



## DEPARTMENT OF HEALTH

Wes Moore, Governor · Aruna Miller, Lt. Governor · Laura Herrera Scott, M.D., M.P.H., Secretary

February 7, 2024

The Honorable Joseline A. Peña-Melnyk  
Chair, House Health and Government Operations Committee  
Room 241, House Office Building  
Annapolis, Maryland 21401

### **RE: House Bill 96 – Health - Newborn Screening Program - Krabbe Leukodystrophy – Letter of Opposition**

Dear Chair Peña-Melnyk and Committee Members:

The Maryland Department of Health (MDH) respectfully submits this letter of opposition for House Bill (HB) 96 – Health - Newborn Screening Program - Krabbe Leukodystrophy. HB 96 mandates the addition of Krabbe leukodystrophy to MDH’s Newborn Screening System.

Under current law, Health-General, §13–111 (d), MDH, in consultation with the State Advisory Council on Hereditary and Congenital Disorders (the Council), determines the screening tests that MDH’s public health laboratory is required to perform. Deliberations within the Council involve extensive discussions on the inclusion of new conditions. Decisions are made using an objective scoring rubric, based on the American College of Medical Genetics Newborn Screening Guidelines, which carefully weighs the individual benefits of adding the condition versus cost to the state and any potential harm to families. In 2014 and 2018, during which time Krabbe Leukodystrophy was not on the HRSA Recommended Uniform Screening Panel (RUSP), the Council considered the addition of Krabbe Leukodystrophy and ultimately voted against its inclusion.<sup>1,2</sup>

Since the inception of MDH’s Newborn Screening System in 1965, no condition has been added via legislation. Adding Krabbe leukodystrophy via legislation would circumvent the existing statutory process of requiring the State Advisory Council to deliberate and make recommendations on the detection and management of hereditary and congenital disorders.

On January 30, 2024, the federal Advisory Committee on Heritable Disorders in Newborns and Children voted to recommend the addition of Krabbe Leukodystrophy to the RUSP. Should the Health and Human Services Secretary choose to adopt this recommendation and add it to the RUSP, current state law requires the Council to review its inclusion in the Maryland Newborn Screening Panel and publish its findings. If the Council opts not to add it at that time, they must review it annually and re-evaluate its inclusion, as mandated by Health-General, §13–111 (e).

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<sup>1</sup> [State Advisory Council on Hereditary and Congenital Disorders meeting minutes \(4/1/14\)](#)

<sup>2</sup> [State Advisory Council on Hereditary and Congenital Disorders meeting minutes \(6/24/18\)](#)

If you would like to discuss this further, please do not hesitate to contact Sarah Case-Herron, Director of Governmental Affairs at [sarah.case-herron@maryland.gov](mailto:sarah.case-herron@maryland.gov).

Sincerely,

A handwritten signature in blue ink, appearing to read "Laura Scott".

Laura Herrera Scott, M.D., M.P.H.  
Secretary