Phil and Amy May’s son, Dylan, was affected by Krabbe Disease.

The Mays third son, Dylan, was diagnosed with Krabbe when he was 8 months old. They were told he wouldn't live until his second birthday, but he was a fighter, and made it to 10 days shy of his 5th birthday. They share that they were blessed to have Dylan with them every single one of those days. They have 2 older sons who are carriers of the disease and after Dylan's diagnosis, they adopted their daughter from Guatemala.

The Mays want to spare other families from some of the struggles that they endured. They feel that no family should have to "recreate the wheel" regarding medical care for their child, especially when they are in the midst of life's greatest struggle.

They want all knowledge and best practices pooled together to make life better for families affected by Leukodystrophies. Each child should have the best care possible and be encouraged to LIVE, not be sent home to die.

Phil and Amy reside in Franklin, Tennessee.