

August 2017

Late Summer Edition



EPILEPSY AND SEIZURE ASSOCIATION OF MANITOBA

# Epilepsy Educator

## News from



2017

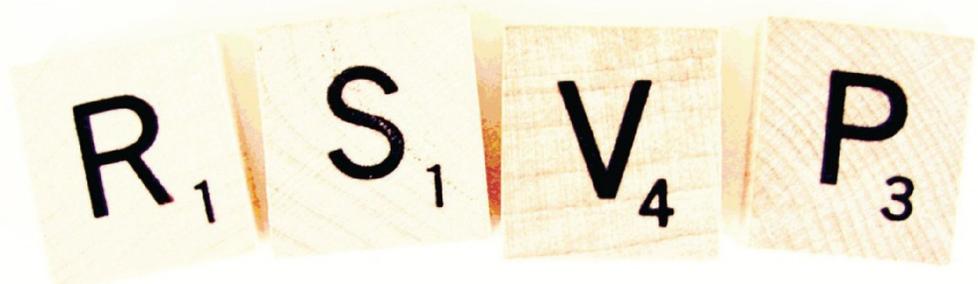
## Annual General Meeting

Date: Tuesday September 12 2017

Location: 170 St. Mary's Road (Central Church of Christ,  
basement)

Time: 6:30PM-9:00PM

Speaker: Dr. Demitre Serletis



To RSVP, please contact ESAM offices:  
Phone: 204-783-0466  
Toll-free: 1-888-780-ESAM  
Email: [epilepsy.seizures@gmail.com](mailto:epilepsy.seizures@gmail.com)

While everyone is welcome to attend, to vote at the AGM, a person must be a current paid member of ESAM for the 2017-2018 year.

# Children's Hospital getting paediatric Epilepsy program thanks to donation



May 9, 2017 1:57 pm By [Keith McCullough](#) Reporter CJOB

Winnipeg's Children's Hospital is getting a new unit specializing in treating children with Epilepsy.

The new paediatric epilepsy and paediatric neurosurgery program is being made possible by a \$2 million donation by Michael Schlater and his wife Lilibeth. Schlater is CEO of Domino's Pizza of Canada.

Schlater suffered his first seizure at 47 and eventually needed brain surgery. His now 26-year-old daughter had her first seizure when she was five.

He said he's happy to help add something that's been missing in Manitoba.

"I was stunned when I found out they didn't have it," he said. "To me this is something that makes a huge difference."

An estimated 9,000 people in Winnipeg live with Epilepsy. It's a chronic neurological condition characterized by recurrent seizures. Nearly 85 per cent of diagnoses are made in childhood but, until now, Manitoba didn't have a special unit to treat children struggling with it.

"Currently wait lists to refer these patients out of province are up to two years in some cases," said Dr. Demitre Serlitis, a neurosurgeon at Children's Hospital who has been behind plans for the new unit. "The province has spent up to \$1.5 million in the last six to seven years, sending these patients out."

The new unit is expected to put Manitoba on the cutting edge of epilepsy treatment. It will feature two new beds and the hospital is hiring two paediatric Epilepsy neurologists. They will start in the fall. The plan is to start seeing patients in 2018.

<http://globalnews.ca/news/3438384/childrens-hospital-getting-paediatric-epilepsy-program-thanks-to-donation/>

# Living with epilepsy-Every Manitoban living with epilepsy has their own story to tell. Here are three

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**Chris Kullman**

Chris Kullman, 37, says he's unlucky, not because he has epilepsy, but because his seizures refuse to co-operate.



About a year ago, Kullman decided he wanted to know if he might be a candidate for epilepsy surgery, which can be successful in freeing epilepsy patients from seizures 60 to 85 per cent of the time.

But surgery cannot be undertaken until the "focus" of the electrical activity in the brain that causes seizures has been located and a determination has been made that surgery can be undertaken safely.

The first step in the long and exhaustive assessment process is to have an electroencephalogram (EEG), a brain scan that records the electrical activity that causes seizures.

But in three tries - the most recent lasting eight, 24-hour days, during which he was off medication - nothing has happened.

"I just have no luck," he says, speculating that it might be years before he has an answer.

Kullman likely has had seizures since birth, during which forceps damaged his skull, causing scarring on the right side of his brain.

But, like many infants and young children, his seizures were never identified as such, and instead were dismissed as a form of daydreaming.

The staring spells lasted into puberty, when growth and hormonal changes likely triggered his first serious seizure, alarming his parents and landing him in hospital and an eventual diagnosis.

Since then, the pattern of his seizures has repeatedly changed, including a three-year period during which he inexplicably was seizure-free.

For the past seven years, his seizures, usually at night, have occurred at fairly regular six-week intervals.

Kullman says the seizures are nothing compared to their dreadful, panicked aftermaths.

"When I come out, I'm in an extreme state of fight or flight. It's terrifying and horrific. I can handle the pain and discomfort, but not that." "I go to sleep at night not knowing if I have to go through it. I want the seizures to end."

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<http://wavemag.ca/2017/06/living-with-epilepsy.php>

## Every Manitoban....continued from page 3

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### Mikaela Boulet



When Mikaela Boulet was just a teenager when she had to make a tough choice - whether or not to have brain surgery. In fact, she had to make the decision twice.

The first time came when she was 16. Doctors had determined that a brain tumour was causing her to have epileptic seizures. Remove the tumour, and the seizures would go away.

Unfortunately, things turned out to be a little more complicated.

During the operation, it was discovered that her tumour was larger and deeper than expected. It was also located close to the hippocampus and temporal lobe, parts of the brain that control memory and speech.

