Hunter's Hope Foundation

Krabbe ~ Leukodystrophies ~ Newborn Screening

Support SB 284 - Newborn Screening for Krabbe and other Lysosomal Storage Disorders

SB 284 would amend Oregon's newborn screening laws to include the following Lysosomal Storage Disorders (LSDs) to its Newborn Screening Panel—Krabbe, Fabry, Gaucher, Niemann-Pick, Pompe, and additional LSDs as screening becomes available.

The Wilson family has experienced firsthand the devastation caused by not having these diseases included in Oregon's Newborn Screening Panel. Their son, Marshall, was diagnosed with Krabbe Disease when he was 17 months old, just after the birth of his younger brother, Michael. At this point, the disease was already too far progressed for Marshall to benefit from the only available treatment, a cord blood transplant. Because Krabbe is a genetic disorder, Michael was also tested for Krabbe and diagnosed early, before he was symptomatic. Michael underwent a transplant and is a healthy and active toddler.

These two brothers have same disease—one is vibrant and healthy, the other is fighting the devastating effects of a terminal illness—all because Oregon, the state where they were born does not screen for Krabbe at birth.

Krabbe is an inherited fatal disorder that affects the nervous system. If untreated, children with Krabbe suffer greatly and are not expected to live beyond their second birthday.

Currently, all babies in Oregon are screened for 39 diseases at birth through newborn screening. These diseases are not otherwise clinically recognizable at birth but if untreated can cause irreversible damage both physically and mentally to children, many result in death. For these diseases, early detection is essential to avoid such devastating outcomes.

Likewise, early detection through newborn screening for Krabbe and other lysosomal storage disorders is *crucial* to give these children a chance at a healthy life. Treatment options are available, however, these treatments are only effective when given before symptoms are present. Most often children are not diagnosed in time and therefore, are not able to receive these life-saving treatments.

Scientists have created a multiplex newborn screening test by which the lysosomal storage disorders listed above can be cost effectively screened together. The total number of diseases being screened for at birth can be increased with little to no incremental cost. Moreover, the patient, who is charged by the hospital at the time of screening, already absorbs much of the cost of newborn screening.

Additionally, by providing early diagnosis for the diseases listed in this bill, millions of dollars will be saved each year. In Marshall's case alone, his medical expenses average $700,000 annually – more than what it would cost the state to implement this screening for all Oregon infants. Comparable legislation has been passed in New York, Illinois, New Mexico, New Jersey and Missouri.

Hunter's Hope was established in 1997 by Founders NFL Quarterback Jim Kelly and his wife Jill after their infant son, Hunter (2/14/1997-8/5/2005) was diagnosed with Krabbe Leukodystrophy, a Lysosomal Storage Disorder and inherited fatal nervous system disease. While Jim and Jill have been blessed with the opportunity to share Hunter's story and the hope of the Foundation named after their son all over the world-their greatest passion is to bring encouragement and hope to families in the midst of suffering.

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