Department of Legislative Services

Maryland General Assembly
2026 Session

FISCAL AND POLICY NOTE
First Reader

House Bill 1537 (Delegate Amprey)
Health

Public Health - Newborn Screening Program - Metachromatic Leukodystrophy

This bill requires the Maryland Department of Health (MDH) to screen for metachromatic leukodystrophy (MLD) as part of the State's Newborn Screening Program.

Fiscal Summary

State Effect: As MDH is currently in the process of implementing screening for MLD through the Newborn Screening Program, the bill has no fiscal or operational impact.

Local Effect: None.

Small Business Effect: None.

Analysis

Current Law: MDH's Newborn Screening Program is a statewide system for screening all newborn infants in Maryland for certain hereditary and congenital disorders associated with severe problems of health or development (except when the parent or guardian of the newborn objects).

The program was codified and centralized by Chapter 256 of 2008, which established the MDH public health laboratory as the sole laboratory in Maryland allowed to perform the screening tests. The system for newborn screening includes laboratory testing, reporting of test results, and follow-up activities to facilitate the rapid identification and treatment of an affected child. The laboratory is required to screen for 61 first-tier metabolic hereditary disorders on all screening specimens collected. These conditions are listed in Maryland regulations (COMAR 10.10.13.12). Second-tier tests can only be performed when requested by an individual authorized to request a medical laboratory test. MDH is required, in consultation with the State Advisory Council on Hereditary and Congenital Disorders, to establish fees for newborn screening that do not exceed an amount sufficient to cover the administrative, laboratory, and follow-up costs associated with the

performance of screening tests. Fees are deposited into the Newborn Screening Program Fund, a special fund that is administered by the Secretary of Health to cover costs associated with performing newborn screening tests.

Chapters 177 and 178 of 2024, among other things, altered the Newborn Screening Program to require MDH to implement testing for a core condition listed in the U.S. Department of Health and Human Services' Recommended Uniform Screening Panel (RUSP) within 18 months of its addition to RUSP. If MDH is unable to implement testing within this timeframe due to a delay in the procurement of necessary equipment or supplies, MDH must report to the Senate Finance Committee and the House Health and Government Operations Committee (now the House Health Committee) on the delay. Specifically, MDH must report on the reason for the delay and the anticipated timeline for implementation within 15 months of the core condition being added to RUSP and every 3 months thereafter until testing is implemented.

MLD was added to RUSP in December 2025. Therefore, MDH advises that it is currently working to add the test to Maryland's screening panel.

Additional Comments: MLD is a rare genetic disorder that causes the buildup of fatty substances in cells – especially in the spinal cord, peripheral nerves, and brain. Those with MLD have a deficiency of sulfatides, an enzyme that would otherwise help break down the fatty substances. Though the disorder can come in three different forms, the infantile form is most common.

Additional Information

Recent Prior Introductions: Similar legislation has not been introduced within the last three years.

Designated Cross File: None.

Information Source(s): Maryland Department of Health; Mayo Clinic; U.S. Department of Health and Human Services; Department of Legislative Services

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Analysis by: Eliana R. Prober

Direct Inquiries to:
(410) 946-5510
(301) 970-5510