

Bill 4109 –

Thank you Representative Prusak and members of the committee

Good morning. My name is Anna Grantham and I am the Director of Newborn Screening for the Hunter's Hope Foundation. Hunter's Hope was established in 1997 by NFL Quarterback Jim Kelly and his wife Jill when their son Hunter was diagnosed with Krabbe Leukodystrophy.

When the federal Advisory Committee on Heritable Disorders for Newborns and Children was formed in 2006, they created the Recommended Uniform Screening Panel, also known as the RUSP. The RUSP was created to be a minimum standard of diseases that should be included in a state's newborn screening panel. It's important to also note that each state maintains autonomy as to how many diseases it includes in its newborn screening program. In the sixteen years since its formation, the Advisory Committee has only added SIX diseases to the recommended uniform screening panel or RUSP... An acquisition rate that is far too slow.

Currently, there is an explosion of scientific and medical advancements in the rare disease community. New clinical trials and treatments are rapidly rolling out, and in most cases newborn screening for these diseases is the only way for children to fully benefit from these lifesaving treatments.

In the case of Krabbe Disease, although there is already an existing disease altering treatment available, there are also two clinical trials for gene therapy underway and a third that will launch this year. Because newborn screening is literally the difference between life and death for children with Krabbe, we've continued to partner with families across the U.S. to advocate for Krabbe Newborn Screening while also working to fill the scientific gaps identified by the Advisory Committee in their first review of Krabbe Disease in 2009, where at a vote of 8 to 7, Krabbe was not added to the RUSP.

Presently, 10 states screen for Krabbe Disease – and the information they've gleaned from screening was essential to the renomination of Krabbe for inclusion on the RUSP which was submitted in July 2021. It takes years to meet the scientific requirements of the Advisory Committee and to prepare a RUSP nomination package, it takes a minimum of 2 years for the Advisory Committee to complete the review of a disease, and several more years for each state to then implement screening for that disease.

Our hope is that states like Oregon will choose to pioneer screening for Krabbe and similar diseases, where the necessary evidence and resources to implement are available. It took over 10 years to meet the committee's requirements to reapply for the RUSP and in that time, dozens of children have died from a treatable disease. When it comes to newborn screening, any delays in adding new diseases to state newborn screening panels are often deadly.

Oregon is a true leader in the newborn screening community not only because of its advanced scientific capabilities but also because of the other states that outsource to Oregon for their newborn screening programs.

Today, I urge you to do all in your power to practice your autonomy as a state and create a system that not only keeps Oregon RUSP compliant, but also ensures that diseases are added to the state's panel as soon as an effective screen and treatment exists.

Thank you for your consideration of this lifesaving matter.