

Maryland Department of Health Advisory Council on Hereditary and Congenital Disorders

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The Honorable Anne Healey, Chair
The Honorable Marvin Holmes, Jr., Vice Chair
Annapolis, Maryland 21401

March 9, 2026

Dear Chair Healey and the members of the Rules and Executive Nominations Committee ,

The Maryland Advisory Council on Hereditary and Congenital Disorders (MACHCD) supports HB1625. 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.

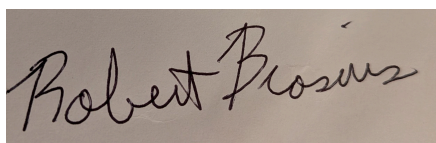
MACHCD is mandated per statute to make recommendations to the Secretary of Health on which health conditions are appropriate for addition to the Maryland Newborn Screening Panel. Legislation passed in 2024 requires the state's Newborn Screening Program to align with the federal Recommended Uniform Screening 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 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.
Vice Chair.



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