



April 2009 Angel of the Month

Cassidy

Angel Foundation®

By Angel Mom Sarah

Mother Teresa once said, "I know God won't give me anything I can't handle, I just wish He didn't trust me so much." I sometimes feel this exact way. Being the Mother of Lily has taught me so much about myself and strengthened me in many ways. However, I certainly have my days where I think God was "kidding himself" when he appointed me as her Mother. "How can I possibly be everything she needs?", is the question I often ask myself. I can break into tears when she's merely going to the lab to get a blood draw, and we're not even to the office yet! It's painful to watch her approach daily life sometimes, with the unplanned complexity of hospital stays, doctors, nurses, therapists, surgeries; the many things that come with caring for a child with a disability and metabolic disorder.

But then I turn to God and remember, while He has had me on this path, and in his purpose, I can grow weary when things don't seem to be going my way. I can feel out of strength and hopeless. But when I look up and say, "Okay God, this is yours. I can't do it myself." He gives me strength I didn't know I had. He brings people in my life that change me forever. He answers my heavy heart, with songs, laughter, dancing - moments that won't ever leave my mind. Best of all, He lights my heart with Lily's irreplaceable smile; the child who has seen many "unfair" things.

Our children are here to teach us that despite every ounce of pain they endure, they live and they do so victoriously. They are here to live out a message; that we must all recognize the good when we just don't feel like it, lift our heads, and smile. We just don't know how much more difficult someone else has it and we owe it to these kids to honor them with our attitude.

Cassidy is also such an "Angel" to her family and those who know her. When I read her journey from her Mother, Anita, I felt absorbed in it. It was beautiful to relate to Anita and completely understand her words. It was also difficult to know what they have endured. But they have made it through, and Cassidy seems to change her family's hearts with her spirit, every day. Read her story and remember that you have a choice to be joyful each day, no matter what your circumstances are.

"Cassidy was born on September 18, 2001 in Virginia Beach, Virginia. We were so excited as we had been planning, expecting and awaiting her arrival. Cassidy was a beautiful newborn with an apgar score of 9 and beautiful skin. Unfortunately, in 2001 Virginia did not participate in Expanded Newborn Screening and therefore, Cassidy's life would take a shocking and tragic turn in early February 2003.

In the early days, Cassidy grew and developed normally. She spoke her first true word at 8 months, sat up at six months and walked at 12 months. She was an irritable infant and she spit up quite often, but this did not seem to alarm the pediatricians. As she was also very happy and enjoyed playing too. Here or there, I would wonder about her smelly breath she had at times, and why she did not sit up correctly when she went down the sliding board. But other than that, things moved along as they "normally" do. Little did I know what was to come.

By 2002 Brian and I had moved our family to North Carolina. This would be a decision that would help us greatly in 2003. Being a college golf coach Brian travels for tournaments and in February 2003, he was in Florida when Cassidy came down with the stomach flu. I called him at 2:30 in the morning to tell him that Cassidy had been throwing up all day and I was so concerned that I was going to take her to the emergency room. I remember carrying her out to the car and the air was cold, the stars were out and it was quiet, just so quiet. We saw the emergency room doctor who told me not to worry, and the nurse gave her a Tylenol suppository and maybe a pheneghren one. They gave her some pedialyte to drink and sent us on our way. I remember noticing Cassidy kind of stumbling a bit but because she had been so sick I did not think anything about it. We went home. She continued to throw up and I called the family practice office we were taking her to at the time. They told me to keep trying to give her little bits of pedialyte or even sugar water. I was using a medicine dropper and forcing her to drink. It was so hard, exhausting and tiring. She just kept vomiting. She seemed to be getting a little better by the time Brian got home? Maybe that Wednesday? And that night I caught the stomach flu.



By that Thursday I was holed up in between the bedroom and the bathroom. I remember Cassidy toddling in and bringing me some of her Fisher Price Farm animals and naming them and then I remember hearing her scream. Not a normal scream a strange scream and her little body was contorted, she was arched back with her fists in a ball. We immediately called the doctors office who told us to take her to the emergency room that maybe she had an abdominal blockage. Unfortunately, I was not able to take her as I was still in the bathroom and Brian drove her alone to the local hospital. Maybe an hour passed and things had slowed down for me and then I had that horrible, awful, feeling. I found the phone book and called the emergency room to check on her. The emergency room doctor I was transferred to told me that I needed to come right away, that they thought Cassidy had meningitis and needed a lumbar puncture to be sure. I immediately called my office and the wife of my boss, Donna volunteered to come and take me to the hospital. When we got there I just walked, right through the waiting room, through doors until a nurse stopped me and finding out who I was looking for said "we are all praying for your daughter". Panic struck me again and time slowed down as I was thinking what? But my daughter only has the flu! I found her arched in Brian's arms, her eyes were blank stares and her body was tight and it kind of sounded like she was whimpering.

