

# WASHINGTON STATE BOARD OF HEALTH

**Date:** October 13, 2021

**To:** Washington State Board of Health Members

**From:** Tom Pendergrass, Board Vice Chair

**Subject:** Briefing – Recommendations of the Newborn Screening Technical Advisory Committee: Ornithine Transcarbamylase Deficiency (OTCD)

## Background and Summary:

The Washington State Board of Health (Board) has the authority under RCW 70.83.050 to define and adopt rules for screening of Washington-born infants for hereditary conditions. WAC 246-650-010 defines the conditions and WAC 246-650-020 lists conditions for which all Washington-born newborns are to be screened. The Board convenes a technical advisory committee (TAC) in order to inform its decisions on which conditions to include in the newborn screening (NBS) panel. The TAC uses available information to evaluate candidate conditions based on an established set of criteria.

Urea cycle disorders like Ornithine Transcarbamylase Deficiency (OTCD) are uncommon but result in debilitating or lethal outcomes. Currently, there are seven states and Puerto Rico that include OTCD in their newborn screening panel. Several of these states have conducted this screening for many years. Board and Department staff conducted a preliminary review, which indicated feasibility of screening for OTCD in Washington and staff recommended further exploration through a technical advisory committee to fully assess OTCD against the Board's criteria. At its August 12, 2020 meeting, the Board voted to direct staff to convene a TAC.

The TAC met twice, on June 16 and July 7, 2021, to consider OTCD against the Board's criteria. At the first meeting, TAC members heard presentations and considered the first four criteria. The TAC reconvened in July to consider the cost-benefit analysis and vote to make a final recommendation.

I have invited Dr. John Thompson and Michael Katsuyama from the Department of Health's Newborn Screening Program, as well as Samantha Pskowski, Policy Advisor to the Board, to presentation information from the OTCD TAC meetings.

## Recommended Board Actions:

The Board may wish to consider one of the following motions:

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The Board directs staff to file a CR-101 to initiate rulemaking for chapter 246-650 WAC to consider adding ornithine transcarbamylase deficiency (OTCD) to the newborn screening panel.

*Or*

The Board determines that ornithine transcarbamylase (OTCD) should not be considered for addition to the newborn screening panel at this time and moves to reevaluate the condition in two years as a candidate for mandatory newborn screening in Washington State.

#### Staff

Samantha Pskowski, Policy Advisor

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