



Complex Child E-Magazine

www.ComplexChild.com

Mito Plus: One Family's Experience with Mito, Autism, and Eosinophilic Disease

by Jennifer Peterson

Thomas is the first of our two children. While pregnant with him, my husband and I had no idea we were about to enter the world of special medical needs. Many of the medical problems he experienced were easily written-off as “colic” or “newborn rash,” and his missed developmental milestones were because, “he’s a boy...they are always slower than girls.” What I had thought was the “worst of the worst” of first-time parenthood was in reality the manifestation of multiple separate medical and neurological conditions. His colic was soon discovered to be GERD. In hindsight, his newborn rash was not the problem—it was hives from being in direct contact with substances he had severe allergies to. Our pediatrician at the time took a wait-and-see approach to the sleepless nights and growing list of skills our son did not acquire, since, in fact, this was three years before the Early Signs of Autism campaign made national headlines.

The diagnoses began with severe food allergies and Eosinophilic Gastroenteritis—an immune disorder of the GI tract in which certain white blood cells, eosinophils, are somehow ‘confused’ and attack the proteins found in most foods that are ingested. Fast forward a year and add on what our local intermediate school district has found to be an Autism Spectrum Disorder. It was comforting to think that the prior Eosinophilic Disease diagnosis eased us into the mindset of the Autism bombshell. To us, it was more or less something else to add to the list of what was different about our child. For a couple of years we had a lot of ups and downs with Thomas’s health. We couldn’t quite explain it and neither could his team of doctors. And then one day things changed.

Thomas is treated at Cincinnati Children’s Hospital Medical Center for his Eosinophilic Disease. His GI specialist, Dr. Philip Putnam, had happened upon a subset of his patients who had symptoms outside of the realm of the typical way that Eosinophilic Disease presents. Dr. Putnam had referred one of these patients to Dr. Ton deGrauw, a Neurologist at the same institution. The first patient underwent a muscle biopsy, which is one of the key diagnostic tools to indicate whether or not someone has a Mitochondrial Disease. That individual indeed tested positive and a new wave of patient referrals was made. Over time, most of this particular subset of patients with Eosinophilic Diseases was also diagnosed positive for some form of a Mitochondrial Disease. Thomas was one of these children.

The connection between Mito and Eosinophilic Disorders is not yet understood and there is no published research on the relationship at this time.¹ Basic science is still trying to understand

how mitochondria function in eosinophils, research that may impact the understanding of both types of disorders.

When Thomas received his positive results for Complex II and IV deficiencies from the prescribed muscle biopsy, we were somewhat relieved. At least we had some kind of an explanation as to why he would wilt in the heat of the summer, easily become dehydrated, or have bouts of lethargy brought on by what we now know as hypoglycemia. What is more complicated, however, is how his Eosinophilic Disease, Autism, and Mitochondrial Disease all fit together. Is one the cause of another? Do they exacerbate each other? In essence, all three are spectrum disorders. No two patients present the same way with one of these conditions, let alone all three.

For example, one thing that has remained constant over time is that Thomas recovers extremely slowly from illness, oftentimes contracting the more serious viruses that are going around. This year during Preschool, he has missed about one-third of his total days due to either genuine illness or that of secondary infection or GI distress, presumably brought on by his Mitochondrial Disease. Suffice it to say, he has a very low threshold for picking up even the slightest cold. Is this a result of his eosinophilic and immune problems, or is this just another guise of Mitochondrial Disease?

Another piece of this multi-dimensional puzzle is the connection between Thomas's Mitochondrial Disease and Autism. The case of Hannah Poling from March, 2008 brought this issue into the public spotlight.² In *Poling*, the nine vaccines she received in one day are thought to have amplified her underlying Mitochondrial Disease, causing autistic-like behaviors similar to those we have seen in Thomas. The March 26, 2008 issue of *The Huffington Post* expanded upon the contents of a multi-national conference call with international scientists and the Centers for Disease Control, suggesting that a significant percentage of children with Autism may actually have underlying Mitochondrial Disease.³ Research on the link between Autism and Mitochondrial Disorders, however, is still in its infancy and primarily consists of case studies at this time. A study on Portuguese children showed approximately 7% of autistic children actually had an underlying Mitochondrial Disorder, while other studies have estimated 5-20% may be affected.⁴ With ever-increasing concurrent diagnoses of Autism and Mitochondrial Diseases, the current prospect of Autism Spectrum Disorders in the world population may be as many as 1 in 50. On the other hand, awareness of Mitochondrial Disease may lead to more widespread screening. The current rate of incidence of Mito is about 1 in 4,000. It is my belief that there are multitudes of undiagnosed Mitochondrial Cytopathies among the general population, just as there were many undiagnosed children with Autism before the rise of Autism awareness.

Add in the fact that Thomas also has an immune-mediated Eosinophilic Disorder, and the question of vaccines brought to light by the *Poling* case becomes unbelievably complex. Everyone seems to have an opinion on the matter—myself included.⁵ In Thomas's case, the fact that his immune system could not compete with his immunizations is a glaring oxymoron. The situation becomes surreal when a parent wonders about how his or her child's entire health picture and vaccination schedule mesh together.

