

Our Craniosynostosis Story

Thomas Belsito

Until you live through the initial shock of sitting across from a doctor and hearing Craniosynostosis, do you fully understand....

Thomas was an anticipated joy. It was a wonderful pregnancy that only required one ultrasound. Everything was perfect. On May 3, 2004, my labor did not progress. I couldn't deliver the baby and our doctor made the call for an emergency c-section. Still, my husband, George, and I had no idea of what was ahead for us and our family. Rushed to the OR, my husband, by my side asking if I was ok...Thankfully, Dr. Fae Nason delivered Thomas to us by c-section, 8lbs. 11 oz. of happiness....

Tommy was in our arms. He had ten fingers and ten toes and bright eyes staring at us. George immediately asked, "Is his head alright?" Our doctor thought it was and said he should be just fine. But, we questioned, "How could his head be so misshapened, if in fact, I just went through a c-section, not natural birth?"

After bringing the baby home, we were so delighted. Things were great. Our two year old daughter had a new little brother, we were a perfect family. We had two beautiful children, good jobs, a nice house with a white fence and swing set in the backyard. Tommy ate; slept, cuddled...Molly had been the opposite. She cried, fussed and only wanted to be held, not sleeping much at all. So, Tommy was so easy....except for our ongoing concern with the shape of his head.

At every feeding or every time we held him, George and I would stare at his head waiting for it to "take shape." It didn't and in fact was getting worse. We didn't talk much about it, but had a sick feeling in our guts that there was a problem.

The morning before Tommy's two week well visit, George asked me to request an x-ray or something to relieve our concern. The pediatrician appeased us with an x-ray, but assured me that he was doing well. She even brought another doctor in to reassure me. Although this made me feel better, my gut was telling me otherwise....

The next day was Saturday. I didn't expect to hear from any doctor with results of the x-ray. The phone was ringing and I could see our pediatrician's name on our caller id, but it wasn't from the office, it was her home number. She spoke calmly, but her voice did shake. "Meg, Thomas needs a specialist, it will be ok, his brain is growing, but...." His brain, what? Spell that word again, C-R-A-N....I hung up frozen in fear. George was outside playing with our toddler and I called, "George, come in, something is wrong."

As I started to tell George about the phone call, he took Tommy into his arms and just stared at him. He didn't say much except, make the appointment. Molly was calling to him so he handed the baby back to me and quietly walked outside again. I sat in our living room, holding this baby and couldn't move.

I made the appointment with the specialist name that the pediatrician gave to us. Still only understanding some of what was said to us. I went online and did some research and my fears were growing worse by the second....Harlequin appearance, developmental delays, genetics, not much known about cause, 1 in 2,000 births.... I just kept holding Tommy and waiting for the 1st appointment which was the following Friday....

We walked into this doctor's office with the baby and didn't expect the bluntness and unemotional response from this pediatric neurosurgeon. He shed light on the disease, but told us that we were in for a lifelong battle with Craniosynostosis. Things like all bones are fused, emergency surgery needed, blood transfusions, vision and hearing problems, opening his head and cutting the bones and putting them back, life risking surgery....My husband asked the question that changed our course of action immediately, "So how many babies do you see in a year with this?" His response, "Maybe one."

The sense of urgency overwhelmed us. Someone must know more, wherever he or she is, we needed to find them, at whatever cost, it didn't matter. We were this baby's advocate. No one else was going to push for help or answers. Tommy needed the best so that we could say that we, as his parents, gave him the best possible chance at life. I searched and searched (I was even looking at medical colleges attended, published research articles, pictures) and I found a doctor at

Children's Hospital Boston, Dr Mark Proctor. I picked up the phone and called and got his secretary. My voice cracking, I asked if Dr. Proctor would see our son. She replied, "Yes, his next available is..." I interrupted and started to tell her about our first appointment and how we felt it was urgent someone see Tommy. She, quickly, put me on hold and came back with, "He is happy to see you on Monday, but he will be in surgery so you may have to wait a while." I said, "We'll wait all day if we have to." Our coma like state continued through the weekend. I couldn't eat, sleep, much less function as a mother of two....

