

Maryland Department of Health Advisory Council on Hereditary and Congenital Disorders

Wes Moore, Governor · Aruna Miller, Lt. Governor · Laura Herrera Scott, Secretary

Current Members

January 30, 2024

Jamie Fraser, MD, PhD, Chair

Dear Chair Beidle

Robert Brosius, Vice Chair

*Shannan Dixon, M.S., Ph.D.,
C.G.C.*

The Maryland Advisory Council on Hereditary and Congenital Disorders (MACHCD) opposes HB96 (SB117) to add Krabbe Disease Leukodystrophy by statute to the Maryland Newborn Screening Panel.

Sharon Dols

John McGing

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.

Gerald Raymond, MD

David Myles, MD

Michelle Smith

Dominique Sessa

Delegate Terri Hill, MD

Senator Johnny Ray Salling

Ex-Officio Members

Robert Meyers, PhD

Stacy Taylor

Council Coordinator

LaPortia Barrows

MACHCD reviews conditions based on the conditions reviewed and added to the federal Recommended Uniform Screening Panel (RUSP), which maintains a rigorous standard for review of data and evidence for additions of new conditions. Per 2022 legislation, any condition added to the RUSP must be reviewed by MACHCD within a year, and if the Council does not recommend adding that condition to the Maryland Newborn Screening Panel, MACHCD must review the recommendation status annually.

On January 30, 2024, the federal Health Resources Services Administration's Advisory Committee on Heritable Disorders in Newborns and Children voted to add early infantile Krabbe Disease to the RUSP. This vote is the first step to add Krabbe Disease to the RUSP as the Secretary of Health and Human Services must finalize the addition, similar to the process in Maryland.

MACHCD believes that conditions should not be added to the newborn screen by statute, bypassing the Council's process. The MACHCD 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.

As a body independent of the Maryland Department of Health, 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 42 years.

Sincerely,

Sincerely,

A handwritten signature in black ink, appearing to read "J. Fraser MD PhD". The signature is fluid and cursive.

Jamie L. Fraser, M.D., Ph.D., DABMGG
Chair