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11-month-old Campbell boy fights for life, parents fight for change

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By Crystal Britt

CAMPBELL, MO (KFVS) - An 11-month-old boy has a rare, terminal disease. Dustin and Jessy Cunningham of Campbell, Missouri say they found out too late to save their son. They say if doctors had tested 11-month-old Brady as soon as he was born, he would have had a fighting chance at living a normal life.

So, they're pushing Missouri lawmakers to pass a bill making screening for Krabbe Disease and four others like it mandatory right after birth.

There are no shortage of kisses for little Brady, even from the family puppy. Brady Cunningham is surrounded by love. He turns one next month, but his parents say they celebrate his birthday every month.

"We just hold on and know that until God says it's his time, we're not giving up," said Jessy Cunningham, Brady's mom. "We pray everyday for a miracle."

When Brady was born he was diagnosed with an immature nervous system. Doctors told his parents his shaking would go away by four months of age, but he didn't get better.

"When we got to Children's Hospital in St. Louis they said they never saw a baby cry this much," Jessy said. "They'd seen babies in pain, but never like this."

Jessy says after a number of tests, doctors diagnosed Brady with Krabbe Disease.

"What it basically does is eat away at his nervous system," she said. "He was developing perfectly fine and slowly he's gotten back to almost a newborn state. He can't sit up on his own, or hold his head up on his own. He'll eventually go blind and deaf is what the doctors say. There's no cure for it."

Brady sees a lot of nurses and therapists these days.

"He needs to be stretched to make his muscles stronger so they'll grow," said Judy Water, Brady's development therapist. "He can make it. He can be the percentage who does because he's so healthy."

He's put on weight, and has survived two rough rounds of pneumonia.

"He's really sounding a lot better than he used to," said Becky Cross, Brady's Hospice nurse, as she listened to his breathing. "He had a couple weeks there where we were concerned he wasn't going to make it. His hope is that he has such loving parents that are taking such good care of him."

Dustin and Jessy stay home around the clock with Brady. They don't want to miss a moment.

"You have your highs and lows," said Dustin Cunningham, Brady's dad. "We just look to the Lord and if Brady doesn't get healed here, he'll get healed up in heaven,"

Brady's parents are fighting to make Krabbe Disease part of newborn screening tests.

"If we would have known when he was born he could have gotten a blood transfusion or bone marrow transplant," said Jessy.

She says that treatment would have stopped the progression of the disease, giving him a 70 percent chance of survival.

"He would have had a chance to live a normal life," said Jessy.

"We think that's why Brady was given to us is for a bigger reason, and we honestly think it's to save more children's lives in the future," said Dustin.

Heartland News has learned Illinois and New York already require Krabbe Disease to be part of newborn screening. We're told the legislation is currently close to making it to the house floor in Missouri.

Meanwhile, the Cunningham's are staying unbelievably strong. They credit God, and an amazing support group of family, friends, church and community.

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