

# 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

## Current Members

Robert Brosius, Vice  
Chair

Alicia Baines

Linda Chell

Shannan Dixon, MS,  
PhD, CGC

Jamie Fraser, MD,  
PhD, FACMG

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 Heather Bagnall, Chair  
The Honorable Bonnie Cullison, Vice Chair  
House Health Committee  
240 Taylor House Office Building  
Annapolis, Maryland 21401

March 3, 2026

Dear Delegate Bagnall and the members of the Health Committee,

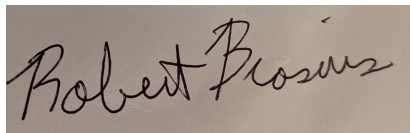
**The Maryland Advisory Council on Hereditary and Congenital Disorders (MACHCD) supports HB1133.** The legislation enacted by this bill will help the Council make better informed decisions when evaluating new disorders for addition to the Maryland Newborn Screening Panel.

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. The Council must be certain 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 has implemented a system by which persons can submit nominations for addition to the Maryland Newborn Screening Panel. Once a submission is received, the Council initiates its formal evaluation process.

By requiring drug manufacturers and certain patient advocacy organizations to register with MDH before conducting a disease awareness campaign in the State, HB1133 will help the Council to work more efficiently by creating an earlier line of communication between all relevant parties. And, by requiring drug manufacturers to disclose their marketing intentions in relation to the disease awareness campaign, HB1133 will increase transparency during the Council's review process if conditions are nominated for addition to the newborn screen as part of the disease awareness campaign.

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