

Submitter: Marilyn Hartzell  
On Behalf Of:  
Committee: House Committee On Health Care  
Measure: HB4109

February 4, 2021

From: Marilyn Sue Hartzell

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I am the parent of a child, now an adult, born with a genetic condition and am honored to serve on the NWRNBS Advisory Board. I am writing to share concerns regarding HB4109. I am doing so solely on my own behalf.

I am concerned by the removal of the phrase “representative of a statewide association of...”2(g), 2(h) 2(i)) to be replaced with “licensed” only. I feel it is not insignificant that a practicing licensed professional maintains an active relationship with a statewide professional association and that they are selected to represent their profession vis-a-vis that association. A statewide perspective is crucial to advising a statewide program; it also assures accountability to a professional community of practice and is a reflection of a level of regard and confidence in the provider’s competence, ethics and responsiveness to the profession as a whole.

The desire to provide access to screening as quickly as possible for inheritable diseases is understandable. However, the rigorous process by which a condition is currently added to the RUSP is central to having a reliable and ethical screening program. I am concerned this recommendation disallows the rigorous scientific review necessary to have full confidence in the decision to add a condition to the NWRNBS panel. I feel Oregon should maintain its current process in determining when a condition is added to the panel.

Section I (10) re: Frequency of meeting: The increase to a minimum of four (4) meetings of the Board a year seems an unnecessary requirement. The Board is able to, and has done so, call additional meetings above the minimum required to make progress on work as needed. This allows flexibility and responsiveness to the needs at hand. I am concerned this requirement may place an unnecessary burden on staff, board members, and program budget. Please consider maintaining the current meeting requirements as they currently stand.

Respectfully, Marilyn Sue Hartzell