



**DATE:** January 13, 2016

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

**FROM:** Diana T. Yu, MD, MSPH

**SUBJECT:** ADRENOLEUKODYSTROPHY NEWBORN SCREENING ADVISORY COMMITTEE RECOMMENDATIONS

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**Background and Summary:**

The Washington State Board of Health (Board) has the duty under RCW 70.83.050 to define and adopt rules for screening Washington-born infants for heritable conditions. WAC 246-650-020 lists conditions for which all newborns must be screened. In order to determine which conditions to include in the newborn screening (NBS) panel, the Board convenes an advisory committee to evaluate candidate conditions using an established set of criteria.

On October 8, 2014, the Board approved a motion to evaluate the current five newborn screening NBS criteria. On March 6, 2015, a Criteria Review Advisory Committee was convened to: 1) review the criteria to see if language is appropriate or needed to be modified, 2) determine if new criteria should be added, 3) identify a small set of criteria to serve as “minimum requirements” or “Qualifying Assumptions” which Board and Department of Health (Department) staff could apply to determine if requested conditions were ready for review by an advisory committee, and 4) develop an ethical framework or guiding principles to govern the evaluation of any new potential condition. On April 8, 2015, the Board approved the committee’s recommendations and directed staff to use them to conduct an evaluation of Adrenoleukodystrophy (ALD).

On October 28, 2016, a committee was convened to evaluate the condition against the Board’s newly adopted NBS criteria for possible inclusion in the NBS panel. Lain Knowles and John Thompson from the Department will present a summary of the discussion of the advisory committee.

**Recommended Board Action:**

***Motion:** The Board approves and adopts the recommendations of the ALD NBS Advisory Committee, and asks staff to begin the necessary steps to add ALD to the NBS panel in Chapter 246-650 WAC.*

**Staff Contact: Tara Wolff**