

To the members of the House Committee on Health Care,
My name is Erika Probst. I am a nurse, a mother, and have been an Oregon resident for 20 years. As a maternity nurse for 16 years, I routinely performed newborn screens on our newborn population. When I had my own children, I was relieved that we had newborn screening mandated in Oregon as a method for determining if there were life-threatening disorders that could be treated and prevented if caught early. What I did not know at that time was that there were additional screenings that were not available on our Oregon test. I was not aware of this until my friend and fellow nurse, Nikki Monaco, started sharing the journey she and her family were experiencing with their son Emmett who was diagnosed with Krabbe disease. By the time Emmett was diagnosed, he was passed the point of being able to receive life-saving treatment. As a parent, I cannot begin to comprehend the heartache of receiving a terminal diagnosis for my child. As a nurse, it is hard to believe that this terminal diagnosis could have been prevented by an inexpensive, routine test that we didn't provide. With this knowledge, I give my full endorsement of House Bill 2563-1 with amendment adding new diseases to the Oregon Newborn Blood test/screen. Please vote yes on this bill and save families the heartache of receiving a terminal diagnosis.

Thank you,
Erika Probst, RN, MSN