



Oregon Pediatric Society

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

DATE: March 26, 2021

TO: The Honorable Rachel Prusak, Chair House Committee on Health Care Vice Chairs Salinas and Hayden, and Members of the Committee

FROM: Cheryl Hanna, MD
Oregon Pediatric Society Member

SUBJECT: House Bill 2987 Regarding Newborn Screening

I am 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 am also one of the 13 voting members of the Northwest Regional Newborn Screening Program (NWRNBS) Advisory Board, created by the Oregon legislature in 2019.

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. HB 2987 adopts rules about newborn screening to detect certain diseases. The Oregon Pediatric Society 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 Secretary 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). This guidance is from evidence-based (scientific) recommendations provided by an advisory board composed of national experts. (These are physicians from academic medical centers specializing in pediatrics, genetics, and child development as well as from CDC, NIH and FDA.) 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.



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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. In spring 2020, the advisory board recommended addition of two conditions added to the RUSP (spinal muscular atrophy and x-linked adrenoleukodystrophy). These conditions were not yet added because of state funding issues.

House Bill 2987 lists many conditions that Oregon already screens for in the five decades that the newborn program has been in place. However, it also includes several conditions not on the RUSP (Section 1 (1): qq, rr, ss, tt, xx, aaa). In addition, the bill has removed several conditions that are on the RUSP and currently screened for, or are awaiting funding in Oregon. Oregon also screens babies for hearing loss, a condition on the RUSP which has been omitted from this bill. There are other problematic changes as well.

The Oregon Pediatric Society is of the opinion that the decision to add conditions to the NWRNBS is best accomplished using the criteria established by the NWRNBS advisory board. We are sympathetic to families of children with conditions that are not yet detectable by newborn screening and/or for which no proven treatment exists. Let me assure you that there is a process in place at the NWRNBS to consider adding conditions as medical science evolves.

Thank you for your consideration of this testimony, and support of the NWRNBS advisory board.