

WASHINGTON STATE BOARD OF HEALTH

Date: April 12, 2023

To: Washington State Board of Health Members

From: Dimyana Abdelmalek, Board Member

Subject: Briefing/Update – Newborn Screening, Ornithine Transcarbamylase Deficiency (OTCD), Chapter 246-650 WAC

Background and Summary:

The State Board of Health (Board) has the authority under RCW 70.83.050 to adopt rules for screening Washington-born infants for hereditary conditions. Chapter 246-650 WAC is the Board's rule for newborn screening in Washington. WAC 246-650-010 defines the conditions, and WAC 246-650-020 lists the conditions on the state's required newborn screening panel.

Ornithine Transcarbamylase Deficiency (OTCD) is an inherited condition with a rapid onset that can result in significant morbidity and mortality if not detected and treated early.^{1,2} OTCD is a urea cycle disorder that causes ammonia to accumulate in the blood, affecting the liver and other body systems. Newborn screening, resulting in possible early diagnosis, is essential to improve the quality of life for infants and their families and reduce infant mortality.

In 2021, the Board convened a technical advisory committee (TAC) to consider adding OTCD to the state's newborn screening panel. At its July 7, 2021, meeting, the TAC voted to include OTCD as a condition for screening. The Board discussed the TAC's recommendations at its October 13, 2021, meeting and voted to proceed with rulemaking to consider rules that would allow for screening of OTCD in the newborn screening program.

The Board filed a [CR-101, Preproposal Statement of Inquiry](#), on February 4, 2022, to initiate rulemaking for chapter 246-650 WAC. Since the CR-101 filing, the Department of Health's (Department) Newborn Screening Program requested a fee increase from the legislature to add OTCD to the screening panel. The Board and Department have not been able to move forward with rulemaking, as authorization from the legislature (additional funding approved in the budget) is necessary to increase the fee to cover costs associated with including a new condition on the panel.

I have invited Molly Dinardo, Board Staff, to provide a brief overview of OTCD and an update on the Department's funding request for OTCD.

(continued on the next page)

Washington State Board of Health
April 12, 2023, Meeting Memo

Staff

Molly Dinardo

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1. Health Resources and Services Administration. Ornithine transcarbamylase deficiency | Newborn Screening. Last Updated December 2022. Accessed March 29, 2023.
<https://newbornscreening.hrsa.gov/conditions/ornithine-transcarbamylase-deficiency>
 2. National Center for Advancing Translational Sciences. Ornithine transcarbamylase deficiency - About the Disease - Genetic and Rare Diseases Information Center. Accessed March 29, 2023.
<https://rarediseases.info.nih.gov/diseases/8391/ornithine-transcarbamylase-deficiency>