



Complex Child E-Magazine

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The Pregnancy Journal of a Mito Mom

by Melody Pohla

As a little girl, I dreamed of all the things little girls often dream of...what I would be when I grew up, who I would marry, what kind of house I would live in, and of course, my future children. How many would I have? Would they be boys or girls? What would I name them? What would they look like? In those dreams, the children I imagined would always be happy, have smiles on their faces, and be running around outside without a care in the world. I never would have imagined children could be any other way than in my innocent dreams as a little girl.

My husband and I decided to start a family and, despite months of trying, found ourselves unable to conceive. After a fertility workup, I was found to have infertility due to polycystic ovaries and my husband had surgery to relieve fertility issues of his own. This was an early sign that I might have Mito myself, but it would take many years before this was even considered. With the help of fertility drugs, our trusty basal thermometer, and a temperature plotting chart, we found ourselves staring at a positive pregnancy test about six months later. I was never more excited and looked forward to the day I would hold my child in my arms.

Nicholas

I had heard rumors of how wonderful pregnancy was, but with the exception of feeling the tiny life inside of me moving, my pregnancy was anything but wonderful. I was plagued with terrible swelling and water retention, awful reflux, high blood pressure that took three months after delivering to resolve, and an amniotic leak. I had several hospital stays. The swelling was so bad I developed carpal tunnel in my wrists from the pressure of the fluid buildup on my nerves, and I could never remove my shoes during the day for fear I would not get them back on. My blood pressure climbed higher and higher until I was unable to continue working and went on bedrest at home. My pregnancy culminated at 35 weeks with me being rushed to the doctor after a particularly difficult day to find out that my blood pressure was so high I needed to go straight to the hospital. My OB had assured me that there was no way I would deliver while she was halfway around the world in Australia. Someone should have warned me that my child was never going to do anything by the books. Along came our sweet Nicholas, five weeks early, due to complications from preeclampsia and an amniotic fluid leak.

He did amazingly well in the NICU and we brought him home, expecting a wonderful babyhood. But nobody can ever prepare you for what lays ahead when your child does

not have the happy storybook ending you dream of. That realization came about when Nicholas' medical troubles first set in. Our son would not eat, would do nothing but sleep, and screamed in pain for hours on end. Medical surprise after medical surprise arose with my tiny son and doctors' visits and medication became a routine part of our lives. Nicholas was hospitalized at only a few days old due to skyrocketing bilirubin levels and was readmitted at six weeks for RSV. The problems continued with a reflux



Nicholas after surgery

diagnosis, failure to thrive, multiple medications, a hospitalization for a severe GI bug and 105 fever, and a two week hospital stay for GI surgery and TPN (IV nutrition). We left the hospital with a child who could no longer eat by mouth and needed to be fed by a tube. After countless tests and procedures, a laundry list of medications and diagnoses, and four hospitalizations, my son celebrated his first birthday. We took it all in stride and accepted it all as our "new normal." We were stressed, but happy.



Nicholas today receiving his Blue Belt

Our plan had always been to have children close together as I am 17 months apart from my younger sister and my husband and his brother are only 19 months apart. We were terrified at the thought of reliving the first year of our son's life with another child and felt we could not go through anything like that again. Our plans for our family were changed and we dodged questions by well-meaning family members about when we would be having another baby.

Nathan

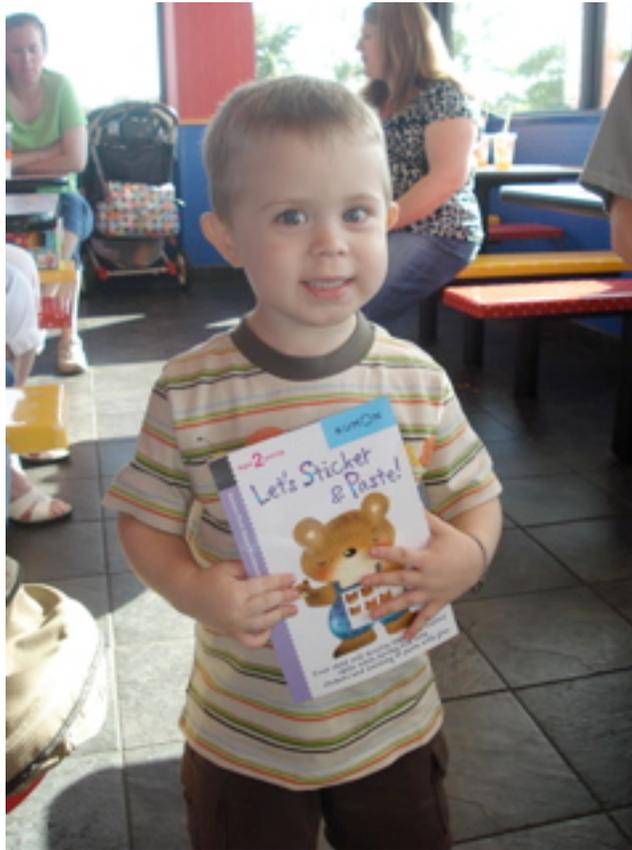
New Year's Day came along and we found ourselves staring at a positive pregnancy test once again. But this time was different as we had not taken any fertility medication and had decided against future children. We were terrified, but tried to be happy. I went in for my first appointment with my OB and we discovered a problem. For the next two weeks, I went in for bloodwork every other day to see if this pregnancy would be viable. We went from being terrified of having another child to being terrified of losing this one. Every day I found myself desperately wanting things to be ok, but they weren't. We were devastated. We had not realized just how much we had wanted another child until this one was taken from us. Back came the fertility medications, the trusty thermometer and chart, and months later, we found ourselves overjoyed at the sight of another positive pregnancy test.