Until now, I had been reluctant to accept the accounts of parents who blamed vaccines for their

child's health or neurological decline. My son had definite neurological differences at birth, but he also didn't particularly breeze through the day or two following each round of immunizations. The slight fever and fussiness he experienced were listed as expected side effects on the information page we received at each doctor visit, so nobody was worried at the time. We became concerned when Thomas suffered serious joint pain the day following his first MMR vaccination. Since the flu shot was the only remaining vaccine that contained the mercury derivative at the time my children were being vaccinated, it was never a strict Autism-mercury link to us. As this new leg of the quest for Autism causation begins, I am suddenly confronted with the prospect of there indeed being an Autism-*immunization* issue, at least for my child.

Time will tell if (and how) we decide to handle his next round of immunizations before Thomas enters Kindergarten. We are considering asking our pediatrician to run titers on current vaccine levels. If levels are still high, he may be able to avoid vaccines that could otherwise put him at risk for a health setback. Taking his Mitochondrial Disease into consideration, it is of the utmost importance that he is in perfect health before receiving any shots, and even then, trying to have each vaccine delivered individually. We must also take his food allergies and Eosinophilic Disorder into account since some vaccines contain albumin (egg), gelatin and other ingredients that Thomas is either overtly allergic to or that have caused a delayed gastrointestinal reaction in the past. Thinking about the list of ingredients for each type of immunization keeps me up at night. Had we known this before each round of injections I wonder what would have happened had we delayed the vaccinations or spaced them individually over time. Would he still have autistic behaviors? It is impossible to know.

Thinking about the connection between Thomas's three primary conditions, Mitochondrial Disease, Autism, and Eosinophilic Gastroenteritis—all conditions with genetic links—makes me wonder a lot about our own genetic background. Firstly, despite the presumed fact that most Mitochondrial Diseases are strictly maternally inherited, reflecting on *both* sides of our family really makes me think. It causes me to wonder about the sickly relatives on my husband's side of the family and the shared history of suspected Asperger's Syndrome, the multitude of undiagnosed cases Irritable Bowel Syndrome, and other autoimmune ailments that plague both sides of our extended family. Thomas's mtDNA (mitochondrial DNA) testing has turned up negative thus far, so we have to wait and take the next logical step of finding out which nuclear DNA sequence(s) are suspect or wait for more sophisticated mtDNA testing to become available. Only time will tell if these three conditions are genetically connected to one another for Thomas, if they are separate conditions, or if one has helped to induce another, with the assistance of environmental agents like immunizations.

In Thomas's case, receiving a diagnosis of Mitochondrial Disease on top of his Eosinophilic Disorder and Autism has dramatically improved our ability to treat his developmental delays. Thomas has been prescribed several supplements to help his body function much more efficiently, specifically Carnitine and CoQ10. He started to make some gains during last summer with the introduction of Carnitine, and has shown significant improvement in fine motor skills and overall participation in classroom activities with CoQ10. His grip strength has increased to the point where he seeks activities involving Play-doh and constantly drums on anything and everyone—to the point that it now hurts. The most significant indicator has been that our five-year-old has been able to open the front and screen door to our house! Self care tasks such as

dressing and undressing himself and buckling his seatbelt have dramatically improved in the past month. To us, this is our definition of a huge success!

As Thomas enters typical Kindergarten during the fall of this year, we still do not quite know what to expect. We are grateful for the support Thomas's school has extended in order to facilitate his education over the past two years. We are encouraged by the steadfast determination of the personnel and educators who help sculpt Thomas's experience as a student. It is our hope that despite his physical limitations, our son can enjoy his childhood and fully participate in everyday life during the years to come. Our son's definition of that may be vastly different than that of other children. It is our hope that he respects this difference and learns in time how to best apply his available energy. In his own words, Thomas has recently stated, "*being sick is no fun.*" And with that, I firmly agree.

We still do not have all of the answers for our child. Some days, I wish this was a static condition—that we knew what to expect day in and day out. However, it is not that way. It is what it is, and this is the way our family's circumstances are defined. If uncertainty is a certainty, than we have become accustomed to that philosophy; we take what we can get and make the most of it.

Jennifer Peterson is an at-home parent and uses her experience as a Paralegal to ensure the medical and educational needs for her children. Her son Thomas is a delightfully complex child with the diagnoses of multiple food allergies, Eosinophilic Gastroenteritis with a GJ tube for enteral feedings, High Functioning Autism, and most recently Mitochondrial Disease (Complex II and IV). Despite everything he has been through, Thomas remains a chipper, smart and cute little kiddo with an infectious smile.

¹ For more information on the connection between Mito and Eosinophilic Disorders, join the Yahoo support group Eos Mito Kids at <http://health.groups.yahoo.com/group/EosMitoKids/>

² Dan Olmstead, ed. "Full text: Autism vaccine case." *Age of Autism* 2008 February 26. Available from <http://www.ageofAutism.com/2008/02/full-text-autis.html>

³ David Kirby. "The next big Autism bomb: are 1 in 50 kids potentially at risk?" *The Huffington Post* [Internet]. 2008 [cited 2008 Mar 28]. Available from: http://www.huffingtonpost.com/david-kirby/the-next-big-Autism-bomb_b_93627.html.

⁴ G. Oliveira, *et al.* "Mitochondrial dysfunction in Autism spectrum disorders: a population-based study." *Developmental Medicine & Child Neurology* 2005;47(3):185-9. See Tally Lerman-Sagie, *et al.* "Should Autistic Children Be Evaluated for Mitochondrial Disorders?" *Journal of Child Neurology* 2004;19(5):379-81, for a review of the earlier literature.

⁵ See <http://www.blog.mitoaction.org/2008/03/21/statement-on-Autism-vaccines-mitochondrial-disease/> for the official statement by MitoAction on vaccines, Autism, and Mitochondrial Disease.