

Maryland Department of Health Rare Disease Advisory Council

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Delegate Jamila Woods

3 East Miller Senate Office Building
Annapolis, Maryland 21401

February 17, 2026

Re:HB1537
Opposed

Dear Senator and Health Committee Members,

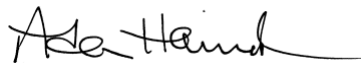
I am writing on behalf of the Maryland Rare Disease Advisory Council (RDAC) in strong opposition to HB1537, which proposes legislating the addition of Metachromatic Leukodystrophy to newborn screening in Maryland.

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, and 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.

Inclusion of Metachromatic Leukodystrophy (MLD) or any specific condition should not be the subject of legislation. They should be reviewed carefully by those appointed to have this responsibility. In fact, this has already occurred for MLD and it has been added to the Maryland NBS Panel.

Please don't hesitate to reach out to me if you have any questions about this bill or about rare disease.

Sincerely,



Council Coordinator

Lauren Whiteman, MPH,
CPH

Ada Hamosh, MD, MPH, Chair