

MARLON AMPREY  
Legislative District 40  
Baltimore City

DEPUTY MAJORITY WHIP

Economic Matters Committee



The Maryland House of Delegates  
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THE MARYLAND HOUSE OF DELEGATES  
ANNAPOLIS, MARYLAND 21401

**March 9, 2026**

Chair Bagnall  
Vice Chair Cullison  
House Health Committee  
240 Taylor House Office Building  
241 Taylor House Office Building  
Annapolis, MD 21401

**FAV Written Testimony in Support of HB1537 Public Health - Newborn Screening Program - Metachromatic Leukodystrophy**

Dear Chair Bagnall, Vice Chair Cullison, and Members of the House Health Committee, Screening newborns for serious conditions such as Metachromatic Leukodystrophy (MLD) is integral to building and maintaining healthy families in Maryland.

Screening helps detect life-altering and threatening diseases early on so that they can be treated before symptoms develop and or worsen. It helps identify the babies that may need care.

In 2024, treatment options expanded for Metachromatic Leukodystrophy. The FDA approved the first gene therapy, Lenmeldy, for children with this disease. Treatment with Lenmeldy significantly reduced the risk of severe motor impairment or death compared to those who were untreated by this therapy.

This bill would help add Metachromatic Leukodystrophy (MLD) to the Maryland Department of Health's screening system. It would drastically help prevent devastating news in future families.

New York has already implemented screening for this disease, on a one-year pilot basis, making it the first in our country to do so. The state estimates that they will identify 1-5 affected newborns per year. The infants identified to have MLD will be referred to a specialty care center in New York to receive confirmation and treatment.

Proposed amendments to this bill will remove the MLD requirement from testing from the bill, create a taskforce of 7 individuals to include folks from MDH, ACHCD, labs, doctors, and health insurance industry, require the taskforce to conduct a study on the implementation and funding of newborn screening, have the Taskforce complete their

study by 12/31/2027, and have the Taskforce produce a study and recommendations in accordance with SGA 2-1257.

Screening for this disease will alert parents to the potential care their child needs before symptoms develop, allowing them to make informed and important medical decisions about their child's future.

No parent should unexpectedly lose their child to a disease that could have been identified early and treated.

**For these reasons, I urge a favorable report on HB 1537.**

Sincerely,

A handwritten signature in black ink, appearing to read "Marlon Amprey". The signature is fluid and cursive, with the first name "Marlon" and the last name "Amprey" clearly distinguishable.

Delegate Marlon Amprey  
40<sup>th</sup> Legislative District of Maryland