

SB495 - Newborn Screening - Gaucher Disease Testim

Uploaded by: Abigail Snyder

Position: FAV



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Baltimore District

WRITTEN TESTIMONY
SB495 - Newborn Screening Program - Gaucher Disease
Senate Finance Committee
February 20, 2026
Support

Background: SB495 would require the Maryland Department of Health, as part of the newborn screening system, to screen for Gaucher disease. While Gaucher disease affects people of all ethnic backgrounds, it is especially common in the Ashkenazi Jewish population. ¹

Written Comments: The Baltimore Jewish Council (BJC) represents The Associated: Jewish Federation of Baltimore and all its agencies, and programs, as well as the organized Jewish Community of Baltimore.

Maryland's newborn screening program under the Department of Health tests for over 60 different disorders, including metabolic, endocrine, and hemoglobin conditions². A two-screen process is used, with samples collected shortly after birth and again around 10–14 days of age. The screening focuses on identifying rare, serious diseases early to allow for immediate treatment.

Gaucher disease is a genetic disorder more prevalent in people of Ashkenazi Jewish (Eastern European Jewish) descent, with about 1 in 10 carriers in this population, compared to 1 in 450 births affected, making it the most common Jewish genetic disease. It's caused by a deficiency in the [GBA enzyme](#), leading to fat buildup in organs, but carrier screening is vital for this community due to the high carrier rate.

An enzyme test called a beta-glucosidase leukocyte (BGL) test is the main tool that physicians use to diagnose Gaucher disease. This is because all patients with Gaucher disease will have low enzyme activity levels.³ This is a simple test that can be added to the already administered blood panel required by the Department of Health for newborns.

For these reasons, we ask for a favorable report on SB495.

The Baltimore Jewish Council, a coalition of central Maryland Jewish organizations and congregations, advocates at all levels of government, on a variety of social welfare, economic and religious concerns, to protect and promote the interests of the Associated Jewish Community Federation of Baltimore, its agencies and the Greater Baltimore Jewish community.

¹ <https://www.gaucherdisease.org/about-gaucher-disease/jewish-genetic-diseases/>

² [Pages - NBS Disorders](#)

³ <https://www.gaucherdisease.org/gaucher-diagnosis-treatment/testing/>

SB495_JewishCaucus_FAV.docx.pdf

Uploaded by: Eden Durbin

Position: FAV



WRITTEN TESTIMONY

FAVORABLE

SB495 - Health – Newborn Screening Program – Gaucher Disease

Finance Committee
February 18, 2026

The Maryland Legislative Jewish Caucus (MLJC), a bipartisan group of Senators and Delegates, **strongly supports SB 495 as a 2026 caucus priority**. This legislation would require the Maryland Department of Health, as part of the newborn screening (NBS) program, to screen for Gaucher disease, a rare and sometimes deadly genetic disorder disproportionately affecting the Jewish community. Gaucher disease is the most prevalent inherited Jewish genetic disease.

Given that Maryland is estimated to have the ninth largest Jewish population in the United States, this program is critical. SB 495 provides a simple and effective option for newborn screening which is essential for early diagnosis and timely access to life-saving treatments. This legislation clearly aligns with MLJC's mission to serve as a liaison for the Jewish community of Maryland.

Adoption of SB 495 would allow Maryland to join several other states including Illinois, Missouri, New Jersey, New Mexico, Oregon and Tennessee, that have already effectively integrated Gaucher testing into their statewide NBS programs. Evidence shows that integration into existing NBS infrastructure is feasible with hardly any financial cost and earlier diagnosis of Gaucher generates cost savings for both families and the healthcare system.

For these reasons, we request a favorable report on SB 495.

2026 ACNM SB 495 Senate Side.pdf

Uploaded by: Robyn Elliott

Position: FAV



Committee: Senate Finance Committee

Bill: Senate Bill 495 - Health – Newborn Screening Program – Gaucher Disease

Hearing Date: February 18, 2026

Position: Support

The Maryland Affiliate of the American College of Nurse Midwives (ACNM) supports *Senate Bill 495 – Health Newborn Screening Program – Gaucher Disease*. Gaucher disease is a rare hereditary disorder where the buildup of fatty substances impacts the functioning of the liver and spleen and cause bone pain.ⁱ We support adding Gaucher disease to the list of required screenings for newborns, as early diagnosis and prompt initiation of therapy can improve the clinical outcomes.ⁱⁱ

We ask for a favorable report. If we can provide any additional information, please contact Robyn Elliott at relliott@policypartners.net or (443) 926-3443.

