



STATE OF WASHINGTON
WASHINGTON STATE BOARD OF HEALTH

PO Box 47990 • Olympia, Washington 98504-7990

November 14, 2012

Ms. Mary Anne Lindeblad, Director
Health Care Authority
626 Eighth Ave S.E.
Olympia, WA 98501

Dear Ms. Lindeblad:

This letter requests that the 2014 contract rebase for hospital services include an increase to allow newborns in Washington to be screened for Severe Combined Immune Deficiency (SCID). SCID, commonly referred to as “boy in the bubble” disease, is a group of congenital disorders characterized by very low, or a lack of, infection fighting cells. Adding SCID to Washington’s newborn screening panel will significantly reduce health care costs and save lives.

The Department of Health (DOH) screens all newborns in Washington for certain congenital conditions that without early detection and treatment would cause permanent disability or death. The Washington State Board of Health (Board) determines the conditions that are included in the newborn screening panel. In 2010, the U.S. Department of Health and Human Services recommended that states include SCID in newborn screening. Based on this recommendation, the Board convened an advisory committee to review the research on SCID. The advisory committee recommended that the Board include SCID as part of the newborn screening panel, and the Board accepted the committee’s recommendations, with the understanding that implementation would be contingent on the feasibility of obtaining sustainable funding.

To determine which conditions to add to the state’s newborn screening panel, the Board applies five criteria to each condition: prevention potential and medical rationale, treatment available, public health rationale, available technology, and cost-benefit/cost-effectiveness. In the case of SCID all five criteria were met. The advisory committee also requested the cost-benefit/cost-effectiveness rationale be explored further to take into account more of the costs associated with false positives. The analysis shows a savings of \$4.36 for every dollar spent on screening. The current treatment for children born with SCID is a stem cell transplant, which is curative. Early detection results in dramatically lower medical costs for screened babies compared to those treated after becoming symptomatic. In addition, the mortality rate for babies born with SCID is greatly reduced with early treatment. The last baby born with SCID in California prior to that state starting screening generated more than \$4 million in medical bills. If SCID is added to the newborn screening panel, DOH projects that about two babies with SCID in Washington will be detected each year. In addition, it estimates that about six babies with other significant immune deficiencies will also benefit from early detection and treatment.

The cost of conducting newborn screening is financed through a fee charged for all infants born in Washington. To implement SCID screening, the current fee of \$60.90 would need to be increased by \$8.10. Hospitals pay these fees as part of the costs of delivery, and are in turn, typically reimbursed through insurance or Medicaid. In order to increase the fee, DOH has submitted a decision package to the Governor for approval. Because more than half of the births in Washington are covered by Medicaid, DOH and Board staff worked closely with Health Care Authority staff to analyze the effect of these new costs. The Washington State Hospital Association has also been an important partner in this work, and while it recognizes that adding SCID to the newborn screening panel is a good public health policy decision, its members are unable to absorb the additional costs of screening for babies covered by Medicaid.

Newborn screening for SCID can save lives and is cost-effective. We are seeking some commitment from your agency that this issue will be included in the January 2014 contract rebase. We are sending you additional information about the criteria, advisory committee, and the cost benefit analysis that supports this request. Thank you for your consideration. If you have any questions please contact Dr. Diana Yu, Chair of the Health Promotion Committee, at (360) 867-2501.

Sincerely,

Dr. John Austin, Chair
Washington State Board of Health

Dr. Diana Yu, Board Member
Chair of Health Promotion Committee

Dr. Patricia Ortiz, Board Member
Health Promotion Committee

Dr. James Sledge, Board member
Health Promotion Committee

Dr. Maria Hernandez-Peck, Board Member
Health Promotion Committee

Attachments:

Cost-Benefit Analysis

SCID advisory group members

US Department of Health and Human Services letter

SCID Fact sheet

Board Criteria for Newborn Screening