



Complex Child E-Magazine

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Epilepsy and Our Journey to a Diagnosis by Nicole Swiers

When I became pregnant with my third child I knew by my second trimester that something was wrong. It was a high-risk pregnancy due to me having some kidney issues, but my ultrasounds were always fine, so it didn't make sense that something didn't feel right to me. Emeric was born at 38 weeks and was a healthy baby. We left the hospital in two days and everything seemed fine. Little did I know that seizures would soon become part of his life.



Early Seizures

When he woke up crying in the middle of the night stiff and gasping for breath at two months old, something was clearly wrong. I assumed at first that maybe he needed his mouth suctioned so I grabbed that little blue bulb that you're given in the hospital and tried suctioning both his mouth and his nose. When I realized that wasn't helping, that feeling I'd had when I was pregnant came back again. Fortunately, as soon as that feeling came, the episode was over. But that was just the beginning.

I remember afterward feeling uneasy but assuming maybe I was making a big deal out of nothing and went to bed. The next morning I woke up and still felt uneasy about what had happened so I decided to call my mom, who just so happens to have had epilepsy, but had since outgrown it, and ask her opinion. My mom thought it sounded like a seizure. I don't remember that the thought had crossed my mind at that point, but after she said it then it made sense. The stiffening and the gasping for breath are classic symptoms.

After I got off the phone with my mom I phoned our doctor. I explained to her what happened and she asked me if he had lost control of his bladder during it. I remember thinking, "What a stupid question!" as he's obviously in diapers so how would I know! I told her I wasn't sure and she said it didn't sound like a seizure and she wasn't concerned. In the weeks and months to follow everything seemed to be fine and I hadn't noticed any more "episodes." However, that would soon change and I would be convinced that what we were seeing was indeed seizures.

At six months old I had Emeric sitting in a play center at our church and I asked my mother-in-law and some ladies with her to keep an eye on him while I ran to the bathroom. When I returned just a few minutes later I noticed he was slumped over. I picked him up and he was completely unresponsive and had lost all muscle control. I was really scared and kept yelling his name thinking I could snap him out of it, and within just a minute or two it was over. I knew it was a seizure.

I called to see about getting into a different pediatrician and within the next couple days I had an appointment. I explained what had happened and she didn't seem to believe it was a seizure but ordered an MRI because she'd heard a murmur when listening with her stethoscope to the soft spot on his head. When the MRI came back normal she determined all was well and there was nothing to worry about unless we started noticing other issues.

Shortly after that visit, I started watching very closely for any of these other issues that she'd spoken of and sure enough, I noticed them. I realized that he hardly ever made eye contact and didn't interact nearly as much as I had remembered my other two kids acting when they were his age. I also realized that when I would call his name he wouldn't turn to look at me.

Daily Seizures

Around the age of nine months he got sick with a high fever that lasted for about five days. The day after his fever broke I started noticing that he'd roll his eyes up in his head. He started doing it quite a few times a day and after a few days of this I took him to his doctor, the same one I'd talked to on the phone that assured me he had not had a seizure. I explained that he had been rolling his eyes up involuntarily and was also really irritable. I shared with her my fear that he was having seizures. She very straightforwardly said, "he's not having seizures, but I do think he probably has autism."

Now I knew that he had some behaviors that could look like autism, but I couldn't believe that she'd make that assumption based on a five-minute conversation I'd had with her. I told her I wanted a referral to a pediatric neurologist because even if he did have autism it didn't explain the eye rolling episodes that he was having frequently. She agreed to refer me to a pediatric neurologist and we had an appointment for a month later.

Again, I left with an uneasy feeling. I really felt he was having seizures, but now I had two doctors who didn't agree. Maybe they were right? Still I felt like we should see a pediatric neurologist and hopefully have an EEG to completely rule out seizures.

About a week later (and still three weeks from our appointment), I had started counting between 30 and 40 eye rolling episodes a day. I was getting frustrated at this point with the fact that no one believed me that these were seizures and upset that he was having so many of them when we were still weeks away from seeing anyone. I called the pediatrician and asked her if she'd order an EEG to ease my mind. I showed her a video that I'd taken of one of these episodes and she said nothing but agreed to order the EEG. A week later the results came back and the EEG was normal. I knew that a normal EEG didn't rule out seizures and I was hopeful that the pediatric neurologist would order a longer EEG because my instincts kept telling me they were missing something.



Finally our appointment with the pediatric neurologist arrived. I gave her a full history, told her of the episodes we'd seen at two and six months and the numerous episodes we'd started noticing within the last month or so. I showed her the video and she immediately agreed that he was likely having seizures. She ordered a 24-hour video EEG where he'd be admitted overnight and videotaped so that we could see how his behavior was during one of these episodes. For some reason I could provoke one of these if he was startled, so in order to catch a few on the EEG I would play peek a boo. Sure enough, his eyes would

roll up. The next day when we were about to be discharged the neurologist came in and said that she'd reviewed parts of his EEG and he was having seizures.



I very distinctly remember her telling me he had epilepsy and being taken aback by it. While I'd known he was having seizures, for some reason the word epilepsy never entered my mind. He was started immediately on medication and a lot of blood work was ordered to try to determine why he was having seizures.

I assumed that once we started Emeric on seizure medication that the seizures would stop. After all, the few people I knew with epilepsy had seizures that were completely controlled with medication. Unfortunately, this wasn't our experience, and after a few medication failures we decided to start seeing an epileptologist to see if he had any more tricks up his sleeve. An epileptologist is a pediatric neurologist with additional education and experience in dealing with epilepsy specifically.

Seeing Improvement

So here we are, four years later. We continue to see the same epileptologist twice a year. Emeric has been able to wean to only one seizure medication and has very good seizure

control. We still have not been able to achieve complete control and with his underlying disorder (Mitochondrial Disease), seizure types, and not so stellar response to quite a few meds, I'm not sure we will. For now we're managing and balancing seizure control with medication side effects pretty well. And for now, that's good enough.

Nicole Swiers lives in MN with her husband and has three children, Kylie (8), Kaydence (6) and Emeric (4). She recently went back to school for nursing and enjoys reading, shopping, and spending time online! Visit Emeric's caringbridge at <http://www.caringbridge.org/visit/emericswiers>