



June 21, 2018

Dr. John Hellerstedt, MD
Department of State Health Services (DSHS)
Attention: Carolyn Bivens
Mail Code 1911
P.O. Box 149347
Austin, TX 78714-9347

Submitted via email to lar@dshs.texas.gov

Dear Dr. Hellerstedt:

On behalf of the 1-in-10 Texas residents with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) submits the following comments regarding funding for newborn screening (NBS) in the 2020-2021 biennium Legislative Appropriations Request (LAR).

With more than 400,000 infants screened annually for 55 conditions currently, the newborn screening program is one of the most important and cost-effective public health strategies administered by the state. Newborn screening helps provide life-saving early warnings of conditions and allows for the earliest access to potentially life-saving treatments for babies.

Given the importance of the state's newborn screening efforts, we are writing to ask the Department to consider updating and expediting its process for implementing newborn screenings listed on the Secretary of Health and Human Services' Recommended Uniform Screening Panel (RUSP). Notably, Pompe Disease and Mucopolysaccharidosis Type 1 (MPS I) were recently added to the RUSP, yet the Department has not begun to fund screening for them. Additionally, the U.S. Secretary of Health is expected to accept the expert committee's recommendation to add spinal muscular atrophy (SMA) to the RUSP later this summer. As the medical field continues to progress, additional conditions will be added. Streamlining the state's process for funding new conditions will ensure the best health outcomes and brightest futures for all babies born in Texas.

Further, NORD recognizes that the strength of the state's NBS program goes beyond the number of conditions detected. To that end, we believe an updated process for funding newborn screening would not only help expedite the addition of new screenings but also address recurring funding shortfalls with the State Public Health Laboratory. We understand and support the Department's current efforts to update its fee methodology and are supportive of efforts to increase the percentage of lab revenue retained for operations. To specifically address the addition of new screenings, we would urge the Department and the Legislature to examine a



rider or another mechanism to provide for start-up costs and “bridge” funding until fee revenue begins.

Once again, on behalf of all Texas families who benefit from the newborn screening program, thank you for the opportunity to comment on the Legislative Appropriations Request. We look forward to working with you to support this incredibly important public health function.

Sincerely,

A handwritten signature in black ink that reads "Tim Boyd".

Tim Boyd, MPH
Director of State Policy
tboyd@rarediseases.org

A handwritten signature in black ink that reads "Deborah A. Skolaski".

Deborah Skolaski,
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