

## Emma was 7 weeks old.

We were new parents, taking Emma to meet her doctor, have him look her over and send us on our way. He assessed her, measured her head and told us he believed she had hydrocephalus. We were sent across the street to our local hospital for an immediate ultrasound and CT scan and were sent directly back to our doctor's office. Our doctor already had an appointment arranged for us at McMaster Children's Hospital. The neurosurgeon confirmed the diagnosis and treatment of a shunt implant was explained to us. A couple days following, she had her surgery and after some recovery, we were discharged. Essentially a week-and-a-half from our first doctor's appointment, Emma had her surgery and we were back home. It was such a whirlwind. We were just learning to adjust to parenthood, now we were trying to deal with this new curveball.

## Those early days were difficult. Once we learned of Emma's diagnosis, her surgery date couldn't come soon enough.

Every time she cried, I worried if she had a headache from the pressure in her head, and I prayed and wished I could take that burden from her and carry it myself. She was so resilient through all of this.

Throughout her first year, Emma participated in physical and occupational therapy to ensure she was hitting all her milestones. She was a very happy and curious little tyke and was able to be discharged from her therapy when she was 12-months old.

Early in Emma's elementary school years, a workmate told me about SB&H (now Hydrocephalus Canada). I connected with them and was so fortunate to benefit from vast amounts of support and educational materials. They have been there for us throughout the years. The Association provided us with a binder that I gave to Emma's teachers with a binder that help them understand her condition, so they could be properly informed and equipped to care for her (ie: signs of shunt malfunction, issues with learning). Having teachers 'tuned in' to her condition became especially helpful when Emma was in third grade. Her teacher noticed a marked difference in Emma's ability to complete writing assignments in comparison to her



*Jeff and Amy (back row), Shawn and Emma (front Row)*

classmates. We found that Emma struggled with reading and comprehension and completing work within a restricted time. We worked together with her teacher and put a learning plan in place. We found verbal explanation helped as well as allotting extra time as she seemed to process a little slower. Over the years, her learning plan has become an important piece in her education and she is thriving. From a young age we ensured she understood that having a learning plan meant that she is just as smart as anyone in the class. She just learned a little differently. Emma has such a positive about using her learning plan. She understands that it helps. Throughout elementary school Emma discovered different activities like jiu-jitsu, guitar, swimming, gymnastics, hockey and then she fell in love with skiing and soccer. For the last couple of years, she's played on an academy soccer team where she trains year round and often plays in Canada and the US. We are likely the only parents on the team that tell their child, "no head balls"! That is our only restriction with her.

Emma started ninth grade this past September, continuing her full-French education, and is absolutely loving high school (well, minus all the school work if you ask her!). She played point guard on the school basketball team and made the varsity soccer team. Emma has been working so hard this year applying herself academically and has been maintaining an honour standing.

We knew the day would come when we would be faced with a shunt malfunction. Honestly, we were surprised she had gone 14 years with her original shunt.

December 20, 2018 Emma stayed home from school. She had a bad headache. Throughout the day taking both Tylenol and Advil, nothing was helping much. My internal flags were quietly up. The following morning, she woke me up at 5:30am to tell me she had been up for half an hour because of her headache and now felt nauseous. We got her ready and I took her immediately to McMaster.

All I can say is we had an amazing array of angels who helped us through that day. Again, here was a day I wished and prayed I could stand in for Emma so she didn't have to experience one ounce of pain or fear. It was important through all of this that I kept strong, calm and positive for Emma and only addressing what we knew as the day unfolded. Once we confirmed that the shunt wasn't working and she needed surgery that day, a child life specialist came in and to talk with Emma. It was amazing to have someone listen to her about her anxiety about surgery and explain some things to help her feel as comfortable as possible. I must share a pivotal point during this day where I am so grateful to Hydrocephalus Canada. The resident doctor had come to explain that they would be replacing the shunt. I then asked if she would be a good candidate for an ETV. He then turned his mind to that option and later confirmed that ETV would be the recommended surgery for her. I'm sure this would have been the option the neurosurgeon would have opted for once they evaluated things. However, I wouldn't have been able to initiate the discussion of an ETV without being armed with all of the information. I recalled years ago at a SB&H AGM, a video of the ETV surgery was played and explained. This helped me to be confident in speaking about this surgical option, understanding what it entailed, and actually brought me some comfort having this familiarity.

It wasn't until Emma was wheeled away from me into surgery that I was able to fall apart for a minute and let out the worry that I had held in all day for Emma's sake. A short 10 minutes later I calmed down knowing it was all out of my hands and I patiently waited. Once we were able to see her in recovery, she was smiling and the first thing she said was, "my head doesn't hurt anymore". My heart lightened and it was all I needed to hear. We were discharged on Christmas Eve and she was able to enjoy some time with family that evening.

We are forever thankful to Hydrocephalus Canada for the information and support provided to our family over the years. The book, "Detour Ahead" was a great book for Emma to read and understand her shunt at her level when she was in elementary school. The resources helped us advocate for her educational support when she was in need of it and when the day came of her malfunction, we knew to recognize it and we were prepared for what was to come next. We are nearly six months post-op and signs are all pointing to a successful surgery! Emma had a gradual return to sport and is now fully engaged in soccer with no issues with headaches. She also was able to return to schooling after the winter break and was able to focus, study and complete her first exams that following month. Her positive attitude and resilience will continue to serve her well in her future

## In Her Own Words - Emma's story

Hydrocephalus for me, is something that I have been proud of and I never let anyone think I'm less than them because of it. I was able to fight through surgeries, learning challenges and difficult times that most people aren't able to say they did, and I'm stronger for it.

Having hydrocephalus has affected me many times in life. I have to be careful every time I play soccer. I am mindful to try not to get a ball to my head or doing head-balls. When I'm sick, we are always watching for symptoms to make sure everything is in check. I don't worry about my hydrocephalus but am always cautious when something doesn't seem right, I step back and let my parents know. It's always good to tell someone if you are not feeling okay because if there is a problem, you can deal with it before it gets worse.

Yes, from time to time I feel different from others but I never let that get me down. I'm open to talk about my condition and I have learned to accept the fact that I'm different and that's okay. I have never been bullied or teased over it but if I was, I know that I am stronger than them! My friends have always known about my condition and have always been a great support. Especially after my recent surgery due to my shunt malfunction, many of my new high school friends and soccer teammates didn't realize I had hydrocephalus and were great in offering support and friendship.

## Hydrocephalus Canada

We are the voice of  
Canadians living with hydrocephalus.

Every day we strive to empower those impacted by the condition to experience the best life possible.



Bridging, Advocacy, Research & Innovation  
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