

## Christin Webb



Christin's daughter, Mabry Kate, (3/13/14 – 2/7/15) was affected by Krabbe Disease, as is her son, Owen.

Mabry Kate was born on March 13, 2015. After developing normally for about two to three months, she slowly began losing her skills and milestones she had already gained. After four months

of trying to get a diagnosis, Christin and her husband Kyle sought a second opinion in Cincinnati. Mabry Kate was diagnosed with Krabbe Disease. Since Mabry Kate was born in Tennessee, a state that, at the time, did not test for the disease, it was too late to receive life-saving treatment. Because of this, Mabry Kate lived her life in pain or on medicine to control the pain. She passed away just shy of 11 months old.

Because of Mabry Kate, her little brother Owen was tested and also diagnosed with Krabbe prior to birth. He was born just over a month after Mabry passed away, and transplanted at Duke Hospital. He was in the hospital for 110 days. The Webbs lived in Durham, North Carolina for the next 8 months so Owen could receive treatment. Owen is now 2 years old and is doing remarkably well, hitting new milestones and doing new things every day.

In August of 2015, the Mabry Kate Webb Act was passed. It will add Krabbe and several other leukodystrophies to the newborn screening panel in Tennessee by July 2017.

Christin has a real desire to connect with families who are new to this journey and are seeking guidance. She also wants to be a part of educating people and bringing awareness to these diseases. Christin's greatest hope is that one day there will be a cure but until then she hopes for more awareness and education to be available for leukodystrophies so that these diseases are more recognizable and are diagnosed much quicker.

Christin is a 5<sup>th</sup> grade teacher and high school basketball coach. The Webbs reside in Powell, Tennessee.

