

Date: August 22, 2025

To: Oregon birth facilities and health care providers

From: Northwest Regional Newborn Bloodspot Screening (NWRNBS) Program

Subject: New disorder to be implemented in November 2025

The Northwest Regional Newborn Bloodspot Screening Advisory Board approved the addition of Infantile Krabbe Disease (IKD) to the Oregon panel. The NWRNBS Program will implement screening for IKD on Saturday, November 1, 2025.

Krabbe disease is a rare, genetic condition that can damage the nerves affecting a person's ability to eat, walk, and speak. In the most severe form and without treatment, Infantile Krabbe Disease can progress to death in infancy. The screening test will target detection of the infantile form.

There is no cure for Infantile Krabbe Disease, but treatment can help manage symptoms and improve quality of life. Currently, the only treatment for Infantile Krabbe Disease is a hematopoietic stem cell transplant (HSCT), which should occur before six weeks of life. Due to the need for early treatment, the time from screening to confirmation and treatment must move extremely quickly.

At this time, no action is required. This notice is for awareness only. Please share this update with all relevant staff and providers to ensure they are informed ahead of the November 1st rollout.

As Oregon prepares for implementation, additional resources and educational materials will become available. For more detailed information about IKD, please review the American College of Medical and Genetics and Genomics [IKD ACT sheet](#).