

Epilepsy News

~ Special Anniversary Edition ~

The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Special Edition - November 2003

Happy 20th Anniversary Epilepsy Newfoundland and Labrador!

Back in 1983 a mother was talking with her son's doctor. The diagnosis was epilepsy. That mom, like so many mom's before and after her was very troubled by the news. Epilepsy - what was it, what would happen, would her son be ok?

The mom decided to learn as much as she could about epilepsy. Searching for support and information, she found little. Something was needed in Newfoundland and Labrador to provide people with epilepsy and their families with the help they needed. And so it was that this mom decided to do something about it. She gathered together a small team of volunteers, and from their work and dedication Epilepsy Newfoundland and Labrador was born.

While small at first, ENL soon began to grow and expand, offering information and services to those in need. Bridging the gap between the medical and the social realities of living with epilepsy.

It's now twenty years later and Epilepsy Newfoundland and Labrador is still going strong thanks to people like you who



recognize the need for our services and make that extra effort to help the more than 10,000 men, women and children who struggle with epilepsy every single day. The assistance you offer allows us to continue to provide vital support and services directly to the people of this province.

Oh, and that mom who started it all, she's still with us and still working hard for epilepsy education. Her name - Gail Dempsey, our Executive Director who has served the people of Newfoundland and Labrador well for the past 20 years, and we hope will continue to do so for years to come.

To celebrate our anniversary, we've printed this very special edition of *Epilepsy News*. In it you'll find the stories of some of the people we have had the pleasure to meet or help throughout the years. We invite you to take a moment and share the touching and amazing stories of their experiences with epilepsy.

Pamela Anstey, Information Officer, Epilepsy Nf & Lab

The Determination to Help

More and more people are understanding what epilepsy is and what it is not, thanks to 12 year old Ashley Tuttle from Shearstown, Newfoundland. Ashley's brother has epilepsy, and because of him, Ashley committed herself to learn, and to help teach others.

Ashley contacted Epilepsy Newfoundland and Labrador to find out everything she could about epilepsy. She wrote a report and presented it to her classmates and grade six teacher at Amalgamated Academy in Shearstown. Ashley also put the information she had gathered into a pamphlet so she could share it with others. She named her pamphlet *Epilepsy is the Misunderstood Disorder*.

Ashley was determined to let people know all she could about epilepsy. In a letter written to Gail Dempsey, Executive Director of Epilepsy Newfoundland and Labrador, Ashley says, "I am very

thankful to have been able to use your information not only to help my project but for my classmates as well as teachers to enjoy, learn and understand more about epilepsy.

In November, Epilepsy Newfoundland and Labrador mailed approximately 2,000 of Ashley's pamphlets across the province to help teach people about epilepsy. Ashley said it was a real honour to have her pamphlet printed and distributed.

Ashley has proven that everyone can do something to help, whether it is canvassing door to door, teaching seizure first aid, or producing a pamphlet - whatever your particular talent may be. Epilepsy Newfoundland and Labrador would like to thank you, Ashley, for all your hard work. You have made a difference!

From Epilepsy News, Winter 1999

*By learning you will teach, by teaching you will learn.
~ Latin Proverb*

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A Helmet for Michael

It was my first day on the job, and like anyone would be, I was nervous. Wanting to do everything just right, afraid I would mess up. I knew very little about epilepsy, but I was determined to learn, and determined to help in any way I could.

As I sat down at my desk I noticed a message waiting for me. It was from a mom who had a son with a severe form of epilepsy called Lennox-Gastaut Syndrome and was looking for some information. Taking a deep breath I called her up.

She told me about her son Michael, who has had myoclonic or 'drop' seizures for some time. Michael was required to wear a helmet to protect his head when he fell. But the hockey helmet he had been wearing just wasn't working well enough. Michael's mom said that the pediatric neurologist had told her about something called a 'seizure helmet', specially designed for kids like Michael, and if she could find one, that would be best.

But where to find one? She didn't know. But like any mom would, she was determined to do all she could to protect her children from harm and injury. And so she had called us to ask for our help. After our conversation, I sat with Gail, our Executive Director. We had never heard of a seizure helmet either, but if there was one to be found, we were determined to find it.

We started our search by sending word out across Canada to all members of the Canadian Epilepsy Alliance, to see if anyone had heard of a seizure helmet. One group wrote back that Bloorview Hospital in Ontario had a program to make such helmets. A lead! We contacted Bloorview and found that Bloorview custom made all their helmets, but to be fitted, the person would have to be there in person. A dead end!

