

FISCAL IMPACT OF PROPOSED LEGISLATION

81st Oregon Legislative Assembly – 2022 Regular Session
Legislative Fiscal Office

Measure: HB 4109 - A

*Only Impacts on Original or Engrossed
Versions are Considered Official*

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Date: February 15, 2022

Measure Description:

Directs Newborn Bloodspot Screening Advisory Board to evaluate and make recommendations on adding diseases to Oregon newborn bloodspot screening panel under specific circumstances.

Government Unit(s) Affected:

Oregon Health Authority (OHA)

Summary of Fiscal Impact:

Costs related to the measure are indeterminate - See explanatory analysis.

Analysis:

HB 4109 - A changes the makeup of the Newborn Bloodspot Screening Advisory Board and directs the Board to meet four times a year instead of twice a year. The measure also modifies reporting requirements, with the Board directed to report to the committees or interim committees of the Legislative Assembly related to health no later than September 15 of every year, instead of every other year. This measure specifies the report is to include a detailed explanation of the information, standards, and reasons underlying any Board decisions to add or remove a disease for the Oregon newborn bloodspot screening panel, or to take no action on a disease following consideration or evaluation of the disease. Finally, the measure directs the Board to evaluate and make recommendations to the Oregon Health Authority (OHA) on adding a disease to the Oregon newborn bloodspot screening panel if ten or more states have already added the disease to their respective screening panels; or, the federal Advisory Committee on Heritable Disorders in Newborns and Children votes to initiate an evidence review of the disease. This measure has no effective date and is assumed to take effect January 1, 2023.

The measure's fiscal impact remains indeterminate due to the difficulty of quantifying the level of work resulting from the changes made in the measure, but is expected to result in the need for additional staff and other expenses in OHA's Public Health Division. OHA estimates the work could cost as much as \$358,608 in 2021-23 and \$988,246 in 2023-25. The source of funding for any costs is expected to be supported with General Fund in 2021-23 due to the uncertainty that Newborn Screening Fees can cover the cost impact without a fee increase. However, because this is a fee-based program, any costs beyond 2021-23 are expected to be supported with fees.

The agency's expected costs result from changes in the determination process for diseases to include on the bloodspot screening panels and related support for the Newborn Bloodspot Screening Advisory Board. Oregon generally determines which diseases should be included on the newborn bloodspot screening panel with federal guidance. Under this measure, Oregon would make these determinations independently. There will be new program elements related to research, data analysis, and administration that will be needed for the Board to adequately evaluate and report on new disorders, including those that may not have existing medical literature to draw upon.

OHA indicates this change will require a new Operations and Policy Analyst 4 position in the Oregon State Public Health Laboratory (OSPHL) to create condition summary reports by organizing scientific data (both published and unpublished) and related data visualizations. The position would also conduct interviews with medical specialists

who have unique knowledge of the condition being summarized, other state programs to gain knowledge about their experience screening for a particular condition, and identify the available testing treatment options, including cost, and the success of available treatment options.

OHA also anticipates the need for an additional three positions, including an Operations and Policy Analyst 3 to coordinate the work of the Newborn Screening Advisory Board and provide program expertise. The measure doubles the number of board meetings and increases legislative reporting requirements. OSPHL is currently covering this coordination work with a different position that is not within the Newborn Screening program and is not focused specifically on the Board. The remaining two staff include an Administrative Specialist 2 to provide administrative support for creating condition summary reports, OHA publications, and support for Board meetings; and a limited-duration Research Analyst 3 to assist with compiling research and creating condition summary reports, developing mechanisms for tracking the conditions that are being screened for by other states, and creating survey tools, if appropriate, for gathering information from other state programs or medical specialists. Contractual expenses may also be necessary for medical consultation to assist with condition summary reports and patient outcome evaluations, as well as for a newborn screening or medical ethicist to contribute to the condition summary reports to provide an ethical analysis.

The agency notes the workload is difficult to determine since the triggering events for the Board to make recommendations on adding diseases to the screening panel are decided externally. Costs could vary widely based on the volume and complexity of the work required. Additionally, the Legislative Fiscal Office notes the work of the Administrative Specialist 2 position could potentially be absorbed within existing staff at OSPHL depending on workload. The extent to which a limited duration Research Analyst 3 is needed also merits further review.

There are additional indeterminate costs for OSPHL. Test results from the newborn bloodspot screening panel are analyzed at the lab, and staff make sure that newborns who test positive for conditions receive medical care. Adding additional diseases to the panel could require additional public health lab staff and testing supplies, among other costs. These costs could require an increase in Newborn Screening Fees, which pay for this testing.

This measure warrants a subsequent referral to the Joint Committee on Ways and Means for consideration of its budgetary impact.