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February 13, 2024

Senator Pamela G. Beidle  
Miller Senate Office Building  
3 East Wing  
11 Bladen St.  
Annapolis, Maryland 21401

Re: SB117/HB095 Health - Newborn Screening Program – Krabbe Leukodystrophy  
POSITION: Oppose

To: The Honorable Pamela G. Beidle, Chair,

I am writing as a private citizen to oppose SB117 (HB96) to add Krabbe Disease Leukodystrophy by statute to the Maryland Newborn Screening Panel.

I am the Dr. Frank V. Sutland Professor of Pediatric Genetics at Johns Hopkins University School of Medicine. I have served as the Clinical Director of Genetic Medicine since 2002. I also served on the Maryland State Advisory Council for Hereditary and Congenital Disorders (MACHCD) from 2000-2009, for the last 8 years as Chair.

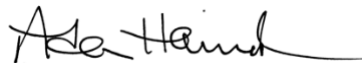
The composition of the MACHCD is mandated by statute since 1982 and includes representatives from the major academic institutions, as well as medical organizations, state legislators, and citizens who are caregivers for or affected by these conditions. This Council has an effective process in place to review and approve changes and additions to the Maryland Newborn Screening Panel. These issues are complex and require medical and public health expertise which is present on the Council and outside experts are also called in to present and discuss new conditions. This is not a process that should be subject to political pressure. There is no place for individual disease mandates through legislation.

The Council uses objective scoring criteria derived from the American College of Medical Genetics and Genomics newborn screening recommendations. MACHCD reviews conditions based on those reviewed and added to the federal Recommended Uniform Screening Panel (RUSP), which maintains a rigorous standard for review of data and evidence for the addition of new conditions. Per 2022 legislation, any condition added to the RUSP must be reviewed by MACHCD within a year, and if the Council does not recommend adding that condition to the Maryland Newborn Screening Panel, MACHCD must review the recommendation status annually. MACHCD reviews occur in open meetings and welcome presentations and discussion from all interested parties, who are given advance notice of meetings and the agenda.

Passage of this bill would set a dangerous precedent that would disrupt an effective and representative process for the consideration of new conditions to add to the Maryland Newborn Screening Panel. I strongly oppose this bill and any that would mandate inclusion of individual conditions by legislation.

Please don't hesitate to contact me with any questions.

Sincerely,

A handwritten signature in black ink that reads "Ada Hamosh". The signature is fluid and cursive, with a long horizontal stroke extending to the right.

Ada Hamosh, MD, MPH