

## MIRACLE GRANDDAUGHTER

I would love to tell you about Alyssa. She is my miracle granddaughter.

When my daughter Catherine was 16 weeks pregnant, her sonogram showed that there was something wrong with the baby. The first sign was that her eyes were cast downward in an unnatural position. This was caused by the excess fluid in the cranial cavities known as ventricles, which meant that the baby had developed a type of hydrocephalus. You could see a large pool of fluid and a small amount of brain. However, as we later learned, you can't see through the fluid to see what's underneath.

The cause of Alyssa's hydrocephalus was a Dandy Walker cyst. This cyst forms with the fourth ventricle of the brain and stops the spinal fluid from leaving the fourth ventricle so that the fluid can bathe the spinal column and the outside of the brain.

The only way to correct this condition was to put a shunt in the baby's cranial cavity, after she was born, and allow the fluid to drain this way. Two catheters are attached to the shunt. One end is placed where the obstruction occurs in the brain, and the other end is placed under the skin and leads into the abdominal cavity. The fluid is drained (into the abdominal cavity) and is then absorbed by the body and discarded.

Two specialists and several tests later, the prognosis was not good. Based on the sonograms, the doctors predicted that Alyssa would be severely retarded, more than likely blind and/or deaf, and would never walk. Also, she could have heart problems and possibly problems with other internal organs. All the doctors we saw said she would be in a vegetative state and they recommended an abortion. They did admit that they couldn't tell the extent of her condition until she was born. Most women, whose baby is diagnosed with this condition, ended their pregnancies, so these doctors told us that they have had little experience with surviving babies.

In a desperate attempt to find any information about Dandy Walker, my two other daughters and I got on the Internet. That brought us to Debbi Fields, she helped educate my one daughter, and she got us to Dr. Muhonen for a second opinion on the baby's condition.

Dr. Muhonen was terrific! He gave us *hope* and was the first positive voice we had heard. He said that you 'couldn't tell about retardation until after the baby was born and brain size didn't matter. What worked in her brain was more important.'

Alyssa was born April 12 by caesarean section and I was there to see her enter the world. I waited while the doctors examined her. I was ecstatic when they said she was healthy and I could hold her and take her to her mother.

Alyssa was given her first shunt when she was 48 hours old. The surgery went well and at 10 days she got to come home. But three days later we encountered our first problem, one of the incisions was leaking fluid. Alyssa had a "y" shunt and part of it had to be removed. At 17 days, she had her second surgery.

This was the start of 16 months, that would be very, very difficult for us as Alyssa had several set backs (shunt failures and infections) and 13 more surgeries. Each time she was in the hospital, either I, her mom or her aunt would stay with her continually.

Alyssa is a fighter and she has continued to grow and develop through all of the surgeries and the numerous weeks she has spent in the hospital.

Alyssa's first neurosurgeon only worked on adults, but did take on Alyssa's case. However, after the first few *mishaps* he advised us to find a pediatric neurosurgeon, so we began the process of having her case transferred to Dr. Muhonen.

In December (of that same year), Alyssa had a shunt malfunction. Dr. Muhonen had to replace her shunt. One good thing came out of that surgery; Alyssa's brain was much larger than first thought! It

was so large that it had pushed the cyst back to less than half of its original size. She spent her first Christmas in the hospital, and she continued to grow and develop while in the hospital.

One of the questions about Alyssa's development was that she needed to find her center of gravity. She would need to do this if she would ever sit, crawl and walk. She was late in doing this because of her surgeries. I decided to sit on the floor with her between my legs. At first she wobbled to the left or the right, but soon she was sitting for 1 minute, then 2 minutes, then five minutes. She could sit up! She couldn't sit herself up but she could sit with a little help.

Alyssa had an occupational therapist (OT) and a physical therapist (PT). When she wasn't in therapy, we (the family members) worked with her on the different exercises, and even tried some different techniques, so that Alyssa would get a good sense of the world around her and learn to do more.

Alyssa didn't do the normal baby crawl. She scooted around the house doing a "monkey" crawl. She was so determined to do things her way. She didn't walk without help until she was two. Now she runs faster than me! She climbs everything. She loves to go to the park and go down the very tall, twisty slide.

The OT and PT ended by the time she was 2. She does have some speech problems and is in a speech class at pre-school. Alyssa has her own words that just like any other child, only she understands. In school, her ability to express herself grows daily. Alyssa wears glasses. But she is a normal, healthy, bright 3 ½ year old. She has surpassed every expectation of every doctor that saw her.

She loves all things, especially music and dancing. She loves her cats. She adores her big brother, Joshua. In fact, her first word was Josh! After she learned to sit, she would sit in the bedroom with him while he played his Play Station 2. She always wants to hang out with her big brother.

School has been good for Alyssa and she's doing wonderfully!

Although, this experience has been harder than we could have ever imagined, it has been so well worth it. I have beautiful granddaughter that will grow up to be a healthy, happy, capable adult. She is truly our *Miracle*.

