

## I was diagnosed with hydrocephalus in 1994. I was 28

Everything just spiralled and happened so quickly. There was no time to process what was going on or what was to take place. It was a very emotional time. I was scared and didn't know what to expect or what the outcome would be. We were told the risks, but basically had no choice. The alternative was worse. It was the longest two weeks in the hospital. Recovery was two months.

To date I have had nine surgeries and five seizures. The emotional strain of living with hydrocephalus can be immense, and at times devastating. The unpredictability of this condition causes feelings of fearfulness and helplessness. I have at times become depressed and frustrated with the uncertainty of not knowing when another shunt revision will be needed.

It is hard to relax and I am always watching for possible signs or symptoms of shunt failure. Since the symptoms appear suddenly, and my condition deteriorates rapidly, timing is everything. A delay in a shunt malfunction and revision could result in permanent brain damage, and possibly even death.

Sault Ste. Marie, Ontario does not have any neurosurgeons, and for the longest time only two neurologists visited on a monthly basis. Thankfully, we now have a full-time neurologist. However, in an emergency, I still need to be taken by air ambulance immediately to Sudbury to be seen by a neurosurgeon. It isn't easy leaving family and friends behind, but I'm thankful that the nurses and staff there were caring and compassionate.

Each surgery takes its toll on me and my family, and recovery is a very slow and long process. But it is the financial burden that is always a constant worry. We have done a lot of research, and have had to fight for financial stability. And even though it has been a struggle and a process, our knowledge, motivation and persistence finally paid off. With the help of many organizations and programs, we've been able to own a home, and secure a steady income as well as medical and transportation benefits.



*Troy and Annette Chandler have turned a difficult diagnosis of Hydrocephalus into dedicated support for others living with the condition*

My condition with its symptoms and treatments has a great impact on daily life. At one point, it forced me to give up my full-time job and switch to part-time. I frequently suffer from fatigue, back pain, osteoporosis, trigeminal neuralgia, short-term memory loss and anxiety attacks. Sometimes it can be difficult, because I feel I am slowly losing my independence and losing control over my life. Frequently I need to follow up with doctor's appointments and regular testing such as physiotherapy, medication monitoring and CT scans, to hopefully prevent any unexpected setbacks.

But all in all, I try to maintain a positive attitude and my outlook on life is very simple, in that I have learned to appreciate life more and not to take anything for granted. We just take one day at a time simplifying and enjoying life with as minimal stress as possible. Health, happiness, and quality time with my family and friends are what are important to me. Life is too short and I just want to live life as normally as I can.

Well it has been 14 years now since my last shunt revision. I'm now 50 years old. Annette and I have been married for 25 years, and have two grown up kids. Both of us wanted to find out if there were other people here in Sault Ste. Marie with hydrocephalus that we can relate to and share our experiences with. We decided to make our own personal website and share it locally.

With the help of SB&H, we now play an important role of being a community contact, offering support to others through the Association's linking program. Thankfully, with the important and useful information they provided us, we will be able to offer support to others.

Annette and I also organize a Spirit Wheel Walk Run in Sault Ste. Marie each June, in honour of Spina Bifida & Hydrocephalus Awareness Month. In the five years we have been running the event, a total of \$10,000 has been raised for SB&H! All proceeds go towards vital SB&H programs, services and direct support. We are so proud of the incredible generosity of the Sault Ste. Marie community! We went from a dozen people participating in the first walk in 2012 to almost 100 participants in 2016! Annette and I are very much looking forward to another successful walk in 2017. After all it's about people helping people right? We just want to pay it forward!

The Association needs the help of donors like you to continue their good work. I urge you to support SB&H with your gift \$40, \$60, or any amount you choose to donate. Consider joining the Monthly Giving Club which may be more convenient for you and provides the Association with stable, predictable funds, while reducing administrative costs.

Please give generously. Your donation now will enable SB&H to continue delivering care, support, guidance and information to people like me. The Association receives no government or United Way funding, so your thoughtful gift will ensure that SB&H will be there when it matters most. Any contribution you can make is very meaningful. Your gift today could make all the difference in someone's life.



## 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.

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



Bridging, Advocacy, Research & Innovation  
With Awareness, Education & Support

[MyBrainWaves.ca](http://MyBrainWaves.ca)