



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

March 18, 2026

The Honorable Heather Bagnall
Chair, House Health Committee
Room 241, House Office Building
Annapolis, Maryland 21401

RE: House Bill 1537 – Health - Newborn Screening Program - Metachromatic Leukodystrophy – Letter of Information

Dear Chair Bagnall and Committee Members:

The Maryland Department of Health (the Department) respectfully submits this letter of information for House Bill (HB) 1537 Health - Newborn Screening Program - Metachromatic Leukodystrophy. HB 1537 would include Metachromatic Leukodystrophy (MLD) on the Maryland Newborn Screening Panel.

Per Health-General, §13–111 (e)(1)(i), the Department shall screen for each core condition listed in the U.S. Department of Health and Human Services' Recommended Uniform Screening Panel (RUSP). MLD was added to the RUSP in December 2025, therefore the Department is required to add MLD to the newborn screening panel by June 2027.

Beyond alignment with the RUSP, Maryland relies on the State Advisory Council on Hereditary and Congenital Disorders (the Council) which was established in 1982 and has served Maryland residents for 44 years. Per Health-General, §13–104, the Council consists of 11 voting members and four nonvoting members from the Department. The voting members include health professionals from all academic medical institutions that serve Maryland children, legislators, and the general public. Part of the Council's purpose is to make recommendations for new conditions to include for newborn screening, ensuring that Maryland follows an evidence-based process informed by best public health practices.

The criteria for a condition to be added to the newborn screening panel are:

- The disorder must pose a serious health threat;
- There must be an accurate screening test;
- The financial cost must be reasonable; and
- There must be an available treatment for the condition.

The Council, after conducting an evidence-based review, voted to recommend the addition of MLD to the newborn screening panel in November 2025. When the Council votes to add a condition to the screening panel, they send a recommendation to the Secretary. However, the official addition of MLD to the RUSP negated the Council's requirement to send a recommendation letter to the MDH Secretary. The Department formed an internal working group in January 2026, consisting of members of the Department's fiscal, procurement, laboratory, and follow-up staff, to oversee the planning and implementation process to ensure routine screening of all Maryland babies for MLD on or before the established 18 month deadline. This working group is committed to the implementation of MLD efficiently and expeditiously.

If you would like to discuss this further, please do not hesitate to contact Meghan Lynch, Director of Governmental Affairs at meghan.lynch@maryland.gov.

Sincerely,

A handwritten signature in blue ink, appearing to read 'Meena Seshamani', with a stylized flourish at the end.

Meena Seshamani, M.D., Ph.D.
Secretary of Health