



Hunter's Hope Foundation

Hope ~ Life ~ Leukodystrophy ~ Newborn Screening

Written Testimony on HB 1625 (FWA)

Position: Support Fee Adjustment; Oppose Changes to RUSP Implementation Timeline

My name is Anna Grantham, and I serve as Director of Newborn Screening for the Hunter's Hope Foundation, an organization founded by NFL Hall of Fame quarterback Jim Kelly and his wife, Jill, after their son Hunter was diagnosed with Krabbe disease.

While we support adjustments to newborn screening program fees as needed to sustain the program, we strongly oppose amending the current law in a way that could weaken Maryland's commitment to implementing conditions added to the federal Recommended Uniform Screening Panel (RUSP) within the timeline established by HB 96 (2024).

The RUSP represents a national, evidence-based consensus on conditions that are ready for newborn screening. It takes many years of rigorous scientific and clinical review for a condition to be added to the RUSP, demonstrating that early identification and treatment can significantly improve outcomes for affected children. When states delay implementation after a condition has been added to the RUSP, infants may lose the opportunity for life-saving or life-altering treatment.

This issue is not theoretical. Maryland families have suffered due to delayed implementation of RUSP conditions when the Maryland Advisory Council on Hereditary and Congenital Disorders determined whether screening would be added. In the case of Krabbe disease, children with the most common and severe form are only eligible for treatment prior to the onset of symptoms, making timely newborn screening absolutely critical. This urgent need also exists for other RUSP conditions that Maryland has yet to begin screening for.

Maryland took an important step forward with the passage of HB 96, which requires the state to implement screening for conditions added to the RUSP within 18 months. This policy ensures that Maryland infants benefit from advances in newborn screening without unnecessary delays.

While we support efforts to maintain a strong and sustainable newborn screening program, we respectfully urge the legislature not to weaken the protections established in HB 96. Maintaining alignment with the RUSP within the designated timeframe is essential to ensuring that Maryland's newborn screening program continues to protect the health and lives of the state's most vulnerable residents.

For families affected by these disorders, newborn screening is not simply a policy issue—it is the difference between early treatment and irreversible harm.

Thank you for your consideration.

Anna Grantham
Director of Newborn Screening
Hunter's Hope Foundation