HB1625_SponsorTestimony

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Position: FAV

TERRI L. HILL, M.D.
Legislative District 12A
Howard County

Health and Government Operations Committee

Subcommittees
Public Health and Minority Health Disparities, Chair
Elder and Long-Term Care
Maternal, Infant, and Child Health

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THE MARYLAND GENERAL ASSEMBLY
ANNAPOLIS, MARYLAND 21401

HB1625- Public Health - Newborn Screening Program - Fees and Core Conditions

April 1, 2026

Chair Beidle, Vice Chair Hayes, and Members of Senate Finance Committee,

HB1625 modifies the statute regulating the Maryland's Newborn Screening Program to ensure its usefulness and sustainability, by making adjustments to how hereditary conditions and congenital diseases are added for testing. Importantly, it gives needed flexibility to the Secretary in following the recommendation of the federal Recommended Uniform Screening Panel so decision can be based on the most current science.

Through the Newborn Screening Program, which is administered by the Maryland Department of Health, infants born in the state are screened shortly after birth for serious hereditary and congenital disorders. Early detection allows health care providers to begin treatment quickly, often preventing severe disability, lifelong complications, or even death. The Maryland Advisory Council on Congenital and Heriditary Diseases, including leading experts in the field, reviews and evaluates all request for new additions and advise the Secretary on inclusions based on considerations of multiple factors. The legislation addresses problems that have developed in the two years since automatic incusions were mandated statutorily and discourages inclusion by legislature and the attendant problems.

HB1625 also updates the testing fees to cover the administrative, laboratory, and follow-up costs associated with screening; by doing so it will ensure that the program remains fully supported and sustainable.

HB1625 is responsive to an urgent need and I urge a favorable report.

Terri L. Hill, M.D.

MD HB 1625.pdf
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Position: FAV

RARE READY
COALITION

The Akari Foundation.org
ACD Association for Creatine Deficiencies
BDSRA foundation
Don't Forget Morgan
The E.WE Foundation
FSIG
Fighting H.A.R.D. Foundation
Helping kids who Have A Rare Disease or chronic illness
Galactosemia Foundation
Linked for Life
Juju and Friends CLN2 Warrior Foundation
Amplifying the Patient Voice
LUPUS and ALLIED DISEASES Association, Inc.
NAF National Ataxia Foundation
National MPS Society
Support for Families. Research for a Cure.
NPKUA national PKU alliance
NTSAD National Tay-Sachs & Allied Diseases Association
N.O.T.A. THE NETWORK OF TYROSINEMIA ADVOCATES
Organic Acidemia Association
Oxalosis & Hyperoxaluria Foundation
STEPPING STONES TO A CURE
PKU Organization of Illinois & Allied Disorders
PWF POMPE WARRIOR FOUNDATION
RESEARCH EDUCATE EMPOWER
Prader-Willi Syndrome Association | USA
SAVING AND TRANSFORMING LIVES
Rare Disease Innovations Institute
RARE MAMAS
sat b2 gene foundation
Shwachman-Diamond Syndrome Foundation
Support...Research...Cure
SCDAI
Sickle Cell Disease Association of Illinois
TSC Alliance

March 30, 2026

Testimony in Support of HB 1625

On behalf of the Rare & Ready Coalition, we appreciate the opportunity to submit testimony in support of HB 1625. Our coalition represents a broad network of advocates committed to improving outcomes for individuals living with rare diseases through earlier diagnosis.

HB 1625 takes important steps to strengthen Maryland's newborn screening program by ensuring it is adequately funded and aligned with the federal Recommended Uniform Screening Panel (RUSP). Establishing sustainable funding for screening, laboratory operations, and follow-up care is essential to maintaining a reliable and responsive system.

As innovation in diagnostics and treatment continues to accelerate, it is critical that state screening programs keep pace. Each newly added condition represents a meaningful opportunity to identify a child earlier and improve long-term health outcomes. Without timely implementation, these opportunities can be missed.

For these reasons, the Rare & Ready Coalition respectfully urges support for HB 1625. This legislation represents a critical investment in public health, health equity, and the future of children and families impacted by rare diseases.

Sincerely,
Rare & Ready Coalition Members

HB1625 Senate Hearing ACHCD Letterhead.docx.pdf

Uploaded by: Robert Brosius

Position: FAV

Maryland Department of Health
Advisory Council on Hereditary and Congenital Disorders

Wes Moore, Governor · Aruna Miller, Lt. Governor

Current Members

Robert Brosius, Vice Chair

Alicia Baines

Linda Chell

Shannan Dixon, MS, PhD, CGC

Jamie Fraser, MD, PhD

Mary Hackbarth

Delegate Terri Hill, MD

Irfan Suleman, MD

Susan Sullivan

Ex-Officio Members

Christine Dorley, PhD

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, Vice Chair
Finance Committee
3 East Miller Senate Office Building
Annapolis, Maryland 21401

March 24, 2026

Dear Senator Beidle and members of the Finance Committee,

The Maryland Advisory Council on Hereditary and Congenital Disorders (MACHCD) supports HB1625 as it passed in the House. The legislation enacted by this bill will help the Council work with improved efficiency and effectiveness when adding new disorders to the Maryland Newborn Screening Panel.