So we went back to the drawing boards. For days we researched, looking for a company that could make Michael's helmet. Time was of the essence because school would be starting soon and without his helmet, Michael couldn't join his classmates back at school.

And then a breakthrough! A company in the states made exactly what we were looking for. But how could we get one fitted? We called up the Orthotics Department at the Janeway Hospital, and even though they had never fitted a seizure helmet before, they were willing to measure one for Michael.

And so it was that not three days later, Michael, along with his mom arrived in St. John's to be measured for his very special helmet.

It's been a few weeks of waiting, but Michael has his helmet now. Michael loves his new helmet and his mom breathes a little easier knowing her son will be just a little safer each day as he faces the challenges of his epilepsy.

No one has to face epilepsy alone. People are here to help, and eager to help if asked. Together we can help to make living with epilepsy a little easier, and a little less lonely.

*By Pamela Anstey, Information Officer, Epilepsy Newfoundland and Labrador
From Epilepsy News, Fall 2003*

*We can't help everyone, but everyone can help someone.
- Dr. Loretta Scott*

A Life Altering Experience

One day four years ago, Anne Marie Hagan was driving to Marystown from St. Lawrence when her Toyota Tercel zoomed off the highway straight into a ditch. Her passenger didn't understand what had happened - he told Hagan that she didn't even touch the brakes as they bundled off the road.

After the accident, Hagan's doctors recommended that she have an EEG, a diagnostic exam which monitors brain activity. The test appeared to show some abnormalities. A subsequent MRI scan showed that there was a growth in the right temporal lobe of her brain. Following that first incident on a lonely stretch of Burin Peninsula highway, the seizures caused by the malformation began to become more and more frequent.

And they weren't characteristic of the violent convulsing and shaking many people envision when they think of epileptic seizures. Instead, Hagan would go into a full fugue state. She would go for a walk and get lost - she would be strolling near St. Theresa's Church, then suddenly find herself a kilometer away on Empire Avenue with no recollection of how she got there. She would have a seizure and hang up on people in mid-telephone conversation. She would spontaneously start smacking her lips, as her brain told her throat that something was wrong.

The changes were difficult to deal with for a 39 year old professional who had enjoyed good health all her life. "You're a grown woman, very independent, you can live your own life, and all of a sudden you're reduced to a child in front of people - lip smacking and mumbling,". Then she recalls intimidation and fear began to set in. At age 40, she gave her sister power of attorney, allowing her to make decisions in case she was incapacitated.

Hagan could never wear button up clothing, because a seizure might cause her to pull at her buttons and remove her shirt. She worried about having seizures while shopping, wandering out of a store with something and being picked up for shoplifting.

And the year after that first seizure, she was forced to give up her driver's licence. For someone who rolled over 55,000 kilometers on the odometer every year, it was a tough pill to swallow - the final signal that she had lost her independence and freedom. "When this happens, it blows your world apart," she says.

While many epilepsy patients can take drugs to control their seizures, that type of treatment regime didn't work for Hagan. She required a more drastic solution. In December 2001, doctors determined that she was a candidate for brain surgery - not everyone is. On February 28, 2002. Surgeons removed pieces of skull, cut under the covering of her brain and removed the lesion. They then put her back together again.

The stakes were high - if things went awry, she risked amnesia, a stroke, even death. "When you have to face an operation that affects your future quality of life, that's an experience that changes you forever," she says.

Since the surgery, she's been seizure free. She realizes there are no guarantees, but aims to make the best of things. "This is a second chance at life," she says. "Whatever time you have left, make the most of it."

There was an upside to her struggle with epilepsy - the disorder made her realize her own inner strength. "A disorder that affects your body, that's intimidating. But something that affects your mind, your ability to concentrate, your memory - it's not only intimidating, it's embarrassing. We take our mind, the ability to think, for granted."

Two years ago when she was gripped by her battle with the disorder many doubted she could continue in financial planning if she couldn't drive. But she decided to stay and battle through. It's a decision she hasn't regretted. "You know what the problem was with my thinking I couldn't do it? People had told me it couldn't be done."

Today in her office overlooking Churchill Square, she keeps a brochure about epilepsy displayed in a prominent place on her window ledge. Whenever a new client comes in, she explains her condition to them, and warns them what a seizure might look like. She tells them not to be afraid. Why does she keep the brochure in the window? "Why hide? Secrets isolate us."

