

I'm Not Alone...Neither Are You



My Name is Hailey Walker, and I have felt so alone and defeated when it comes to having spina bifida, that was until I found Hydrocephalus Canada (HC).

When I was born, I had what we called a "tail". It was a little sac at the base of my spine and my left foot was completely paralyzed. Turns out, I was born with myelomeningocele, the most severe form of spina bifida.

At two months old, I was seen at Sick Kids Hospital in Toronto, where my family met the most wonderful neurosurgeon, Dr. H. He took one look at my back and confirmed the diagnosis. I had my first surgery to repair the sac at five months.

I endured many additional surgeries throughout my childhood, including two surgeries for tethered cord. I was able to start and keep walking and I gained strength in many areas. Until the age of 16, I continued with physiotherapy and checkups at Sick Kids and Holland Bloorview Kids Rehab. Dr. B, who was also a one of a kind doctor, who monitored my condition.

I'm 25 years old now and have fallen through the cracks of our healthcare system. I have experienced everything from no support to being told "oh you're fine, you don't have anything to worry about", to being sent home from hospitals because I am a "hypochondriac."

Well, I did have something to worry about... for the past 7 years I have been in constant, agonizing, brutal pain in my lower back, and both legs. I've suffered with massive migraines, numbness, loss of balance, falling, and more. I never felt heard or understood by the numerous health care providers I encountered and would often be told I was seeking drugs (because I'm young with a tattoo) or that "I'm young and should bounce back."

Eventually, I lost my job, had no income and was in even more pain because I couldn't afford any medication do deal with it, not even over-the-counter. I couldn't physically participate in family events like Christmas or birthdays because the pain was unbearable.

My new family doctor was trying everything he could to figure out what was wrong with me, but with him not knowing much about spina bifida, it seemed he was going in a circle. Then one day, I broke down, and I googled "spina bifida support group" and I found Hydrocephalus Canada. I found out through their website, that even though it isn't in the name, they provide information and support to people like me living with spina bifida.

I picked up the phone, and on the other end was someone who knew exactly what I was going through, who listened to me and made me feel like I actually am a human being. I do have family and friends who support me to the fullest, but to know that I was speaking with someone who could relate on my exact level, that was one of the most amazing feelings!

HC staff listened, supported me, and could actually relate to everything I was saying. With their help, we put all the pieces together and suggested I contact a nurse practitioner who assists young adults with spina bifida transition and connect to appropriate adult health care providers. The nurse practitioner booked me an appointment and she is helping me get to exactly where I need to be. Tests were done that confirmed my spinal cord has tethered again. The testing also indicated additional concerns that if left unmonitored and/or untreated could lead to serious health issues.

I am beyond grateful that this is all happening. I am 100 times closer to being where I need to be than I have been in the past 7 years!

I want, actually I need, to express to those living with spina bifida and/or hydrocephalus to know that you are not alone. I can honestly say that after years of being pushed aside and told “no” and wanting to give up - It does and will get better!!! I can’t stress this enough.

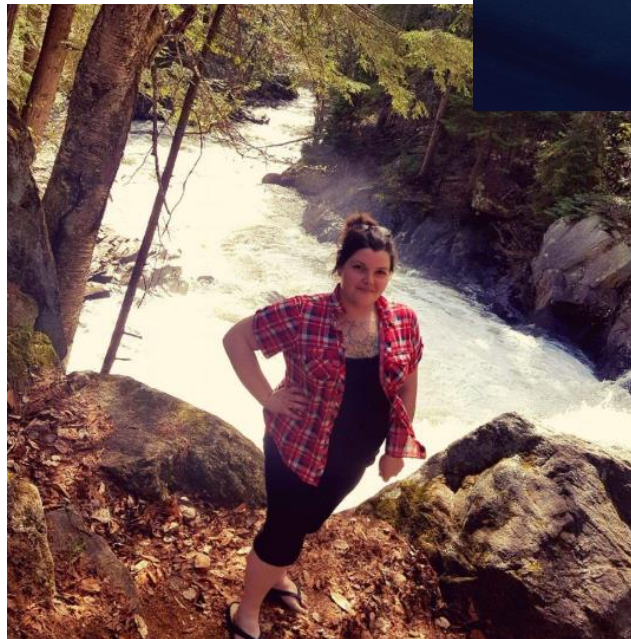
Without Hydrocephalus Canada’s support and assistance, I don’t know where I would be or if I would have actually got the help I needed before any more damage was done.

Thanks to Hydrocephalus Canada, they may have potentially saved my life in more ways than one! Remember, you are never alone in this!

Sincerely,

Hailey Walker

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Hydrocephalus Canada

We are the voice of Canadians living with hydrocephalus & spina bifida.

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

We do this by establishing environments that protect, support and enhance the lives of those living with, or at risk of developing, hydrocephalus.



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