MACHCD 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. Legislation passed in 2024 requires the state's Newborn Screening Program to align with the federal Recommended Uniform Screening Panel (RUSP). The federal advisory committee that oversees the RUSP is currently inactive and the state remains responsible to carry out careful evaluation to ensure that any changes to the newborn screen cause no harm and lead to improved identification of individuals who will benefit from evidence-based, approved treatments.

MACHCD keeps track of conditions that are possible candidates for addition to the RUSP by consistently reviewing research about disorders and their associated treatments. It has also implemented a system by which persons can submit nominations for addition to the Maryland Newborn Screening Panel. Once a condition is identified, the Council initiates its formal evaluation process which includes review of complex medical and scientific information. The Council spends significant time in consultation with disease experts, Maryland Department of Health (MDH) staff, and other public health professionals. The final step of the review process uses an objective scoring criteria derived from the American College of Medical Genetics newborn screening recommendations.

HB1625 helps to ensure that conditions added to the Maryland Newborn Screening Panel are properly assessed for the safety and health of Maryland's babies. HB1625 also helps MACHCD to remove the financial barriers that often contribute to delays in implementation of testing for new conditions added to the screening panel by ensuring the cost of testing is fully covered by the fees collected.

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

Sincerely,

Robert Brosius

Jamie L Fraser, MD PhD

Robert Brosius
Interim Chair

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

RDAC_HB1625_approved_crossfile.pdf

Uploaded by: Ada Hamosh

Position: FWA

Maryland Department of Health
Rare Disease Advisory Council

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

March 10, 2026

Re: House Bill 1625
Support, with amendment

The Honorable Pamel Beidle, Chair
The Honorable Antonio Hayes, Vice Chair
Maryland Senate Finance Committee
3 East Miller Senate Office Building
Annapolis, Maryland 21401

Dear Chair Beidle and members of the Finance Committee,

I am writing on behalf of the Maryland Rare Disease Advisory Council (RDAC) in support with amendments of House Bill 1625. 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 would recommend changing the date in Health- General 13-111 (e) (1) (i) to a time when the composition of the Recommended Uniform Screening Panel is known (e.g. 1/1/26) as opposed to a future date. We support this bill to ensure that the newborns in Maryland continue to receive the most up to date and efficient tests, follow up and care for conditions that can be detected by newborn screening. Since the dissolution of the federal committee considering additions to the Recommended Universal Screening Panel in April 2025, there is no national review. Fortunately, in Maryland we have the legislated Department of Health Secretary's Advisory Committee on Hereditary and Congenital Disorders. This committee composition is legislated and its purpose has always been to review and evaluate the newborn screening panel and program. This bill will allow that committee to assess conditions and testing for addition to the Maryland Newborn Screening (NBS) Panel. It also extends time to implementation to 24 months from 18 months to allow the State Lab to buy necessary equipment and reagents and to establish standards and cutoffs appropriate to our State's population of newborns. It also reinforces that NBS should be cost neutral, i.e., the cost of the test should cover the cost of reagents and equipment, so that there is not a drawn out procurement process. The RDAC supports all of these measures.

The RDAC's purpose is to increase awareness of rare disease and improve access to care and outcomes for people living with rare diseases. This is certainly accomplished by improved testing, early detection, and preventative treatment with those rare diseases that are detectable by NBS.

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

1625 Senate NBS 2026 .pdf

Uploaded by: Mary Morlino

Position: FWA

HB 1625 - Public Health – Newborn Screening Program – Fees and Core Conditions

Sponsored by: Delegate Hill
Delegates: Alston, Bagnall, Cullison, Guzzone, Hutchinson, Kaufman, Lopez, Martinez, Reilly, Rosenberg, Ross, Taveras, White Holland, and Woorman
Senate - Hearing: 4/1 at 1:00 p.m. **Submitted:** 3/30/26

Thank you for the opportunity to provide testimony for HB 1625 - Public Health – Newborn Screening Program – Fees and Core Conditions.

My name is Mary Morlino. I am the Founder and CEO of Maryland Rare, which supports the rare disease community of Maryland through advocacy, education and community building.

I have worked professionally with The EveryLife Foundation for Rare Diseases, a nonprofit and nonpartisan organization dedicated to empowering the rare disease patient community to advocate for impactful, science-driven legislation and policy that advances the equitable development of and access to lifesaving diagnoses, treatments and cures. I worked with Global Genes, a nonprofit committed to providing information, resources and connections to all communities affected by rare diseases. In addition I worked with The Undiagnosed Diseases Network Foundation (UDNF), whose mission is support and improve access to diagnosis, research, and care for all individuals with rare and undiagnosed diseases.

