

Hello, my name is Susan Monaco, I live in Beaverton and I am Emmett Monacos' Grandma. I support HB 2563. Please add Krabbe to Newborn Screening in Oregon.

Last Tuesday you saw video of Emmett before Krabbe symptoms, heard testimony, and met Emmett and his parents Joseph and Nikki. You may have seen Jaxon, Emmett's older brother along the side of the room standing with me. You also met Michael Wilson, a Krabbe survivor, survivor because he was diagnosed and able to receive a stem cord transplant. He was diagnosed because his older brother, Marshall, had Krabbe and therefore Michael was tested. Marshall saved his brother's life.

We are very thankful for what time we had with Emmett before Krabbe started taking away his life, but we are so very heartbroken at the same time. Every family, when they welcome a new little one into their lives has dreams and hopes for that child. Unfortunately, none of those dreams and hopes for Emmett will be fulfilled. Emmett should be playing in the sandbox with his older brother Jaxon, playing chase with his cousins Eleanora and Lily, getting horsey rides from his Grandpa, snuggled up on my lap reading endless Curious George stories and being an active part of his loving family, telling stories, playing games, going for walks with his parents as he improves his tricycle driving skills.

Krabbe has taken away Emmett's eyesight, ability to eat, stand, sit, play, interact with us, and it will continue to take away his hearing, ability to breath and the beat of his heart. As we watch this wretched disease progress, we accept that it is too late for Emmett, but we cannot accept that other families should have to experience this, to watch the lives of their children erode, when a blood test would change everything.

Had Krabbe been added to newborn screening in 2015, Emmett and others who have been recently diagnosed would have a chance at the life they deserve. Can we take that hope and life away from any more Oregon children? Adding Krabbe to the Newborn Screening would insure that every child born in Oregon has a chance to survive this horrible and devastating disease.

You can change the future reality for countless families in Oregon. Be the ones who go out there and make a difference in Oregon families. Please add Krabbe to the Newborn Screening list. Making a difference in others' lives is a gift that you hold in your hands. Please don't allow a shortened life of Krabbe affect another child in Oregon.

Thank you,  
Susan Monaco