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PATIENT STORIES OF HOPE AND INSPIRATION – ‘MEET THE WILSON BROTHERS!’

By Heather Earley on February 7, 2012



MY BROTHER, MARSHALL IS MY HERO! HE SAVED MY LIFE.

At 17 months of age, he was diagnosed with a RARE Leukodystrophy called Krabbe's Disease. A genetic disorder affecting the nervous system and it's

communication to the brain. There is NO CURE and it is fatal!

Once my family and our doctors determined what was affecting my brother, we were encouraged to have me tested. Exactly one month after his confirmed diagnoses, I tested positive for the same disease. The only difference between the two of us is that I have no symptoms and became a candidate for a cord blood transplant.

At four months of age I had a CBT and though I had complications with the chemo treatments, the transplant has been considered a success, as a recent MRI showed no disease activity. Thank You Brother for Saving My Life!

Marshall is now 2.5 years of age and I am 15 months old. Though I am delayed a bit, with all the therapies, love of my family, and spiritual pep talks from my brother, I am thriving, and achieving my developmental milestones, just as my brother hoped for. Without his heroism, I would not be able to SEE my brother, play with my toys, watch a flower bloom, and kiss his angelic cheeks (my brother is blind). I would not be able to giggle and babble and one day tell my brother that I love him, 'Thank You', and that he is my hero (my brother never spoke his first word).

I can hear my Mommy's voice sing to me, my Daddy talk about fishing, and the fun activities of my brothers and sister (my brother is deaf). I can roll everywhere and sit up; I even get to hug on my brother. I get to smile, eats solid foods, get older. I will go to school, possibly college, and someday I hope to marry and have a family of my own and tell my children the story of my gene family.

MY BROTHER.....MY HERO!

Tammy Wilson
Oregon

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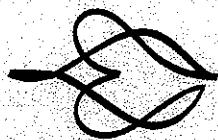
Let's screen every child, in every state for the same diseases.

The panel of newborn diseases screened for varies from state-to-state. Right now only two states require all newborns to be screened for 54 potentially fatal diseases, most others, less than 30. Only one state screens for Krabbe disease, and only three have passed legislation to add Krabbe within the next couple of years.

With Universal Newborn Screening, we can give every child the chance they deserve. To find out which newborn screening tests are routinely conducted in your state, visit the Hunter's Hope website at www.huntershope.org.

Alabama (42)	New Hampshire (35)
Alaska (46)	New Jersey (54)
Arizona (28)	New Mexico** (30)
Arkansas (30)	New York** (51)
California (48)	North Carolina (42)
Colorado (45)	North Dakota (50)
Connecticut (46)	Ohio (41)
D.C. (52)	Oklahoma (48)
Delaware (45)	Oregon (39)
Florida (36)	Pennsylvania (38)
Georgia (29)	Rhode Island (33)
Hawaii (46)	South Carolina (53)
Idaho (45)	South Dakota (50)
Illinois* (45)	Tennessee (51)
Indiana (52)	Texas (30)
Iowa (51)	Utah (47)
Kansas (31)	Vermont (35)
Kentucky (31)	Virginia (30)
Louisiana (51)	Washington (29)
Maine (39)	West Virginia (33)
Maryland (52)	Wisconsin (49)
Massachusetts (29)	Wyoming (31)
Michigan (50)	
Minnesota (54)	
Mississippi (48)	
Missouri* (52)	
Montana (31)	
Nebraska (32)	
Nevada (44)	

() Number of diseases screened
 ** Screening for Krabbe
 * Legislation to add Krabbe
 Data as of 1/1/2011



The Hunter's Hope Foundation was founded in 1997 by Pro Football Hall of Fame member and former Buffalo Bills quarterback Jim Kelly, and his wife Jill, after their infant son, Hunter was diagnosed with Krabbe disease.

Hunter's Hope was established to address the acute need for information and research with respect to Krabbe disease and related Leukodystrophies. In addition, the Foundation strives to support and encourage those afflicted and their families as they struggle to endure, adjust and cope with the demands of these fatal illnesses.

The Foundation also supports efforts to raise awareness of the importance of Universal Newborn Screening.

Hunter's Hope Foundation
 P.O. Box 643
 Orchard Park, NY 14127
 716-667-1200
www.huntershope.org

UNIVERSAL NEWBORN SCREENING

Every Child. Every Time. Everywhere.™



*"For I know the plans I have for you,"
 declares the Lord,
 "plans to prosper you and not to harm you,
 plans to give you Hope and a Future."
 Jeremiah 29:11*



HUNTER'S HOPE

WHY UNIVERSAL NEWBORN SCREENING?

Most babies appear healthy at birth, full of life and possibility. Yet they could be hiding a rare or potentially devastating disease. By screening every baby at birth we can prevent serious mental or physical disabilities, even death. And by making the requirement universal-in every state-we can ensure that no family will have to suffer unnecessarily.



In 1997, Hunter James Kelly, the son of NFL quarterback Jim Kelly was born, a seemingly healthy baby boy. Four months later, he was diagnosed with Krabbe disease, and at the age of eight, Hunter went to heaven.

With Universal Newborn Screening, Hunter's story could have been different.

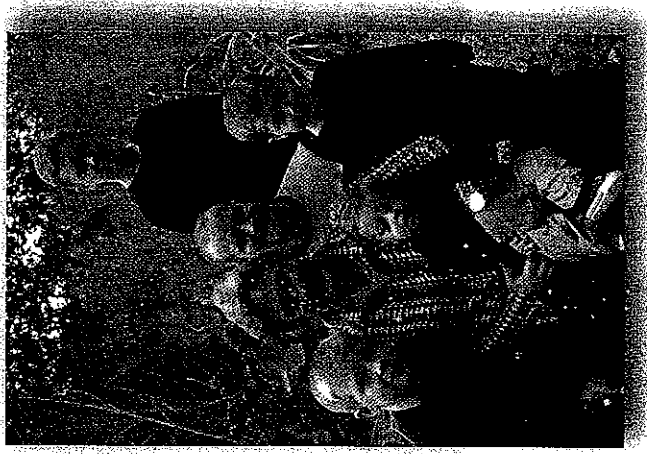
All it takes is ...

*One Heel prick
One Test
Together*

we can save lives.



Imagine your child's life cut short or devastated by disability, just because they were born in the wrong state. Universal Newborn Screening seeks to provide necessary newborn testing for every child in every state.



Bill and Nicole Morris Family

In December 2009, baby Greyson Morris lost his battle with Krabbe disease. His 9 year old brother, Seth, has PKU. Seth is healthy because his disease was screened at birth and is now managed.

Greyson's disease was not screened for at birth. His parents didn't know what he was suffering from until an autopsy indicated he had Krabbe.

Seth asked his parents "Why is my disease more important than Grey's?"

The Morris family began a battle of their own.