ⁱ <https://www.mayoclinic.org/diseases-conditions/gauchers-disease/symptoms-causes/syc-20355546>

ⁱⁱ <https://pmc.ncbi.nlm.nih.gov/articles/PMC12101256/>

SB495_FAV_Hettleman.pdf

Uploaded by: Shelly Hettleman

Position: FAV

SHELLY HETTLEMAN
Legislative District 11
Baltimore County

Chair, Rules Committee
Budget and Taxation Committee

Subcommittees
Capital Budget
Health and Human Services
Chair, Pensions

Joint Committees
Senate Chair, Audit and Evaluation
Senate Chair, Pensions



THE SENATE OF MARYLAND
ANNAPOLIS, MARYLAND 21401

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Shelly.Hettleman@senate.state.md.us

TESTIMONY OF SENATOR SHELLY HETTLEMAN
SB 495 - HEALTH - NEWBORN SCREENING PROGRAM - GAUCHER
DISEASE

Madam Chair, Mr. Vice Chair, and members of the Senate Finance Committee, I am writing to express my strong support for **SB 495 - Health - Newborn Screening Program - Gaucher Disease**.

What Is Gaucher Disease?

Gaucher Disease is a rare genetic condition that causes a buildup of fatty deposits throughout the body, which can lead to progressive organ damage, chronic pain, anemia, bone disease, and, in severe cases, life-threatening complications. Although Gaucher Disease affects individuals across all racial and ethnic backgrounds, it disproportionately impacts people of Ashkenazi Jewish descent. The incidence of Gaucher Disease in this population is approximately 1 in 450 individuals, compared to roughly 1 in 100,000 in the general population.¹ This disparity underscores the importance of equitable public health measures that ensure early identification and intervention for communities at elevated genetic risk, while also recognizing that Gaucher Disease can affect any child born in Maryland.

Regardless of background, without early diagnosis, the symptoms of Gaucher Disease may go unrecognized for years, during which time irreversible harm can occur. Newborn screening for Gaucher Disease is both feasible and effective. Reliable screening methods already exist and are used in several jurisdictions worldwide, enabling early identification and timely intervention.

Maryland law mandates that the Maryland Department of Health screen for all disorders on the Recommended Uniform Screening Panel (RUSP), which provides federal recommendations for disorders to be included on state newborn screening panels. Each year, newborn screening performed per the RUSP identifies approximately 14,000 infants with serious conditions that benefit from early intervention.² However, despite evidence that newborn screening enables timely monitoring and treatment to prevent irreversible organ damage and reduce disease complications, Gaucher Disease is not currently part of the RUSP. SB 495 fills this gap.

Federal Changes and Their Impact on Maryland

Historically, Maryland relied on vetting from the federal Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) to add new disorders to its newborn screening panels. The role of the ACHDNC was to evaluate scientific evidence and make recommendations to the U.S. Secretary of Health and Human Services regarding which conditions should be added to the RUSP. However, the ACHDNC was dissolved in April 2025, creating uncertainty about the future of disorders being added to the RUSP.

Following the dissolution of the ACHDNC, Maryland's State Advisory Council on Hereditary and Congenital Disorders (the Council) established a transparent and objective process for nominating, reviewing, and recommending new disorders to add to the Maryland newborn screening panel. The Council comprises experts in genetic disorders and community members with lived experience who review scientific literature to determine if a disorder meets inclusion criteria for newborn screening. These criteria include the availability of a reliable test, effective treatment, and evidence that the disorder causes irreversible harm to the child during the newborn period if left untreated. In the absence of federal RUSP inclusion, a disorder can now be added to the Maryland newborn screening panel through this new Council review and recommendation process.

The Role of SB 495

Maryland has already taken a proactive and thoughtful step by empowering its State Advisory Council on Hereditary and Congenital Disorders to evaluate disorders using transparent, evidence-based criteria. This process ensures that decisions about newborn screening are grounded in scientific rigor, clinical effectiveness, and ethical responsibility. Gaucher Disease is precisely the type of condition this process was designed to evaluate.

Yet, this process is still evolving and does not guarantee timely implementation. SB 495 directly addresses this gap by requiring the Maryland Department of Health to include Gaucher Disease in the state's newborn screening program without unnecessary delay. This ensures that infants in Maryland are not left vulnerable to preventable harm due to federal delays in RUSP inclusion.

Newborn screening is one of the most effective public health interventions available. It is designed to identify serious conditions before symptoms appear, when intervention can make the greatest difference. By adding Gaucher Disease to Maryland's newborn screening program, SB 495 affirms the state's commitment to preventing avoidable harm, promoting health equity, and using science-based evidence to guide our policy.

Therefore, I respectfully urge a favorable report on SB 495.