On March 1, 2003, if she remains seizure free, her driver's licence will be reinstated. When - and if - she gets it back now seems a bit more trivial in the grand scheme of things. "A driver's licence will never be as important to me again. Do you know why? Anything that you lose that hurts you, never quite becomes as important again."

She feels she must share her story to let people know it could happen to them, and show her appreciation for the support provided by her family, friends and co-workers. "I never would have chosen epilepsy; it's too frightening," she says, "but epilepsy chose me."

By Rob Antle, The Telegram, November 2002

Editor's Note: Anne Marie remains seizure free to the present day. Her driver's licence has been reinstated.

*No act of kindness, no matter how small, is ever wasted.
- Aesop*

A Baby to Hold

I was diagnosed with epilepsy when I was 25. During my first pregnancy I suffered the usual backache and morning sickness. (well morning, noon and night sickness!) However my seizures were well controlled, and even though I was on high doses of anti-epileptic medications, I had a beautiful little baby girl; Leah.

When Leah turned 2 ½, my husband, Leah and I decided it was time to have another baby. I was prepared for the usual pregnancy symptoms but nothing could have prepared me for what we would face during my second pregnancy.

I was in my fourth month of pregnancy when I started seizing. They were small at first, then gradually progressed to grand mal seizures. I seized so often I knew almost all the ambulance drivers on a first name basis. Two weeks before Christmas, 1999 I was hospitalized for 10 days. My medication was increased and my seizures subsided - temporarily.

My husband Calvin and I were desperately worried about the medications affecting our unborn baby not to mention the effect all of this was having on our daughter Leah. There is nothing more heartbreaking than having your 3 year old crying in the window as you are being loaded into an ambulance, especially after she has just witnessed you having a grand mal seizure.

Thank God most of my seizures occurred while my husband was with me. Sometimes I had to call him at work when I felt one coming on and started to seizure. He would have to leave immediately. Those times were especially difficult for Calvin and I because we have no family living close by.

I was hospitalized for the second time in late spring. My neurologist again increased my medications and added another one. However my seizures were unrelenting. I returned to the hospital in late May for the duration of my pregnancy. My mother had to take Leah to Gander. I hated to be separated from her but it was our only option.

June 19, 2000 at 8:43 am our 5lb 15 ounce beautiful baby girl, Amy Dawn, arrived prematurely. Due to her premature birth, Amy had a few minor problems, but otherwise was in perfect health. The doctor's had to take Amy early because they could not get my seizures under control. Considering everything that she had been through we were amazed and thankful.

My seizures continued after Amy's birth. Life was hectic enough with a 3 year old and a newborn baby, but having to deal with seizures constantly certainly added to the frenzy. My husband was a nervous wreck when he went to work. Luckily we were able to get a home care worker with us for when I was alone.

Currently, I might have one small seizure a week, which is a walk in the park compared to what I had before. Amy is a happy thriving handful. I am so thankful for my girls and a very supportive husband. Although at times my pregnancy with Amy was hard to cope with, it made us a much stronger family. My husband and I are so grateful for our two little miracles, Leah and Amy.

*By Yvonne White, Portugal Cove
from Epilepsy News, Summer 2001*

Did You Know?

- Epilepsy can affect anyone at any time
- About 1 or 2 in every 100 people has epilepsy.
That's about 10,000 men women and children in Newfoundland and Labrador alone.
- Epilepsy is the second most common neurological problem (behind headaches)
- Each day in Canada, an average of 38 people learn that they have epilepsy.
- 60% of new patients are young children or senior citizens.
- The prevalence of epilepsy in persons over the age of 65 is approximately 7%: 1 in 14 seniors.
- 10% of the population will have at least one seizure in their lifetime
- Childhood is the most likely time of diagnosis, with 55% of the cases diagnosed before the age of ten
- Some of the most creative and talented people in history have had epilepsy, including: Alexander the Great, Julius Caesar, Dante, Joan of Arc, Isaac Newton, Napoleon Bonaparte, Beethoven, Charles Dickens, Vincent Van Gogh, and Agatha Christie.
- Most people are more hurt by the ignorance of others and the stigma than they ever are by the epilepsy itself.
- You can learn lots more at the Epilepsy Newfoundland and Labrador website: www.nfld.net/epilepsy/



Want more epilepsy information? Contact **Epilepsy Newfoundland and Labrador**, 261 Kenmount Road, St. John's, NL, A1B 3P9

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