

August 2015

Summer Edition



EPILEPSY AND SEIZURE ASSOCIATION OF MANITOBA

# Epilepsy Educator

## News from ESAM

# 2015 AGM Annual General Meeting



Date: Thursday September 17, 2105.

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

Time: 6:30PM-9:00PM

Guest Speaker: Dr. Marcus Ng will be speaking on seizures and sleep.



# RSVP

Please contact ESAM offices if you are thinking of coming to the AGM, it helps us to know the number of people when we are planning the event.

We hope everyone can make it to the AGM, your attendance and support is appreciated!

# IN MEMORIAM

SHIRLEY HUTCHINSON (nee MIDDLETON)

Peacefully, on July 9, 2015, Shirley passed away at the Health Sciences Centre, at the age of 86 years. She was predeceased by her parents, Thomas and Mildred Middleton. Shirley is survived by her brother Jack (Margo) and their children, Sean (Heather) and Lori Oxenforth (Ted); great-niece Zoe and great-nephews, Troy and Ethan; her Uncle Ray, her cousin Rhona, good friend Phyllis, as well as numerous extended family and friends. Shirley will be forever remembered for her caring nature and her willingness to give of herself to others. This is exemplified by her many hours of volunteer work for the St. Thomas Anglican Church-Weston, St. John's Ambulance, where she received her 50 year pin, her Legion at the Logan Branch and the Epilepsy and Seizure Association MB, where she received her 35 year pin.

In memory of Shirley, donations may be made to St. Thomas Anglican Church-Weston, 1567 William Avenue, Winnipeg, MB R3E 1A7. The family would like to say a special thank you to Allie, who was there for Shirley in her time of need. For those who wish to sign the online Guest Book, please visit our website. Chapel Lawn [www.chapellawn.ca](http://www.chapellawn.ca) 885-9715.

*As published in the Winnipeg Free Press on July 11, 2015*

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Kathryn (Kitty) Mary Newcombe (nee: O'Neill)

Nov 1921-July 2015

It is with deep sadness that we announce the passing of our beloved mother Kitty Newcombe, at the age of 93. Devoted wife of 49 years to the late Lloyd.

She will be deeply missed and always remembered by her children - Paul, Peter (Sharon), David, Barb Revoy (Gary) and Kathy White (David), along with her grandchildren Jennifer, Kevin, Christopher, Taylor, Kenneth, Carolyn, Heather, Leanne and Sheryl. Great-grandchildren Max, Sam, Lachlan, Rayne, Lucas, Parker and Arcadia. Sisters Anna and Billie, brother in law Wally and sister in law Vicki.

Kitty was predeceased by her parents Alva and Bill, along with her siblings Al, Shirley, Hilton, Barb, Rite and Jack. She will be remembered by many nieces and nephews.

The family would like to extend a special thank you to the staff at Oakview Nursing Home, and Kitty's wonderful friends and neighbours.

In memorial donations to the Canadian Cancer Society would be appreciated.

*As published in the Winnipeg Free Press on August 01, 2015*

## Brandon Epilepsy and Seizure Support Group Donates to BRHC

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The Brandon Epilepsy and Seizure Support Group donated proceeds from the Jeans Day 2014 campaign held in Brandon, Manitoba to the Brandon Regional Health Centre Foundation.

The group targeted the donation to the Pediatric and Neonatal Intensive Care Unit and funds were allocated towards a new cameral for their “Keepsake Program” for the Unit.

Photo: Karen Chrest, BRHC Foundation Director

Of Development and Sheena Ford, Brandon Epilepsy and Seizure Support Group Facilitator. Picture reprinted with permission from BRHC Foundation.



## Brandon Epilepsy and Seizure Support Group Changing Months Group Will Operate

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The Brandon Epilepsy and Seizure Support Group will now meet March-October, taking a break for those bitterly cold winter months.

The meeting time and location remain the same. Group meets the second Thursday of every month from 7-8:30 PM at the First Presbyterian Church located at 339, 12th Street S.

New faces are always welcome! If you have any questions about the group or would further information, please contact Sheena Ford at [sheena-fordm@gmail.com](mailto:sheena-fordm@gmail.com).

Information about the Brandon Epilepsy and Seizure Support Group may also be found in the CONTACT manual :

<http://www.contactmb.org/record/VMB7046?Number=1>



First Presbyterian Church



# 23rd Annual Maurice Dumontier Memorial Golf Tournament



What a wonderful day. The weather was beautiful, the people were great and the turnout was excellent! Thank you to everyone who supported the 23rd annual Maurice Dumontier Memorial Golf Tournament! A special thank you to Grant Drowsy and Birchwood Honda on Regent for sponsoring the hole in one.

