As I sit back to reflect and write this article, I can’t help but wonder about all the signs I missed. It’s amazing sometimes how you can have such a wealth of knowledge and when it comes time to use it on your own child you become incoherent. I have always been the type of person to research things in order to have the information needed to make decisions. When Isabel first started to show signs at one week old that something wasn’t right, I did my research. Even armed with all my knowledge, I couldn’t save my little girl from the frightening experience she was about to have. My hope is that through her story we can somehow help other families.

Isabel’s Story

Isabel had her first apnea episode at five days old. I was just started to get the hang of nursing and we had settled in to watch a movie. I realized suddenly that she was no longer sucking nor was she breathing. We called 911 and she was rushed to a local hospital and later transferred to a children’s hospital. After a quick 48-hour observation to rule out sepsis we were on our way home.
Through the next few weeks there would be more dusky episodes along with the new symptom of vomiting. The pediatrician referred her to a GI specialist thinking it was severe reflux. I made her appointment and did my research since I was now armed with a potential diagnosis. Severe reflux can cause apnea when an infant will hold her breath in response to pain or discomfort. It sounded like Isabel, so we sat her up for an hour after feeds, elevated her mattress and all was good again.

Shortly thereafter we went to see the GI specialist, whom I believe saved her life and also changed our lives forever. The GI specialist discovered that Isabel had a milk-soy protein allergy and was failing to thrive. He also noticed a few neurological issues that might be going on. He recommended admitting her for the failure to thrive and getting a neurology consult. Not happy about another admission, my husband and I reluctantly agree and went home to pack her bag. She saw neurology, genetics, and cardiology, but two days later Isabel has gained weight and was happy and ready to go home.

Right before discharge, Isabel had a severe apnea episode and needed to be resuscitated and was transferred to PICU. I always say that the GI specialist saved her life because if she would have had that severe episode at home and no one was in the room, things may have turned out differently. After seven days in PICU with five of those spent on CPAP, we came home with only a diagnosis of reflux and apnea. We were sent home with a monitor and instructions to follow up with all her specialists.

Seizures

Twelve days later she woke up and was coughing a lot and having many more apnea episodes. We went to see her pulmonologist and determined she had bronchiolitis. That evening would be the start of a whole new life for my family. Call it mother’s intuition,
but something kept telling me to look at Isabel. I noticed she just didn’t look right, but the apnea monitor was not sounding. I went to pick her up and suddenly she was so stiff that I could not open her arms and legs. She was locked in the fetal position.

My brain automatically compiled all my research and yelled to me, “Seizure, call 911.” My husband held her while I called 911. After the paramedics arrived we were so shaken that we were not sure how to explain what happened. Well, Isabel decided to show us again with another seizure and in the ambulance we went. During the next three days Isabel had an EEG and was put on Phenobarbital.

Just as I was thinking that we finally had an answer and a treatment plan, things got even worse. I decided to go home to my other five children and get some rest on the third night Isabel was inpatient. I will always punish myself for this decision and for not being there when Isabel needed me. I called PICU the next morning to say I was on my way and they said Isabel was doing great. Within the two hours it took us to get ready and get to the PICU, Isabel started to seize uncontrollably. By the time we got there she was in a constant state of seizure.
Isabel was in Status Epilepticus and no medicine was stopping it. The PICU doctor, who would become our greatest gift in life, told us she would need to intubate Isabel and put her on a benzodiazepine drip to help control the seizures. I remember going to Isabel’s side before she was intubated and telling her how sorry I was that this happened to her and that this was how her life was meant to be.

The next few days would prove challenging. The doctor did every blood test and culture to rule out infections. She did a lumbar puncture to rule out meningitis and all was negative. Isabel was still having about two major seizures a day each lasting about two hours. They would continue to increase her Phenobarbital levels and had added in Dilantin. They finally decided to be a little more aggressive with the benzodiazepine drip. My husband and I continued to pray to GOD to please heal our baby. I remember saying I just wanted to see her open her beautiful eyes again. I wanted to hold her so badly and just take away her pain.

Then suddenly the seizures stopped. Isabel was opening her eyes and she looked happy. They would slowly wean her off the drip and would extubate her when she was off. A few days later my little missy was on regular oxygen, extubated, and she was happy and playing. It took high doses of Phenobarbital and Dilantin to get there but we were there. Isabel would stay in the PICU for another week. We would also later get the genetic testing back and learn that Isabel has Trisomy 13 Mosaicism. Children with Trisomy 13 often have seizures, and this diagnosis now showed us the whole picture.

**Trust My Intuition**

It has been an amazing five months since Isabel’s adventure. Today she is seven months old and about 17 pounds. She continues to take Phenobarbital for her seizures and we have recently taken her off the Dilantin. I now know to look for repetitive motions, shaking, and a whole array of other things.

When I look about, I ask myself, “How did you not know?” Isabel would make repetitive facial movements, she would twitch one arm or blink too fast. I researched all these things and had them in the back of mind. But when it comes to your own child, you forget everything.

The best advice I could give to another parent is to listen to your heart. If something doesn’t look right, get it checked. I would rather be the crazy mother who is in the Pediatrician’s office every day than the regretful mother who should have gone.