

## THE EAGLE FAMILY STORY

My name is Dawn, and I am the lucky mother of two boys. Jack age 5, Charlie age 2 1/2, and we also have another baby due in September. I must start my story with Charlie. Since Charlie was born he always had problems with sleeping, feeding, and he was easy to upset. I always felt frazzled, exhausted, and didn't understand why things were so difficult with Charlie. My oldest son Jack made everything so easy that I just didn't understand what I was doing wrong with Charlie. Every time I expressed concern with my pediatrician I got the same answer. "It's your son's personality, or welcome to Charlie's personality, or he'll grow out of it." Needless to say I always left the pediatrician's office feeling just as lost as when I came in.

I finally had a light bulb moment at one such doctor's appointment. Any parent knows that most "well check-ups" are more like "Well hello, height, weight, shots, then see you in 3 months, 6 months, etc." If you do voice concerns they are most likely to give a response of "Oh, that's their personality, or they'll grow out of it" at least that was my case. Well, at Charlie's 1 year check-up I told our pediatrician that we observed Charlie nodding his head quite frequently where it looks like he "checks-out". Then the worst and best thing happened next. The pediatrician gave me a look of "listen lady you are crazy", and he didn't even acknowledge my concern beyond that. I of course didn't press the issue because I trusted our doctor and he must be right.

That look, however, did not sit right with me. So, I started to research head drops on the computer, and finally YouTube gave me an answer. I was able to see several videos of children with similar head drops to Charlie. Unfortunately, they were titled as a head drop seizure, and so began my heartbreak, panic, and determination to make this right and help my baby.

On June 30, 2008 I dropped Jack off at summer camp and immediately called our doctor to announce that Charlie was having seizures. Fortunately, they were concerned, and wanted to see him as soon as I could get him there. I had a video of what was happening to Charlie and without a second thought they ordered an EEG with bloodwork. They told me he would be put to sleep for the EEG, and then they would monitor his brain to see if they could find the seizures, if that was it.

Being the person that I am I had to keep my comments short to the pediatrician, and just get the information we needed to start this whole process. I gathered up Charlie and our things, and then got to the car to start scheduling the necessary appointments. Then I had to make the call to my husband, Dave.

It was such a horrible moment to call Dave and verbalize that Charlie had to have an EEG where they'd put our baby to sleep. I just cried. I could hardly get the words out. My fear was coming true. I worried for so long that something was off with Charlie, and now things were in motion to find out what it was. The thought of my baby being put to sleep was terrifying, and on top of that we had no idea what we would discover.

On July 2, 2008 after two EEGs we received some wonderful news. Yes, Charlie has Epilepsy, (pure heartache) but, it's a mild form that shows promise he will out grow it. Specifically, it's Benign Myoclonic Epilepsy of Infancy. Our neurologists reassured us that medicine was the safest route to take. We were very grateful we had an answer, a cure, life would be perfect now. Little did we know, this was just one piece of Charlie's puzzle.

Within 3 months we saw our last seizure. Charlie was finally sleeping a little more, and we thought everything else would just fall into place. Well, 3 more months passed and still no seizures, but he's not really talking, no babble, not even a "mama". He could never stay still. The slightest bump would hurt him so badly, and he would start hitting his head with his fist, or on objects out of frustration. The only thing he would ingest was milk, and McDonald's french fries on a good day. He was stumbling, and just couldn't manipulate himself like he should be able to. Everything still just felt off, but I believed the doctors suggestion that this truly was just Charlie.

Thankfully, my best friend Kelly told me about Early Intervention, and how she had her son Riley evaluated to find out he qualified for various therapies. Kelly and I always thought Charlie and Riley were so similar, so naturally I went ahead and had Charlie evaluated. This led to our findings of his speech delay, gross motor, and fine motor delays. Unfortunately, he only "qualified" for speech because he fell into the appropriate range for therapy need. The other delays were felt I could work on at home. So I finally started to have some new hope that our chaotic life with Charlie didn't have to be.

