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# Memo

**DATE:** August 15, 2023

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

**THROUGH:** Dan Huff, Assistant Commissioner, Health Protection Bureau

Myra Kunas, Director, Public Health Laboratory Division /s/

Sara Vetter, Assistant Director, Public Health Laboratory Division /s/

**FROM:** Rae Blaylark, Chair, Advisory Committee on Heritable and Congenital Disorders  
Katie Pfister, Vice Chair, Advisory Committee on Heritable and Congenital Disorders  
McKayla Gourneau, Committee Coordinator, Newborn Screening, Public Health Laboratory  
Amy Dahle, Committee Coordinator, Newborn Screening, Public Health Laboratory  
Jill Simonetti, 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).

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The Minnesota Advisory Committee on Heritable and Congenital Disorders would like you to consider the expansion of the Minnesota newborn screening panel to include Krabbe Disease.

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 June 6, 2023, Advisory Committee meeting, members voted as follows to add the proposed condition to Minnesota’s newborn screening panel.

- 11:4 to recommend the addition of Krabbe Disease

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.

On the national level, eleven states currently screen for Krabbe Disease even though Krabbe Disease is not included on the federal Recommended Uniform Screening Panel (RUSP). The most recent nomination to the RUSP resulted in the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) voting that Krabbe Disease was not ready for addition to the RUSP. Materials from that meeting were provided to the MN NSAC during their consideration and are enclosed.

At this time, we are asking you to review the Advisory Committee's recommendation to add Krabbe Disease to Minnesota's newborn screening panel. The enclosed documentation includes information provided to committee members and highlights the benefits and risks of screening for Krabbe Disease. 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.

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 Krabbe disease to the screening panel:

I approve the addition of Krabbe Disease and the submission to the State Register

I decline the addition of Krabbe Disease

Need more information

/s/

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Brooke Cunningham, MD, PhD  
Commissioner of Health

**August 21, 2023**  
Date

Enclosures:

Chairperson's letter

Krabbe Disease Nomination from the Legacy of Angels Foundation

Condition Readiness Criteria & Matrix

Meeting slides from May 31, 2022; October 4, 2022; and June 6, 2023

Minutes from meeting on May 31, 2022; October 4, 2022; and June 6, 2023

Letters of Support

Longitudinal Follow Up Fact Sheet

Slides from the federal ACHDNC meeting February 9, 2023, discussing the vote and review of Krabbe Disease for the RUSP

Submission for the State Register