

Stephanie's Story

After more than 6 years, we finally have answers.

I grew up knowing I wanted to work with kids. I majored in elementary education in college. I taught in daycare centers. I even worked with special needs children. And I have worked in the educational publishing field. However, even with all that, I have still needed ideas and support with my own child. I knew from early on that something was different with Emma. My background was a big help, however, doctors did not see it and would not listen to my concerns. So it has taken almost 7 years to get someone to listen and see.

The story of my daughter, Emma, begins before she was born.

When I found out I was pregnant, I was beyond excited. The first half of the pregnancy was uneventful. At 22 weeks, I went in for my routine visit and found out we were having a GIRL. I was so happy! We had a girl name picked out, but my husband and I just could not agree on a boy name. Well, the name choosing stopped there! We also were happy to find out that she was growing well . . . in the 50th %ile. However, as time went on, her growth rate slowed. Concern arose. I had special ultrasounds and weekly stress tests. By 36 weeks, she was down below the 3rd %ile in weight. The doctor hoped to wait until 39 weeks for delivery, and an induction date was set. She was born at 39 weeks gestation and weighed 5 pounds, 8 ounces.

For the first year, we were so focused on trying to get her to gain weight. Her doctor said to keep her on baby formula longer, instead of switching to cow's milk, for the calories and added nutrition. When Emma was 14 months old, her pediatrician sent her for a bone age x-ray which showed her at 9 months old.

It was when Emma was about a year old we noticed she still spit up a lot. We kept mentioning this to her doctor, but there was no concern. At about 11 months old, Emma had her first ear infection. It would improve, come back, improve, and come back, but never completely cleared up; all with trying several antibiotics. Then after about 6-7 months of this, Emma got her first set of ear tubes. Her spitting up often still continued. We also noticed how much she fought to avoid lying down. Changing her diaper and putting her down to sleep were very difficult. Emma was also coughing a lot. After a while of this, the doctor prescribed a strong cough medication to see if it would help. It did not. At about 15 months, doctor ordered a sweat chloride test, to rule out cystic fibrosis. Negative.

When Emma was just over 2 years old, the pediatrician suggested allergy testing. Negative. Also did celiac panel; results positive and negative. As a result, Emma was sent to a pediatric gastroenterologist. This doctor diagnosed her with GERD/reflux. Since then, Emma has been on and off medications and we have been avoiding foods such as citrus fruits and juices, chocolate, tomato, onion (incl. onion powder -- which is in everything!), garlic, and greasy/fried/fatty foods. Emma growth rate did improve. Over time, we have realized that we need to make meals from scratch or to ask many questions when eating out. And, on top of that, at times Emma can be a picky eater. She will not eat multi-texture foods, such as

casseroles. But she will eat stew if I separate the meat, veggie, and potatoes. At least in a stew they are easy enough to separate.

And at about the same time (just over 2 years old), Emma was evaluated by Early Intervention and was eligible for PT and OT services. She received PT and OT until 3 years old. She improved greatly at the time too, so seemed as no further concerns and we did not go on to the school district for further services. The PT really helped straighten Emma up and the constant colds/coughing finally went away.

As time went on, I still noticed little issues: she did not want to be held, would not sit on my lap to listen to a story, always been difficult to wake her in the morning, never put anything in her mouth the way most infants do, screamed when toilets flushed, screamed during bath time until we put towels around the bathroom as noise buffers—and the screaming stopped. However, I brushed them off. She's been doing so well, right? I began to think I was over-analyzing. But then when Emma was just over 4 years old, a therapy center came to her daycare center to do developmental screenings. Several red flags came up through the screening. I began to second-guess myself again, and thought I was a horrible mother for not continuing the services after EI. We decided to take Emma for a screening at the elementary school. This was March of the year she was about to enter kindergarten, but I hoped to get answers before kindergarten started. The therapist who did the evaluation at the elementary school did not have concerns at that time. Ok. So, I WAS over-analyzing. However, a few months later, end of August 2009, Emma did the routine kindergarten screening that is done a week before school starts. I soon received a call that the school therapists wanted to do additional evaluations and then the IEP meeting was soon scheduled. HA! Mother's intuition! I was right! I was, however, very frustrated about the screening in March. Not happy with that therapist. Anyway, Emma qualified for Speech therapy.

Through the 2009-10 kindergarten school year, Emma received Speech therapy; however, she really struggled through kindergarten. It was decided about half way through the year that she would repeat kindergarten in the fall. The whole process of deciding that she would repeat kindergarten was a difficult one, but it led to me taking her to a new pediatrician to hopefully get more answers on how to help her. From that first visit with the new pediatrician, the path to answers was found. The pediatrician referred us to a pediatric neurologist and a developmental pediatrician. The developmental pediatrician only confirmed ADHD and recommended medication. We wanted to find out other opinions and options first. The pediatric neurologist saw auditory processing issues, sensory processing issues, and ADHD symptoms. She referred us to a pediatric psychologist. The pediatric psychologist did cognitive testing and recommended a central auditory processing eval. She gave us the name Jeanane Ferre, PhD for the central auditory processing eval. Dr. Ferre confirmed CAPD and said that she also saw other sensory processing issues, but that there is not a diagnostic code for SPD.

With the reports from the evaluations in hand, I went to Emma's school to see about her getting OT in addition to the Speech services she was already receiving. An IEP review meeting was scheduled. The reports stated that 2 hours of Speech per week was recommended and OT was recommended. At the IEP meeting, it was determined that the hour of Speech she gets at school is accurate for her need in school and OT is not needed at this time due to things going well in the classroom. However, I made sure my concerns were noted in the IEP regarding any difficulties that would arise during the rest of this

year and in 1st grade in the fall. It was decided that OT would be added if there is a need. I did add outside Speech and OT services at a therapy center per the recommendations in the doctors and therapists reports.

So, we now know that Emma has SPD, CAPD, ADHD, and GERD. Each day has its challenges, but now that we have the answers to our long time questions, those challenges are a little easier to face. The more we know about what Emma's challenges are, the easier it is for us to help her.

Stephanie Bonifazi

March 22, 2011