

Maryland Department of Health Rare Disease Advisory Council

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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 3, 2026

Re:SB0495
Opposed

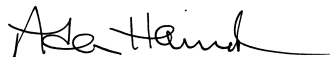
Dear Senator Beidle and the members of the Finance Committee,

I am writing on behalf of the Maryland Rare Disease Advisory Council (RDAC) in strong opposition to SB0495, which proposes legislating the addition of Gaucher Disease to newborn screening in Maryland.

The RDAC is a legislated Governor's Advisory Council tasked with improving access to care and outcomes for people in Maryland living with Rare Disease. We are very fortunate to live in a state where there is extensive expertise in newborn screening. In 2024, legislation passed that mandated the implementation by the Maryland Department of Health of any conditions added to the federal Recommended Universal Screening Panel within 18 months of approval. In addition, since 1984, we have a Secretary's Advisory Council on Hereditary and Congenital Disorders whose purpose is to systematically review the newborn screening program, including which conditions, which methods, which protocols are used. The addition of a specific condition, not included on the RUSP and not reviewed by the Maryland State Advisory Council on Hereditary and Congenital Disorders, undermines the proven efficacy of the system in place in Maryland and introduces political interference into complex scientific, medical, and public health decisions best made by experts and a legislatively mandated representative committee. The inclusion of Gaucher Disease, or any specific condition, should not be the subject of legislation. They should be reviewed carefully by those appointed to have this responsibility.

Please don't hesitate to reach out to me if you have any questions about this bill or about rare disease.

Sincerely,



Ada Hamosh, MD, MPH, Chair