We surpassed the proceeds raised at last year's tournament. The success of the tournament would not have been possible without the help of phenomenal people such as Tom, Robyn, Diane, Wes, Chris, Hanna, Joel, Stacey, Paul and Keith who continue to volunteer their time and energy at the MOE year after year and without whom, the day would not be possible. Thank you so much. ♥ ♥

A full list of hole sponsors and donors is available on both our website and our Facebook page.



## West Jet Ticket Winner

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Our West Jet Ticket fundraiser was an amazing success! The winning ticket was drawn on June 20, 2015 at the Maurice Dumontier Memorial Golf Tournament. Congratulations Dale! Our heartfelt thanks to West Jet for the donation of the plane tickets to ESAM.

## Teen gets device to prevent sudden death from epilepsy

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CBS News June 11, 2015 -**LOS ANGELES** -- There is new hope for [young people with epilepsy](#) after the U.S. Food and Drug Administration approved the implantation of a special device aimed at preventing people from dying in their sleep.

[CBS Los Angeles reports](#) 17-year-old Johnny Escolero is the first patient on the West Coast to receive the breakthrough treatment. He is recovering well after undergoing the procedure at Children's Hospital Los Angeles on Tuesday. The graduating senior suffers from as many as 250 [seizures](#) a day, but most of the time he remains conscious and aware of what's going on.

"It's really hard. You can hear the bones cracking and you could kind of twist a little and it hurts when you twist," he told KCBS-TV's Kristine Lazar. His biggest concern is when he has a seizure overnight, as 58 percent of sudden, unexplained epilepsy deaths occur during sleep. "Sometimes I stop breathing and sometimes I change colors," he said. His mother used to sleep in her son's bed, but now that he is a teenager, she reluctantly lets him sleep alone.

"I choose the room across him so I'd be able to hear him breathe," Olga Espinoza said. "I don't sleep." After years of sleepless nights, doctors have given Johnny and his mother hope in the form of the device called the AspireSR.

The device, which has a sensor attached, was implanted in Johnny's chest. It monitors his heart rate, which is important because studies have shown that more than 80 percent of people with [epilepsy](#) will have a rapid increase in their heart rate right before a seizure.

When his heart rate increases, the device kicks on, stimulating a nerve. "[It's] a nerve in the neck that sends information up to the brain, and by stimulating this nerve off and on during the day, we can send information to the brain, change the way the brain works, and we can decrease seizures," explained Dr. Deborah Holder of Children's Hospital Los Angeles.

After the procedure, Johnny and his mother went home and took a three-hour nap. It's the most uninterrupted sleep they say they've both had in years.

Source: <http://www.cbsnews.com/news/teen-with-epilepsy-gets-device-prevent-seizures-sudden-death/>

# Neurologists evaluate application of smartphones in epilepsy care

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July 1, 2015 -While many people with epilepsy can control their seizures with medication, those unpredictable and involuntary changes in behavior and consciousness can be limiting for others. Neurologists writing in the International Journal of Epilepsy evaluated the application of smartphones in epilepsy care.

The paper by Lakshmi Narasimhan Ranganathan and colleagues at the Madras Medical College Institute of Neurology in India has been selected for an Elsevier Atlas Award. Ranganathan's team evaluated the mobile applications available for the everyday care of patients with epilepsy. Those apps include seizure diaries as well as medication trackers with reminders to take the next dose of medication. In addition, apps are available to answer any questions patients with epilepsy might have, to detect potential drug interactions and to detect seizures. The latter type of apps senses the irregular motions characteristic of an epileptic seizure and automatically set off an alarm to alert caregivers and doctors.

"Almost all smartphones have a built-in GPS," Ranganathan said. "They have motion detectors and/or accelerometers. All of those gadgets, if properly integrated into a program, support epilepsy management." Ranganathan is already encouraging his patients to take advantage of these technologies. He predicts smartphones will be capable of much more. Already, researchers have shown it is possible to monitor electrical activity in the brain with a headset that sends the electroencephalography (EEG) signal directly to a smartphone. Continuous EEG monitoring could detect the spikes in activity that typically precedes seizures, to alert patients in advance.

The authors say that special sensors integrated into smartphones might allow continuous drug monitoring too. Rather than taking anti-epileptic drugs continuously and suffering from their cognitive side effects, people might take those drugs only when a seizure is coming on.

