SB 495

Department of Legislative Services

Maryland General Assembly
2026 Session

FISCAL AND POLICY NOTE
First Reader

Senate Bill 495 (Senator Hettleman)
Finance

Health - Newborn Screening Program - Gaucher Disease

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

Fiscal Summary

State Effect: MDH special fund expenditures increase by $3,600 in FY 2027 for supplemental testing, as discussed below. Future years reflect annualization and inflation. Revenues are not affected.

(in dollars)	FY 2027	FY 2028	FY 2029	FY 2030	FY 2031
Revenues	$0	$0	$0	$0	$0
SF Expenditure	3,600	4,900	4,900	5,000	5,000
Net Effect	($3,600)	($4,900)	($4,900)	($5,000)	($5,000)

Note:() = decrease; GF = general funds; FF = federal funds; SF = special funds; - = indeterminate increase; (-) = indeterminate decrease

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.

State Expenditures: Maryland currently screens for newborn hereditary disorders as provided on RUSP, which does not include Gaucher disease. The Maryland Advisory Council on Hereditary and Congenital Disorders has not recommended Gaucher disease for the screening panel. However, MDH's Laboratories Administration has engaged in discussions regarding the efficacy of screening for Gaucher disease with State advocacy groups and community stakeholders.

The Laboratories Administration advises that testing for Gaucher disease uses similar chemical reactions to other lysosomal disorders and thus the cost for first-tier screening can be absorbed with current staff, equipment, reagents, and supplies. However, a small amount of supplemental testing by a reference laboratory (an estimated 30 specimens annually) is required to improve the specificity of the first-tier test and improve Gaucher disease detection. Therefore, MDH special fund expenditures increase by $3,638 in fiscal 2027, which reflects the bill's October 1, 2026 effective date. This estimate reflects the cost for supplemental testing by a reference laboratory, including shipping costs. Future years reflect annualization and inflation.

Additional Comments: Gaucher disease is a rare, inherited condition that leads to the buildup of a fatty substance in tissues that can damage tissues and organs, especially the spleen, liver, and bones. Treatments can limit the growth of fatty substance or break it down. Gaucher disease is more common among people with Eastern and Central European Jewish Ancestry (also called Ashkenazi Jews). At least six states (Illinois, Missouri, New Jersey, New Mexico, Oregon, and Tennessee) screen for the disease as part of their newborn screening programs.

Additional Information

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

Designated Cross File: HB 1055 (Delegate Solomon, *et al.*) - Health.

Information Source(s): Mayo Clinic; National Gaucher Foundation; *International Journal of Neonatal Screening*; Maryland Department of Health; Department of Legislative Services

Fiscal Note History: First Reader - February 15, 2026
caw/jc

Analysis by: Eliana R. Prober

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