March 18, 2019

To Whom It May Concern:

My name is Christin Webb, and I am writing to you today to express to you the effectiveness and importance of newborn screening for Krabbe Disease and other similar Lysosomal Storage Disorders and Leukodystrophies. It is our family's hope and prayer that Oregon will add Krabbe Disease to your newborn screening. Our family's story paints a bittersweet picture of both sides of the spectrum.

Our daughter, Mabry Kate, (3/13/14 – 2/7/15) born in Knoxville, TN, was affected by Krabbe Disease, as is our son, Owen. Mabry Kate was born on March 13, 2014. After developing normally for about two to three months, she slowly began losing her skills and milestones she had already gained. She stopped smiling, moving, eating, among many other things. She could not hold down anything she ate and began losing weight. Needless to say, every specialist in our area was puzzled. None of her symptoms seemed to fit together, and no one could give us any answers. We were terrified, and all the while, she kept deteriorating and we could not figure out why. After four months of trying to get a diagnosis, my husband and I sought a second opinion in Cincinnati, Ohio, 4 hours from our home. After reviewing the gamut of tests, including a muscle biopsy that Mabry Kate had to endure, she was finally diagnosed with Krabbe Disease. Since Mabry Kate was born in Tennessee, a state that, at the time, did not test for the disease, it was too late to receive life-saving treatment. Because of this, Mabry Kate lived her life in pain or on medicine to control the pain. She was on supplemental oxygen, constant monitoring of her oxygen saturations and heart rate, she was fed through a feeding tube, and we had to suction her many times a day to keep her airway clear since she was not strong enough to do this on her own. While she required 24-hour care, we made the most of our short time with her, and loved her unconditionally. Every day it is so hard to come to terms with the fact that we could not help her, that we were too late in getting her what would have been life-saving treatment. She passed away just shy of 11 months old.

Because of Mabry Kate, her little brother Owen was tested and also diagnosed with Krabbe Disease prior to birth. He was born just over a month after Mabry Kate passed away, and received a stem cell transplant at Duke University Hospital. He was in the hospital for 110 days. While this was hard on all of us, it does not compare to losing our first child, and that feeling of not being able to help her. Our family lived in Durham, North Carolina for the next 8 months so Owen could receive the best available treatment. Some may argue that many parents would not or could not arrange such treatment on a whim, but I would beg to differ. Our family, among many others who we are now connected with, have dropped and would drop everything to save the life of their child. Owen will now be 4 years old on March 30th, and is doing remarkably well, hitting new milestones and doing new things every day. He attends preschool and interacts normally with his peers. It is astounding to see the difference in his life versus our daughter's. She was robbed of this chance because Tennessee did not screen for Krabbe Disease at the time. This is unacceptable. These children deserve a chance at life, and their parents deserve the knowledge in which to help them make the best decision for their child and their family. Whether to treat our children or not, should be our, the parents, decision to make. In August of 2015, the Mabry Kate Webb Act was passed in Tennessee. It added Krabbe and several other Leukodystrophies to the newborn screening panel in July of 2017. While it was too late for

Mabry Kate, we can now rest knowing that no other child in the state of Tennessee will have to go through what she did. Others may also argue that the treatment is not a cure. If you could meet Owen, you would see that regardless of it not being considered a cure, it certainly looks to be. How many cancer patients would be robbed of their lives if chemotherapy and radiation were not available simply because they are not a full-on cure? We are thankful to Tennessee for stepping on board with this screening, and have already been able to meet several families who have been impacted in a positive way because of it. Their children are now receiving treatment that they would have otherwise not known about until it was too late. Thank you for your time in reading this letter and considering adding Krabbe Disease to Oregon's NBS panel.

Sincerely,

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