
Memo

DATE: April 18, 2025

TO: Brooke Cunningham, MD, PhD
Commissioner
Minnesota Department of Health

THROUGH: Myra Kunas, Assistant Commissioner, Health Protection Bureau
Sara Vetter, Director, Public Health Laboratory Division
Jill Simonetti, Assistant Director, Public Health Laboratory Division

FROM: Rae Blaylark, Chair, Advisory Committee on Heritable and Congenital Disorders
Katie Pfister, Vice Chair, Advisory Committee on Heritable and Congenital Disorders
Amy Dahle, Committee Coordinator, Newborn Screening, Public Health Laboratory
Carrie Wolf, Manager, Newborn Screening, Public Health Laboratory
Nicole Brown, Manager, Children and Youth with Special Health Needs, Child and Family Health

SUBJECT: Request for response on the recommendation made by the Advisory Committee on Heritable and Congenital Disorders (also called the Newborn Screening Advisory Committee).

Minnesota's Advisory Committee on Heritable and Congenital Disorders has met multiple times regarding the nomination to add metachromatic leukodystrophy (MLD) to Minnesota's newborn screening panel.

The mechanism for revising the list is described in Minnesota Statute, 144.125 "Tests of infants for heritable and congenital disorders," as follows:

"The list of tests to be performed may be revised if the changes are recommended by the advisory committee established under section 144.1255, if approved by the commissioner, and published in the State Register. The revision is exempt from the rulemaking requirements in chapter 14, and sections 14.385 and 14.386 do not apply."

At the April 15, 2025, Advisory Committee meeting, advisors voted to recommend the addition of MLD to the Minnesota newborn screening panel. Below are the voting outcomes.

- 16:2 to recommend the addition of MLD

Committee members understood that implementation would require MDH to secure resources, establish follow-up

protocols, make changes to laboratory information management systems, develop education plans, and coordinate other necessary implementation efforts.

At this time, we are asking you to review the Advisory Committee's recommendation. The enclosed documentation includes information provided to committee members and highlights the benefits and limitations of screening for MLD. We also provided draft language to update the State Register for your review and approval. We hope you find this package helpful as you thoughtfully consider this recommendation.

Please provide us with your response at your earliest convenience. We are available for questions or discussion as needed. Please contact Carrie Wolf, Manager, Newborn Screening, Public Health Laboratory, at: 651-201-5458, or carrie.wolf@state.mn.us.

After reviewing the enclosed materials, we ask that you sign and date this page to indicate your decision.

With regards to the Committee's recommendation to add MLD to the screening panel:

☒ I approve the addition of MLD and the submission to the State Register

☐ I decline the addition of MLD

☐ Need more information

/s/ Brooke Cunningham

Brooke Cunningham, MD, PhD
Commissioner of Health

4/29/2025

Date

Enclosures:

Chairperson's letter

Nomination

Public comments from 4/23/2024 meeting

Condition Readiness Criteria

Minutes from meeting on 4/23/2024

Meeting slides from 4/23/2024

Minutes from meeting on 10/8/2024

Meeting slides from 10/8/2024 meeting

Letter to Nominators after the vote on 10/8/2024

Response Letter from Nominators

Meeting slides from 4/15/2025 meeting

Select literature

Longitudinal Follow Up Fact Sheets

Submission for the State Register

Pending items to be received later:

Minutes from meeting on 4/15/2025