Notably, I have been an advocate for over 20 years, supporting families, individuals and communities living with the extensive challenges faced by the rare disease, chronic illness and disability communities. I have the honor of serving on the Johns Hopkins Sarcoidosis Patient Advisory Board as well various roles with the Foundation for Sarcoidosis Research.

Additionally, I am a rare disease patient living with multisystem Sarcoidosis and I have multiple family members affected by various rare diseases.

I, on behalf of the Maryland Rare community, support HB 1625 - Public Health – Newborn Screening Program – Fees and Core Conditions.

This impactful bill will:

- Ensures sufficient funding to cover the newborn screening fee helping to ensure that it's enough to cover the administrative, lab, and follow up costs.
- Requires the state to screen for all the RUSP approved conditions.
- Require the State Advisory Council on Hereditary and Congenital Disorders (ACHCD) to advise the department on the risks, harms, accessibility, and costs of implementing testing for the condition, and provide recommendations on whether or not to implement.
- Create a mechanism of reporting to inform the Department of potential missed deadlines 9 months before the deadline so that there is transparency and understanding, especially if the delays are occurring because of other state administrative process problems such as procurement of equipment and supplies or it is decided to delay or NOT to implement a condition recommended by the ACHCD.
- Ensure reporting within 1 year & 3 months of RUSP approval and every 3 months after if they cannot implement the condition within 2 years of RUSP approval.
- Ensure reporting to JUSTIFY their decision NOT to implement or why it was delayed along with an anticipated implementation date.

In 2022, the Maryland General Assembly passed HB 109 and SB 242, ensuring the implementation of the two-year timeline in which screening must begin for new conditions added to the federal Recommended Uniform Screening Panel (RUSP). Since the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) was terminated, it is imperative that Maryland continues to support and advance Newborn Screening for babies born in Maryland.

“As new treatments and new diagnostic tests are developed each year, an increasing number of disease communities will be able to utilize newborn screening to deliver life-saving diagnosis early in life. RUSP alignment legislation ensures that Maryland will keep up with those developments,” Annie Kennedy, EveryLife Foundation Chief of Policy, Advocacy, and Patient Engagement.

Time is of the essence with newborn screening. Families seeking answers and impactful action do not have the luxury of time to address crucial and timely action. This bill would help you and your constituents by ensuring that their children can access treatments when they need it most. Improving the outcomes and effectiveness of treatments is the priority to ensure disease progression is limited and addressed as soon as possible.

In closing, I urge you to support HB 1625 - Public Health – Newborn Screening Program – Fees and Core Conditions.

Thank you for your consideration of this crucial bill.

With Hope and Gratitude,
Mary Morlino
Founder & CEO

HB 1625 - FIN - MDH - LOI (3rd Reader).docx.pdf

Uploaded by: Meghan Lynch
Position: INFO

Maryland
DEPARTMENT OF HEALTH

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

April 1, 2026

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

Re: House Bill 1625 – Public Health – Newborn Screening Program – Fees and Core Conditions - Letter of Information

Dear Chair Beidle and Committee Members:

The Maryland Department of Health (the Department) submits this letter of information regarding House Bill (HB) 1625 - Public Health – Newborn Screening Program – Fees and Core Conditions.

As amended, the bill will ensure that when updating the newborn screening fee, the fee sufficiently covers administrative, laboratory, and follow-up costs associated with implementation of screening tests. The Department is also required to screen for each core condition on the federal Recommended Uniform Screening Panel (RUSP) through January 31, 2026, wherein the Maryland Advisory Council on Hereditary and Congenital Disorders (Advisory Council) will thereafter provide recommendations on whether the Department should implement testing for each core condition added to the RUSP. An extension to the 18-month requirement for implementation of a new condition on the RUSP to two years (if the Department has decided to implement testing upon the recommendation of the Advisory Council) has also been provided.

The Division screens for more than 60 hereditary and congenital disorders for infants born in the State of Maryland. The Division is entirely funded through the Newborn Screening Program Fund pursuant to Maryland Code Ann., Health – General § 13-113. This is a non-lapsing special fund designed to provide funding for the screening of newborn infants, the funds of which are collected by birthing hospitals for the screening tests that are performed. According to State statutory and regulatory requirements, currently, fees are based on true costs required to cover expenses, such as purchasing equipment, reagents, and supplies or hiring additional personnel.

In addition, extending the implementation period for a new condition added to the RUSP from 18 months to two years (if the Department chooses to implement testing after the Advisory Council's recommendation) would give the Division more time to secure funding, begin validation studies, and launch screening. Most states allow three years for implementation of screening for new disorders, and Maryland's current 18-month timeline is the shortest of any state that aligns with the RUSP. In regard to the potential for HB 1625 to remove the requirement for Maryland to align with the RUSP, the Department could implement this change should the bill pass.

If you would like to discuss this further, please do not hesitate to contact Meghan Lynch, Director of Governmental Affairs at meghan.lynch@maryland.gov.

Sincerely,

Meena Seshamani, M.D., Ph.D.
Secretary of Health