



STATE OF WASHINGTON
WASHINGTON STATE BOARD OF HEALTH
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January 9, 2008

TO: Washington State Board of Health Members
FROM: Dr. Diana Yu, SBOH Member
SUBJECT: **NEWBORN SCREENING ADVISORY COMMITTEE UPDATE**

Background and Summary

Recent medical and technological advances have made it feasible to screen newborns for a large number of disorders. Many disorders can be detected using the dried blood specimen routinely collected to test infants in Washington State. In 2004, the U.S. Department of Health and Human Services Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children accepted a report from the American College of Medical Genetics (ACMG). This report recommended early detection or identification of 29 disorders by utilizing newborn screening. Sixteen of these disorders are currently not screened for in Washington State. (To see a list of what is currently screened for in Washington, please refer to Tab 6.)

This report prompted the Board to ask DOH to look into the feasibility of expanded screening, its estimated cost, Washington's capacity to detect and treat the disorders, and the number of newborns in Washington who could potentially have the 16 conditions. DOH presented its preliminary findings to the Board in October 2005. The Board then asked that an advisory committee process be used to apply its five criteria (prevention potential and medical rationale, treatment available, public health rationale, available technology, and cost benefit/cost effectiveness) to the 16 conditions and bring recommendations back to the Board.

In September 2006, Dr. Kim Thorburn, then-Board chair, and Dr. Maxine Hayes, State Health Officer, convened a small committee of technical experts to evaluate the 16 disorders against two of the Board's criteria (available technology and treatment). The committee ranked the 16 disorders as those having most, intermediate and least concordance with these criteria. They also added a condition that has been found to be common in Alaska natives for further consideration.

In February 2007, I agreed to assume leadership for this work in partnership with Dr. Hayes. We invited a larger, broadly representative, advisory group to apply the Board criteria to the 17 candidate disorders. This advisory committee is composed of parents, representatives from children's advocacy groups, representatives from professional associations, medical/clinical specialists, principal payers' representatives, medical ethicists, and public health professionals.

It has met twice and completed its application of four of the five conditions on December 10, 2007. The next step is to apply the cost benefit/cost effectiveness criteria.

Today we will have a chance to hear more about the Newborn Screening program and the review process to date.

After the Department of Health has concluded its cost benefit/cost effectiveness analysis, the advisory committee will reconvene to decide on its final recommendation. I anticipate that the advisory committee will have completed its review of the disorders by the end of March. I hope to bring a proposal to the Board at the April or May 2008 meeting. Based on the information presented at that meeting, the Board may elect to add a number of new conditions to Chapter 246-650 WAC.

Recommended Board Action

No action recommended at this time.