



WASHINGTON STATE Board of Health

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DATE: March 14, 2012

TO: Washington State Board of Health Members

FROM: Dr. Diana Yu

SUBJECT: BRIEFING – NEWBORN SCREENING PROGRAM AND AND SEVERE COMBINED IMMUNODEFICIENCY (SCID) ADVISORY COMMITTEE

Background and Summary:

All children born in Washington are tested for certain congenital conditions through newborn screening. The Board determines which conditions should be included in the newborn screening panel according to Chapter 70.83 RCW, and designates conditions in Chapter 246-650 WAC. The Board relies on recommendations from an advisory committee that applies five criteria (attached) to determine whether a proposed condition should be added to the newborn screening panel. The advisory committee is made up of parents of affected children, children's advocacy groups, professional associations, medical/clinical specialties, principle payers, medical ethics, and public health professions. The Board makes the final decision as to whether to accept the advisory committee's recommendation. During this process the Department of Health, which is responsible for operating the screening program, examines the fiscal effect of adding the condition and determines the feasibility of finding funding to add the new condition to the rule. If the Board approves the advisory committee's recommendation, the Department of Health also implements the screening for a new condition once funding has been secured and the condition is added to the rule.

In 2010, Kathleen Sebelius, secretary of the Department of Health and Human Services (HHS), added Severe Combined Immunodeficiency (SCID) to the panel of 30 congenital disorders it recommends states screen. This was after members of the Advisory Committee on Heritable Disorders in Newborn and Children carefully reviewed SCID against their criteria and recommended it be added to the national panel.

SCID is a group of congenital disorders characterized by very low or absent production of primary infection-fighting cells. It is sometimes known as "bubble boy disease." SCID is typically treated with a bone marrow transplant. It is critical to perform the treatment early to avoid deaths from infections, or serious infections that complicate the bone marrow transplant, and substantially raise costs deaths related to treatment failure. After looking at the HHS findings and other studies, I asked that an advisory committee be convened to look at SCID in relationship to the Board's five criteria. The committee met on February 22, 2012, and Dr. Maxine Hayes and I co-chaired the meeting.

Mike Glass, director of the Newborn Screening (NBS) at the Department of Health, is here today to present the NBS program, the five criteria, to describe SCID in more detail, and to explain the advisory committee process. I have also asked him to share the voting results of the SCID advisory meeting. In June, Mr. Glass will present the committee's review of the five criteria in detail so that the Board can determine whether to accept the committee's recommendation.

Recommended Board Action:

No action recommended.

Staff Contact: Tara Wolff