

Hello, my name is Ellie Monaco.

I strongly support the bill to add Krabbe Disease to Newborn Screening in Oregon.

Krabbe Disease's signs and symptoms usually develop in babies before six months of age, with death occurring by age two. This degenerative disease affects the nervous system, and takes away the sight, hearing, ability to crawl or walk or sit up alone or eat without assistance.

Stem cell transplants have shown some success in babies who are treated before onset of symptoms, which is why it is imperative that Krabbe Disease be added to newborn screening.

My nephew, Emmett Monaco was diagnosed just before the age of two years. This bill will give other babies with Krabbe the chance at life—something my nephew never got.

We all ask your help in this matter.

Thank you,
Ellie Monaco