

# Blayze

A BLAYZEN GOOD STORY SHARED BY A FAMILY WHOSE CHILD HAS  
MEDIUM CHAIN ACYL-COA DEHYDROGENASE DEFICIENCY (MCADD).

Blayze was born on May 15, 2004. He was a beautiful, healthy, baby boy. We were so excited to have a son. At the hospital, all of our friends and family could not believe how beautiful and perfect he was.

The first few days at home were challenging as we learned the ropes of being first time parents. Five days after the birth of Blayze, we received a startling phone call. I will never forget that moment. Some friends were over visiting in the evening and the phone rang. I answered it, and the voice on the other end was Blayze's pediatrician. He told me that I needed to sit down. He then proceeded to tell me that my son had been diagnosed through newborn screening with a genetic disorder called, MCADD.



I had never heard of this disorder and our doctor was not very familiar with it either. He told me to make sure I fed Blayze every 4 hours. I began to cry because I was so afraid. I didn't know how serious the disorder was. We began to immediately do research online. Some of the information was very scary and I was afraid to leave his side. They said that these kids could die if the necessary precautions were not taken.

Two days later we drove to University of Michigan. The doctor there was much more experienced and knowledgeable than anyone in our area. She really calmed our fears and made us realize how lucky we were to find out about Blayze's MCADD.

After the initial shock we realized how fortunate we really were. We read about other families who had lost their children to this silent killer. These children lived very normal lives and then in a split second, without warning, they were gone. We thank God everyday that our state has a mandatory test for MCADD. Unfortunately, it took other families losing their children to make it mandatory.

I, also, would like to thank all the families who fought to add MCADD to the newborn screening. It's because of them that my son will lead a healthy, happy life. We are helping in the fight to get every state to add more testing to the newborn screening. My son is now a healthy 11 month old. He is such a blessing to us and we cherish every day with him.

Written April 2005 by Dale & Cassie Coulter  
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