

**ADVISORY COMMITTEE:
AN EVALUATION OF NEW CONDITIONS AGAINST SBOH CRITERIA
TO MAKE RECOMMENDATIONS TO THE SBOH**

DECEMBER 2007

PURPOSE: Review the conditions set forth in the American College of Medical Genetics' report and one additional condition that are currently not included in Chapter 246-650 WAC against the Board's five criteria for evaluating new disorders.

PRODUCT: A report detailing recommendations on additional conditions that might be included in Chapter 246-650 WAC. This report will be presented to the State Board of Health which will decide if the screening panel should be expanded.

RATIONALE: Chapter 70.83 RCW gives authority to the Board of Health to determine which disorders, in addition to phenylketonuria (PKU), are to be included in Newborn Screening required by the statute. Medical and technological advances in recent years have made it feasible to screen for an increasing number of additional disorders. A study commissioned by the federal Health Resources and Services Administration has recommended that every state should screen for a standard panel of disorders. This panel has been endorsed by the American Academy of Pediatrics and the March of Dimes. Of the 29 disorders recommended, 16 are not currently screened for in Washington. An additional disorder, recommended by a state Technical Advisory Committee, will also be considered.

MEMBERSHIP: Stakeholders from the fields of public health, pediatrics, family medicine, hospital care, medical ethics, plans, payers, and child advocacy as well as representatives from families.

PROJECT DESCRIPTION: It is anticipated that the committee will meet twice to review the conditions against four of the five criteria:

PREVENTION POTENTIAL AND MEDICAL RATIONALE

Identification of the condition provides a clear benefit to the newborn; preventing delay in diagnosis; developmental impairment; serious illness or death.

TREATMENT AVAILABLE

Appropriate and effective screening, diagnosis, treatment, and systems are available for evaluation and care.

PUBLIC HEALTH RATIONALE

Nature of the condition (symptoms are usually absent, such that diagnosis is delayed and treatment effectiveness is compromised) and prevalence of the condition justify population-based screening rather than risk-based screening.

AVAILABLE TECHNOLOGY

Sensitive, specific and timely tests are available that can be adapted to mass screening.

The fifth criteria - cost-benefit/cost-effectiveness (that the benefits justify the costs of screening) - will be applied, once a list of conditions meeting the first four criteria has been created.

LEADERSHIP: This project will be led by the State Board of Health and the Department of Health.

LOGISTICS: The advisory committee will meet twice. The meetings will last all day (9 a.m. - 4 p.m.) and will be held at the Department of Health's Public Health Laboratory in Shoreline. The first meeting was held September 24, 2007. The second meeting will be held December 10, 2007.