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The lumbar puncture came back clean, and we were sent upstairs to the floor. The nice nurse upstairs on the floor asked if the clergy could come by, I was still so lost in what was happening that when she tried to hold Cassidy and her body flopped down she said "did she use to know how to sit?" The nice nurse also asked me if I thought Cassidy was in pain and I said, I think it may be a seizure because of her eyes. She called the other hospital in town where the neonatologist was and got orders to give Cassidy Adavan. This seemed to help her. Dr. Berry finally arrived and he looked her over as Brian and I waited in shock. He measured her head and thought it may be a brain tumor, and off to CT scan we went. No brain tumor. No strange Herpes disease, no illegal drugs in our house. I remember how he was trying to eliminate every thing he could come up with. I remember the first time I saw her connected to so many wires it looked like spaghetti coming out of her body. I remember Brian calling my parents to come; I remember being angry and scared, so scared. I remember how hard Dr. Berry worked to figure out what was wrong with my little girl. The neurologist in town was consulted and he felt it was viral meningitis and that Cassidy should have steroids. The good news is that Dr. Berry did not agree. He consulted, Dr. Roach a new neurologist at Wake Forest University about Cassidy. Dr. Roach, called Dr. Berry back and said he thought it may be a metabolic crisis and that she needed levocarnitine. Dr. Berry ordered the levocarnitine and Cassidy also had an MRI.

Thanks to Dr. Berry's persistence, Cassidy is still alive today. We were ambulated to Baptist Hospital, based out of Wake Forest University and there they confirmed Cassidy's diagnosis of Glutaric Acidemia Type one. Unfortunately, Cassidy had suffered significant damage to her basal ganglia which caused Secondary Generalized Dystonia. Cassidy's dystonia was too much of a challenge for them and we left there for UNC Chapel Hill. We arrived at UNC late at night, a dystonic child being held by a bitter mother.

At UNC Chapel Hill we met a team of individuals ready to help us, Dr. Muenzer, Dr. Muge Calikoglu, fantastic specially trained nurses, and Diane Frazier, PhD. a metabolic nutritionist. Together they worked for the next few weeks to teach us how to care for our new child, our new Cassidy, who now required an NG feeding tube to eat, who could no longer speak, sit up, walk, or coordinate her muscles to move. Cassidy could now only eat a certain small amount of intact protein, and would need to have her toe stuck regularly to determine if her diet was working and if everything was okay. She would now need medica-

tions to fight the brain damage, the Dystonia that had taken over her body that was caused by the crisis because we did not know. We did not know that Cassidy was born with an inborn error of genetic metabolism called Glutaric Acidemia type 1 and should have followed a strict diet and had IV fluids at times of crisis such as infections and viruses. I don't remember all the dates but I remember the day we left UNC with our new Cassidy. I remember Stacey, the nurse waiting with me and Cassidy as Brian drove the car around. I remember crying, because as much as I had not wanted to be at the hospital, at that point I was scared to leave knowing so much care was now up to me and Brian.

The next year existed with the challenges of learning to pull medications, dropping NG tubes, calculating vomit and intake, getting a G tube and learning how to replace that and check balloons. Deciding to take Cassidy out and about and learning to live with the stares and comments. And finding the blessings and the happiness of it all. Finding out what was really important in life and learning to live for the day, fully and entirely and not trying to control what was not in my control. Cassidy would begin PT, OT and Speech therapy. I would try and learn to not be scared every minute of every day.

But then it happened again, in February 2004, about 3 weeks after the birth of my second child, Maisie, we would find ourselves with a very sick little Cassidy. Cassidy had been having such dystonia and we had been on the phone with the neurologists and genetics doctors and the neurologists kept telling us to keep going up in the valium and baclofen. And Cassidy continued to throw up on a regular basis. She seemed to tolerate the babyfood in her g tube better than the formula so I would give her the babyfood first and then the formula but she continued to throw up. We could only get her dystonia to go away when she was asleep and she could only keep her feeds down when she was asleep and it was suggested that we just keep her asleep. This was not an answer. This was not a way to live. I hated seeing my little girl in so much pain. We would check into the hospital a few times, things would somewhat stabilize and we would go home only to return about a week later. Finally, she would throw up blood on an ambulance ride to UNC and she was admitted with a stomach bleed. Cassidy was in so much pain, she was in a full posture with her head almost touching her feet, and she was again screaming that awful sounding scream. They tried to get her out of pain on the floor but it was so challenging that she was brought to the



PICU and the Pain Team then got involved. I sweated as I watched the amount of medications they administered to try and alleviate her suffering. Cassidy would be in the hospital that year more than she had the year of her original diagnosis. She would get new equipment, a porta-cathator, a G/J tube and her first wheelchair, it was purple.

As life is a circle we again found ourselves at UNC in February of 2009 and a very sick Cassidy with breathing difficulties, suffering with immense pain and stuck in a new dystonic posture. A new chapter of Cassidy's life with her disease has begun just like February 2003. And we will battle the dystonia that battles with Cassidy, with physicians that care for her and our family, new friends who understand (something I never thought was possible), and faith. Cassidy is my angel, she has shown me the true meaning of life, she has helped me to be a better person and her smile and laughter light up a room. Cassidy has an amazing spirit and strength and we will continue to live each day with her with joy.

Anita

