



March 18, 2026

Delegate Heather Bagnall
Chair, House Health Committee
240 Taylor House Office Building
Annapolis, MD 21401

Re: House Bill 1537 - Public Health - Newborn Screening Program - Metachromatic Leukodystrophy

Dear Chair Bagnall,

We respectfully submit this letter regarding House Bill 1537, proposed legislation that would add the rare neurogenetic disorder, metachromatic leukodystrophy (MLD), to the newborn screening panel in Maryland.

On December 16, 2025, the federal Department of Health and Human Services approved the addition of MLD to the Recommended Uniform Screening Panel (RUSP).

As you know, this proposed legislation would amend Maryland Statute 13-111 to specifically add MLD to the newborn screen. However, thanks to a law passed in 2024, this statute already delineates a process that requires the Maryland Department of Health to screen for each core condition listed under RUSP, with implementation within 18 months after the core condition is added to the RUSP.

We understand and appreciate the motivation for this proposed addition. Kennedy Krieger Institute agrees with and celebrates this determination by RUSP. **It is extremely important, in our opinion, that the State of Maryland is in alignment with newborn screening for all conditions listed under RUSP, including MLD. Further, it imperative that sufficient funding is allocated for the inclusion and implementation of MLD to the newborn screening process.** We also appreciate the extant language in 13-111, describing the required steps (and the required 18 month timeline for those steps) to be taken by the Maryland Department of Health, in consultation with the State's Advisory Council on Hereditary and Congenital Disorders, now that MLD has been added to RUSP.

For more than 40 years, Kennedy Krieger has been globally recognized as an authority on the study and care for patients diagnosed with a wide range of leukodystrophies. The Moser Center for Leukodystrophies at Kennedy Krieger provides comprehensive care to patients with leukodystrophies through an interdisciplinary approach, bringing together the fields of neurogenetics, genetic counseling, neurorehabilitation, endocrinology, and urology, along with

physical, occupational, speech, and aquatic therapy. The Center works collaboratively with other leukodystrophy centers across the country and around the world.

Newborn Screening allows for the early detection of treatable rare genetic disorders, resulting in a dramatic improvement in the lives of young babies and children, as well as their families. MLD is a type of neurodegenerative condition called a leukodystrophy. All leukodystrophies are rare inherited diseases that affect myelin (the “white matter” which insulates nerve cells in brain, spinal cord, and peripheral nerves). Recent data indicate that leukodystrophies affect approximately 1 in 7000 newborns. MLD is a rare hereditary disorder that results in the build of cells in the brain, spinal cord and peripheral nerves. The brain and nervous system progressively lose function because the substance that covers and protects the nerve cells, called myelin, is damaged. There are three forms of MLD, late infantile form, juvenile form, and adult form. The infantile form is the most common and progresses more rapidly than the other forms.

Currently the only available treatment to halt the rapid decline of MLD is hematopoietic stem cell transplantation and gene therapy. Underscoring the critical importance of newborn screening, this treatment is only effective in changing disease trajectory if patients receive the stem cell transplant within the first year of life before there is clear presence of neurological or developmental deficits.

In sum, Kennedy Krieger celebrates the very recent addition of MLD to the federal Recommended Uniform Screening Panel and is willing and available to assist the Department in their implementation.

Sincerely,



Bradley L. Schlaggar, M.D., Ph.D.
President & CEO
Zanvyl Krieger Faculty Endowed Chair
Kennedy Krieger Institute



S. Ali Fatemi, MD MBA
Chief Medical Officer
Director, Moser Center for Leukodystrophies
Blum-Moser Endowed Chair
Kennedy Krieger Institute