



DEPARTMENT OF HEALTH

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

February 16, 2024

The Honorable Pamela Beidle
Chair, Senate Finance Committee
3 East, Senate Office Building
Annapolis, Maryland 21401

RE: Senate Bill 117 – Health - Newborn Screening Program - Krabbe Leukodystrophy – Letter of Opposition

Dear Chair Beidle and Committee Member:

The Maryland Department of Health (Department) respectfully submits this letter of opposition for Senate Bill (SB) 117 – Health - Newborn Screening Program - Krabbe Leukodystrophy. HB 96 mandates the addition of Krabbe leukodystrophy to the Department’s Newborn Screening System.

Under current law, Health-General, §13–111 (d), the Department, in consultation with the State Advisory Council on Hereditary and Congenital Disorders (the Council), determines the screening tests that the Department’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.^{1,2}

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.

The federal government has not yet added Krabbe Leukodystrophy to the Health Resources and Service Administration Recommended Uniform Screening Panel (RUSP). On January 30, 2024, the federal Advisory Committee on Heritable Disorders in Newborns and Children voted to recommend the addition of Infantile Krabbe Leukodystrophy to the RUSP. In order for the screening to actually be added to the RUSP, the Health and Human Services Secretary must choose to adopt the federal Advisory Committee recommendation, a step that has not yet occurred. The State Advisory Council on Hereditary and Congenital Disorders (Council) is committed to reviewing the addition of Infantile Krabbe leukodystrophy to Department’s Newborn Screen System as soon as the findings of the federal Advisory Committee are available.

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

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

The Department understands the need to review the latest data considered by the federal Advisory Committee and make a determination as soon as possible. For these reasons, the Department respectfully recommends that the committee vote unfavorably on SB 117.

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.

Sincerely,

A handwritten signature in blue ink, appearing to read "LH Scott", is positioned above the typed name.

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