

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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Council Coordinator

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The Honorable Pamela Beidle, Chair
The Honorable Antonio Hayes, Co-Chair
Senate Finance Committee
3 East Miller Senate Office Building
Annapolis, Maryland 21401

February 10, 2026

Dear Senator Beidle and the members of the Finance Committee,

The Maryland Advisory Council on Hereditary and Congenital Disorders (MACHCD) opposes SB0495 (HB1055). This bill bypasses the process delineated by Maryland legislature by which disorders are added to the Maryland Newborn Screen.

MACHCD has been in existence since 1982 and is mandated per statute to make recommendations to the Secretary of Health on which health conditions are appropriate for addition to the Maryland Newborn Screening Panel. Since the inception of Newborn Screening in Maryland, no disease has ever been added to the panel by direct legislative action. From the Council's founding statute, the MACHCD's diverse membership ensures that all viewpoints are represented in the recommendations of the council. MACHCD members include clinical experts on genetic, metabolic, and other conditions; general pediatrics; state legislators; and lay community members who are affected by congenital or hereditary disorders, either as affected individuals or caregiver/family members. The Council uses an objective scoring criteria derived from the American College of Medical Genetics newborn screening recommendations.

MACHCD reviews conditions added to the federal Recommended Uniform Screening Panel (RUSP). Per 2024 legislation, any condition added to the RUSP must be implemented in 18 months.

The federal advisory committee is currently inactive, and the states remain responsible, as they have in the past, to carry out careful evaluation to assure that any changes to the newborn screen cause no harm and lead to benefit by identifying individuals who will benefit from evidence-based, approved treatments. SB0495/HB1055 specifically addresses Gaucher disease. Gaucher disease is currently under review by the MACHCD, and experts from the Maryland catchment area and external experts have been scheduled to present to the MACHCD in February and March, 2026. To ensure that the risks and benefits of screening are presented and evaluated for all Maryland newborns and other stakeholders, Gaucher disease should be reviewed in the same manner as all conditions considered for addition to the Maryland Newborn Screen.

MACHCD believes that conditions should not be added to the newborn screen by statute, bypassing the legislatively established, fair, equitable, and evidence-based public health process. This process involves the review of complex medical and scientific information, including expert analysis of the disease-based literature and evidence of public health benefit. The Council spends significant time in consultation with disease experts, member discussion and questions for the experts and MDH laboratory and clinical follow-up staff, and scoring the condition against the objective scoring criteria.

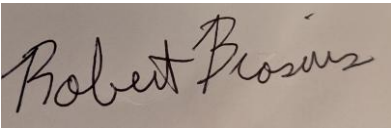
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As an independent body convened by the Maryland General Assembly for the purpose of advising the MDH on these issues, MACHCD feels no disease should be added to the panel via legislation. Instead, the state should continue to use the statutorily-defined process that has been in effect for 44 years.

Members of the MACHCD remain available to address any questions or concerns that the legislators may have regarding this or similar legislation.

Sincerely,

A rectangular box containing a handwritten signature in black ink that reads "Robert Brosius".

Robert Brosius
Interim Council Chair

A handwritten signature in black ink that reads "Jamie L. Fraser, MD, PhD".

Jamie L. Fraser, MD, PhD, FACMG
Appointed Council Member
Medical Biochemical Geneticist