

Re: Bill 2563

Date: March 11, 2019

Dear chair Salinas, Vice-chairs Hayden and Nosse, Members of the Committee:

I am writing on behalf of Emmett Monaco and all other children born with, or yet to be born with, Krabbe Disease and their families. I work in Early Intervention and Early Childhood Special Education (ECSE) as a Physical Therapist. With this job I have the privilege to meet and work with the most beautiful, amazing children. In September of 2017 I entered the home of Emmett Monaco. At that time his family was working with the medical community to figure out what might be causing Emmett's developmental delays. Emmett was talking, able to scoot on his bottom, pull himself to standing, eating solid foods, giggling, smiling, and oh so happy, but he was behind for his age in communication and motor skills. Within 3 visits, we noticed Emmett's skills started to regress. The medical community could not find a reason why and Emmett went through test after test for answers. His family was sent in circles and they decided to do their own research to try to get to the bottom of why Emmett was losing his previously gained skills. It was not until February of 2018 that Emmett's family was finally given a diagnosis. That diagnosis was Krabbe Disease. His family dug in and research the country, and the world, about what could be done to help him. It was from this research they learned that Krabbe Disease has a treatment that can stop the progression of the disease. They flew out of state to have Emmett put through another round of tests to see if he could be treated, but it was determined it was too late for Emmett because the disease had already progressed too far. Devastating. To know that states can do something about this by adding Krabbe, and other leukodystrophies, to new born screenings brings hope. Hope to Emmett's family, to other families in our state and region that have lost a child or currently have a child with Krabbe, hope to me as an early interventionist. How can we morally not do this? These babies deserve life. Life without pain, without feeding tubes, without muscle spasms, without seizures, without suction machines and hospitalizations; life with laughter, music, smiles, big brothers and sisters, hugs, running, skipping, a way to show how smart they are, to be a kid.

Emmett requires care 24 hours a day. He has lots of specialized equipment to keep him healthy and comfortable. He has outpatient therapies (OT/PT/Speech). He has many doctors that work with him. He works with an audiologist. He has been admitted to the hospital multiple times. He has had more testing than any one person should have in a lifetime. Before he turned 3 he had early intervention at his home, with a team including PT, Speech, and an Augmented Communication Specialist. He recently turned 3 and now has an ECSE team of a special education teacher, a PT, a speech pathologist, a vision teacher, a hearing specialist, a school nurse and deaf blind consultant. All of this comes with a dollar cost that I cannot begin to imagine. Much of this cost is put on the state and this should be taken in consideration when thinking about this bill.

As Emmett's early intervention and now his ECSE physical therapist. I have done my best to help his family travel down this road. I have watched his body change due to the decreasing myelin slowly causing the nerve connections throughout his body slip away. I have watched Emmett lose his vision and his hearing decrease. I have watched his parents be champions for Emmett. Working with state services to help support his care. To fight for what Emmett needs to have the best life possible. To fight for this bill to help future babies, and their families, not go through what they are going through. Most importantly, I have watched them love Emmett and Emmett showing love for his parents. Emmett

recently let us know that he still has the capacity to communicate with us through eye blinks. His amazing parents and big brother discovered that he blinks 3 times for "I love you." He truly is amazing.

Members of the committee, you have the ability to move bill HB 2563 forward. You have the power to help future babies born in this region have a near immediate diagnosis. If that diagnosis is Krabbe, you have the power to get them the treatment they need to give them a full life, to allow them to avoid 7 months of tests to discover they have a disease that it is now too late to treat. The cost savings to the state is an important piece of what this testing can provide, but the life these tests can give is what matters the most. Thank you for your time and for considering moving bill HB 2563 forward.

Sincerely,
Keri Esser, DPT