



Hunter's Hope Foundation

Krabbe ~ Leukodystrophies ~ Newborn Screening

March 12, 2019

Re: HB 2563

To the Distinguished Members of the House Committee on Health Care:

I am writing in support of newborn screening for Krabbe Disease in Oregon.

I am the CEO for the Hunter's Hope Foundation, which was established in 1997 by NFL Hall of Fame Quarterback, Jim Kelly and his wife Jill when their son and my grandson, Hunter (2/14/97 – 8/5/05) was diagnosed with Krabbe Disease, a fatal genetic disorder that deteriorates the white matter in the brain. This devastating disease affected every aspect of Hunter's body. He never smiled or spoke, he never walked and could not eat by mouth, and he fought daily.

Newborn screening (NBS) for Krabbe Disease offers hope for children like Hunter to be diagnosed in time for lifesaving treatment to stop the progression of this horrific disease. Six states are currently screening for Krabbe Disease, NY, MO, KY, OH, IL and TN. We have the privilege of knowing several families who have benefitted from Krabbe NBS in these states, many of whom have been born and treated in just the last two years... It is a joy to see these children meeting milestones, rather than losing them. They are walking, talking, laughing, attending school – they are *living*.

Today, you will once again meet Michael Wilson, who is also affected by Krabbe Disease but received treatment for Krabbe prior to the onset of symptoms, thanks to his older brother Marshall (6/15/09 – 3/5/16). As you will see, Michael is thriving – he is an active eight-year-old, who is able to live unencumbered by his disease. His family has advocated for Krabbe NBS in Oregon for years, beginning with a bill in 2013, yet the legislature chose not to add this lifesaving measure to the state's law.

Because of this tragic decision, you will also meet three-year-old Emmett Monaco. Emmett was not diagnosed with Krabbe until he was symptomatic – too late to receive the same treatment Michael did.

Since the first Krabbe NBS bill was introduced, OR has begun screening for Pompe, MPS-I, Fabry and Gaucher – four of the six Lysosomal Storage Diseases that can be screened with Krabbe Disease. These diseases are screened in the same assay, or test, as Krabbe Disease, therefore the OR NBS lab already has the capability to easily and cost effectively screen for Krabbe. Furthermore, this screen costs \$6 per baby – whether you screen for one of those diseases or all six. It is easier than ever for Oregon to implement Krabbe NBS and this could be easily implemented within the next year.



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On behalf of Marshall, Emmett, Michael and every other family who has and will be affected by Krabbe Disease in Oregon, I implore you to do everything in your power to ensure that Krabbe NBS becomes a reality in your state. And, please make this happen as soon as possible, before another child is born in Oregon with Krabbe disease.

You had the opportunity to give Emmett the same chance at life that Michael received... Today, you can decide to ensure that no future Oregon children suffer and die from this treatable disease the way Marshall did, the way Emmett is...

Thank you for your support.

With hope and prayer,

Jacquie Waggoner
CEO, Hunter's Hope Foundation
Hunter Kelly's Grandma