

February 3, 2022

Paul Terdal
Resident, NW Portland (HD-36)

Representative Rachel Prusak, Chair
House Committee On Health Care

Re: Support for HB4109

Dear Chair Prusak and members of the committee,

I'm writing – as a health consumer advocate – in support of HB4109, which would improve the functionality of the Newborn Bloodspot Screening Advisory Board and ensure that newborn testing in Oregon keeps up with scientific advancements.

As the father of children with developmental disabilities, I am keenly aware of the urgency of making a quick and early identification and diagnosis of health conditions in newborn children.

I am also well acquainted with the trauma that parents experience on realizing that their child may have permanently lost developmental milestones that could have been achieved if he or she had been identified and treated in time.

The policy changes in HB4109 are straightforward, commonsense proposals to improve the independence and operation of this board. The revisions to the membership structure – which changes language about members being “representative of a statewide association” to simply identifying their professional qualifications – merely bring the board composition in line with nearly all other Oregon boards and commissions, and should not be controversial.

Similarly, the guidance in the bill on when the Board should evaluate and make recommendations on potential additions to the bloodspot screening panel serves to preserve the original intent of the statute, which was for Oregon to make independent, evidence-based decisions to keep up with scientific advancements.

Many of the written comments in the record today seem to suggest that Oregon should not even consider an addition to Oregon's bloodspot screening panel until the Federal Advisory Committee on Heritable Disorders in Infants and Children has completed its evaluation and made a decision to include the condition in its' Recommended Uniform Screening Panel (RUSP).

That was clearly never the intent of the existing statute ([ORS 433.299](#)) – which created this advisory board. If it had been Oregon's policy decision to simply follow the Federal recommendations, the board would never have been created – it would have been enough to simply direct the OHA Director to follow the Federal recommendation.

Nothing in HB4109 requires the Oregon board to adopt an unproven or unnecessary test.

If the Committee is open to further improvements to HB4109, I recommend strengthening the health consumer voice in this process. This could be by increasing the number of patient or family members on the panel, to specific requirements for the committee to consider health consumer input in the committee's evaluation process.

Sincerely,

Paul Terdal