Monday finally came and off to Boston we went with questions and a baby boy who was going to get the best, we prayed. We waited patiently and it felt like forever and then he came out of his office and called Thomas in....He listened patiently as we told him our story. When we finished, he said, just by touching Tommy's head, "He has Sagittal Craniosynostosis and I can help him." Dr. Proctor went on to explain in full detail that we were given a misdiagnosis, what was in store and what we needed to do to make sure Thomas would fully recover. Immediately, calming us down, but how could this be so different from our first appointment? But, our confidence in Dr. Proctor was immediate. Then we asked the question, "How many babies do you see in a year with this condition?" His response, "About 200 to 250." Our intuition as parents was right to look further than that first appointment. We knew Tommy's life was going into Dr. Proctor's hands....

Thomas was going to need to wait until he was three months old for the surgery due to lung development. We, of course, didn't want to wait, but this was going to give him the time to develop and grow physically in order to handle what was in store....During this time, one day felt like a year, three months felt like a lifetime.

On July 21, 2004, when Tommy was 3 months old, he went into neurosurgery at Children's Hospital Boston with Dr. Proctor and his team. We had blood taken in case Tommy would need it; we met with the anesthesiologists, nurses, interns, residents....This was it. We covered all bases. Even the night before the surgery, George and I were wondering if his team would have good night sleep. We even

wondered if we should bring them breakfast, just in case they forgot to have a good meal before operating on our son....

Holding Thomas and then having to give him to them in the OR was so heart wrenching. I held him and kissed him until the last possible moment, then fell into my husband's arms as they walked down a hall into the OR. Those hours were awful, phone calls from the OR helped a little, but the fear of losing a child is so indescribable and unforgettable.

Thomas came out of surgery and spent time in the PICU until things were stable. He had a terrible reaction to morphine so that is on the allergy list! We couldn't hold him for almost 24 hours which was terrible. Listening to the cries, I felt so helpless because I knew he was in terrible pain, but we had to do this, no choice. The next few days were emotional, but the hospital was wonderful. The team would come in to see Thomas in rotations and found me in the crib with him many a time. I had to be near him, it calmed him as he couldn't see. His eyes swelled shut....My husband's sweatshirt on the other side as Tommy knew his scent. Dr. Proctor was very confident everything went well. He expected Thomas to do great....Thank God.

As the first few weeks went by, we noticed changes in Tommy's head for the better. We went for our follow up visit and it was decided that Tommy would benefit from a helmet to continue to shape his head further. Thankfully, we never had an insurance issue. Everything was covered. The severity of Tommy's Craniosynostosis was documented and until he turned one, Tommy wore a helmet for 23 hours a day, with a smile. Thomas is now 6 years old and in 1st grade. He loves Star Wars, Legos, Baseball, Soccer and Basketball. His favorite team is the Red Sox (strong MA family influences at work), but will tell people that he likes the man on the Yankees whose son has the same thing as him, Jorge Posada, because he helps children with Craniosynostosis.

Tommy's story is like many children who go through this condition. Good days and Bad, Happy Days and Sad....As we told Dr. Proctor, we are more than happy to help anyone going through this with their child. As my research continued, I came upon CAPPS KIDS and then the Jorge Posada Foundation. My questions and

quest still continues as to why our son, why we are on this journey....some day we may know, but on our last visit with Dr. Proctor, he said, "If you make Tommy different, he will be different." We live each day, thankful and appreciative of the support and advice given to us....Although, I still cringe and bolt to Tommy whenever he hits his head or falls on a playing field. My husband gives me the reality checks I need in order to realize, we can't hold Tommy back because of Craniosynostosis.

I joined both organizations as a mentor immediately. As a Special Education Coordinator/Chairperson, I work on a daily basis to ensure children with disabilities receive the appropriate services they deserve. I'm not a stranger to advocacy, but when it comes to your own child and their needs nothing should get in the way.... No one should ever feel like they are alone in this battle, but as all mothers know, at times we are alone in our hearts battling for our babies. No one fully understands what this is like until you hear those words, Craniosynostosis....

Written by Meg Belsito