SUPPORT HB 3192: OREGON'S NEWBORN SCREENING PROGRAM

Background: For patients living with rare disease, early diagnosis and interventions can mean improved quality of life or premature death. In recognition of the profound impact that timely diagnosis can have for Oregon families living with rare diseases, Oregon's Northwest Regional Newborn Bloodspot Screening Program (NBS Program) screens infants for certain rare conditions. Newborn screening empowers families to make informed decisions about necessary care, helps families avoid years of difficult and unnecessary diagnostic journeys, and avoids subjecting patients to counterproductive treatments, and reduces long-term health care costs.

Approximately one in 250 babies born annually in Oregon are diagnosed with a treatable condition identified through Oregon's NBS Program. Without newborn screening, treatable conditions present at birth may go undiagnosed for years or even decades, resulting in missed opportunities to access life-changing care and leading to adverse health outcomes for affected children, including premature death.

Problem: Unfortunately, Oregon's NBS Program lacks the resources to review new conditions and to clear its current backlog of treatable rare conditions:

- Mucopolysaccharidosis Type II, GAMT Deficiency, Krabbe, Duchenne Muscular Dystrophy and Cytomegalovirus, are all at various stages of nomination, review or approval for inclusion on the Oregon newborn bloodspot screening panel.

- With a simple bloodspot, infants with these conditions can receive early diagnosis and seek interventions that can prevent irreversible damage to patients' nerves, brains, muscles, and other vital organs, improve quality of life, slow disease progression, and save lives.

- The pace of progress in newborn screening lags advances in treatments for genetic conditions.

Solution: Oregon has the power to help families, change the trajectory of these rare diseases for the newborns, and save lives with a simple bloodspot. Legislative investment in the NBS Program will provide the best potential outcomes for our most vulnerable children and their families, by clearing the current backlog and request list. Directing resources to the NBS Program will also ensure that the costs for expanded testing is not passed on to providers, hospitals, insurers and new families that pay out of pocket.

Ask: Support HB 3192 and provide $4,000,000 to Oregon's Newborn Screening program to clear the backlog of conditions, purchase test supplies, and hire personnel to begin screening newborns for these rare conditions.

Contact: Rocky Dallum (rocky.dallum@tonkon.com), Maureen McGee maureen.mcgee@tonkon.com), or Benjamin Gurewitz (bgurewitz@droregon.org)