Washington State
House of Representatives
Office of Program Research

BILL ANALYSIS

Health Care & Wellness Committee

HB 1697

Brief Description: Ensuring timely, efficient, and evidence-based additions to newborn screenings.

Sponsors: Representatives Stonier, Parshley, Reed and Hill.

Brief Summary of Bill

- Modifies the newborn screening panel (panel) and the process for the State Board of Health to add new conditions to the panel.
- Establishes the Newborn Screening Revenue Account.

Hearing Date: 2/14/25

Staff: Kim Weidenaar (786-7120).

Background:

Newborn Screenings.
The Department of Health's (DOH) Newborn Screening Program tests most newborn infants born in any setting in Washington for a number of rare congenital disorders. Screening tests are completed by collecting a blood sample from the infant within 48 hours of birth and again in the first few weeks after birth. Screenings are not required for newborn infants whose parents or guardians object to screening tests on the grounds of religious tenets and practices.

Newborns are screened for a variety of amino acid, endocrine, fatty acid, lysosomal storage, organic acid, and other disorders. In order to determine which conditions to include in the newborn screening panel (panel), the State Board of Health (Board) convenes an advisory committee to evaluate candidate conditions, and the Board adds tests to the panel only after a consideration of the following criteria: available technology, diagnostic testing, and treatment

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available; prevention potential and medical rationale; public health rationale; and cost-benefit and cost-effectiveness. The panel consists of 32 conditions listed in Board rules. The DOH charges a screening fee of $135.10 per infant.

Laboratories, attending physicians, hospital administrators, or other persons performing or requesting the performance of tests for phenylketonuria must report to the DOH all positive tests. The Board must require, by rule, that positive tests for other heritable and metabolic disorders be reported to the DOH when it deems appropriate.

Federal Recommended Uniform Screening Panel.
The federal recommended uniform screening panel (RUSP) is a list of disorders that are supported by the Advisory Committee on Heritable Disorders in Newborns and Children and recommended by the Secretary of the Department of Health and Human Services for states to screen as part of their state newborn screening programs. As of July 2024 there are 36 core conditions listed on the RUSP.

Disorders on the RUSP are chosen based on evidence that supports the potential net benefit of screening, the ability of states to screen for the disorder, and the availability of effective treatments.

Conditions listed on the RUSP are part of the comprehensive preventive health guidelines supported by the Health Resources and Services Administration (HRSA) for infants and children, which health plans must cover without cost sharing beginning on or after the date that is one year from the Secretary's adoption of the condition for screening.

Summary of Bill:

The DOH must conduct screening tests of newborn blood samples of the conditions listed in the panel determined by the Board in rule.

By July 1, 2026, the Board must reestablish the panel in rule. This initial panel must include:
- all newborn screening conditions currently required by Board in rule as of January 1, 2025; and
- all conditions included in the existing RUSP as of January 1, 2025.

Within 12 months of the addition of a new condition to the RUSP, the Board must determine whether to add that new condition to the Panel. In making its determination, the Board must avoid duplicating research and evaluation efforts, and complete and consider the findings of a feasibility review. The feasibility review must identify costs to screen for the condition, available federal funding, recommendations of changes to the fee charged for the newborn screening, and a timeline for including the new condition on the panel. In conducting the feasibility review, the Board must consult with the Health Care Authority to consider impacts on state-purchased health care programs.

The public may request that the Board consider additions to the panel and the Board must adopt standards for reviewing these requests to determine if there is sufficient evidence to evaluate the proposed addition. For additions that have sufficient evidence, the Board must conduct a feasibility review that also include:

- whether screening technology exists that can be made available to mass screen newborns;
- the availability of diagnostic testing, treatment, and interventions; and
- the need for population-based rather than risk-based screening.

If the Board determines that the condition should be included in the panel, the Board must complete rulemaking to include the condition in the panel within 12 months of the determination. The Board may add other conditions to the panel if it completes a feasibility review.

Laboratories, attending physicians, hospital administrators, or other persons performing or requesting the performance of tests for the disease and conditions included on the panel must report all positive tests to the DOH.

The Newborn Screening Revenue Account (Account) is created in the custody of the Washington State Treasurer and all receipts collected from newborn screening fees must be deposited in the Account. Funds in the Account may only be used for newborn screening purposes and only the Secretary of Health or designee may authorize expenditures. Interest earned by this Account is retained in the account.

Appropriation: None.

Fiscal Note: Requested on February 10, 2025.

Effective Date: The bill contains multiple effective dates. Please see the bill.