

To whom it may concern,

My name is Lilly Brubaker. I am writing this letter from Akron, Ohio in support of HB 2563. My 10 month old son David was born with Krabbe Disease. We would not have know about it, were it not for the Ohio Newborn Screening test. David was the third baby to be diagnosed with Krabbe Disease in Cleveland Hospital. The doctors at Cleveland Hospital tried their best to explain Krabbe to us using 10 year old data about Krabbe from New York. At that time, we choose not to give David a transplant because the data presented led us to believe that David's case was hopeless. A couple days later, one of the genetic doctors at Cleveland Hospital referred me to Doctor Escolar, a Krabbe Specialist in Pittsburgh. We brought David to Pittsburgh for tests and talked to Doctor Escolar about David's Krabbe procession. Because David was diagnosed early thanks to NBS, he still had a chance of transplant and a normal life. Eight months later, after two bone marrow transplants, David is still bringing smiles to everyone he meets. I personally met Nikki and Emmett at the Pittsburgh hospital during my son's first transplant. When I listened to Nikki tell Emmett's story and saw his condition, I could not help but cry. My son was lucky to be born in one of the six states that had Leukodystrophy testing in New Born Screening. This is why I am writing this Letter. Please support HB 2563. Oregon and the rest of the states need Leukodystrophy testing in Newborn Screening. If it was not for people like Nikki and Hannah Jones and many others fighting for Leukodystrophy testing, my son who is now 10 months would not be living and smiling today. Please support HB 2563 so future Krabbe babies and families will have the chance to have a normal life.

Thank you



This is David at 9 months, if it was not for NBS in Ohio and Bone Marrow Transplant, the Krabbe Disease would rob his precious smile and life from us. Please Support HB 2563.