

Our Precious Angel, Madison DeJarnette

My husband, Mike and I found out we were pregnant, and as with any other pregnancy, the excitement was tremendous. All went well throughout our pregnancy, and on September 30, 2003, Madison Alexis DeJarnette came into our world. The doctor made a comment that we might have a small problem, suspecting that she might have Down Syndrome. Then through a physical exam and a blood test, the pediatrician confirmed this. We were somewhat frightened at first, not knowing the possible complications with a Down Syndrome baby. That same day, they whisked Madison off to Cardinal Glennon's Children Hospital due to her low blood oxygen level, which meant she had a heart defect as well.

We were thrilled to bring her home after her first week of life was spent in the pediatric intensive care unit, entangled in tubes, wires and monitors. She was quiet for her first few months, due to her heart defect. She had three holes, and two valves in her heart, that didn't work properly. She took constant medication. She could only drink 2 ounces of formula at a time, as she would tire easily. So we fed her every 3 hours around the clock, to be sure she could gain a little weight for her impending surgery. The nighttime feedings were so special, I was able to spend more time with her, and just cuddle, those were wonderful memories.

We made many trips to the hospital for Doctor appointments. And she had therapy almost every evening. In this short time, she had brought so much joy to so many people's lives, it's immeasurable. She was an extremely good baby, and tried really hard at everything that was put before her, as in holding her head up, rolling over, grabbing for toys, and such.

At five months of age she had major open-heart surgery. A fantastic Doctor, at Cardinal Glennon's Children's hospital, prepared her for surgery. We were so frightened, just hoping and praying that he could fix her defect and bring her back to us. The surgery was 6 excruciating hours long, but afterwards he came to us and said that the surgery went without a hitch. She had gone on the by pass machine perfectly and had come off of it just the same. She was in the hospital for weeks, again, entangled in tubes, wires and monitors – there were so many, and it was frightening. But then she came home once again!

Well, with her heart mended, she was able to completely stop all of her medications, and was a normal baby girl! Her therapy sessions skyrocketed, and she advanced with flying colors. She was definitely on her way. Now she had the energy and smiles that we had so long waited for. She started babbling, and eating much better. Her therapists were thrilled daily, with her progress. We (Mike and I, her brother Bradley, her grandparents, and her babysitter) worked with her daily. She was truly amazing. Her smile, and personality were extraordinary. There was just something about her – she made her way into everyone's heart, quite deeply. Before we knew it she was performing sign language, eating baby food, reaching milestones, dancing to music, commando crawling, then crawling on all four, climbing steps and even pulling up to standing, and cruising along the couch! She loved it when we read books to her; she listened intently and pointed to pictures on the page. She loved to play with her brother Bradley, and pull his hair, or his nose! He was her biggest fan, and she was his. They were so great with each other. Every time Dad came home, she would crawl to him, pull his hat and glasses off and throw them to the floor. And with Mom, she loved to pull my long hair, sometimes with both hands. It was one of her favorite things, she just laughed and laughed. We were so proud of her and all that she had accomplished in such a short time.

Then, on December 8, 2004, our fabulous babysitter, Diana, called us at work. She said that when she awoke from her nap, her right side was not moving, and that when she sat her down on the floor, Madison could no longer hold herself up; she just fell to the side. We called the Doctor immediately and rushed her to the hospital. No one could understand how a young baby could have a stroke, but after testing, that's what the diagnosis was. It was a major stroke in the left side of the brain; almost the entire left side had been affected. She was in the hospital for four days, and in an induced coma to try to stop the swelling of the brain, when she had yet another stroke. This time the stroke occurred in the back of the brain. After additional testing, and tons of medications, we were told that she probably wouldn't wake up again. We were absolutely devastated, but remembered a Neurosurgeon making the comment that it could be possible to perform surgery to remove part of the skull to allow room for the brain to swell, and not harm the

unaffected right side of the brain. We asked the doctors if this was possible, and if she was strong enough to withstand surgery. They said that they could start immediately, but with no promises of recovery, and that they did. Within 1 hour she was in surgery and every member of our immediate family was there to comfort us while she was in surgery. Amazingly she made it through the surgery, and after a couple days, they took her off all medications to see if she would wake up on her own. To every doctor's amazement, she DID! She moved her arm, and opened her eyes. We stayed in the hospital for a total of 3 months, with ups and downs along the way. They had inserted a drain, to release fluids off the brain, and later performed surgery to replace the skull area that had been removed. She started intense, daily therapy again, and was able to come home on February 25, 2005. That was such an amazing day; we were so thrilled to have her home again.

The only concern was that we still did not know what had caused her to stroke. She regained a lot of what she had learned in her next weeks home, rather quickly, except for the use of her right side. She struggled with that immensely. But she tried her best, and she once again amazed the Doctors and therapists. Forty-four days later, she had another stroke while sleeping in her crib. She cried out once, and I ran into her, and she couldn't open her eyes or move anything. We rushed to the hospital, and they did another CAT scan. The Neurologist came into her room, and was crying, she said, "I'm so sorry, she's had another stroke, and it's affected the entire right side of her brain."

There was nothing left of her brain to sustain her life. After MRI's and MRA's they determined the cause of the strokes, it was called, Moya Moya, a very rare disease, which affects the main blood vessels to the brain. They clot and small spidery like veins form and try to go around the clot to provide the blood supply to the brain, but it causes you to stroke instead. There is no cure for this disease, and it can't be stopped from clotting again, and causing additional strokes, until death occurs. Some surgeries have been performed, but you have to catch the disease before a stroke occurs. There were no more surgeries to do, and no more options. Her brain had been damaged so severely that she could not talk, walk, move, see, hear, cry, feel, or even understand noises or words if she could hear them. Her processing center was gone. The hospital allowed us to stay there with her, and comfort her, while they kept her comfortable through medications.

She lived for 10 days after her third stroke, and passed away in her sleep very peacefully on April 21, 2005. She was in my arms, and her Dad, and our families were there with her. It was obviously the hardest day of our lives. While knowing that she could not exist with the medical condition she now had, we still couldn't bear the thought of losing her.

We miss her terribly; as do the family and friends that she touched during her short time here. She will be remembered always, for the way she touched our family, our friends, and for the way she showed us that differences can be very beautiful and extremely special, and that love above all is the most important aspect of our lives. Our little girl taught us much more than we could have ever taught her.

God Bless our precious angel, Madison.

