



Hunter's Hope Foundation

Hope ~ Life ~ Leukodystrophy ~ Newborn Screening

The Honorable Joseline A. Pena-Melnyk
Chair, House Health, and Government Operations Committee
Room 241, House Office Building
Annapolis, MD 21401

RE: HB096 Health - Newborn Screening Program - Krabbe Leukodystrophy

Dear Madam Chairwoman Pena-Melnyk and Distinguished Committee Members:

I am Anna Grantham, the newborn screening director at the Hunter's Hope Foundation.

For 25 years, we've wept with families reliving the same nightmare caused by a symptomatic diagnosis of Krabbe disease. Their baby is born, seeming to be perfectly healthy. Just a few months later, the baby is relentlessly screaming in pain. Those who have encountered a baby as they become symptomatic with Krabbe disease are forever haunted by the baby's piercing, high pitched scream. It's unlike any sound a typical baby would make, and indicative of the agony these innocent babies endure.

After weeks or months of suffering and misdiagnoses, parents learn their baby will continue to suffer as they rapidly lose milestones until they are unable to swallow, cough, speak, laugh, smile, and have lost almost all basic and voluntary function. Parents are told they will need to use a suction machine at all times to manage their baby's saliva, that their baby will need a feeding tube, and that it is too late for their child to receive any disease-altering treatment. They're told to take their baby home, make them comfortable, and to prepare for their funeral.

If you think the benefits of Krabbe newborn screening are insufficient, then you do not understand the horror of Krabbe disease. We are not just talking about an early death. We are talking about an early death preceded by agonizing suffering. Krabbe disrupts every system and function within the body and 100% of these children die, usually by their second year of life. No child should have to suffer like this when there is a screen and treatment available.

Newborn screening for Krabbe profoundly improves length and quality of life. Children diagnosed and treated early are spared from the suffering untreated babies experience and they are so full of life. They go to school, play with their siblings and friends, they're independent, they smile, laugh, communicate – *and they live.*

Krabbe Disease was just voted for inclusion on the federal Recommend Uniform Screening Panel (RUSP) and includes psychosine to identify babies with Krabbe disease without falsely identifying babies who are not at risk. These babies can be cost effectively screened at birth with other RUSP conditions MD is already screening for and diagnosed in time to have a chance for a better and much longer life. They deserve to have this chance.



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When there is a newborn screening process that avoids false positive screening outcomes, why wouldn't you give affected children a chance to live?

Please, help us save these precious children's lives. Vote to support the addition of Krabbe disease to the Maryland's Newborn Screening panel today.

With hope,

Anna Grantham
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