

Submitter: Silke Akerson

On Behalf Of:

Committee: House Committee On Health Care

Measure: HB4109

Chair Prusak and Members of the House Committee on Health Care,

I strongly support the work of the Northwest Regional Bloodspot Screening Program but have concerns about two proposed changes in House Bill 4109. I am a current member of the Northwest Regional Bloodspot Screening Advisory Board, a Licensed Direct-Entry Midwife, and the director of the Oregon Midwifery Council.

Here are my two concerns:

I think the removal of "representative of a statewide association of..." from 2(g), 2(h), and 2(i) about the nurse, midwife, and pediatrician members of the advisory board could cause harm to the newborn screening program. It is important that these members of the advisory board be able to represent a state association rather than just their individual perspective. For example, as an individual midwife in an urban area I don't have problems mailing newborn screening specimens but since I represent a statewide organization on the advisory board I know that there are huge newborn screening mailing issues in rural areas of the state that the board and the program need to know about to address issues with timely testing.

Beyond this, I do not support the addition of section II to the statute. I do not support the Newborn Bloodspot Screening Advisory Board being mandated to evaluate adding new disorders before they are approved by the RUSP. I think approval by the RUSP is an appropriate criteria for the advisory board to consider screening for new conditions so that clear information on risks and benefits of screening and access to effective treatment are available. I fear that requiring the board to consider screening for new disorders before this information is available may be both costly and unethical. I think the processes already in place are sufficient and effective. Please consider leaving the current statute in place.

Thank you for considering my input,

Silke Akerson, MPH, CPM, LDM