



Chloe Ribaric

A mothers story
Click the link to read Chloe's story.

Did you know that June is Brain Injury Awareness Month in Canada? This month, we're shining a spotlight on Brain Injury. Help us raise awareness about brain injury in Canada by following along with our posts & sharing our posts with your friends!

#SPOTLIGHTONBRAININJURY

I was asked to write about what it is like to be Lincon's caregiver. First, I must tell you a bit about my son. Lincon was born October 13, 2016 and was the most beautiful baby. As he grew, he met all his milestones right on time. He loved to play outside, colour and play ball. He was the perfect baby in every way.

Things changed for us on December 22, 2017, when he was 14 months old. Lincon was not acting his usual self while he was at daycare. He had a seizure and was rushed to the hospital where it was discovered he had a brain bleed. Lincon had to have an emergency craniotomy. We were awfully close to losing Lincon, thankfully that surgery saved his life.

This was the start of a long and never-ending journey of learning how to care for Lincon and his new needs. Lincon has many disabilities as a direct result of his brain bleed. Most days I feel like a mom, a nurse, and a therapist. I am his main care giver, and I am responsible to do physio with him and ensure he gets all his meds. I do this day in and day out some days it is exhausting. This has been our new life for three and a half years now. Your whole world changes when someone you love has a brain injury.

Lincon is in a wheelchair full time because he has right side hemiplegia. I Do not have a lift for him, so I do all the transfers. Lifting him in and out of the tub is by far the hardest. Lincon is about 40lbs now and he is still growing. We use his walker daily and he has made some gains with it but mostly uses it for standing. Over the years Lincon has made some gains with his motor skills. Two and a half years after his brain injury he started to sit with some assistance. Now he can sit in a w position with no assistance. He can go from laying to sitting on his own but does not have the ability to stand on his own due to the right-side hemiplegia.

For a long time, it was a goal of mine to help Lincon learn how to eat again. It would take me over an hour to feed him half a jar of pureed food. It just was not enough to sustain him. Then with his increasing seizures he seemed to have less and less interest in eating. I know he is getting the food he needs through his g tube so now we just have food for fun. On a good day Lincon can only manage a few bits. However, he has recently learned how to drink from a straw, he may only drink half an ounce but is a skill we will continue to work on. Practice makes better but not perfect! We always stride for better.

Lincon has a g tube for all his nutritional needs. When I first learned how to set it up, run a feed and give meds I was always so fearful I would do something wrong. Now it is second nature to me. To us Lincon's g-tube has become normal. I push his medication through a syringe 3 times a day and I have had this routine for over 3 years now. Everything Lincon eats and drinks goes through his g-tube. I set the pump up and clean it four times a day everyday. In the past I would panic when Lincon has pulled out his button. It was a trip to the emergency room every time. Now I change it at home every three to six months with out a worry. I have begun to accept that I realize that he may have a g-tube his whole life.

Some of Lincon's disabilities I seem to forget at times. The other day we were at the doctors and they asked about Lincon's vision because he is legally blind. He can see about 3 ft, but doctors are not sure how well he can or cannot see. Its just a habit to hold things close to Lincon for him to see them. I know that Lincon legally blind, but it was like for a moment I had forgot. When I buy toys for Lincon I always buy things that have lights or make sound because of his poor vision. It become so normal for me that at times I completely forget.

I have come to accept the reality that my son might not ever have words to say I love you. All though his smile is enough for me. His laughter when I tickle him, his cry when he is upset and his yells/screams when he is excited is how he communicates. I have hoped for years he would start to learn some words. Even if his only word was mom. Its okay though because I have learned his language and I understand him.

The one thing that always reminded me that Lincon had a brain injury is his seizures. They are hard to manage with medications as he is on the max dose for each. Every morning and every night I give him his anti epileptic medications twice a day and his CBD oil three times a day. Despite the medications he still has seizures everyday. They started as absent seizures that were extremely hard to notice. Most people would not know Lincon's was having a seizure if they did not know him. Then the atonic seizures started they were more noticeable. Lincon would just go limp for 10 to 20 seconds. Thankfully, these stopped with an increase of his medication. Then the clusters of myoclonic started. At first, he would have one every few days. They increased more and more until on a good day he would have 10 and a bad day 30 or more. So, his neurologist added a third medication to decrease the myoclonic seizures. We had a period of decreased seizures, but it came with many side effects. He was Tired, drowsy, had a loss of coordination and he drooled constantly. At one point I told his doctor I would not increase it any further as the side affects were too great. We had some good seizure control for a few months, but they came back like they always do. As seizures begin to increase again, we had to increase this medication to the recommended dose very. We gradually increased it over about three months. Every time we think we are starting to get some seizure control they come back. When they come back its like they are worse than before.

It is a difficult reality I live raising a son with a brain injury and special needs. I always wished he would just be "normal" again. I wished for years that Lincon would relearn some of his lost skills. I wished for so long that he would be able to eat, walk, talk, watch TV, play with regular toys, use his right hand or even tell me when he needs to use the toilet. I love my son very much. I am at a point that I am coming to terms with our new reality, but I am scared. I fear how I will continue to care for him. Some days I worry about how I will continue to care for him as he grows. No matter what I will manage, and I will adapt. I will continue to learn the best possible way to care for Lincon and help him reach his full potential. Ill care for him for the rest of his life because I love him unconditionally. Even if that means my life and dreams are on hold. As long as I am physically able to care for him.

Brain injury is very misunderstood. They range from mild to severe and are devastating to the individuals and their families. Lincon's brain injury left him with severe disabilities. It has affected not just Lincon but our whole family. I would love to see more awareness and more education about brain injuries. I will wear green for someone I love everyday this June. Let us shine a spotlight on brain injury this month!