



# Hunter's Hope Foundation

*Krabbe ~ Leukodystrophies ~ Newborn Screening*

April 24, 2017

Representative Angel Cruz  
Members, House Human Services Committee  
Pennsylvania House of Representatives

Dear Representative Cruz and Distinguished Committee Members,

I am writing today in support of HB 1081. Although I might be best known for my time on the football field, I am most passionate about helping children like my son, Hunter, have the same chance to dream like I did as a little boy growing up in East Brady, PA.

Hunter (2/14/97 – 08/05/05) was diagnosed with Krabbe Leukodystrophy when he was only four months old. My wife and I were told to take him home, make him comfortable, and that he would not live beyond his second birthday. My son is the toughest guy I have ever known. He far exceeded medical expectations by living a courageous 8 ½ years, but he suffered every day of his life.

Through Hunter's Hope, I began to advocate for expanded newborn screening, not only for Krabbe, but for all disorders. A simple heel prick can mean the difference between life and death for so many of our nation's children.

In 2013, I traveled to Harrisburg to meet with members of the Pennsylvania legislature and the governor of my home state. I was so proud when Hannah's Law (Act 148 of 2014) was signed into law in October 2014, especially since the occurrence rate of Krabbe Disease seems to be higher in PA than in other states.

Today, I enthusiastically offer my support of HB 1081, which will not only finally guarantee the timely implementation of NBS for Krabbe Disease, but also provide the funding needed for Pennsylvania newborn screening (NBS) to reach its fullest potential.

There are currently 4 states (NY, MO, KY and OH) that include Krabbe in their NBS panels and several more in the process of implementation. The two most recent children to be diagnosed with Early Infantile Krabbe, Tygh from Kentucky and Ezra from Missouri, are proof that early detection and treatment through newborn screening for Krabbe is not only possible, it's the only way to ensure that all future affected children have the chance at life they deserve.

These two amazing baby boys are out of the hospital, thriving, and meeting new milestones each day. Without Krabbe NBS in their states, Ezra and Tygh's parents would just now be receiving the same devastating news my wife and I did, after it was too late for treatment.



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Through our Foundation, Hunter's Hope, which is entering its 20<sup>th</sup> year as an organization, we've met countless other children, who like Hunter were diagnosed after it was too late. I've also met dozens of children who have been diagnosed and treated early, before they become symptomatic of this terrible disease. The difference is incredible. These children are walking, talking, they go to school, and most of all they are living.

Please, I urge you, to do everything in your power to ensure that Hannah's Law is finally implemented. Let's come together for the sake of Pennsylvania's children and make sure they are screened for Krabbe and dozens of other diseases at birth by supporting HB 1081.

With hope,

**Jim Kelly**

President and Co-Founder  
Hunter's Hope Foundation