

State of Wisconsin Department of Health Services

Tony Evers, Governor Karen E. Timberlake, Secretary

May 12, 2022

Dr. Jennifer Kwon kwon@neurology.wisc.edu

Dr. Mei Baker mei.baker@slh.wisc.edu

Dear Drs. Kwon and Baker,

Thank you for submitting a nomination to add X-linked adrenal leukodystrophy (X-ALD) to the 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: <u>Nominate a Condition</u> for Addition to the Wisconsin Newborn Screening Panel | Wisconsin Department of Health Services.

On December 3, 2021, the Newborn Screening Program Umbrella Committee, consisting of experts who specialize in caring for children with various disorders such as X-linked adrenal leukodystrophy (X-ALD), reviewed this condition and the available evidence. The Umbrella Committee also reviewed the nomination and recommended adding X-ALD to the newborn screening panel.

On March 4, 2022, 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 X-ALD to the newborn screening panel.

Based on the recommendation of the SACNBS, I am approving the addition of X-ALD 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,

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Karen E. Timberlake Secretary-designee

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