Office of Representative Susan McLain

HB 2617
Improvements to Newborn Screening

Background

HB 2563 (2019) established the Northwest Regional Newborn Bloodspot Advisory Board to evaluate diseases for addition to Oregon's Newborn Screening list. The Board's directive is to use the best available science, treatment developments, and patient-centered advocacy to decide which diseases get added to the screening list.

The Oregon State Lab and the Advisory Board will have the opportunity to improve by keeping up with cutting-edge testing and treatment protocols. The current addition process is not transparent and is restrictive since it does not allow for public input or the consideration of diseases that have not been added at the Federal level on the Recommended Uniform Screening Panel (RUSP).

Objectives of HB 2617

Oregon must provide a **transparent and pristine process** for adding new diseases to the Newborn Screening list so that families, the public, and Legislators can be confident in the protocols used for evaluation.

Oregon will ensure that **newborn screening keeps up-to-date as scientific reviews bring important breakthroughs**. In addition, new diseases must be considered promptly when advancements are made in treatment and testing.

Oregon must **ensure that all babies born here can be tested** by supporting families that must pay out of pocket for the screenings. In 2020, that number was 843.

Emmett Monaco was a very special voice for children born with rare and often fatal genetic diseases. He had Krabbe, which Oregon does not currently test for. If we did, he could have received life-saving treatment. He passed away in 2022 but we will continue to advocate for better screening processes for Emmett and for all babies born in Oregon.

NEWBORN SCREENING TESTS SAVE LIVES!

Each year in the United States, approximately four million babies are screened for serious disorders that are present at birth. Of those, newborn screening identifies over <u>12,000 infants</u> with a condition that, if left undiagnosed and untreated, would cause severe disability or death.

What HB 2617 Does

HB 2617 requires that the Advisory Board consider and, to the greatest extent practicable, implement screening for a new disease no later than 18 months after the date on which the federal Advisory Committee on Heritable Disorders in Newborns and Children recommends adding the disease to the federal RUSP.

HB 2617 requires the Advisory Board to develop standards, criteria, and processes for the medical community, members of the public, and parents of children with rare diseases to request that the Board consider adding diseases for evaluation.

HB 2617 requires the Advisory Board to conduct a pilot study on its implementation mechanisms and processes using the three most current diseases to have been, or are currently being evaluated, at the Federal level. The Board must provide a preliminary report on the pilot study's findings by September 2024.

HB 2617 requires that the Oregon Health Authority waive the Newborn Screening fee for parents or guardians of an infant who pay for the test out of pocket and continue to pay for those who cannot. OHA estimates this cost to be **$500,000 per biennium. HB 2608 is the companion bill that appropriates the money from the General Fund.**