

Meet Waawaate

Personal Story

Waawaate Ma'iingan (Anishinaabe for Northern Lights Wolf) was born August 13th 2016 via emergency c-section at 28 weeks exactly. She weighed only 740 grams (1 lbs 10oz). I sought help 24 hours before she was born, because I couldn't feel her moving. Her movements became less and less and that really became a huge worry for me.

The on-call obstetrician decided that I needed to be rushed by ambulance from my small town to the big city where there was a neonatal intensive care unit (NICU) equipped to deal with high risk pregnancies and premature infants.

When we got to Toronto, an ultrasound revealed that I had a very large, concealed hematoma and that baby was brain sparing (baby adapting its circulation to preserve oxygen and nutrient supply to the brain). The risk for me bleeding out was incredibly high. The doctors explained to me that the chances of Waawaate being born still would be extremely high and to prepare for that outcome.

Despite what the doctors had thought, my beautiful baby was born breathing and was immediately whisked away to the NICU. She suffered several brain bleeds leaving her with post hemorrhagic hydrocephalus. I didn't even know what hydrocephalus was, let alone how to pronounce it.

The neonatologists tried to convince us that our baby should be taken off of life support. That her brain was too damaged and that she wouldn't have any sort of good quality existence. We ignored them and let Waawaate choose whether she wanted to stay here with us or not.

They waited until she was a little over three pounds to do her first surgery giving her an Ommaya Reservoir. The neurosurgeons would come by daily to check if she needed tapping. We began to know exactly when she needed to be tapped, because she would do what they call in the NICU as "swinging" which I believe just means that her heart rate and respirations would plummet significantly and then climb back up.



Her first ventriculoperitoneal (VP) shunt was placed in late October of 2016. Soon after surgery Waawaate developed bacterial meningitis - a severe infection of her entire shunt system, which nearly took her from us. That initial infection made her hydrocephalus more complex. They actually implanted a second shunt to manage her hydrocephalus better, after the infection was treated.

She was in the NICU for 131 days and then in and out of hospital because of hydrocephalus complications and shunt related issues for another 6 months.

She had 9 brain surgeries in her first year of life.

Waawaate has a cystic fourth ventricle in her brain that requires ongoing sedated MRIs every three months. Her neurosurgeon keeps a very watchful eye on her.

The fourth ventricle has been a constant worry for us, it creates a lot of anxiety and stress. The cystic ventricle is located very close to some of the most delicate parts of her brain. It

lives very close to the brain stem. If anyone has ever studied the brain, then you would know that the brainstem is life. It controls all involuntary muscles, such as the heart rate, smooth muscles of the digestive tract, our consciousness and our breathing. If that weren't enough to worry about, this cyst is also pushing up against Waawaate's cerebellum, which is in charge of balance, coordination, speech, etc.



As it stands right now, Waawaate does not walk or talk. Her doctors are unsure if her cyst is causing these issues or if it's a little of everything combined. She has also been diagnosed with triplegia cerebral palsy.

Despite her medical fragility and her diagnosis (and everything else that she has been through so far) Waawaate is by far one of the happiest kids I have ever been around. I am just so in awe of her strength, determination and love for life. She is a true gift and she is my hero.

-Amie Walker



Hydrocephalus Canada

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Canadians living with hydrocephalus.

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