RDAC_SB00495 Approved.pdf

Uploaded by: Ada Hamosh

Position: UNF

Maryland Department of Health Rare Disease Advisory Council

Wes Moore, Governor · Aruna Miller, Lt. Governor · Meena Seshamani, M.D., Ph.D., Secretary

Current Members

Chair: Ada Hamosh, MD,
MPH

Felicia Brannon, MPA

Celinda Carr, LCSW-C, CCM

Elisdel Garcia-Bousquet,
MD

Peter Hill, MD

Philip Iffland, PhD

Senator Clarence Lam, MD

David Mann, MD, PhD

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Kristopher Rusinko,
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MS

Jamie Sexton, JD

Lauren Shillinger

Constance Smith-Hicks,
MD, PhD

Jeneva Stone, PhD, MFA

Delegate Jamila Woods

Council Coordinator

Lauren Whiteman, MPH,
CPH

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

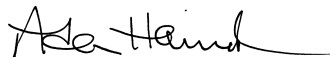
Dear Senator Beidle and the members of the Finance Committee,

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

ACHCD SB495 (Gaucher) Approved Letter.pdf

Uploaded by: Robert Brosius

Position: UNF

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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Linda Chell

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CGC*

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Delegate Terri Hill, MD

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Susan Sullivan

Ex-Officio Members

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Mary Mussman, MD, MPH

Robert Myers, PhD

*Theresa Wavra, MSN, RN,
APRN, PCNS-BC*

Council Coordinator

LaPortia Barrows, RN, BSN

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.

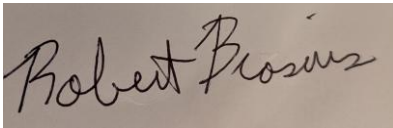
Maryland Department of Health Advisory Council on Hereditary and Congenital Disorders

Wes Moore, Governor · Aruna Miller, Lt. Governor · Meena Seshamani, M.D., Ph.D., Secretary

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

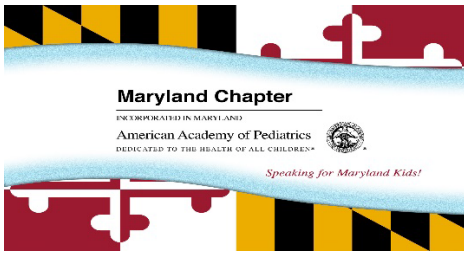
A handwritten signature in black ink that reads "Jamie L. Fraser, MD, PhD".

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

SB0495_LOI_MDAAP_Health - Newborn Screening Progra

Uploaded by: Christine Krone

Position: INFO



Senate Finance Committee
February 18, 2026
Senate Bill 495 – *Health – Newborn Screening Program – Gaucher Disease*
LETTER OF INFORMATION

The Maryland Chapter of the American Academy of Pediatrics (MDAAP) is a statewide association representing more than 1,100 pediatricians and allied pediatric and adolescent healthcare practitioners in the State and is a strong and established advocate promoting the health and safety of all the children we serve. On behalf of MDAAP, we submit this letter of information for Senate Bill 495.

Senate Bill 495 proposes adding Gaucher disease to Maryland’s newborn screening panel. While we recognize the importance of expanding early detection for treatable conditions, we offer this information to clarify how the newborn screening process is currently implemented in Maryland.

Currently, Gaucher disease is not included on the federal Recommended Uniform Screening Panel (RUSP), which lists conditions the U.S. Department of Health and Human Services recommends for universal newborn screening. Typically, states follow recommendations on the RUSP. Importantly, Maryland law allows the state to add conditions to the newborn screening panel independently of the RUSP, provided the Department and Advisory Council follow the established review and approval process.

In Maryland, the Department of Health, in consultation with the State Advisory Council on Hereditary and Congenital Disorders, has the authority to recommend which conditions are added to the newborn screening panel. This process allows for careful consideration of state-specific factors, including:

- The prevalence of the condition within Maryland’s population.
- Availability of reliable diagnostic tests and follow-up treatment resources.
- Capacity of the Maryland Newborn Screening Program to perform testing and coordinate care.

MDAAP supports the goals of Senate Bill 495 to expand early detection of treatable conditions, and we appreciate the Legislature’s attention to newborn health. We offer this information to ensure that any addition to the screening panel continues to follow Maryland’s established process, which balances timely implementation with careful evaluation of state-specific considerations, testing capacity, and follow-up care. By maintaining this structured approach, we can ensure that newborns receive accurate screening and appropriate clinical support, maximizing the benefits of early detection while safeguarding program quality.

For more information call:

Christine K. Krone
J. Steven Wise
Danna L. Kauffman
Andrew G. Vetter
410-244-7000