June 3, 2019

Governor Greg Abbott,
P.O. Box 12428
Austin Texas 78711

**Re: NORD Support for S.B. 747**

Dear Governor Abbott,

On behalf of the 1-in-10 Texas residents with one of the over 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to sign S.B. 747 into law. This legislation will help improve newborn screening in Texas, which is vital to ensuring the proper diagnosis and treatment of many rare diseases.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

With more than 400,000 infants screened annually for 55 different conditions, the newborn screening program is one of the most important and cost-effective public health initiatives administered by the state. All of the disorders for which the state screens are rare, meaning that they affect fewer than 200,000 individuals in the United States. Further, they are all conditions that, if left undiagnosed and untreated during the early stages of their progression, can cause severe physical and developmental impairment or even death.

To ensure its continued success, Texas' newborn screening program requires constant upkeep, resources, and coordination between various stakeholders. In addition, for the Department of State Health Services (DSHS) to expand the program to screen for additional conditions, it must be fully capable of carrying out implementation. Rushed implementation can often lead to harmful scenarios, such as a high rate of false positives or false negatives or an abundance of scared and confused parents who are unsure of where to turn. Whether it is a matter of developing educational materials, ensuring proper follow-up, improving lab infrastructure, or identifying disease specialists in the state, DSHS must be empowered to operate a well-functioning and comprehensive newborn screening program.

S.B. 747 helps secure the success of the newborn screening program by strengthening the Department's ability to better utilize its sources of revenue for improving and growing the program. First, the legislation enables DSHS to set fees for screening that are sufficient to cover the cost of performing the tests. Second, the legislation creates a newborn screening preservation account to house fees, donations, grants, and other sources of revenue for the express purpose of funding program expansion and improvement. This preservation account is prohibited from being used for general operating expenses. Finally, when using the preservation fund to adopt

screening for additional disorders, the legislation requires DSHS to submit to your office and other officials in the state an implementation plan detailing the proposed expansion.

Once again, on behalf of the Texas rare disease community, we urge you to sign S.B. 747 into law. Please note that the provisions of S.B. 747 are also included in S.B. 748 (which is awaiting your signature as well). NORD supports both of these pieces of legislation, and the enactment of either one will ensure the modernization and continued success of newborn screening in Texas.

Sincerely,

Tim Boyd,
Director of State Policy

Debbie Skolaski,
Texas Rare Action Network Volunteer State Ambassador