

HB 1625 - Public Health – Newborn Screening Program – Fees and Core Conditions

Sponsored by:

Delegate Hill

In the House - Hearing 3/17 at 1:00 p.m.

Thank you for the opportunity to provide testimony for HB 1625 - **Public Health – Newborn Screening Program – Fees and Core Conditions**.

My name is Mary Morlino. I am the Founder and CEO of Maryland Rare, which supports the rare disease community of Maryland through advocacy, education and community building.

I have worked professionally with The EveryLife Foundation for Rare Diseases, a nonprofit and nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures. I worked with Global Genes, a nonprofit committed to providing information, resources and connections to all communities affected by rare diseases. In addition I worked with The Undiagnosed Diseases Network Foundation (UDNF), whose mission is support and improve access to diagnosis, research, and care for all individuals with rare and undiagnosed diseases.

Notably, I have been an advocate for over 20 years, supporting families, individuals and communities living with the extensive challenges faced by the rare disease, chronic illness and disability communities. I have the honor of serving on the Johns Hopkins Sarcoidosis Patient Advisory Board as well various roles with the Foundation for Sarcoidosis Research.

Additionally, I am a rare disease patient living with multisystem Sarcoidosis and I have multiple family members affected by various rare diseases.

I, on behalf of the Maryland Rare community, support **HB 1625 - Public Health – Newborn Screening Program – Fees and Core Conditions** with the amendments previously submitted to Delegate Hill attached.

This impactful bill will:

- Establishes a floor for the newborn screening fee helping to ensure that it's enough to cover the administrative, lab, and follow up costs.
- Requires the state to screen for all the RUSP approved conditions.
- Require the State Advisory Council on Hereditary and Congenital Disorders (ACHCD) to advise the department on the risks, harms, accessibility, and costs of implementing testing for the condition, and provide recommendations on whether or not to implement.
- Create a mechanism of reporting to inform the Department of potential missed deadlines 9 months before the deadline so that there is transparency and understanding,

especially if the delays are occurring because of other state administrative process problems such as procurement of equipment and supplies or it is decided to delay or NOT to implement a condition recommended by the ACHCD.

- Ensure reporting within 1 year & 3 months of RUSP approval and every 3 months after if they cannot implement the condition within 2 years of RUSP approval.
- Ensure reporting to JUSTIFY their decision NOT to implement or why it was delayed along with an anticipated implementation date.

Since the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) was terminated, the amendments proposed language address Maryland's RUSP alignment statute, as there is not any language about reviewing non-RUSP conditions. The amendments are to include language to ensure that the state can continue to review conditions as well as clarify the criteria for determining non-RUSP conditions that should be reviewed. Aligning the timeline for reviewing and reporting on non-RUSP conditions to match that of RUSP conditions.

Time is of the essence with newborn screening. Families seeking answers and impactful action do not have the luxury of time to address crucial and timely action. This bill would help you and your constituents by ensuring that their children can access treatments when they need it most. Improving the outcomes and effectiveness of treatments is the priority to ensure disease progression is limited and addressed as soon as possible.

In closing, I urge you to support **HB 1625 - Public Health – Newborn Screening Program – Fees and Core Conditions.**

Thank you for your consideration of this crucial bill.

Best regards,

Mary Morlino

Founder & CEO Maryland Rare