Nathan in the NICU

We figured surely things with this pregnancy could not be any worse than with my first one. Boy, were we wrong! Reflux, borderline blood pressure, and swelling returned with this pregnancy along with some new surprises. This time, we added in preterm labor at 26 weeks, 11 weeks of bedrest, countless hospital stays, and undiagnosed gestational diabetes. The final straw was the polyhydramnios (too much amniotic fluid) that led the OB to induce labor at 37 weeks. Along came our precious little Nathan. We brought him

home and hoped for the best, longing to experience the “normal” babyhood we missed out on with Nicholas. We found out all too soon that it was not to be.



Nathan Today

Our second son started in with problems almost immediately. He began with reflux and added medical issues such as ear infections, high fevers of unknown origin, plagiocephaly, and hypotonia. We celebrated the day he held up his head on his own at age seven months. Our home was always full of therapists. We had countless tests and procedures, a laundry list of medications and doctors, and four surgeries by 18 months old. But, we took it all in stride as we knew nothing different. Our boys went through all of this together. Life was not easy, but by then we were used to the chaos and uncertainty. We settled into a routine and were happy.

Daniel

The plan had always been to have two children and after the difficulty I had with pregnancies, we decided we were done. At the time, it was an easy choice to make. Everyone was relieved as they had worried through so much with us and the emotional roller coaster had taken its toll. My OB, however, had other ideas. I think she knew, deep down, that I harbored a secret desire for “just one more” and she worked on me every time I came in and somehow convinced me that things would be better if we tried for one more.

It was quite a job convincing my husband though, especially since we had no idea what was going on with our boys. Mito was being considered and we were not sure if we could have another child with Mito or not. My health was better than it had been, but a third pregnancy worried us both. We decided to talk with the Mito specialist on our trip to Cleveland and get his thoughts on future children. We had a very candid discussion about this with the doctor and he determined that our boys were medically very similar and any future children we may conceive would probably be similarly affected, if at all. Because they are both mildly affected, “What you see is what you get,” is basically what it boiled down to. After agonizing over it, we followed our hearts and decided that it was worth the risk. We had already been living with all of these issues since day one and doing well with them. Our boys were happy and loved living life to the fullest. They are bright, curious, fun-loving, and just the joys of our lives. We prayed about it a lot and decided this time we would set limits. We would only try for a set period of time and then no more. If it was meant to be, it would happen, and if not, we were ok with that, too. The first month of fertility medicine, we conceived. Immediately, we just knew this child was meant to be here.

About midway through my pregnancy, we met the wonderful neurologist/Mito specialist who would eventually diagnose our boys with Mitochondrial Disorder and who would also discover the genetic mutation behind their Mito. In this process, she discovered that it was highly likely that I had Mito as well. It would explain all my health issues, along with why I have had such a hard time getting pregnant and why I have had such complicated pregnancies. Everything suddenly made sense. Initial bloodwork confirmed her suspicions that I am likely to have it. She did quite a bit of research, only to discover there is little published about women with Mito being pregnant. She took on the challenge of helping my OB get me through the pregnancy and delivery, spoke to our pediatrician at length about the baby and what things he needed to do to help care for him at birth, and had a plan in place for the baby should anything go wrong during the delivery. Amazingly, while not free of complications, this pregnancy was far easier than either of the others. My OB said she had no medical explanation for it. I knew the reason though...this baby was meant to be here.

I made it 38 weeks without a single overnight hospital stay, and we decided not to tempt fate. Daniel was born and we were in love the minute we laid eyes on him. Even after only a few short weeks of having him here with us, I cannot imagine our lives without him. He is adored by his older brothers and has brought us so much joy already. He smiled his first smile the other day and that was my confirmation of just how much this child was meant to be here. I knew we had made the right choice.

Will he have Mito and health issues like his brothers? We don't yet know. The week he was born we got back the report from the boys' mitochondrial DNA testing that showed a mutation in the mitochondrial DNA. This means I probably have it and the baby probably does too. We will both be tested for the mutation soon. Does that change things for our family? Nope...we are used to our “normal” here and we will take any challenges that arise in stride. We have wonderful doctors who are taking care of us and

we are confident that they will do their very best to help us through whatever lies ahead. Our doctor has assured us that since I likely have Mito and have done so well thus far, there is no reason at this time to think that our boys will not do the same.



Daniel under the Bili Lights

Our lives might not be the fairy tale I envisioned as a child, but we feel so very blessed to have three precious little boys who mean the world to us. We don't need the storybook ending as long as we are happy...and we are.

Melody Pohla lives outside of Houston, Texas and is a stay at home mom to three wonderful little boys: Nicholas who is 5, Nathan who is 3, and Daniel who just turned 8 weeks old. 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/tx/nicholasp/>] or check out their story on the CMHH website [http://www.memorialhermann.org/services/PS_Pediatric_CH_NichNath.html].