

## A Family Story

### **Katelyn**

In my 36th week of pregnancy, my blood pressure became elevated and I was admitted to the hospital for an induction. After more than 24 hours on pitocin with very little progression, I was taken to the operating room for a cesarean section.

On November 5, 2000, Katelyn Renee was born, 6 pounds 7 ounces. A perfectly healthy, perfectly perfect baby girl -- or so we thought.

Although, looking back earlier, there were some indications that something might be wrong, it was when she was around three months old that we started becoming concerned that something wasn't quite right. It was then that she started reaching with her left hand to grab things, but never with her right. Her right hand was often in a tight little fist. She was not even beginning to push up on her arms.

After several evaluations and an MRI, finally in summer 2001, we got the diagnosis -- right hemiplegic cerebral palsy. The cause -- a *stroke* to the left side of her brain -- which most likely occurred in utero. *What?* Apparently, kids and even unborn babies can have strokes. Katelyn is living proof of it.

Her neurologist, from the beginning, felt her prognosis was good. She would walk -- though perhaps with a limp; she would talk, though perhaps it would be delayed. Limited ability to use her right hand would always be her biggest challenge. So far, he has been pretty on target.

In any event, if you see Katelyn today, unless you are a trained professional, you would likely not notice at first glance that Katelyn is any different than any other 5 year old. She walks; she runs; she jumps -- perhaps not as gracefully or as quickly as other kids her age, but she does it all. She is practicing buttons -- though she does them with her left hand only. She has limited, though continuously improving, use of her right hand. Her language and cognitive ability have not been affected -- unless, perhaps they have been enhanced as she is advanced in these areas.

Katelyn has not had an easy road to get where she is today -- she has had occupational and physical therapy since 7 months of age. She had speech and developmental therapies for a short time around the age of one. She got her first AFO (ankle-foot orthotic which goes from the foot to just below the knee) at about 16 months. She began therapeutic horseback riding at 18 months. She has taken swimming lessons through our local park district, has tennis lessons and gymnastics and recently started karate. Thanks to an early diagnosis, early intervention and new treatments, she has come a long way in her 5 years. She has worked very hard to get where she is today.

Unfortunately, Katelyn's struggles are not over. She is about to have her first Botox injections along with serial casting in order to stretch the muscles in her right foot and leg -- she recently had a growth spurt and her muscles couldn't keep up with her faster growing bones. She will continue therapy in one form or another for an indeterminate amount of time. There is no guarantee she will not have some type of learning disability, or develop seizures, which are very common in brain-injured children. We are not going to worry about those things right now though. Our family concentrates on all of the remarkable progress she continues to make. She is a beautiful, intelligent, happy, strong-willed little girl and we wouldn't trade her for anything.

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## A Family Story

**Katie**

### **My daughter had a stroke.**

These have been the most difficult words for me to say. It has been the most unusual thing that I've had to explain to others. The pregnancy was uneventful; I was 34 years old and pretty healthy. "My daughter had a stroke."

Katie was born in October 2000. The labor was difficult, but that hardly matters now. There were no signs that she had suffered any trauma during those first few months of her life. Being my first child, I read child development books and eagerly anticipated the milestones, ready to write the dates in the baby book. At about 4 months old, I noticed that she wasn't losing some infantile responses on her left side, and she tended to keep her left arm tight to her body with her little hand fisted. I watched and noted it in my journal. I called the pediatrician at 5 months and asked when kids chose their dominant hand. She said not until they're about 18 months old. She paused and asked why. I told her we needed to come in.

Dr. Chris wrote the prescriptions for evaluations and a CT scan. The journey into this whole other life began. We muddled along those first few months, figuring out what all of the initials meant – PT, OT, ST, CT, AFO, MRI, MRA. Then we learned about the brain, the body and physiology. Babies have strokes – why didn't anyone tell us this? 2001 is a little blurry.

My husband and I didn't know anyone who had been down this road. We found support on the Internet, through our family, and by chance. We continue to make connections and offer help to other parents. I have learned how to be a mom and an advocate for my daughter. Her father and I are like any other parents, with hopes, dreams and fears. But, we also know a little more medical jargon, anatomy and special education rights.

Fast forward to 2006. Katie is a delightful, beautiful, determined and amazing little girl who loves Barbie, ballet, swimming, baking cookies and the color pink. She has received physical and occupational therapy (PT & OT) weekly for nearly 5 years now. Play is therapy. She is healthy and we are blessed that the MRI shows her stroke, which occurred in utero, was small. At this time, she has no other known complications or effects of the stroke other than her gross and fine motor skills. Her speech and language are advanced for her age.

Katie has cerebral palsy, presenting as left hemiplegia, due to a stroke in the right parietal region of her brain. That's how the insurance company and medical record departments see her.

But that's not Katie to me, or anyone who knows this little dynamo. She is my daughter. She is my hero.

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## **A Family Story**

### **Nick**

One of the worst days of our lives was the day that we learned that Nick, our 9-year old son, had suffered a stroke to his brain. He was diagnosed at 13 months with stroke in utero, damaging the left side of his brain. This neurological damage resulted in the diagnosis of right hemiplegia, or right-sided weakness to his entire body.

Initially, we were overwhelmed with fear, confusion, anger and depression. We didn't know where to go for more answers. Except that we did begin therapy for Nick immediately, as the doctor strongly urged us to do. Since 13 months of age, Nick has had weekly physical and occupational therapy.

As time went on, we were able to use our strength in the family to reach beyond our emotionally charged state of mind and look for additional resources to help both our family and Nick. In this search, we found more doctors willing to help and guide us, more therapeutic centers better able to help Nick improve and strengthen his body, and a wonderful support group to enlighten us and let us share our experiences with others.

Beginning early on, he persevered through his weekly workouts – hardworking and anxious to please his therapists. These strenuous workouts have brought him far in terms of his progress. He amazed us with some of his accomplishments . . . he learned to ride his bike w/training wheels by age 5, and without training wheels by age 6. With his disability, that was truly remarkable. He currently plays soccer, basketball and baseball.

All of his therapy takes a toll on him and his family. He fatigues in general more quickly than kids his age, most likely because his body just isn't as efficient in overall movement. So at the end of a school day, he has a hard time controlling his emotions and behavior once home from school. For his family, it means weekly commutes to DuPage Easter Seals in Villa Park for therapy, babysitting arrangements for his two sisters during the therapy sessions, and other regular and sometimes urgent visits to his physiatrist, neurologist and orthotist (for his ankle/foot brace). In addition, additional testing and services have been performed at school and with a neuropsychologist to ascertain if other cognitive assistance is needed due to the brain damage that occurred long ago. All of these services take a toll on both Nick and his family.

Today, the challenges continue. As Nick matures, his emotional and cognitive weaknesses are accentuated. Dealing with the “softer” side of Nick we think will be the more difficult challenge that lies ahead of us. Our goal going forward is to keep a positive attitude – both in Nick and in the family - and staying resourceful; this will lead to quality improvements ahead.

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