Michelle

This is a personal story shared by a family who lost a child to undiagnosed Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCADD).

She was born on May 21, 1977. A perfectly healthy, brown eyed, brown haired little girl. She was my firstborn and I was very young, I also knew that I was very inexperienced. But we would meet this challenge together.

We had all the things and experiences any new parent can expect. The sitting up, the crawling, then walking. We made all our visits to the pediatrician, and all seemed well. However, just before her second birthday she became ill.

We had taken her for a weekend trip and she had developed a fever. On Monday I went back to work and left her with her grandma. When I returned home Michelle had been sleeping for several hours and when I went to check on her she wouldn't wake up. We left immediately for her doctor's office, which wasn't far. As soon as we arrived the doctor took Michelle and I to the hospital. There was no time to wait for the ambulance.

At the Hospital they checked her blood and told us she had "severe low blood sugar". When they started the IV she seemed to respond. She sat up and played with me, but it wasn't for long. She quickly became very tired and laid down. I remember sitting there with her holding her hand while they were still checking to see what was wrong with her. The doctors couldn't seem to keep her blood sugar up and she soon slipped into a coma. Michelle stayed in that coma in ICU for 5 days at Texas Children's Hospital in Houston. Other than the "normal" screenings her tests included Bacteriology tests for her blood and spinal fluid, Heterphile screen, Leptospirosis Clutures, ECHO virus 7. As I thumb through the tests they ran, there are over 70 lab reports that I have copies of. All negative.

Our many prayers were answered when Michelle began to respond and just as quickly as she seemed to fall ill, now she seemed to be doing fine. When they released her from the hospital they told us "it was probably a fluke". That they had not found exactly what had caused her illness, but that "now she was fine". They even felt it could have been a slight case of Hepatisus. But she was coming home and that is all we cared about.

Her next 18 years, health wise, were uneventful. She was "perfectly healthy." Never anything more than a cold. Her life by all accounts was completely normal. School plays, choir, driving, her first boyfriend, the prom, and even rebellion against Mom.

When Michelle was 20 she decided to go camping with some friends during Spring Break in Garner Texas State Park. They were due to leave on a Friday. It would not have been uncommon for her to stay up most of Thursday night with excitement. The weather had been cold and her friends had told us that none of them had gotten much sleep on Friday or Saturday. On Saturday after climbing a mountain, they relaxed at their camp-site and had a few "drinks".

She first became ill on Sunday morning at about 5:00am. They all finished their packing and headed home. Michelle continued to be ill and took some Pepto Bismol to see if that would help. It was about 8:00pm that they first took her to a hospital in Wiemer, a small country hospital, about 65 miles from Houston. The doctors in Wiemer felt they would be unable to treat her, mostly because they could not find the nature of her illness. I advised them to bring her to Herman Hospital here in Houston.

When Michelle arrived at Herman I met her at the ambulance doors. When they opened the doors she seemed fine. She recognized her father and I immediately. She was also able to give her address, name, phone number and knew it was after midnight and was worried about her friends getting to work the next morning. With the exception of the times she was talking to us, she would sleep. It was common for Michelle to be a deep and restless sleeper. The doctors checked her blood pressure, temperature, heart rate, and did a body check for bug bites all of which I was present for. The blood and urine tests came back with a negative blood alcohol level, illegal drug use, glucose and electrolytes were "well within range" per her doctors. They then did a CT scan it also revealed nothing. The doctors wanted to keep an eye on her just to be on the safe side and moved her to Observation at about 7:00am on Monday. She passed away approximately 3 hours later.

The autopsy took four months and proved nothing. The cause of Michelle's death was listed as "Natural Causes-Cause unknown". I tried every avenue I could think of to try and get answers. We checked with the "Reyes Foundation", Liver counsel, even SIDS groups trying to get answers. Trying to find out if the illness when she was two and the cause of her death were related. When we reached the one-year mark I had to make a call to the Medical Examiner's office to find out what I needed to do to keep her tissue sample longer than the "one year" time frame. I wanted more done to find answers.

Our answer finally came 14 months after her death from the attending physician who took care of her in Observation. It was as if he was almost as disturbed by her untimely death as we were. We were told Michelle's illness when she was two and her death were most probably related. She had died of M.C.A.D. (Medium Chain ACYL-CoA Dehydrogenase) Deficiency.

M.C.A.D. is an autosomal recessive disorder of fatty acid oxidation. An M.C.A.D. case is certain fats that can not be broken down and metabolized into energy. Michelle was born during a time that tests for this were not offered. However, now there are newborn screenings that can test for M.C.A.D. and about 40 other possible disorders as well. These expanded newborn screenings could prevent illnesses and definitely save lives.

Michelle would have been alive today, had she known that on the day she climbed that mountain with her friends that she needed to keep her sugar level up. Her "perfectly normal healthy" status worked against her. Our family is a painful sad reminder that these screenings don't have to be limited to newborns. We live knowing that we were given 18 years more than medical science could have offered us 24 years ago, but we also know that, had we known, she would be alive today.

Written March 2002 by Theresa Murray
Parent of:
Michelle Murry (May 21, 1977 - March 16, 1998)