



Integrative Pediatrics

To whom it may concern,

I am writing to ask that Oregon add Krabbe and the other leukodystrophies for which there are screening tests to our standard newborn screening panel.

The importance of screening for these conditions is that there are now treatments available that are not only life saving, but completely transformational in regard to the course of these illnesses for anyone experiencing these conditions.

I had in my office today my patient Emmett Monoco who just turned 3 years of age. He was diagnosed with Krabbe's at about age 2 having been normal until 9 months of age. He currently has lost his vision, is losing his hearing, is fed through a feeding tube, experiences significant contractions of his extremities and lives in constant pain. He is not expected to live much longer. Although he could continue to suffer for many more years.

In contrast, also at his visit today was Michael Wilson who is now 7 years old. Michael's older brother Marshall was diagnosed with Krabbe's at 18 months and went on to die from this condition at age 6. Because the family became aware of Krabbe's disease through this diagnosis, Michael received an early diagnosis and the cord blood transplant at OHSU. He now is in 2nd grade, living a basically normal childhood with multiple physical scars from his procedure, but is otherwise emotionally and academically on track for his age group.

Please add screening for Krabbe and the leukodystrophies to the routine newborn screening panel.

Sincerely,

Paul Thomas, MD, FAAP