Early Intervention placed us with Birth to Three and Beyond Pediatric Therapies. We started speech on March 2, 2009, and that was good. Then, a few months later, I had him reevaluated again by the Occupational Therapist and Physical Therapist at Birth to Three and Beyond Pediatric Therapies. We discovered that he needed so much more. Thankfully, our insurance covered Speech, Occupational, and Physical Therapy. This meant he would start getting therapy for everything he needed on a weekly basis. Charlie was going to finally start his journey for giving him a balanced life. That's when we found out we were not dealing with just Epilepsy, but also Sensory Processing Disorder. We finally started to see progress, once we started treating all of Charlie.

I mentioned earlier that my older son Jack made having a baby easy, and he has always been such a good sweet boy. Jack was such a joy as a baby, everything was just text book, he slept through the night at 2 months, never fussed, ate everything we gave him, spoke so well. Such a pleasure! He was never interested in being really active. Never one to jump off the furniture, didn't want to climb up high, didn't like the swing, didn't like gymnastics, couldn't ride a tricycle. Basically, he wasn't doing the major gross motor things most kids do, but everything else was so great, that it didn't bother us that he seemed so introverted, or that he wasn't interested in doing a lot of physical stuff.

Thankfully, through all the Occupational Therapy and Physical Therapy experiences with Charlie, I became educated to realize that there was something delayed about Jack's gross motor development. At first I just shrugged it off b/c I didn't want to think that A) I neglected a need for my oldest child and B) How could I possibly have two children that need therapy!

Well, we had Jack evaluated and it turned out that he needed glasses badly, as well as weekly Occupational Therapy. It's remarkable, since he started wearing his glasses and began Occupational Therapy, he can do so much more in the matter of a few months! He can write better, recognize his letters and numbers better. He is beginning to make the pedals work on a bike, he's jumping off the furniture, he likes the swing, and all around he is just becoming more of an extrovert in terms of expressing himself physically. Lately, we catch him jumping from his dresser to his bed! Which is most parents nightmare, but according to our therapist it's exactly what we want him to be doing.

Everything happens for a reason, I always say that. If it wasn't for our struggles and victories with Charlie, Jack would probably still be walking around with his poor vision, and not wanting to run around like most 5 year olds. Now Jack will have a better start for kindergarten and hopefully feel like he has the skills to handle the activities ahead of him for years to come. It may be that down the road Jack will always prefer to sit and read over playing baseball. We just want to make sure the reason he's not choosing to participate in activities isn't because he doesn't know how to use his body.

Anyone knows that being a parent means you have to be ready for change. Include a child with SPD, and things can become really challenging, as well as draining. Thankfully, those challenging and rough moments are more sporadic for me, but they are definitely still there. It only takes a moment to have something happen to remind me that Charlie has different needs, and can't follow the same rules.

Nothing is perfect. We are still on this journey, and putting the puzzle pieces together for Charlie, and now for Jack. However, because of a lot of hard work, by a great team of doctors, therapists, and loved ones, Charlie and Jack are happy, thriving, and enjoying life, and so are Dave and I. Therapy has given our family the gift of understanding Charlie and Jack, which allows us to have a stronger family bond. Therapy for us was like the light at the end of the tunnel.

How do you explain that to someone? How do you not feel alone in helping your child, your family, and yourself? I know I wouldn't be as happy as I am today if it wasn't for my friendship with Kelly. Even though my husband has been absolutely wonderful and there every step of the way, she truly understands the struggles and the victories. Just knowing she'll listen makes things better, easier to cope somehow. That's why we are trying to spread awareness through sharing our stories, and through our SPD support group. We want to be able to reach other parents who could be struggling like we did for so long, and let them and the world know there is hope out there. We want individuals to know that they should feel like their situation is real, and that they are

understood. That each journey is special, and should be celebrated and supported unconditionally.

I definitely see life in such a different way, and my motherhood experience is not what I imagined it to be. It's so much more. I have learned so much about my children, and myself through all the ups and downs. I am such a better mother, wife, and friend because of everything I have gone through with my boys. I wouldn't change my story for anything, and I'm excited to see what the next chapter holds.

Dawn Eagle