

## Gracie

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

On Friday night, February 6, 2004, my 19-month-old daughter Gracie came down with a stomach flu. She vomited a couple times around 5 to 5:30, and my wife decided to put her down early around 6:30 or 7 because she was sick. She had no fever or any other symptoms other than the vomiting, which she did periodically until about 3 a.m Saturday morning. One or both of us checked on her every half hour to hour throughout the night.



Gracie never had a fever, and only seemed to be very tired, which we thought was normal, since she had been up all night with the flu. By 3 or 4 in the morning she had stopped dry heaving or having any symptoms at all, but about every half hour to 45 minutes she would cry for just a few seconds, mostly in her sleep. Not a desperate cry, but a complaining cry. We were a little confused why she would keep crying like that since she seemed to have gotten over the stomach flu, but we figured she was just still a little nauseous or something.

I checked her around 6:45 or 7 and she was sound asleep. I stroked her hair and whispered to her, and thought to myself she is sleeping so soundly, she must really be tired from the night before. That was the last time I saw my baby alive. My 4 year old son got up soon after, and I went down with him to make breakfast. I heard Gracie cry one more time in the monitor we had in the kitchen, again only a moderate complaining cry, and then she was quiet.

My son left with his Grandfather around 8, and I waited until 8:30 downstairs to call the pediatrician when they opened. They wanted me to bring Gracie in, because she had also had a stomach flu the Tuesday before, and they thought I should have her checked out. I told the nurse she had just finally gotten to sleep for about an hour and couldn't I let her wake up on her own before I brought her in? She said I should just get her up. So I went upstairs and told my wife I was taking Gracie to the doctor.

When I went in her room to wake her up, she was gone. Of course, I performed CPR on her until the paramedics arrived, but she had been gone too long. I knew before the paramedics arrived she was not coming back. We didn't know for two weeks what had taken her from us, during which time the examiners hypothesized things like infections of vital organs, congenital heart disorders, SIDS, Reye's syndrome, and others. Then some liver tissue tests came back and the medical examiner called with the news that Gracie had MCADD.

We live in Atlanta, and newborn screening for MCADD is not one of the mandatory screens in Georgia. We now know that a simple glucose IV administered to Gracie at the right hour that night would have saved her life. If we happened to live in one of the states that routinely screen for it, or if we had known we could have the screening done ourselves at birth, we would have known she had the condition, and known how easy it is to manage. But we had no idea a test was out there that cost so little and screens for so many disorders. We would have had one done had we known.

Gracie blessed our lives with hers for a little over a year and a half, and we continue to be blessed with our memories of her now and forever. Hopefully stories like ours will help raise the awareness of MCADD and other disorders that can be detected through newborn screening, and can help save other babies from the fate of our girl.

Written April 2004 by Alexander S. Clay  
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Father of Gracie June 19, 2002 - February 7, 2004