This legislation would revise the current Texas Department of State Health Services (DSHS) reporting requirements related to the newborn screening preservation account to focus annually on implementation steps, anticipated completion dates, and potential barriers related to adding recommended newborn screening tests not currently included in the state's regimen. In addition, it would require part of the report to include information on whether DSHS can implement the required core RUSP conditions within a 24-month period. These additional reporting requirements provide important transparency of processes and will help facilitate opportunities to work through screening implementation challenges to ensure conditions are added to the state panel in a timely manner.

For these reasons, we are proud to support H.B. 2478 and S.B. 1697. 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
Texas Rare Alliance