MEET MICHAEL WILSON OF OREGON

DIAGNOSED AT 2 MONTHS OLD ON 12/19/2010

TREATED AT OHSU/DCH AT 4 MONTHS OLD ON 2/10/2011


JOHN DEERE
Michael

Thank you to the committee for taking the time to hear my testimony. My testimony is of a mother, a mother who has buried one son and fought to save another. A mother who continues to fight to save ALL babies that have a fighting chance.

Our two youngest biological children were diagnosed with a rare, brutal and fatal disease called Krabbe Disease. It is a Leukodystrophy that attacks the nervous system. My son Marshall who earned his angel wings on March 5, 2016 was diagnosed with this horrible disease on November 19, 2010 though symptomatic beginning July 2010, just shortly after his first birthday. Marshall lived six years with this disease.

On September 25, 2010, Marshall's youngest brother was born. On December 19, 2010; on the exact same day just one month later, we received the devastating news that Michael tested positive for the same disease.

Though Michael was not screened at birth, he was tested for this disease because of his brother. Marshall saved his brother's life. On February 10th, 2011, Michael received a life-saving cord blood stem-cell transplant. Michael is now 14 years old. He is active in FFA and Entrepreneurship. As of today, he has no signs of this disease.

Michael was diagnosed with a terminal disease and as of today he is KRABBE FREE, no disabilities.

Imagine, if you will, the joy of holding your newborn. The tiny fingers, the soft breaths, the boundless hope. That was Marshall. My third normal birth. Then, the creeping dread. The subtle changes, the milestones missed leading to the devasting diagnosis of Krabbe Disease. A death sentence for my baby.

We cradled him, we sang to him, we prayed. But the disease was relentless. It stole his mobility, his voice, his very essence. It turned our home into a hospice, our lives into a constant roller coaster of emotions and unknowns. Six years of watching our child suffer from a disease that has a life-saving treatment and newborn screening detection. It was and IS treatable…….death could have been prevented.

Then, Michael. Fifteen months later. Another baby. Another test. Another diagnosis. But this time, there was hope. A stem-cell transplant. A CHANCE! A CHOICE…to save my baby's life.

Michael was treated and saved right here in Oregon at Doernbecher's Children's Hospital.

Michael survived. He thrives. He is a testament to the power of early intervention.

I write my testimony, not just as a mother, but as a witness. I have seen the devastation of Krabbe Disease firsthand. I have seen the amazing treatment for Krabbe Disease firsthand. You are here to make decisions about budgets, about policies. But these are not just numbers on a page. These are lives. These are children. These are available treatments. These are available screenings. This is about saving lives because PARENTS HAVE OPTIONS. A test that could have saved my Marshall and the babies diagnosed with Krabbe Disease in Oregon since. A test that should have given Michael a chance. Because of Marshall's diagnosis, Michael was tested for the same devasting disease and treated. Oregon NBS should have screened and diagnosed both of my boys and the babies that followed who were diagnosed with this same fatal disease.

Every dollar spent on newborn screening is an investment in the future. It is an investment in hope. It is an investment in the lives of our children. Please, I implore you, do not deny them that chance. Please, choose options. Please, choose life. If HB3192 requests a certain amount of money that seems out of reach. Please decide on a budget that allows babies/children to be screened at birth for all diseases that have viable screenings and treatments like Krabbe Disease and so many more.

Thank you for your time and consideration.

Tammy Wilson

Mother of Michael and Marshall Wilson, Oregon