



**Senate Health and Human Services Committee**  
**SB 748 – Creating the Newborn Screening Preservation Account**  
**Testimony by Charleta Guillory, MD, MPH**  
**March 5, 2019**

Testimony submitted on behalf of:

Texas Pediatric Society  
Texas Medical Association  
March of Dimes  
Texas Public Health Coalition

Good morning Chair Kolkhorst and Committee Members,

My name is Dr. Charleta Guillory and I am a neonatologist from Houston and I am here testifying on behalf of the Texas Pediatric Society, the Texas Medical Association, the March of Dimes and the Texas Public Health Coalition. I appreciate the opportunity to testify in support of SB 748. Thank you, Chair Kolkhorst, for filing such an important piece of legislation and your historical leadership on this issue.

Texas has one of the most successful and robust newborn screening programs in the entire world. We screen every newborn Texan baby twice for 53 separate disorders or conditions – any one of which could potentially lead to an early death or lifelong disability. However, by screening children at birth we have the ability through the miracle of modern medicine to change the developmental outcomes of these children and give many of them the opportunity to live healthy lives. Nearly 800-900 infants per year are diagnosed early and treated for life-altering disorders. Texas' newborn screening program is a perfect example of true public health at work – saving lives, alleviating population morbidity and reducing health care costs.

Senate Bill 748 is a crucial next step to ensuring the long-term viability and stability of our newborn screening program. State statute requires the Department of State Health Services (DSHS) to implement any new disorders that are on the Recommended Uniform Screening Panel of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (RUSP), but only as state funds allow. Currently, the federal screening panel recommends 61 core and secondary disorders. The Texas Newborn Screening Advisory Committee, in which I Chair, concurs with the need to add these new disorders. The next four disorders would include XALD, MPS 1, Pompe and SMA. Our Advisory Committee has heard countless hours of testimony from families of newborn children who would have benefited from being screened for these disorders and whose children are now disabled as a result.

Through your bill, Chair Kolkhorst, a dedicated account for newborn screenings would be created to establish consistent and more timely funding to our state laboratory in order to repair, upgrade and expand screening conducted by the lab. This will secure the financial health and stability of the newborn screening programs for years to come.

Thank you again for your leadership on newborn screening and I would be pleased to answer any questions.