

State of Wisconsin Department of Health Services

Tony Evers, Governor Andrea Palm, Secretary

May 26, 2020

Michael and Stephanie Clubb 918 Merry Lane Milladore, WI 54454

Dear Mr. and Mrs. Clubb:

Thank you for submitting a nomination on August 26, 2019, to add Pompe Disease to the newborn screening panel of conditions. We appreciate and share your concern for children and families who are profoundly affected by this terrible disease.

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, using established criteria. You can read more about this process and the committees involved at https://www.dhs.wisconsin.gov/newbornscreening/process-additions.htm.

On December 6, 2019, the Newborn Screening Program Umbrella Committee, consisting of experts who specialize in caring for children with various disorders such as Pompe Disease, reviewed this condition and the available evidence. The Umbrella Committee also reviewed the nomination, and recommended adding Pompe Disease to the newborn screening panel.

On March 6, 2020, the Secretary's Advisory Committee on Newborn Screening (SACNBS) reviewed the nomination, as well as the recommendation of the Umbrella Committee. The SACNBS also recommended adding Pompe Disease to the newborn screening panel.

Based on the recommendation of the SACNBS, I am approving the addition of Pompe Disease to the newborn screening panel through the administrative rule-making process.

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

Sincerely,

Andrea Palm

Secretary-designee