DEPARTMENT OF HEALTH

Protecting, Maintaining and Improving the Health of All Minnesotans

July 7, 2026

Reena Kartha, MS, PhD
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2001 6th Street SE
Minneapolis, MN 55455

Dear Dr. Kartha and Co-Sponsors (Ms. Aviva Rosenberg and Dr. Chet Whitley),

The Advisory Committee on Heritable and Congenital Disorders thanks you for your nomination to include Gaucher disease on the Minnesota (MN) newborn screening (NBS) panel. We appreciate your interest and the time you invested in the nomination and review process.

As part of the committee's consideration process, a workgroup was convened to evaluate the current evidence regarding the suitability of population-based screening in MN. This work group consisted of individuals from MN with expertise in Gaucher disease. Key findings were presented and discussed at the Advisory Committee meeting held on April 14, 2026. Advisors then completed their own review utilizing the nomination materials submitted, published literature, and the findings from the evidence review. The committee has finished its review and formally voted on June 16, 2026. **The Advisory Committee voted 14:5 to not recommend Gaucher disease be added to the MN NBS panel.**

Below are key findings and discussion points:

- The current screening method is feasible; however, it cannot differentiate between the subtypes of the disease. Therefore, type 1 (the most common, least severe, and latest onset form) would likely be the most common subtype identified by NBS.
- Intervention/treatment cannot improve neurological symptoms of types 2 and 3. There is some evidence of benefit with earlier treatment for type 1.
- Data on the outcomes of NBS for Gaucher disease are limited despite multiple states screening newborns for the disease for a number of years.
- While specialists are available in MN who can diagnose and treat these patients, there are no data-driven clinical guidelines to advise them on the management and treatment of individuals identified through NBS without symptoms.

While Gaucher disease is not recommended at this time, re-nomination can occur once some of the above items have been addressed. If you have any questions, please contact the committee coordinators via email at health.nsac@state.mn.us.

Sincerely,

Rae Blaylark

Rae Blaylark, Chairperson
Advisory Committee on Heritable and Congenital Disorders