



# Hunter's Hope Foundation

*Krabbe ~ Leukodystrophies ~ Newborn Screening*

## **Newborn Screening for Krabbe Disease**

NFL Hall of Fame Quarterback Jim Kelly and his wife Jill created the Hunter's Hope Foundation in 1997 after their son, Hunter (2/14/97 – 8/5/05), was diagnosed with Krabbe Leukodystrophy. Krabbe is a rare inherited disorder that affects the central and peripheral nervous systems. If untreated, children affected by the disorder suffer greatly and are not expected to live beyond their 2<sup>nd</sup> birthday.

**In order for the only available treatment for Krabbe to be effective, the disease *must* be detected at birth through Newborn Screening.**

In 2006, New York became the first state to begin screening for Krabbe disease. Missouri (2012) Kentucky (2015), Ohio (2016), Tennessee and Illinois (2017) are also screening for Krabbe and similar disorders. New Jersey, New Mexico, Pennsylvania, and Louisiana have all passed similar laws with implementation dates varying by state.

Effective treatment for Krabbe disease is available and supported by data gathered during clinical trials and published in the medical literature. Umbilical cord blood transplantation has been shown to significantly extend and improve the quality of life for children with Krabbe. If the procedure is performed early in the course of disease, 80-90% of patients survive with good quality of life. It is clear that treatment must be initiated at a very early age to be effective, before any clinical manifestations appear.

Should a state begin screening for Krabbe, a quality assurance program for Krabbe newborn screening is in place at the CDC and would be available to the laboratory. Additionally, significant reduction in costs can be anticipated, as the care of children with Krabbe disease would be much less costly when children are treated prior to occurrence of irreversible damage and, therefore, do not require continuous nursing care and numerous and costly hospitalizations. It is estimated that the medical expense of an untreated child affected by Krabbe costs a state a minimum of \$700,000 annually.

**Newborn screening for Krabbe is *crucial* to ensuring all future children born in your state have a chance for the healthy life they deserve. Please help by sponsoring this lifesaving legislation.**

**For more information, please contact:**

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