



# Oregon Pediatric Society

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

DATE: February 25, 2025

TO: Chair Nosse and members of the House Committee on Behavioral Health and Health Care

FROM: Cheryl Hanna, MD  
On behalf of the Oregon Pediatric Society

SUBJECT: Concerns with House Bill 3192 Regarding Newborn Screening

My name is Dr. Cheryl Hanna, representing the Oregon Pediatric Society (OPS), the state chapter of the American Academy of Pediatrics. I am a retired pediatric endocrinologist with 35 years of experience working with the newborn screening program. I was also one of the original voting members of the Northwest Regional Newborn Screening Program (NWRNBS) Advisory Board, created by the Oregon legislature in 2019. We submit this testimony with concerns about the process outlined in HR 3192, as well as suggested bill amendments.

As described in ORS 433.299, the NWRNBS board has met regularly from 2019 to the present and has created a consensus process to recommend which conditions affecting newborn infants are added or removed from the panel. The Oregon Pediatric Society believes that the decision to add conditions to the NWRNBS is best accomplished using the criteria established by the NWRNBS advisory board.

HB 3192 appropriates State funding and adopts rules about newborn screening to detect certain diseases. OPS does not support changes to the current Oregon Health Authority procedure guiding newborn screening (ORS 433.285 policy to control metabolic diseases) or putting the newborn diseases to be tested in statute.

For background: The US Department of Health and Human Services provides guidance to state newborn screening programs about which conditions should be included in screening called the Recommended Uniform Screening Panel (RUSP). In general, these are conditions that are not obvious on newborn examination, that can be tested for, and where there is a proven treatment that can be applied equitably to all infants which results in a better outcome for the infant. This guidance is from evidence-based recommendations provided by an advisory board composed of physicians from



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academic medical centers specializing in pediatrics, genetics, and child development, as well as national experts from the CDC, NIH, and FDA.

Oregon's NWRNBS advisory board builds on the national expertise provided by the RUSP, and considers for addition to Oregon's newborn screening program those conditions that are added to the RUSP. Of the five diseases specified in HB 3192, the advisory board has recommended that Mucopolysaccharidosis type II (MPS II) and Guanidinoacetate methyltransferase deficiency (GAMT), both of which are now on the RUSP, be added to Oregon's testing panel. The advisory board meets next month to consider whether infantile Krabbe disease (recently added to the RUSP) be added to Oregon's panel.

It should be noted that only the infantile form of Krabbe disease has been added to the RUSP. Other forms of Krabbe disease are not on the RUSP. **HB 3192 should be amended to clarify that it is infantile Krabbe disease that will be screened for.**

Two other conditions in HB 3129, Duchene's muscular dystrophy (DMD) and congenital cytomegalovirus (CMV), are not currently on the RUSP and per the process developed by the NWRNSP advisory board, are not being reviewed for addition. **These two conditions should not be added by statute, and should be removed from this bill.**

Another potential amendment to HB 3192 is that residual funds – after adding MPS II, GAMT, and infantile Krabbe to Oregon's screening tests – would be used to prepare for addition of DMD, CMV, and any other conditions as they get added to the RUSP. This would speed up the process by which Oregon is able to add new conditions.

Thank you for your consideration of our recommendations, and support of the NWRNBS advisory board.