

Maryland Department of Health Advisory Council on Hereditary and Congenital Disorders

Wes Moore, Governor · Aruna Miller, Lt. Governor · Meena Seshamani, M.D., Ph.D., Secretary

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House Health Committee
240 Taylor House Office Building
Annapolis, Maryland 21401

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March 9, 2026

Re: HB1537 – Public Health – Newborn Screening Program – Metachromatic Leukodystrophy Request for Unfavorable Report in Current Form

Chair Bagnall and Members of the Committee:

On behalf of the Maryland State Advisory Council on Hereditary and Congenital Disorders (ACHCD), we respectfully request an unfavorable report on HB1537 in its current form with request for amendment.

Our concerns with HB1537 are procedural; our objection focuses on the precedent that legislative addition of conditions to the Maryland Newborn Screen circumvents the evidence-based, public health-focused analysis of utility and efficacy for proposed conditions.

The bill requires the addition of metachromatic leukodystrophy (MLD) to the Maryland newborn screen, and in November 2025, the ACHCD voted to recommend that MLD be added to Maryland's Newborn Screening Panel, and we understand that implementation is forthcoming. The objective of screening for MLD has therefore already been achieved through the Council's established, rigorous scientific review process. The reason for opposing HB1537 in its current form is therefore not an objection to the addition of MLD to the newborn screen, but that adding it to Maryland law is contrary to the legislatively-established procedure for newborn screening, and it creates an extremely dangerous precedent.

The ACHCD is charged with conducting rigorous, evidence-based evaluations before recommending additions of new disorders to the newborn screening panel, including analysis of peer-reviewed data, treatment efficacy, laboratory validation standards, assay performance, workforce capacity, and long-term follow-up infrastructure. Adding conditions by legislative mandate, however well-intentioned, circumvents this structured, evidence-based process, and risks undermining the integrity of Maryland's newborn screening framework.

At our March 3, 2026, meeting Mr. Thomas Akras, who worked with Delegate Marlon Amprey to introduce HB1537 on behalf of his daughter, Carmen Akras, who has MLD, explained that the bill was introduced out of frustration with the approximate 18-month implementation timeline following approval of a new condition. That timeframe reflects the

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practical realities of acquiring specialized equipment, procuring reagents, validating testing protocols, and hiring and training qualified personnel to ensure accurate screening for every newborn in the State.

Metachromatic leukodystrophy (MLD) is a rare, inherited lysosomal storage disorder caused by deficiency of the enzyme arylsulfatase A. The resulting accumulation of sulfatides destroys myelin in the central and peripheral nervous systems, leading to rapid neurologic deterioration. In its most severe form, affected children experience developmental regression, loss of motor and cognitive function, seizures, paralysis, and ultimately respiratory failure. When not identified and treated in the earliest months of life, MLD is uniformly fatal. These are the reasons that MLD was added to the Newborn Screening Panel, and the Council shares the concern of the families related to delays in implementation.

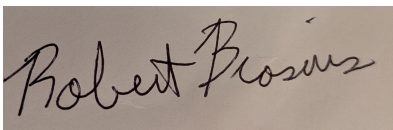
The delays in the implementation of MLD are largely administrative and financial and are potentially being resolved. We were informed that the Maryland Department of Health is seeking a supplemental deficiency appropriation—approximately \$700,000 in FY26 and \$500,000 in FY27—to support equipment, reagents, and staffing necessary for MLD screening. With appropriate funding and expedited procurement, the Department has indicated screening for MLD could be implemented within 6 months. The Council fully supports providing the Department with the resources necessary to expedite implementation. Mr. Akras and the Council share the goal of preventing delayed implementation of future conditions to the Maryland Newborn Screen.

While we request an unfavorable report on HB1537 as drafted, we would support an amendment replacing the statutory screening mandate with the creation of a stakeholder workgroup to examine sustainable funding and procurement mechanisms for implementing ACHCD-approved newborn screening conditions. A structural funding and procurement solution—independent of annual budget cycles and supplemental appropriations—would allow timely implementation of recommended conditions while preserving the Council’s evidence-based advisory role.

The ACHCD supports newborn screening for MLD and has already recommended its addition. Our request for an unfavorable report on HB1537 is intended to protect the integrity of Maryland’s established review process while ensuring that sufficient and reliable funding and procurement mechanisms exist to implement recommendations without unnecessary delay.

We appreciate your consideration and stand ready to assist the Health Committee, if they see fit to amend the bill as the ACHCD recommends. We are also available for any questions you may have regarding our testimony.

Respectfully submitted,



Robert Brosius

Interim Council Chair



Jamie L. Fraser, MD, PhD, FACMG

Appointed Council Member Medical Biochemical Geneticist