



FROM THE OFFICES OF

REPRESENTATIVES SUSAN MCLAIN & MARK OWENS

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Representatives McLain & Owens Celebrate Vote to Screen Oregon Newborns for Krabbe Disease, Call for Critical Funding

Oregon's Newborn Screening Advisory Board approved the addition of Infantile Krabbe Disease to the newborn screening panel, but the Legislature must act this session to ensure the life-saving program has the funds necessary to update testing protocols

SALEM, Ore. – On Tuesday, the [Northwest Regional Newborn Bloodspot Screening Advisory Board](#) voted to recommend the addition of Infantile Krabbe Disease to Oregon's newborn screening panel. In 2024, Krabbe was approved for addition to the [Recommended Uniform Screening Panel \(RUSP\)](#), the list of conditions the U.S. Department of Health and Human Services recommends states test for in their newborn screening programs. Twelve states already test for Krabbe, and another ten have policies to align their screening programs with the RUSP and are now in varying stages of implementation.

“It is essential that Oregon's newborn screening program keeps up with the latest scientific breakthroughs to ensure newborns with rare and devastating diseases receive timely diagnoses to obtain life-saving treatments,” said **Representative Susan McLain (D-Forest Grove)**, who has been advocating for adding Krabbe Disease to Oregon's screening panel since 2018. “Without newborn screening, babies with Krabbe have no chance at survival, and life-saving care should not be dictated by the state you live in. With the Board's recommendation, we are giving real hope to families affected by this disease.”

Krabbe Disease is a rare genetic disorder that takes away a baby's ability to eat, sit up, or grasp objects and causes extreme irritability, blindness, and seizures. For babies that live in states that do not test for Krabbe, their life expectancy is rarely more than 2-3 years of age. However, if a Krabbe baby is screened at birth and receives a bone marrow or hematopoietic stem cell transplant within the first 30-45 days of life, which is before symptoms appear, they have an excellent chance at living a full life.

Oregon's newborn screening program is drastically underfunded and has a backlog of approved diseases waiting to be added to the testing protocols. Without funding from the Legislature, Krabbe screening will likely not be implemented soon, even with the Advisory Board's recommendation.

Representative McLain and Representative Mark Owens (R-Crane) are chief sponsors of [House Bill 3192](#) this session, which would allocate \$4 million to the newborn screening program to clear the backlog of diseases and allow testing for Krabbe and other approved conditions to begin.

"I'm pleased that the Northwest Regional Newborn Bloodspot Screening Program has approved adding Infantile Krabbe Disease to Oregon's screening panel today," said **Rep. Owens**. "By investing in the expansion of our newborn screening program, we can identify and treat conditions early, significantly improving outcomes for affected children. Securing funding through HB 3192 will be critical to making this lifesaving screening a reality."

Oregon has taken an important step to save lives with the recommendation of Krabbe, but the Oregon Legislature must pass HB 3192 to ensure our program has the resources it needs to help more families, save lives, and reduce the burden of undiagnosed diseases.

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