

Representative Susan McLain

House District 29



February 1, 2022

Members of the House Committee on Health Care

Re: Support for House Bill 4109 - Refining the Newborn Screening Advisory Board

Dear Chair Prusak, Vice-Chairs Hayden and Salinas, and Members of the Committee:

I encourage you to support my priority bill, [HB 4109 \(-1\)](#), which makes adjustments to the Northwest Regional Newborn Bloodspot Screening Program Advisory Board's membership, meeting, and reporting requirements and sets new sideboards outlining when the Advisory Board must consider the addition of new diseases to the screening program. It is a bill that will improve the functionality of the Advisory Board and ensure that newborn testing in Oregon keeps up with scientific advancements.

Diagnosis through newborn screening saves lives, improves healthcare outcomes, and reduces long-term healthcare costs by allowing for detection and intervention of rare diseases at the earliest moment possible. This is why I led the fight to create the Advisory Board, which was established when the Legislature unanimously passed **House Bill 2563 in 2019**. The intent was for the Advisory Board to use the best available science, treatment developments, and patient-centered advocacy to decide on additions to the Oregon newborn disease screening list. Despite this mission, Oregon still lags behind states like California and Minnesota in the number of diseases we screen for and the current system for adding new diseases is cumbersome and slow.

HB 4109 with the **-1 amendment** allows the Advisory Board more opportunities to deliberate by increasing the number of times the Board is required to meet each year, from twice to four times yearly. It also reduces the term that a Board member serves from four years down to two, as the Oregon Health Authority has advised that it is difficult to get qualified candidates to commit to a four-year term. Finally, it removes the requirement that the Advisory Board can only consider the addition of new diseases if they have already been added to the Federal Recommended Uniform Screening Program (RUSP), and instead requires the Board to consider diseases that have either been added to screening protocols in at least 10 states, or that have been accepted into the evidence review stage of the RUSP process.

The current requirement that diseases must be on the RUSP list to be considered for addition in Oregon ignores the fact that adding diseases to the RUSP takes several years beyond when scientific advancements occur. By removing this requirement, we empower the Advisory Board to consider the addition of diseases as scientific breakthroughs develop, which ensures our state is proactive in saving the lives of as many children as possible. Please take a minute to watch this [video](#), which was made by an Oregon family as a testimonial to the impact that delaying or denying newborn screening opportunities has on families, and in particular the children with rare diseases.

Thank you for your consideration of **HB 4109 -1** and I hope you will join me in providing Oregonians an efficient and effective newborn screening process that ensures we are following scientific breakthroughs on testing and treatments.

Sincerely,

Susan McLain

Representative Susan McLain