



FROM THE OFFICES OF
REPRESENTATIVES SUSAN MCLAIN & MARK OWENS

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**Representatives Owens & McLain Champion Funding For
Life-Saving Newborn Screening**

HB 3192 would allocate \$4 million to Oregon's newborn screening program and add five new diseases to the panel of rare conditions that babies are tested for at birth

SALEM, Ore. – On Tuesday, the House Committee on Behavioral Health and Health Care heard testimony on [House Bill 3192](#), a bill to increase funding for the [Northwest Regional Newborn Bloodspot Screening Program](#), sponsored by **Representatives Susan McLain (D-Forest Grove) and Mark Owens (R-Crane)**.

“Newborn screening is a critical program that saves lives, but it lacks sufficient funding,” said **Rep. Susan McLain**, who has worked on improving Oregon’s Newborn Screening program since 2018. “Without newborn screening, treatable conditions present at birth may go undiagnosed, resulting in missed opportunities to access life-changing care and leading to adverse health outcomes for affected children, including premature death.”

“Our state has the opportunity to make a real difference in the lives of newborns and their families,” said **Rep. Owens**, the first chief sponsor of the bill. “By investing in the expansion of our newborn screening program, we can prevent irreversible damage, improve quality of life, and even save lives. No family should have to endure years of uncertainty when a simple blood test could provide answers and early treatment.”

HB 3192 would also add five new diseases to the testing panel, bringing the total number of conditions screened to fifty. Two diseases, Mucopolysaccharidosis Type II and GAMT Deficiency, were approved for addition in recent years, but insufficient funding means they are still not on the panel. The new funding would also cover screening for three additional diseases currently in, or likely will soon be in, the review stage for addition to the screening panel: Krabbe, Duchenne Muscular Dystrophy, and Cytomegalovirus. In addition, the funding will help purchase testing supplies and hire the necessary personnel to begin screening for these rare and devastating diseases.

“My family and I are so grateful to Representatives Owens and McLain for championing House Bill 3192 for Oregonians living with rare diseases. Despite significant missed milestones and multiple doctors’ visits, my son, Abel, is among the many children who received a delayed diagnosis for Duchenne Muscular Dystrophy,” said **Amanda Bain**, whose son’s treatment was hindered because Oregon does not currently screen for Duchenne Muscular Dystrophy at birth. “Living in a rural community where healthcare workers are even less familiar with this rare disease, we are hopeful that HB 3192 can help children born with Duchenne get the care they need from day one as early intervention is so important.”

This bill will ensure Oregon’s program has the resources it needs to help more families, saving lives and reducing the burden of undiagnosed diseases.

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