

HB 2617 -1, -2 STAFF MEASURE SUMMARY

House Committee On Behavioral Health and Health Care

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Sub-Referral To: Joint Committee On Ways and Means

Meeting Dates: 2/15

WHAT THE MEASURE DOES:

Updates membership and reporting requirements of Newborn Bloodspot Screening Advisory Board (NWRNBS Advisory Board). Requires NWRNBS Advisory Board to meet four times per calendar year and subjects meetings to public meetings law. Directs the Oregon Health Authority (OHA), in consultation with NWRNBS Advisory Board, to adopt rules for addition and removal of disease from newborn bloodspot screening panel. Requires rules to permit members of public to request NWRNBS Advisory Board subject a disease to evaluation and recommendation process. Requires OHA to consider, and to greatest extent practicable implement, screening for disease no later than 18 months after federal committee recommends adding disease to federal Recommended Uniform Screening Panel (RUSP). Requires OHA conduct pilot study evaluating and deciding whether to add Krabbe disease, Mucopolysaccharidosis type II (MPS II), and Guanidinoacetate methyltransferase deficiency (GAMT) to newborn bloodspot screening panel to demonstrate evaluation standards, criteria, and process. Requires OHA to submit preliminary report on pilot study to Legislative Assembly by September 15, 2024 and final report by September 15, 2025. Clarifies requirement that OHA adopt rules establishing procedure for waiver of fee for infant screening for disease of phenylketonuria and other metabolic diseases. Declares emergency, effective on passage.

FISCAL: May have fiscal impact, but no statement yet issued.

REVENUE: May have revenue impact, but no statement yet issued.

ISSUES DISCUSSED:

EFFECT OF AMENDMENT:

- 1 Clarifies NWRNBS Advisory Board member eligibility for reappointment.
- 2 Clarifies requirement that OHA adopt rules establishing procedure for waiver of fee for infant screening for disease of phenylketonuria and other metabolic diseases.

BACKGROUND:

According to the Health Resources & Services Administration (HRSA) screening of newborn babies in the first few days of life is important to find conditions that could require swift treatment or intervention. Newborn screening has three parts: bloodspot screening, pulse oximetry screening, and hearing screening. The Secretary of the Department of Health and Human Services maintains the Recommended Uniform Screening Panel (RUSP) as the national guideline for newborn screening, though each state adopts its own panel.

In 2019, the Legislative Assembly passed House Bill 2653 creating the Newborn Bloodspot Screening Advisory Board (NWRNBS Advisory Board). The NWRNBS Advisory Board is made up of 13 members appointed by the Director of the Oregon Health Authority and provides advocacy, advice, and recommendations on newborn screening policies and priorities, including the addition or removal of newborn screening tests.

House Bill 2617 updates the membership and reporting requirements of the Newborn Bloodspot Screening Advisory Board and requires the Oregon Health Authority to conduct a pilot study evaluating specified diseases to demonstrate standards, criteria, and process for evaluation to add diseases to the newborn bloodspot screening

This summary has not been adopted or officially endorsed by action of the committee.

panel.

PRELIMINARY