

Keagan

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHO LOST A CHILD TO
3-METHYLGUTACONIC ACIDURIA (3MGA)

Keagan Yancy Fife was born on November 21, 2006. The pregnancy pretty much went fine except for me going into labor off and on. But he was born healthy and happy and came home 24 hours after birth.

When he was about 6 months old, he stopped gaining weight, and he had very bad reflux. In August of 2007 he had a nasal feeding tube placed because he started to lose weight. He was 9 months old at that time and was only 11 lbs 8 oz. They found out that his liver enzymes were high and so were his lactic acid levels. A geneticist did some tests and found out that he had 3-Methylglutaconic acid in his urine and diagnosed him with a metabolic genetic disorder.



In September, 2007, Keagan went back to the hospital for a fundoplication and a g-tube placement. During the surgery he mysteriously coded and they brought him back. Afterwards they discovered that he needed a blood transfusion. Other than that he was fine, so we took him home. He then started to see his geneticist, and we found out in November that he had a Mitochondrial defect. They were not able to tell us much about what problems he would have, or if they would ever be able to isolate the gene causing the problem. For a lot of what they were looking for there is either no testing, or the testing is so expensive that medical insurance does not cover it. We were warned that it could take several months to investigate, and we could wind up with no answers at the end.

On January 9, 2008, Keagan was doing fine. He sounded like he might be coming down with a cold; however, he wasn't running a fever or acting too different from normal. My husband came home, and around 6:00 P.M. he fed him and put him down to go to sleep. He woke up around 8:00 and was having problems breathing, and his lips were blue. So I rushed him to the hospital, where they discovered that his blood sugar was 700. This is odd because in this type of disorder the blood sugar is usually low. They put him on a respirator, and that was the last time I saw my baby awake. His heart stopped when they were inserting the breathing tube. They were able to resuscitate him; however, from that point on everything started to shut down, and Keagan passed away around 9:20 the next morning.

Through all of this Keagan was a happy baby. He loved sitting and playing with his blocks with his older brother Sebastian. He was so laid back and calm; he smiled and laughed constantly. We miss him so much that words can not describe it. The pain of losing him is unbearable. I know that he is in Heaven with his brother Christian and sister Destiny-Li, but I wish he was here in our loving arms. I long to hear his laughter and see his smile. He is missed by all that knew and loved him.

Sincerely,
Crystal D Fife
Submitted February 3, 2008 by Crystal D Fife
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Mother of Keagan, Christian and Destiny-Li