DEPARTMENT OF HEALTH

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).

The Minnesota Advisory Committee on Heritable and Congenital Disorders would like you to consider the expansion of the Minnesota newborn screening panel to include guanidinoacetate methyltransferase (GAMT) deficiency and mucopolysaccharidosis type 2 (MPS II).

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 conditions to Minnesota's newborn screening panel.

- 14:2 to recommend the addition of GAMT deficiency
- 15:1 to recommend the addition of MPS II

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, both conditions are on the recommended uniform screening panel (RUSP). Currently, three states screen for GAMT deficiency and three states screen for MPS II nationwide.

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

If these are satisfactory, we ask that you sign and date this page to indicate your decision.

With regards to the Committee's recommendation to add GAMT deficiency to the Minnesota Newborn Screening Panel:

_X___ I approve the addition of GAMT deficiency and updating the State Register

____ I decline the addition of GAMT deficiency

____ Need more information

With regards to the Committee's recommendation to add MPS II to the Minnesota Newborn Screening Panel:

__X__ I approve the addition of MPS II and submission to the State Register

____ I decline the addition of MPS II

____ Need more information

/s/
_____ August 21, 2023
Brooke Cunningham, MD, PhD — Date
Commissioner

Enclosures:

Chairperson's letter
Recommended Uniform Screening Panel
Meeting slides from October 4, 2022
Minutes from meeting on October 4, 2022
Meeting slides from June 6, 2023
Minutes from meeting on June 6, 2023
Guanidinoacetate methyltransferase deficiency – Evidence Review from federal Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC)
Mucopolysaccharidosis type II – Evidence Review from federal ACHDNC
Longitudinal Follow Up Fact Sheet
Submission for the State Register