



State of Wisconsin
Department of Health Services

Tony Evers, Governor
Kirsten L. Johnson, Secretary

April 23, 2026

Jill Beirl
National Niemann-Pick Disease Foundation
jbeirl@nnpdf.org

Dr. Justin Hopkin, MD
National Niemann-Pick Disease Foundation
jhopkin@nnpdf.org

Dr. Robert Steiner, MD
University of Wisconsin
rsteiner3@wisc.edu

Dear Ms. Beirl, Dr. Hopkin, and Dr. Steiner,

Thank you for submitting a nomination to add acid sphingomyelinase deficiency (ASMD), also known as Niemann-Pick Disease Types A, B, and A/B, to Wisconsin's newborn screening panel of conditions. We appreciate and share your concern for children and families who are profoundly affected by this condition.

When we receive nominations to add a condition to the Wisconsin panel, we follow a careful process to ensure that they are thoroughly reviewed by doctors and scientific experts in Wisconsin. You can read more about this process, the established criteria, and the committees involved at: [Nominate a Condition for Addition to the Wisconsin Newborn Screening Panel | Wisconsin Department of Health Services](#).

The initial condition nomination was reviewed by the Newborn Screening Metabolic Subcommittee on October 18, 2024, which recommended tabling the nomination. The subcommittee forwarded their comments to the Newborn Screening Umbrella Committee which met on December 6, 2024, to review the nomination which also recommended tabling the nomination. Then the Secretary's Advisory Committee on Newborn Screening (SACNBS) met on March 14, 2025, to review the nomination. The SACNBS voted unanimously to table the nomination due to inadequate information about the ability to differentiate between severe and more mild forms of ASMD on the screen, and inadequate information about the impact of treatment on the more severe acute neurovisceral forms.

After obtaining this information, the Metabolic Subcommittee met on October 17, 2025, and the Umbrella Committee met on December 5, 2025, and determined that ASMD meets all the criteria for inclusion on Wisconsin's newborn screening panel. The SACNBS met on March 6, 2026 to review the condition nomination further. The SACNBS voted unanimously in favor of adding ASMD to Wisconsin's newborn screening panel.

Based on the recommendations of SACNBS, I approve the addition of ASMD to the newborn screening panel through the administrative rule-making process. You can read more about this process at: [Administrative Rules | Wisconsin Department of Health Services](#).

Thank you for your contribution to the Wisconsin Newborn Screening Program.

Sincerely,

A handwritten signature in blue ink that reads "Kirsten Johnson". The signature is fluid and cursive, with a long horizontal stroke at the end.

Kirsten L. Johnson
Secretary-designee
Department of Health Services

cc: Dr. Norman Fost, MD, MPH
Chair, Secretary's Advisory Committee on Newborn Screening
ncfost@wisc.edu

Paula Tran, MPH
Wisconsin Department of Health Services
State Health Officer
paula.tran@dhs.wisconsin.gov