

13 March 2026

3 East Miller Senate Building  
Annapolis, MD 21401

**Subject: HB1625 – Public Health-Newborn Screening Program-fees and core conditions**

My name is Jessica Blackwell and I am writing this letter with the intent to strongly oppose HB1625 and change to newborn screening.

My niece is 14 years old living with Krabbe Disease. Because she was born in the state of Maryland she was not screened for this devastating disease as a newborn. If she had been born in a state that screened for this disease, she would have been tested shortly after birth. Early detection could have allowed her to receive a treatment before symptoms began. And instead of being wheelchair bound, unable to speak or eat and not even able to hold up her own head, she would be an active teenager enjoying life and school.

Our family spent twelve years advocating for Krabbe disease to be added to Maryland's newborn screening panel. During that time, we witnessed firsthand how the state's newborn screening advisory committee functioned—and how often it failed to function.

Meetings were frequently canceled because there were not enough members present to form a quorum. Months would pass with no progress at all. Families and physicians took time to prepare testimony, only to see discussions delayed or cut short. In one instance, a physician calling in to explain the medical urgency of screening was repeatedly spoken over and not given the opportunity to fully present critical information.

These delays have real consequences. Every year that screening is delayed means more children who could lose the chance for early treatment.

Maryland should not be re-litigating decisions that have already been carefully evaluated at the federal level through the Advisory Committee on Heritable Disorders in Newborns and Children and the national Recommended Uniform Screening Panel (RUSP). These recommendations are based on extensive scientific review, expert consensus, and years of evidence.

Creating additional layers of state bureaucracy only slows the adoption of life-saving tests. Looking at Maryland's record, there were years where no new conditions were added to the newborn screening panel at all. During those years, children were born without access to screenings that were already being used elsewhere in the country.

Newborn screening should move as quickly as science and evidence allow, because every delay can mean the difference between a healthy child and a lifetime of severe disability. For the sake of future children and families, Maryland should adopt a streamlined process that automatically aligns our newborn screening panel with federal recommendations, without unnecessary delays.

Respectfully,

Jessica A. Blackwell