

March 18, 2026,

The Honorable Heather Bagnall
Chair, Health Committee
Maryland House of Delegates
241 Taylor House Office Building
Annapolis, Maryland 21401

Re: HB1537 – Public Health – Newborn Screening Program – Metachromatic Leukodystrophy
Committee: Health
Position: Favorable with Amendments

Dear Chair Bagnall and Members of the Committee:

I write to respectfully request that the Committee issue a Favorable Report with Amendments on HB1537 – Public Health – Newborn Screening Program – Metachromatic Leukodystrophy. Specifically, the proposed amendments to the bill establish a task force to study ways to shorten the timeline between recommendations made by the State Advisory Council on Hereditary and Congenital Disorders (ACHCD) and the implementation of screening within Maryland’s newborn screening program.

Under current Maryland law, the State has up to eighteen months to implement newborn screening after the ACHCD recommends adding a condition to the State’s screening panel. While this timeline reflects the operational challenges of implementing new screenings, HB1537, when amended, highlights the need to examine whether Maryland can safely accelerate this process so that life-saving screening becomes available as quickly as possible.

Restructuring HB1537 as a task force would allow the State to examine barriers that delay implementation, including funding for equipment, laboratory capacity, staffing, and procurement of reagents. The task force should include representatives from hospitals, the Maryland Department of Health, procurement specialists, and health insurance providers so that operational and financial barriers can be fully evaluated. The task force should report its findings and recommendations to the Maryland General Assembly in time for consideration during the 2028 legislative session.

This issue is deeply personal to my family. My daughter, Carmen Akras, is currently suffering from a terminal case of Metachromatic Leukodystrophy (MLD), a rare genetic disease that progressively destroys the nervous system. Our family learned of her condition in the fall of 2024 after blood and urine testing confirmed the diagnosis, by which time the disease had already progressed to an advanced stage.

In March 2024, the U.S. Food and Drug Administration approved a treatment that can allow children with MLD to live relatively normal lives, but the treatment must be administered very early—generally within the first three months of life—to be effective. If newborn screening for MLD had been in place in Maryland at the time of Carmen’s birth, her condition likely would have been detected in time for treatment.

MLD has now been recognized as appropriate for newborn screening. It is therefore critical that Maryland move quickly to implement testing once the ACHCD recommends inclusion of the condition in the State’s screening panel. Delays caused by funding gaps or implementation barriers can have devastating consequences for children and their families.

By establishing a task force to study strategies for accelerating implementation of ACHCD newborn screening recommendations, Maryland will move one step closer to saving the lives of newborns with genetic diseases through earlier identification and timely treatment.

For these reasons, I respectfully urge the Committee to issue a Favorable Report with Amendments on HB1537 – Public Health – Newborn Screening Program – Metachromatic Leukodystrophy.

Thank you for your time and consideration and I look forward to answering any of your questions or concerns.

Sincerely,

Thomas R. Akras