



# Complex Child E-Magazine

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## The Never-Ending Sinus Infection

by Melody Pohla

It seems like we have been dealing with headaches, facial aches, thick colorful drainage, sore throats, teeth pain, congestion, and coughs related to sinus infections in my family since before I can remember! I have had ongoing issues with sinus infections, as has my dad. Little did I know that sinus infections would affect my children even more!

### **Nicholas' Infections**

Nicholas, my oldest, had a lot of issues his first year of life, but they were mostly GI-related. It wasn't until he was around a year old that the sinus infections started in with a vengeance. He would get sick, go on medication, get better, and then get ill almost immediately upon completing the antibiotics. Any respiratory illness he would catch would turn into a full-blown sinus infection within days. He learned to blow his nose before the age of 18 months, because he was so tired of me chasing him down with the bulb syringe.

We went through several different medications and tried all sorts of things including nasal sinus washes, daily preventative medications like Nasonex, and allergy testing. Nothing seemed to make a difference. It was then that an online friend suggested testing his immune system since her youngest was having many problems with illness as well. Our allergist humored me with my request for immune system testing and we were all stunned when the tests came back showing his immune system was deficient. This was likely the cause of his difficulty with infections.

We then were caught up in a whirlwind of appointments with immunology and a considerable amount of testing that yielded no concrete answers and a whole lot of "Let's wait and see what happens." Summer came and the infections subsided for a time, only to start back up again once "sick season" reared its ugly head. Along with the lovely infections came more suggestions: CT scans, cultures for every infection, and more immune testing. We did find out that he was at least clearing the infections in between episodes of illness, but our poor two-year-old remained the picture of misery. He also had to be on each course of antibiotics for 20 days instead of the usual 10-14 days.

This vicious cycle continued until he was around four years old and then, as suddenly as it appeared, it was gone with no explanation. Around that same time, his immune system finally started kicking in on its own and he was overall much better.

## **Nathan's Infections**

When Nicholas was two, his younger brother Nathan was born. Nathan seemed fine at first, but it was around the age of seven months that the cycle of illness kicked in with him. He started out with ear infections and persistent fluid. Ear tubes solved that problem, but around age one, he started experiencing the same problems with sinus infections. Any respiratory bug he would come into contact with would develop into a sinus infection in no time.

Nathan had his immune system checked at a year of age and he was found to have the same deficiency as his older brother. As time wore on, his symptoms and illness rate worsened until at age three he was on antibiotics for 100 days in four months. He seemed to get sick again within 48-72 hours after completing his course of antibiotics. This trend of illnesses showed that his immune system was spiraling downward over time. He was no longer responding to continual revaccinations of Prevnar and Pneumovax to prevent pneumonia, either.

We were fastidious. We obsessed over every surface he touched. We avoided places, like the church nursery, that were potential infection risks. We washed hands in our house many, many times a day. We wiped down public surfaces. We kept him isolated as much as we could. We have pump dispensers of antibacterial hand gel in almost every room of the house, both cars, my purse, and both diaper bags. We go through cans of Lysol or Clorox wipes as if they are going out of style. And still we were unable to keep him well.

We sought out the expert opinion of an asthma/allergy specialist to see if she had any ideas. Because of his ear tubes, he was not able to do well with nasal sinus washes nor was he the most cooperative patient. We did saline spray and syringed out his nose and that did nothing for his symptoms or illness rate. Allergy testing yielded nothing. He had medicine changes from one nasal spray to another with no improvement. We tried umpteen different antibiotics and breathing treatments to no avail. He had CT scans multiple times that showed that it often took more than one course of antibiotics to clear a single infection. We then sought out the advice of our trusted ENT and the only suggestion he had for us that we had not yet tried was sinus surgery to clean out his sinuses. It was scheduled within the month.

