



Oregon Pediatric Society

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

DATE: March 28, 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 3107: Support for funding SMA and X-ALD in Oregon's Newborn
Screening Program

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 a member of the Northwest Regional Newborn Screening Program (NWRNBS) Advisory Board, created by the Oregon legislature in 2019.

The -1 amendment to HB 3107 provides General Fund appropriations to the Oregon Health Authority for testing newborns for spinal muscular atrophy under the NWRNBS. The Oregon Pediatric Society supports this amendment and also asks that x-linked adrenoleukodystrophy be added to this bill.

Oregon's NWRNBS advisory board builds on the national scientific expertise provided by the Recommended Uniform Screening Panel (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 the addition of two conditions to Oregon's program that are on the RUSP: spinal muscular atrophy (SMA) and x-linked adrenoleukodystrophy (X-ALD). Neither of these conditions were added because of the lack of state funding. HB 3107 can rectify that in an equitable way, allowing babies who suffer from both diseases to be tested.

OPS urges you to vote yes on HB 3107 and fully fund the recommendations by the NWRNBS advisory board for Oregon's newborn screening program. Thank you for your consideration of this testimony.