With almost one percent of people below the age of 20 and three percent of the total population suffering from epilepsy, and 30 percent of those patients refractory to medication, the development and adoption of these apps is of indisputable benefit.

Source: <http://www.news-medical.net/news/20150701/Neurologists-evaluate-application-of-smartphones-in-epilepsy-care.aspx>

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## ESAM Awards Two Scholarships

ESAM is pleased to announce that this year two scholarships were awarded to students in Manitoba living with epilepsy/seizure disorder(s).

The Ron Dixon Memorial Technical scholarship was awarded to a student at R.B. Russell school. Staff from ESAM presented the scholarship on June 26, 2015 at convocation.

The Darryl Dacombe Memorial Scholarship was awarded to a student from Kildonan-East Collegiate.

The Board and Staff of ESAM wish both students success with their future studies.





# Apple Watch app lets you call for help during a seizure

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April 23, 2015-Greg Pabst and his neurologist were trying to get a handle on his adult onset epilepsy when the doctor's mention of the newly announced Apple Watch gave Pabst an *ah-hah* moment.

The doctor was discussing tools for Pabst to chart his seizures and send alerts to emergency contacts.

"Then he said, 'It's only a matter of time before somebody does that for the Apple Watch,'" Pabst, 38, recalled. "Then I thought maybe it should be me."

Pabst, of Orlando, Fla., and a developer friend quickly went to work creating SeizAlarm, which appeared in the iTunes store for the iPhone last week and is available for the watch, the pre-orders for which begin arriving Friday.

Epilepsy affects more than 3 million Americans, with around 500 new cases diagnosed every day, according to the [Epilepsy Foundation](#). There are apps for charting seizures and even a smartwatch, recently funded on [Indiegogo](#), that detects seizures. The [Embrace](#), designed by a company called in Empatica, makes use of sensors and a gyroscope for detection and an alert feature for emergency contacts.

Pabst wants the [SeizAlarm app](#) to ultimately have a detection feature but said Apple is not granting app developers access to the accelerometer in the watch.

Many people with epilepsy or other seizure disorders experience auras in the very beginning of what could turn into a grand mal seizure, which would make a person unresponsive.

[SeizAlarm](#) works during these critical moments, giving a user the option have the app alert emergency contacts or press a delay function that starts a short timer. If a user is in the middle of a seizure, an alert will go out immediately after the timer goes off, usually set for between 45 and 60 seconds.

A user's activity is automatically logged or there is an option to manually chart symptoms and other experiences related to a seizure.

"Hopefully this app will bring that sense of comfort and independence to those coping with the condition," Pabst said.

A web designer, Pabst was diagnosed nine years ago after experiencing a growing number of auras that were accompanied by a distinct pitch sounds. He said medication has kept auras and grand mal seizures at bay since late last year.

The announcement of an Apple Watch came shortly after a seizure while he was in the middle of diagnostic tests.

"I'm pretty lucky because some people have grand mal seizures every day and can't drive or do anything on their own," Pabst said. "My main goal is to contribute something helpful to the epilepsy community."

Source: <http://www.cultofmac.com/320147/apple-watch-app-lets-you-call-for-help-during-a-seizure/>

# Soy Harvest Candle Fundraiser

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A very big thank you to the volunteers who manned the table at the St. Norbert Farmer's Market on Saturday July 11.

Our dedicated volunteers braved the sweltering heat and humidity to set up a table for our soy candle fundraiser. The table looked great! Thank you Kim, Mikaela and Mike for your ongoing help and support.

We would also like to take a moment to recognize the hard work of the Brandon Epilepsy and Seizure support group with the soy harvest candle fundraiser. Incredible work, Brandon group! Thank you!

We would also like to send out a thank you to Arlene and Karen who are selling candles in Selkirk. Thank you so much for your support!

## The Purple Pumpkin Project

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Here at ESAM, we realize it is still early in the year to be thinking about Halloween, but we'd like to remind everyone of the upcoming Purple Pumpkin Project. ESAM has participated in this awareness event for the past two years and we can't wait to get started on our pumpkins this year.

Becoming involved is as easy as painting or decorating your pumpkin purple to help raise awareness of epilepsy.

Please help us to make this year our best yet. When you are planning your Halloween décor and activities, consider having a Purple Pumpkin Painting Party. It is a fun way to promote epilepsy awareness!



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We would like to leave everyone with an inspirational quote from Christopher Reeve.