"Since I was asleep during this surgery, they (members of the medical team) were unable to talk to me, which prevented them from knowing if they could remove the entire tumour and surrounding tissue," explains Boulet. "They had to stop, leaving a part of my tumour and a section of my brain where seizures were taking place."

Following the operation, Boulet would experience more than her fair share of fear and anxiety.

The complex partial seizures continued, typically lasting two to five minutes, leaving her confused and exhausted. Despite being a high achiever as a student, she quit school.

But by the time she turned 18, though, things started to turn around. Medical tests, including a three-week EEG examination at a clinic in London, Ont., established that the tumour could be removed.

This set the stage for Boulet's decision on whether to go forward with the second operation.

Like the first operation, the second one was intended to remove what remained of the tumour and portions of her hippocampus and temporal lobe. But, given the location and depth of the tumour, the operation also carried the increased risk of leaving the straight-A's student incapable of learning or talking.

She says she was told the surgery could rob her of her memory. "The best description was that I might end up like Dory," the little fish in the movie *Finding Nemo* who suffers from short-term memory loss.

But while in London, she witnessed a patient whose seizures were so extreme that he was a danger to himself.

"I felt terrible for him, but I also knew that anyone can have the same thing. It could be me." Boulet chose hope, and decided to have the surgery. Now 20-years-old, Boulet says she is seizure free, but continues to take medication, just in case.

She's completing her first year of university.

"I'm surprised," she says. "I'm getting an A or an A-plus in everything."

### Tammy Humphreys



The way Tammy Humphreys remembers it, one minute she was riding in the back of a military vehicle on a night training exercise at Shilo, and the next she was waking up in hospital with her skull bruised in three places.

She has no memory of what happened that night in 1994, but it wasn't difficult to conclude that she had been tossed around and hit her head repeatedly.

Twenty years ago, a bang on the head wasn't taken as seriously as it might be today, says Humphreys. And besides, she was a young reservist who wanted to "look tough."

She dismissed her injuries, returned to Winnipeg and resumed her studies at university.

About one month later, her sister was visiting and found Humphreys in the throes of a severe seizure. She had never had a seizure prior to the Shilo incident, but frequent, severe nighttime seizures and occasional daytime "absences" have been the norm ever since.

Humphreys refuses to let her seizures hold her back. She's married, has a family and, until recently, had a part-time job.

"I'm not embarrassed by it," she says. "I have seizures. So what? I don't let it stop me. You can't put yourself in bubble wrap."

But three years ago, she'd had enough and decided to look into the possibility of having epilepsy surgery to address her problem. "I was tired of taking medication," she says.

So, like many Manitobans before her, Humphreys had a preliminary assessment and is now awaiting word from the medical team in London to learn what happens next.

"Yeah, it's hurry up, and wait," she says.

To read the full WAVE magazine, including the multiple articles on epilepsy in Manitoba, access the WRHA website at:

<http://www.wavemag.ca/2017/06/brain-storm.php>

ESAM would like to thank WAVE for including us in the article, and we would like to thank the people who volunteered to be interviewed for the article. What an amazing opportunity for epilepsy/seizure disorder awareness!

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<http://wavemag.ca/2017/06/living-with-epilepsy.php>

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# Australian researchers developing breakthrough treatment for epilepsy

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The Australian-12:00AM August 9, 2017-[Andrew Burrell](#)-



Researchers in brain bio-mechanics at the University of Western Australia hope the methods they are developing could be proven within two years.

As many as 70 million people have epilepsy, but about a third of patients are resistant to medications to control seizures. In extreme cases, sufferers can experience several seizures an hour.

University of WA researcher Karl Miller. Picture: Colin Murty

UWA's Karol Miller, leading the research in Perth, said surgery to stop seizures was risky.

He said a procedure being developed in Boston involved inserting invasive electrodes into a patient's brain to look for the sources of abnormal electrical activity. Researchers at UWA's Intelligent Systems for Medicine Lab — the world's most cited in the field of brain biomechanics — are then sent images to create a computational model of the patient's brain.

Professor Miller said this could better inform a neuro-surgeon about what part of the brain was emitting abnormal signals, minimising the risk of the operation.

“Opening the skull and inserting electrodes significantly deforms the brain,” he said.

“So if you can figure out the brain tissue displacement induced by opening the skull and inserting electrodes, the surgeon will know which bit of the brain to cut out.”

UWA last month signed a research collaboration agreement with Boston Children's Hospital, which is regarded as the world's best pediatric hospital.

Professor Miller said if the project with BCH were successful, his method should be adopted worldwide. “If this happens, I can retire,” he said. “I've worked on biomechanics of the brain for about 22 years now and if I can cure millions of people from epilepsy, then I can retire happy.”

# Moe 2017

The 25th annual Maurice Dumontier Memorial Golf Tournament was an amazing success! Thank you to everyone who golfed in the tournament, volunteered their time and donated to the event. With your help, ESAM raised over \$6,000.00!!! These funds help to ensure that our doors stay open to provide education, support and services to person living with or impacted by epilepsy/seizure disorder in Manitoba.



# Volunteer Board Members Needed

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## Get involved! Board members needed!



Are you passionate about helping to raise awareness of epilepsy/seizure disorder in Manitoba, committed to the continued provision of support and services to people impacted by epilepsy/seizure disorder? Then do we have an opportunity for you.....

ESAM is currently seeking volunteer board members!

The time commitment required is one evening per month for attendance at the general meetings. Additional commitment of volunteering at fundraisers/events whenever possible.

If you are interested in joining the board, or have any questions about joining the board, please contact ESAM offices at :

Phone: 204-783-0466

Executive Director Email: [esam@manitobaepilepsy.org](mailto:esam@manitobaepilepsy.org)

Administrative Email: [epilepsy.seizures@gmail.com](mailto:epilepsy.seizures@gmail.com)

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