



To: The Honorable Rep. Rachel Prusak, Chair  
Members of the Oregon House Committee on Health care

From: Joanne Rogovoy  
Representing March of Dimes-Oregon

My name is Joanne Rogovoy. I am the Director of Maternal and Infant Health for the March of Dimes-Oregon. I am writing on behalf of the March of Dimes to share my concerns about HB 4109 as written regarding the Oregon Newborn Screening Program and the Northwest Regional Newborn Bloodspot Screening Advisory Board.

Newborn screening efforts took root in the 1960's with the development of a screening test to detect PKU in newborns 24-48 hours after birth. In February 2003, at the federal level the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) was formed to advise the HHS Secretary on newborn screening. ACHDNC worked closely with the American College of Medical Genetics (ACMG) as progress was made toward developing a recommended uniform screening panel (RUSP) as an equitable process for adding additional conditions to state panels. In September 2005, ACHDNC recommended the RUSP to the HHS Secretary as the nation's newborn screening standard.

Disorders on the RUSP are chosen based on evidence that supports the potential net benefit of screening, the ability of states to screen for the disorder, and the availability of effective treatments. The March of Dimes recommends all states screen for all conditions on the RUSP and refrain from adding tests that have not yet been added to the RUSP. Scientific advances may allow some conditions to be identified through testing before they meet the criteria for inclusion on the RUSP. Once a disorder is added to the RUSP March of Dimes will actively advocate for its inclusion on state panels.

In 2019 Oregon HB 2563 created the Northwest Regional Newborn Bloodspot Screening Advisory Board to provide recommendations, information, and advocacy to guide the Newborn Bloodspot Screening Program with strategic planning and recommendations on operational changes and recommendations on a process for the addition or removal of disorders from the Oregon panel. I am a member of this advisory board. I am not representing that Board in this testimony only March of Dimes.

March of Dimes has concerns with the language as written in HB 4109. The bill states the NWRNBS advisory board shall review a condition for consideration on the Oregon NBS panel if it is submitted for inclusion on the RUSP not if it is selected for addition to the RUSP by the ACHDNC. HB 4109 also states that a condition shall be evaluated for the Oregon NBS Panel and

a recommendation for inclusion of the condition be made once 10 states have added the condition to their panels. Both of these recommendations would be bypassing the rigorous scientific reviews that take place within multidisciplinary teams when reviewed by the ACHNDC for addition to the RUSP .

Lastly, the bill as written will no longer require that NWRNBS advisory board members from the professions of nursing, medicine and midwifery to be representing the position on NBS issues held by their state associations. We feel that it is important for these members on this state advisory board to represent their statewide association's position on NBS matters.

March of Dimes opposes HB 4109 as written.