When the immunologist heard about his scheduled sinus surgery, she disagreed and got another specialist on her side. They both pleaded with us to cancel the surgery. So, in frustration and against our better judgment, we cancelled. According to the immunologist, when you alter the mucosal membranes and other sinus structures during surgery, you not only stir up bacteria, but you change the function of the sinuses and permanently modify the function of those areas. When you scrape the mucosal membranes, it can damage or alter the way these membranes later work to fight infections. Another procedure they sometimes do in surgery is to remove the bony structures in the main nasal passage...and those are there for a reason. Because the structures are not completely formed for quite a while in a young child, performing this

surgery can affect the completion of growth and development of the sinuses later down the road. Our specialists suggested that instead of rushing into surgery, we seek out the opinion of a local sinus specialist and if that did not work and the infections did not cease, we would look at doing a treatment called IVIG to replace the defective parts of his immune system. We agreed.

As the months passed while we waited for our consult, the infections continued along with a host of other infections including Cocksackie, the Flu, and a GI bug that landed him into the hospital for fluid replacement. His body was taking a beating from the continual infections and had no chance to rebound from one before he was beaten down with another. He looked terrible, had no energy to do anything, and was run down all the time.

Finally, our consult with the sinus specialist came, and while the doctor was very personable and kind, there was nothing he had to offer us. He said we had tried everything he knew to suggest at that point except surgery. In his expert opinion, surgery was not an option due to his age and development, and he felt that IVIG infusions would be a much less invasive and logical next step in our game plan. Last month, at the age of four, Nathan had his first IVIG treatment. We are holding out hope that this will be the thing that will help him stay well once and for all.

### **Underlying Disease a Contributing Factor**

My kids are an unusual case, though. All three of my children have a Mitochondrial Disease. This comes along with several problems, one of which is a secondary immune deficiency. Nicholas is fortunate in that he seems to be outgrowing most of his immune issues and his labs are proving that by trending up over the past year or so. He is also retaining his protection from his vaccines better than he was when he was younger.

Nathan, however, is the other side of that coin. While his brother is showing improvement, lower infection rates, and upward trending labs, Nathan is showing a decline in overall health, an increase in illness rate, and downward trending labs.

Our youngest, Daniel, is still too young to predict his infection future. He has had his fair share of infections his first year of life with sinus infections playing a big part, but time will tell how things will play out with him.

If you or your child is experiencing recurrent sinus infections, make sure you seek out the guidance of a specialist who deals with respiratory illness, such as an asthma/allergy doctor or an ENT. They will have many suggestions and treatment options that can help and they have the ability to order more sophisticated testing to find an underlying cause.

If infections become persistent, recurrent, and difficult to get rid of, you may want to consider looking into immune system testing to rule out any potential problems. It is a simple series of blood tests that can tell a lot about the body's ability to fight off illness

and protect itself through vaccines. If there is a problem detected, a clinical immunologist is the most qualified physician to help you explore the issue further.

*Melody Pohla lives outside of Houston, Texas and is a stay at home mom to three wonderful little boys: Nicholas who is 6, Nathan who is 4, and Daniel who is 1. In her former life, she was a teacher of 3rd and 4th grade students for six years. Since early on in her oldest son's life, she has researched and educated herself about everything dealing with her children's medical diagnoses as she feels the best advocate for her kids is an informed parent. Living daily with Mito has not been easy, but her boys are amazingly resilient and live life to the fullest without regard to any of their medical diagnoses. She and her husband have been active in promoting Mitochondrial Disorder awareness in their community and their boys have just taken part in an ad campaign for the hospital that treats their Mito. She is also active on a support board [<http://www.parent-2-parent.com/forum/>] for parents of children facing Mito or related metabolic disorders and those on the journey to a diagnosis for one of these disorders. Please visit the boys' Caringbridge site [<http://www.caringbridge.org/visit/pohlaboys>] or check out their story on the CMHH website [<http://www.memorialhermann.org/patientstories/childrens/content.aspx?id=3238>].*