

A mom in search of help

Jennifer contacted the Feingold Association in September of 2016. Here is her first email, reproduced with her permission.

I am a very frustrated mother of 3. I am so thankful to have found this group. This is a long post, so forgive me, but feel free to offer any and all support, ask questions. Just be kind, as this has been a really long road and this morning, I am in tears. I am just so tired of doing this all by myself. My husband has been very supportive, but I feel like I am the only mom who is struggling with these issues. Hopefully everyone here can help.



My daughter will be 3 in May, and for the past 3 years, we have battled just about everything you can imagine. She was born healthy at 8.5 pounds and 21 inches long, but ended up falling below the growth chart as she did not do well nursing. She was severely constipated starting from day one.

Between 1.5 and 4 months, I eliminated dairy, soy and egg (my oldest is allergic to egg) at the insistence of our gastroenterologist, and she fattened up, nursed better, but it still did not seem to matter in regard to the constipation. So I added those things back into my diet. She continued to nurse well and continue to fatten up, still constipated.

However, she also got farther and farther behind with her development. Didn't roll over until 10 months, crawl until 13 months, and walk until 18 months. Began occupational therapy at 12 months and graduated when she walked at 18 months. She continued to be severely constipated and we continued giving her a diet of Miralax.

At 18 months, she was finally walking, but it was nothing to write home about. About the same time, she began having severe ear infections where I was at the doctor about 1-2 times every month. We were recommended for tubes. From there, our ENT suggested OTC Zyrtec, saying that her chronic runny nose was probably just seasonal allergies and not having to do with her ear infections. We started giving her Zyrtec every day.

We got tubes in her ears at 20 months, and her chronic runny nose did not go away. But that's when the behavior changes began cropping up. She was overly aggressive with her baby brother, kicking him in the face, pushing his head into the carpet etc. She would kick and scream, stare through you like no one was there. She continued to fall behind in her development. When she walked, it was not a "normal" walk and we never saw her run. Her fine motor skills were nonexistent and she would say complex words that we would never hear again, like "popcorn" and "James" - even when she had NO vocabulary, we would hear words like "tickle" and "feet" clear as day. She couldn't smile, there were no facial expressions, she had a glazed look in her eye, and she was always very up-and-down. She wouldn't sleep and with a newborn, I don't know how I survived. We never knew what Catherine we were going to get.

At 22 months, we had her evaluated for Early Access Education, since she was not developing. We suspected Autism - ruled it out. We suspected Apraxia of Speech - ruled it out. We suspected a neurological disorder - ruled it out. Everything that we thought might be wrong with her ended up having some element that would prove us wrong.

Right before she turned 2, I called our pediatrician and told her I was done with the "wait and see" game. It was time to figure out what was wrong with my little girl. Our doctor was on board and started referring us to various doctors. First was a general pediatrician, where I begged for a milk allergy test. I was right, she had a milk allergy. We went to the neurologist - nothing wrong with her brain. We went back to the gastroenterologist, as she was still severely constipated. Nothing wrong with her intestinal tract. Not to mention as we took milk out of her diet, we noticed the constipation relieved itself. Beyond that, we also noticed her chronic runny nose went away. We continued to give her Zyrtec as she seemed to do "better" with it rather than without it.

At 26 months, I demanded that we be seen by the University of Iowa Children's Hospitals. Our doctor sent in a referral and we went. We had begun speech therapy with Early Access, and it was not getting any better. You would think there would be ONE word that would begin to pop out, but nothing. Nada.

So to the U of I we went at 27 months. The U of I doctor told me "There are a lot of things wrong with your daughter in a number of areas." She recommended we continue the now TWO different speech therapies, add occupational and behavioral (she was so aggressive with the doctor that she threw a cup at her head). That same day, our daycare provider, whom we LOVE, sat me down and said that if we didn't get Catherine's aggression figured out, she would have to go someplace else. I came home, cried a lot, then posted on a mom's blog. Someone recommended I look into the adverse side effects of Zyrtec, so I did.

The results were appalling and if you have some time, feel free to look up what they can be. Mainly, everything that was going on with my little girl. Loss of speech, fine motor skills, changes in gait, hallucinations (hence the temper tantrums all night long and the room light being on and NO SLEEP for anyone.).

We took her off the Zyrtec right away and in 24 hours we had 6 new words. In 48 we had 10 and in 72 we had 16. Clear as day. She began to run like the wind within a couple days, and her temper tantrums and meltdowns had subsided.

We had a lovely month or so of Catherine blossoming. It was like she was a completely different kid. Her development was astonishing and all of her therapists could not believe it. She tested out of occupational therapy before she began, and we didn't even pursue the behavioral therapy because she stopped being so aggressive.

About two months later, we started downhill again. She has always had a hard time focusing, but it seemed her focus was getting worse. She began hitting her baby brother (now almost as big as she was, since she continues to be at the low end of the growth chart), throwing temper tantrums. She slept better, but I started to wonder if she had ADHD (I am a teacher, so this is nothing new to me). I talked to the special education teacher in our school, and she suggested taking all red dye 40 out of my daughter's diet. It took a few days, but she was a different kid AGAIN. And again, everyone who works with her day in and day out was astonished at the change in her.

NOW, we are at the point where we have taken all red, blue and yellow dyes out of her diet. We can notice a HUGE difference in her when she has had them. The past three weeks, she has been using a new fluoride toothpaste. Believe it or not, she has slowly gotten "worse." Last night, we were up almost all night with temper tantrums, asking for things but not making sense (wanted me to take her downstairs and kept pointing places for me to take her). When she has dyes, she is not good at communicating and screams and cries A LOT. Her aggression comes back and she is a crazy person. I discovered on Sunday that she has been using toothpaste with blue dye 1 in it.

In my limited research, it seems like my daughter is incredibly sensitive to just about everything - extra sugar, dyes, she is allergic to milk protein, bananas, all berries, melons and latex. My mom and I are incredibly sensitive to sugar and caffeine - if I drink a 12 oz. Mountain Dew after noon, I will not be able to sleep until well after midnight.

Right now, it seems as though anything that crosses Catherine's central nervous system, and/or anything "synthetic" affects her greatly. This isn't a medical diagnosis, it's an experienced mom diagnosis, because I am a desperate mom trying to search for answers to help ease our family of five with two full-time working parents. Any help, insight you can give, stories you can tell, I would appreciate anything at this point. I am trying to give her as normal of a life as possible.

Here's a post from Jennifer send on April 9th.

This kid has always be terrified of the vacuum and I thought she had sensory issues. But after two months on Feingold she was tolerating loud sounds including vacuuming. Not only is she tolerating the noise, she asks to vacuum! Here is living proof that Feingold works. A year ago today they thought she needed speech therapy but now she doesn't. I saw a behavior doctor who thought she had ADHD but now she's a different kid. Doctors no longer think she has ADHD. I'm shocked and blown away.

A post from April 11

Today I went to the mall and she sat in her wagon or stayed beside me and not once ran around any store. She sat and played with her stuffed animals. Also she now sits still for story time and can color for short periods at a time. She is also learning to check foods and won't eat stuff unless she knows it's safe. In the waiting room at the doctor's a girl handed her M&Ms and my daughter brought them to me and said "I think these have red dye, then she walked over to the trash and threw them away. She is 3 years old, but smart!

