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Glimpses of Italy: When Your "Typical" Child Faces Medical Issues by Jennifer A. Peterson

One of the more difficult aspects of special needs parenting is the possibility that your “typical” child may turn out to have special medical issues of her own. While pregnant with my daughter Natalie, we learned that she had a high likelihood of also being affected by Eosinophilic Disease, which her brother Thomas has. It was a scary proposition, considering that at the time we had just finished absorbing the shock of our son’s diagnosis.

I am often reminded of the essay by Emily Perl Kingsley, "Welcome to Holland." Her writings explain the expectation of heading to Italy, but instead winding up in another country. Italy is the metaphor for the expectation of having a typical child, while Holland is instead viewed as having a child with extraordinary needs. After getting past the dashed preparations and expectations, the essay explains that the experience of Holland is not so bad after all, just different. I once commented to a relative that my husband and I had the advantage of enjoying both countries.

After Natalie was born, I let out a breath of relief once she started developing as a baby should, instead of being declared as Failure to Thrive, like her brother. She met several milestones on time, if not early. Her advanced nature, if anything, helped her brother meet the skills he was lacking. Complacency and contentment with her growth became my friend.

Waiting and Watching

Over time, Natalie started experiencing many of the symptoms associated with Eosinophilic Disease. She fit a lot of the criteria, both physically and behaviorally. There was a latent dread of my daughter’s complaints of reflux, tummy pain, food feeling stuck in her throat, immediate moodiness after eating certain foods, headache, and joint pain in her extremities. Then again, each of these symptoms by themselves could be written off as growing pains or a result of her emotionally sensitive nature.

As parents, it is our obligation to practice due diligence and encourage further investigation when appropriate. At the same time, I am afraid of being branded as a "Munchausen by Proxy Mom," or disbelieved by the family and service providers who treat our son. Adding to this fear is Natalie's lack of definitive test results, such as

negative results for skin prick testing, which are supposed to detect underlying food allergies that might be responsible for her reported symptoms. Natalie's perception of her health is also important. As a mother, I want her to know that if she experiences social, physical or neurologic differences from her peers, it isn't because she is not trying hard enough or being manipulative.

Here We Go Again

With my son Thomas, things were easier because his pediatrician suspected something other than just allergies and referred him to the local children's hospital. A year later, our health department noted autism through our state's Child Find procedures.

This time around, the burden is placed on me to prove diagnosis in order to seek appropriate school supports once a diagnosis is made. As a parent advocate for special education, I will try my best to insist on adherence to guidelines and deadlines for appropriate action by the school and the medical establishment.

With our daughter, in addition to the new Eosinophilic Esophagitis diagnosis, I still wonder if there is an outstanding undiagnosed condition that may explain her neurologic and behavioral presentation. Needless to say, I am currently reluctant to look into this. I might just find the answer, as before.

Lowest Common Denominators

I find myself wading through the grief process once again. What amazes me is the clarity of the varied emotions, as well as an uncanny sense of déjà vu. It feels the same as it did five years ago with Thomas. This time around, though, we have experience on our side and can maintain control of choices available to us.

A statement overheard from a parent at this year's United Mitochondrial Disease Foundation Symposium stuck in my head: "Even with a new diagnosis, your child is still the same person they were yesterday." This rings true because Natalie is still the same outgoing, precocious and active child. What her diagnosis provides is a way for her to identify with others like her and gain understanding of her inner workings--something all people long to have, even at an early age. Truth be told, my four year-old daughter was more gung-ho and ready for the elimination diet required by her disease than I was.

The immediate impact on our family unit is the same as when we experienced Thomas' diagnosis. Natalie's prescribed elimination diet of the top eight allergens is a way to focus on eating healthier foods, instead of selecting the easiest and less healthy alternatives. I have the copy of the Food Allergy and Anaphylaxis Network cookbook to explore safe recipes and experiment in the kitchen. We have also discovered that major grocery stores carry more allergy-friendly products not available five years ago. Natalie

was still able to have a tasty chocolate birthday cake with alternative ingredients instead of a lackluster substitute.

Acceptance of Natalie's diagnosis does not end here. In fact, it is the start of a long journey marked by a lot of unknowns. I am hopeful that our family's combined resilience will sustain us through the times of uncertainty.

It is most definitely food for thought.

Jennifer Peterson is an at-home parent and uses her experience as a Paralegal to ensure the medical and educational needs of her children. Both of her children are medically complex with diagnoses spanning multiple food allergies, Eosinophilic Disease, Mitochondrial Disease and High-Functioning Autism. Despite everything they have been through, Thomas and Natalie remain chipper, smart and cute kiddos with infectious smiles and curious natures. Although her family has been dealt the tougher hand, they make it by relying on resources, tricks of the trade and an offbeat sense of humor.