

Submitter: Cary Harding
On Behalf Of:
Committee: House Committee On Health Care
Measure: HB4109

I am a pediatrician and medical geneticist practicing at Oregon Health & Science University. I am also a clinical consultant to the Northwest Regional Newborn Screening Program. This testimony and the opinions therein are my own and not necessarily those of OHSU or anyone affiliated with the Northwest Regional Newborn Screening Program. I support the proposal of Section 1 in HB 4109 to establish a Newborn Screening Bloodspot Advisory Board with a broadly diverse membership for the purpose of advising the Oregon Health Authority on newborn bloodspot screening matters. The provisions of Section 2 outlining criteria for when disorders should be considered for inclusion in the screening panel are more problematic. Many disorders are nominated to the federal Advisory Committee on Heritable Disorders in Infants and Children for possible inclusion in the Recommended Uniform Screening Panel (RUSP) but are not accepted for inclusion after a thorough review by the Committee of the available evidence regarding the efficacy and feasibility of screening for the disorder. The Newborn Screening Bloodspot Advisory Board will not have the expertise nor resources to complete as thorough an evidence review as can be performed by the federal Advisory Committee. Nomination for inclusion to the RUSP should not be sufficient to trigger a state level review for inclusion. I strongly recommend that only disorders for which screening has been deemed efficacious and have been officially added to the RUSP should be considered for inclusion in the Oregon newborn screening bloodspot panel.

A chronic issue this bill does not attempt to address is funding the expansion of the screening panel when the advisory committee does recommend an expansion. Even after a disorder is added to the recommended panel, the Oregon Health Authority must currently undertake an arduous legislative and rule making process to raise sufficient funds through increasing the fee charged for the newborn screening test kits in order to pay for implementing the new tests. This process frequently delays implementation of screening for a new disorder by two or more years after the initial inclusion recommendation. Furthermore, because newborn bloodspot screening is nearly entirely funded through the newborn screening bloodspot filter paper card fees charged to hospitals, midwives, and other practitioners who administer bloodspot screenings, these entities bear the brunt of financing the entire newborn screening program in Oregon as there is no insurance reimbursement specifically for the cost of the kit nor for the administration of the testing. The Oregon Newborn Screening Bloodspot Advisory Panel can recommend whatever disorder they would like to add to the screening panel, but under current financing structure, the Oregon Health Authority will continue to struggle to act on any expansion.

I thank the House Committee on Health Care for allowing written testimony on HB 4109.