



Epilepsy: Canadian organizations support research and raise awareness

By Elaine Cohen

The odds are you know someone with epilepsy. The seizure causing disorder affects one in 100 Canadians. About 15,500 Canadian cases of epilepsy are diagnosed annually. There is no cure for the condition, but medication allows up to 70 percent of those living with epilepsy to manage the seizures and live productive lives.

Gary Collins, president of Epilepsy Canada, one of the leading advocates for epilepsy research, says, awareness of epilepsy and its effects on families has been muted by the historical reluctance of patients to talk about their disorder. "When a person is diagnosed with epilepsy they are immediately subjected to a series of restrictions. Their driver's license is suspended, they can lose their standing at school, and in many cases become subject to job discrimination." The fears of others and the stigma that accompanies epilepsy has, until recently, discouraged people with epilepsy from speaking out.

It is interesting to note that Epilepsy Canada was founded in Montreal but is now headquartered in Markham, Ontario. Epilepsy Canada is an important funder of epilepsy research at Canadian hospitals and universities. It is celebrating its 50th anniversary and assists those with epilepsy to tell their stories. You can read some of them at www.epilepsy.ca.

Epilepsy is characterized by sudden, brief changes in how the brain functions. It is a symptom of a neurological disorder that affects the brain and results in seizures. The latter is an outward sign of a temporary electrical dysfunction of the controls of the brain. A seizure may appear as a convulsion, a brief stare, muscle spasms, odd sensations or altered consciousness. Although many people can be successfully treated, research is needed to find a solution. Drugs are not a cure and work better for some than others.

The Savoy Foundation

The legacy of American-born, pro-active visionary George A. Savoy illustrates how tolerance, education and support for medical research have improved the quality of life for thousands with epilepsy. Savoy came to



George A. Savoy
(Photo credit, The Savoy Foundation)

Quebec in 1921 to manage his ledger business. In the early years, Savoy was called upon to supply items Dr. Herbert Jasper, a pioneer in Electroencephalogram (EEG) testing, needed at the Montreal Neurological Institute (MNI). Dr. Jasper and MNI founder Dr. Wilder Penfield used EEG tests to pinpoint the source of seizures in epilepsy and other brain disorders. Savoy developed fan-folded and EEG lined paper first used at the MNI. He also empathized with the needs of people with epilepsy and immersed himself in several organizations and fundraising programs. To counter sectarianism, Savoy built Dieppe House, an inclusive institution that served as a home for individuals with epilepsy. Subsequently, renamed Foyer Savoy, the facility was sold in 1988. Proceeds were used to increase the endowment of the Savoy Foundation.



Johanne Gaudet cuddles daughter, Emma.
(Photo courtesy of Johanne Gaudet)

A spokesperson for the foundation recently pointed out, Savoy is the only private Canadian foundation that distributes large amounts specifically for epilepsy research at hospitals and universities in Canada. Close to \$400,000 are dispersed annually in studentships, fellowships and grants.

Since the 1930s, family members George Arthur Savoy, Paul Savoy, Harolde J. Savoy, George M. Savoy, Caroline Savoy and Sophie Savoy, along with generous donors, have consistently supported research in the prevention, diagnosis and treatment of epilepsy. For information, visit www.savoy-foundation.ca.

Parents share stories and offer advice

JoAnne Mosel and Johanne Gaudet are savvy parents of children with epilepsy. They share their experiences with readers and offer practical tips.

JoAnne Mosel's adult son has a neurological disorder that manifests mainly in sleep issues, traits of autism spectrum disorder and seizures. "The seizures and side effects of the medication he takes to control them impact his gait and energy levels," she said.

Mosel believes Richard was probably having absence type seizures most of his childhood. "We only began to medicate him at 13. At 18, he experienced his first generalized tonic-clonic (grand mal) seizure. Richard has been on many different medications."

Mosel encourages parents not to hesitate when it comes to questioning pediatricians. "I wish I knew then what I know now. Young parents today are still unsure of how to proceed when they suspect their child may be seizing."

Gaudet, a resident of Saint-Lin, is the mother of Emma, five-and-a-half. Emma has Shaaf-Yang syndrome, which is caused by heterozygous mutation in the MAGEL 2 gene. Although Emma has faced multiple challenges since birth, she did not have a seizure until July 2016. "Emma's absence (petit mal) seizures tired her out and nothing [medication] helped until December, when we found two drugs that worked together. So far, she has been okay," Gaudet said, adding Emma cannot communicate but is a happy child and is able to entertain herself tuning into Disney movies on her iPad.

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"Do not despair," she advises parents. "It's a long process and very frustrating but there is hope. It takes time." Several caregivers interviewed expressed similar views. Although it took time to find the right prescription and build up a level, patience and compliance did pay off.

(Epilepsy Canada input courtesy of Phillip Newsome, Telescope Brand Vision)