



Oregon Pediatric Society

A Chapter of the American Academy of Pediatrics. Incorporated in Oregon

February 1, 2022

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

FROM: Cheryl Hanna, MD hannac@ohsu.edu
Representing the Oregon Pediatric Society

SUBJECT: Opposition to House Bill 4109 on Newborn Screening Process Changes

For the record, I am Dr. Cheryl Hanna, writing on behalf of the Oregon Pediatric Society (OPS). I am a retired pediatric endocrinologist with 35 years of experience working with the Newborn Screening Program. I am also an original member of the Northwest Regional Screening Program (NWRNBS) Advisory Board that was created by the legislature in 2019. OPS is the state chapter of the American Academy of Pediatrics, and our members are committed to improving the health and well-being of all Oregon children. While OPS strongly supports the NWRNBS program and board, we have significant concerns with HB 4109 in its introduced text and a proposed amendment.

The advisory board has met regularly from 2019 to present and has created a process by which conditions affecting newborn infants are added to Oregon's screening panel. HB 4109 makes changes to the membership of the NWRNBS advisory board and the frequency of the board meetings (Section 1). HB 4109 also directs the NWRNBS advisory board to change the process it developed for evaluating conditions to be added to the screening panel (Section 2), **bypassing the thorough national vetting process by diverse experts.**

The rules for advisory board membership currently include members representing statewide associations of licensed pediatricians, nurses, and midwives. OPS believes it creates broader accountability, input, and adherence to health care best practices when larger professional groups are represented in this process. OPS opposes the proposed elimination in HB 4109 section 1 (g, h, and i), of the statewide associations requirement for these three Oregon advisory board member categories.

The federal process for adding health conditions to a newborn screening panel is quite rigorous. It is meant to ensure that all families have a voice, not just the advocacy groups and disease researchers that are the most resourced. The US Secretary of Health and Human Services provides guidance to state newborn screening programs



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about which conditions should be included in newborn screening through the Recommended Uniform Screening Panel (RUSP). This guidance is from evidence-based (scientific) recommendations by the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC). This federal advisory committee is composed of national experts, including physicians from academic medical centers specializing in pediatrics, genetics, and child development, as well as from the Centers of Disease Control and Prevention, National Institutes of Health, and the Federal Drug Administration. The individuals on the advisory board have access to published and unpublished data on the nominated condition to aid in their informed and detailed decision making. Oregon does not have the capacity to replicate these extensive and expensive resources and expertise; luckily, we do not need to under our state's current process.

Individuals and organizations form multi-disciplinary teams and submit nominations for conditions to be considered for RUSP inclusion. Teams include researchers and/or clinicians with expertise on the condition being nominated; advocacy and/or professional organizations with knowledge of issues relevant to newborn screening; and interested consumers/individuals.

In general, conditions considered for newborn screening are conditions that are not obvious on examining a newborn baby; conditions that can be tested for on filter paper blood spot samples; and conditions where there is **a proven and available medical treatment that can be applied equitably and quickly (often within 30 days) to all infants** and which should result in better health outcomes for an infant. However, after in depth medical, scientific, and ethical expert scrutiny, not all nominated conditions are selected for addition to the RUSP. As a pediatrician, I know how disheartening this can be for some parents.

The process to get a condition on the RUSP can be arduous because advances in science can follow a winding course. The time needed for the process allows questions to be answered; outcomes in pilot screening programs to be observed; expertise in treatment of rare conditions to expand; and even new treatments to become possible.

Oregon's NWRNBS advisory board builds on the national expertise provided by the ACHDNC by considering adding conditions to Oregon's screening panel once they are added to the RUSP. For example, in the spring of 2020, the advisory board recommended the addition of two conditions after they were added to the RUSP: spinal muscular atrophy (SMA) and X-linked adrenoleukodystrophy (X-ALD).



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HB 4109 directs the NWRNBS advisory board to evaluate and make recommendations to the Oregon Health Authority based on (1) if a condition (not on the RUSP) has been added to screening panels in 10 or more other states; and (2) an evidence review has been initiated by the RUSP board [ACHDNC], instead of waiting for the actual addition to the RUSP. Conditions that have not been accepted by the national advisory committee for addition to the RUSP should not be part of the criteria for Oregon's board to make decisions. The threshold should be, and is now, conditions included on the RUSP.

Thank you for your consideration. Please let me know if I or OPS can provide additional information about the RUSP and NWRNBS advisory board screening process, or answer any questions.