

## State of Wisconsin Department of Health Services

Scott Walker, Governor Linda Seemeyer, Secretary

March 22, 2018

Dr. Khoon Ghee Queenie Tan Clinical Genetics 1500 Highland Ave Madison, WI 53705

Dr. Patrice Held Co-Director, Wisconsin Newborn Screening Laboratory Wisconsin State Laboratory of Hygiene 465 Henry Mall Madison, WI 53706

Dear Drs. Tan and Held:

Thank you for submitting a nomination on April 6, 2017, to add carnitine palmitoyltransferase 1A (CPT1A) deficiency to the newborn screening panel of conditions. We appreciate and share your concern for children and families who are profoundly affected by this disorder.

When we receive nominations to add a congenital or metabolic disorder to the Wisconsin newborn screening panel, we follow a careful process to ensure the disorder is 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.

In January, 2017, a subcommittee of Wisconsin physicians, who specialize in caring for children with metabolic disorders, such as CPT1A, reviewed this condition and your presentation materials, as well as other available evidence. These doctors recommended that CPT1A be added to the newborn screening panel.

In May, 2017, a larger committee of Wisconsin newborn screening specialists reviewed the nomination and also recommended adding CPT1A to the newborn screening panel.

In October, 2017, the Secretary's Advisory Committee on Newborn Screening (SACNBS) reviewed the nomination, as well as the recommendations of the earlier committees. The SACNBS also recommended adding CPT1A to the newborn screening panel.

Based on the recommendation of the SACNBS, I am approving the addition of CPT1A to the newborn screening panel through the administrative rulemaking process.

Thank you for your interest and support for the Wisconsin Newborn Screening Program.

Sincerely,

Linda Seemeyer Secretary