



Tyler's Story

By Jannick Theriault

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Tyler was born early, at 35 weeks, in October 2010. My water broke spontaneously in the middle of the night. We weren't expecting the arrival of our first baby so soon and were definitely not ready for his condition when he was born. When I delivered Tyler, the doctors noticed he was swollen on one side of his face and had some excess skin under his chin. He was taken to the nursery since he had trouble with his



Tyler at 5 months

breathing and was put in an incubator. The doctors didn't know what was wrong with Tyler and decided to wait a day to see if the swelling was due to the delivery. I remember not wanting to see Tyler because I was so afraid to get attached to him in case he wasn't going to pull through. I was also scared of what he would look like since I had only been able to catch a glimpse of him after his birth.

After a few days and still no progress with the swelling they then realized that we were dealing with a more permanent condition. To further diagnose his problem, Tyler was in need of an ultrasound/MRI. The doctors had a pretty good idea of what his diagnosis could be but the ultrasound technicians did not feel confident enough to make a proper diagnosis following the results. Tyler was then flown to the IWK in Halifax where they had specialists able to diagnose the problem.

As the days passed, it was hard. We were dealing with the early arrival of our baby boy plus the surprise of a health condition. It was an emotional roller coaster. As

a new mother, I had feelings that I didn't know I could have. They ranged from anger to fear, sadness to spite, happiness to guilt and everything in between. Not knowing what is wrong with your baby is the scariest place to be.

Once we got the diagnosis, things started to calm down and it's like we began to breathe. Tyler was diagnosed with Cervical Lymphangioma, a rare congenital veno-lymphatic malformation that causes benign cysts-like formations. Tyler's condition affects the right side of his face, more so in the neck and cheek area. Tyler has both microcystic and macrocystic cysts, an even rarer type of lymphangioma. This type is harder to treat due to the facts that the microscopic cysts are harder to drain. Tyler was also born with a separate condition that caused breathing and eating issues. The team of doctors at the IWK were spectacular and they made sure we understood the conditions and everything that came with it.

After 3 weeks in various hospitals, we were able to bring Tyler home. That's when reality set in, you begin to ask yourself questions of how will you react when people look at him and notice he is different? How will you answer? Will you be able to accept that he is different? Will he be teased at school? Will you be able to protect him? The uncertainties and questioning went on and on. We decided we were going to be



honest about his diagnosis and explain that he may look different but it's not a life threatening condition. Tyler has such a great personality that now people hardly notice his facial difference.



Tyler at 15 months

I am glad I was made aware of AboutFace from a social worker at a hospital, and happy to have found such a great organization. The information provided was helpful and made us feel less alone in the journey we were living.

At 3 months old, Tyler had an operation (sclerotherapy) to drain some of the cysts. The procedure was a success and shrunk most of the cysts located under his chin. Now, 16 months, Tyler is thriving everyday!! We cannot wait for what is to come and now fully love and accept Tyler as he is. We are ready to conquer anything and know Tyler can as well!