

March 17, 2026,

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

**Re: HB 1625 – Public Health – Newborn Screening Program – Fees and Core Conditions
Position: Favorable with Amendments**

Dear Chair Bagnall and Members of the Committee:

I write today to respectfully request a favorable report with amendments on House Bill 1625 – Public Health – Newborn Screening Program – Fees and Core Conditions.

HB 1625 increases the cap on the fees that the Maryland Department of Health may set for newborn screening and modifies the responsibilities of the State Advisory Council on Hereditary and Congenital Disorders regarding the State's newborn screening program. The bill also authorizes the Department, after consultation with the advisory council, to delay or decline implementation of screening for certain conditions and modifies reporting requirements related to those decisions.

The bill also provides the Secretary of Health and the Advisory Council with greater flexibility to consider, adopt, and implement screening for diseases as they are added to the federal Recommended Uniform Screening Panel (RUSP). As medical science advances, an increasing number of serious genetic diseases can now be detected at birth and treated effectively if identified early.

However, the bill does not establish a dedicated funding mechanism to ensure the timely implementation of new screening requirements once a condition is recommended. Without reliable funding, the State may face delays in procuring laboratory equipment, validating tests, and hiring specialized staff needed to implement screening for newly recommended diseases.

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 Carmen's condition in the fall of 2024 after blood and urine testing confirmed the diagnosis. By that time, her 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. However, 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 added to the Recommended Uniform Screening Panel. It is therefore critical that Maryland move quickly to implement testing once the Advisory Council recommends inclusion of the condition in the State’s newborn screening panel. Delays caused by funding gaps or implementation barriers can have devastating consequences for families.

For this reason, I respectfully urge the Committee to consider amendments establishing a dedicated fund within the Maryland Department of Health’s budget to support implementation of newborn screening panel recommendations made by the Advisory Council. A dedicated funding source would help ensure that when new diseases are recommended for screening, Maryland has the resources necessary to implement testing as quickly as possible.

No family should learn of a devastating diagnosis only after the window for treatment has passed. Early detection can make the difference between life and death for children affected by rare genetic diseases.

For these reasons, I respectfully request a favorable report with amendments on House Bill 1625 – Public Health – Newborn Screening Program – Fees and Core Conditions.

Thank you for your time and consideration.

Sincerely,

Thomas R. Akras