



**Senate Health and Human Services Committee
Senate Bill 1404 by Senator Beverly Powell
Testimony by Mai Duong, MD
April 23, 2019**

Testimony submitted on behalf of:
Texas Pediatric Society
Texas Medical Association

Good afternoon Chair Kolkhorst and committee members,

Thank you for the opportunity to testify today. My name is Dr. Mai Duong, and I am here to speak on *Senate Bill 1404* by Senator Powell on behalf of the Texas Pediatric Society and Texas Medical Association. I am a general pediatrician and Chief of Pediatrics at Austin Regional Clinic.

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 using the blood spot filter paper – 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. We thank Senator Powell for her intent to improve our newborn screening program.

While SB 1404's stated intent is to streamline the disclosure and consent for long-term storage process for newborn screening our organizations are concerned about potential unintended consequences. First, we want to thank Senator Powell's office for removing the provision in the bill as filed which allows for these processes to take place prenatally. While we understand the intent is to ensure a greater uptake of consent for storage, we feel that this responsibility remain with the treating pediatrician in the birthing facility. The pediatrician and their delegated health care team is the physician with the most expertise to provide disclosure about newborn screening and educate the new parents about potential diseases and disorders that could be caught early by early screening. OB/GYNs have indicated that this is not an area of expertise they feel comfortable performing among their already heavy responsibilities during the prenatal period.

Secondly, we have a multitude of questions about how the proposed electronic process would be implemented. Any change to our already extremely successful newborn screening program should have complete buy-in from all stakeholders including physicians, providers, system participants and hospitals. Some of our questions include:

- What impact will this change have on consent for long-term storage of newborn screening samples?

- Since this is a voluntary option, what impact will fragmentation of processes at various birthing facilities have on the system as a whole?
- Does the Department of State Health Services have the infrastructure in place to receive electronic submission of disclosure and consent?
- What data exists to show these changes will lead to improvements to program performance and reductions in lost to follow-up cases in Texas?

Finally, Texas physicians have not identified electronic capture of this information to be a critical need of the newborn screening program. This legislation seems to be the first mention of any need to move the program in this direction. We recommend that any changes to state statute regarding the newborn screening program be first thoroughly discussed with physician associations and the Texas Newborn Screening Advisory Committee prior to the next legislative session so there can be complete buy-in before changes are made that could have unintended consequences.

Thank you again for the opportunity to testify, for Senator Powell's intention to improve newborn screening and for this Committee's commitment to fixing other critical problems associated with the newborn screening program this session.