

Brickman

THIS IS A PERSONAL STORY SHARED BY A FAMILY WHOSE CHILD HAS
MEDIUM CHAIN ACYL-COA DEHYDROGENASE DEFICIENCY (MCADD).

My firstborn son, Brickman, was born in Plano, Texas on November 7, 1996. He weighed 8 lbs 15 oz and was 21.5 inches long. He was full-term, born on his exact due date. A perfect baby boy!

He received the state mandated newborn screening for 5 disorders shortly after he was born. I thought the heel stick test was cruel and a waste of time. My family has never had any of those diseases...Why did they have to do this to my baby?



The test results were negative and I was told that he was perfectly healthy. He grew quickly and topped the charts in development. The pediatrician raved about him at every visit. But there was an unknown problem lurking inside of him, like a time bomb ticking...

At the age of 19 months, he became ill with a stomach virus and went an extended period of time (18 hours) without eating. He began to have seizures and slipped into a coma. He spent 15 hours in a coma, 2 days in ICU and 4 more days in the hospital. We came extremely close to losing our baby.

Testing revealed that he has an inherited metabolic disorder called MCAD. (No family history...My husband and I are both carriers and he received both of our carrier genes.) This disorder, as well as 35 others at the same time, could have easily been detected through a simple blood test costing around \$25.00.

Had we known about the expanded screening at the time he was born, the incident could have been prevented. MCAD is treatable if you know it exists. The problem is not knowing about the option to have a baby screened for additional disorders, when states are not providing the full spectrum of screening that is available.

Fortunately, Brickman is doing well and did not suffer any lasting effects from the crisis in his body. Many other children with his condition are not so lucky, either suffering permanent brain damage or dying.

It is my goal and mission to educate and inform as many parents as possible about this available screening to prevent trauma or tragedy from happening to yet another family.

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