



STATE OF WASHINGTON
WASHINGTON STATE BOARD OF HEALTH
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May 14, 2008

TO: Washington State Board of Health Members

FROM: Dr. Diana Yu, SBOH Member

SUBJECT: **NEWBORN SCREENING CONDITIONS RULE—CHAPTER 246-650 WAC**

Summary

The Newborn Screening Advisory Committee (NSAC) finished its application of the Board's five criteria to the candidate conditions in March 2008. The committee concluded that 16 of the conditions met all five criteria. On April 1, the Board filed a Proposed Rule Making (CR-102), which proposes language to add the 16 new conditions to Chapter 246-650 WAC. It appeared in the Washington State Register as WSR 08-08-086. In response to the notification of the proposal to add the new conditions, Dr. Wylie Burke, Chair of the Department of Medical History and Ethics at the University of Washington, submitted a comment to the Department of Health. Dr. Burke indicated that her medical colleagues in Alaska and British Columbia and representatives from Alaska Native organizations have concerns about carnitine palmitoyl transferase deficiency type 1-A (CPT-1) screening. They noted that while there is a high frequency of the unique genetic variant among native populations, there is a lack of clear information about the health effects of the condition.

Mike Glass looked into these concerns (the results of his analysis are included in Tab 11) and shared them with Dr. Hayes and myself. After careful review, we determined that identification of the condition does not provide a clear benefit to the newborn such as preventing delay in diagnosis; developmental impairment; or serious illness or death. We also concluded that the significance of the diagnosis is in question since there is not a sufficient understanding of what it means to have the homozygous recessive variant of CPT-1 in the Native Alaskan population. Accordingly, we recommend that CPT-1 not be included in Chapter 246-650 WAC at this time. Our recommendation was shared with the NSAC and interested parties in April 2008.

Today the Board will hold the formal public hearing on this proposed rule change. I have invited Dr. Jude Van Buren, the Assistant Secretary for the Division of Epidemiology, Health Statistics and the Public Health Laboratories, and Mike Glass, the Director of the Newborn Screening Program, to provide a brief update on the rule revision and answer questions. The Board will then hear public testimony.

Recommended Board Action

Depending on testimony offered and the Board's own discussions, the Board may choose to consider, amend if necessary, or adopt the following motion:

Motion: The Board adopts the revised Chapter 246-650 WAC as published in WSR 08-08-086 with the following amendments: strike the references to carnitine palmitoyl transferase deficiency type 1-A (CPT-1) in WAC 246-650-010 (8) and in WAC 246-650-020 (2)(a)(xii).