

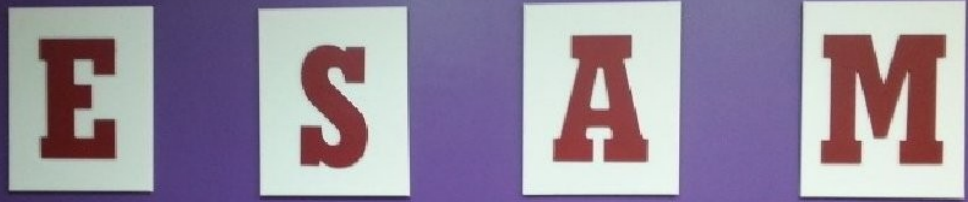
March 2017
Spring Edition



EPILEPSY AND SEIZURE ASSOCIATION OF MANITOBA

Epilepsy Educator

News from



Have you seen the beautiful Community Relations bus with the ESAM ads?





Epilepsy and Seizure
Association of Manitoba

**A SEIZURE WILL
STRIKE 1 IN 10
MANITOBIANS
IN THEIR LIFETIME**

EPILEPSY IMPACTS THE LIVES
OF TENS OF THOUSANDS
OF PEOPLE IN MANITOBA

Chances are someone you
know is impacted by epilepsy.

Please support epilepsy care
in Manitoba by supporting
Purple Day on March 26th.

Wear purple in support of
epilepsy awareness!

www.manitobaepilepsy.org



ESAM applied for, and received, a free month of advertising on the Community Relations bus through Winnipeg Transit.

For the entire month of March 2017, bus 419, will run with one ad on the outside and two on the inside promoting epilepsy awareness and Purple Day! Thank you Winnipeg Transit for your support!

Purple Day 2017



Purple Day is just around the corner-March 26th. How are you celebrating Purple Day this year? We would love to see your pictures! The official Purple Day hashtag is #purpleday2017 , and if you can tag us, that would be wonderful!

ESAM Facebook: @epilepsy.seizures

ESAM Twitter: @MBEpilepsy

ESAM Purple Day Awareness Table at Health Sciences Centre



ESAM staff will be at the Health Sciences Centre, near the William Street entrance (by the gift shop) on **Thursday March 23, from 10AM-2PM**. We will be handing out Purple Day bracelets, resources, and there is even a rumour of a purple cake.....

If you are in the neighbourhood, stop by and say hello!

Canadian researchers to study cannabis oil to treat kids' epilepsy

Published Saturday, March 11, 2017 1:15PM EST , Last Updated Saturday, March 11, 2017 3:03PM EST –Angela Mullholland- One of the researchers launching a study into the potential benefits of cannabis oil on childhood epilepsy says he is interested to learn how the drug affects the children's quality of life.

Dr. Richard Huntsman, a pediatric neurologist and a professor at the University of Saskatchewan, is leading the cannabis oil study along with Dr. Richard Tang-Wai, a pediatric epileptologist at the University of Alberta.

The main goal of their study is to learn if concentrated cannabis oil can be used safely in children with epilepsy. But they also want to look at whether it helps control seizures and whether it helps children's lives improve, he told CTV News Channel Saturday.

ARTICLE CONTINUED ON NEXT PAGE

<http://www.ctvnews.ca/lifestyle/canadian-researchers-to-study-cannabis-oil-to-treat-kids-epilepsy-1.3321008?autoPlay=true>

Canadian researchers to study cannabis oil to treat kids' epilepsy..continued

"For me, I would feel as a parent, having better quality of life would be just as important as control of seizures, so that's something we really want to look at," he said.

The study is due to recruit 30 children between the ages of one and 10 with severe epilepsy in Saskatoon first, then kids in other sites across Canada later. The team will be focusing on kids with the most severe forms of epilepsy who don't respond to regular treatments or who incur significant side effects from the usual treatments, Huntsman stressed. Some of these children have 50 to 300 seizures a day, struggle with basic life skills and have regressed developmentally because of their condition.

Huntsman says parents of many of his own patients tell him they are already giving their kids cannabis oil to help control their epilepsy, despite the fact that the drug's use for the condition is not well understood. "Right now there is very little research on cannabis use for the treatment of epilepsy," he said. "There are a few small studies that have been performed, retrospective reviews, that seem to suggest there are some children with very severe epilepsy... who do respond to cannabis oil."

Cannabis oil does not contain THC (or tetrahydrocannabinol) the compound that gives marijuana smokers a "high." Instead, it contains a concentrated form of cannabidiol, or CBD, another key marijuana compound that many believe helps control epilepsy.

"It seems to have an effect on certain neurotransmitter receptors in the brain," Huntsman said of cannabidiol. "That's one of our theories on how it works." Many parents of kids with epilepsy order the oil from licenced medical marijuana producers here in Canada or they obtain it from the U.S., despite laws against importing marijuana or any of its derivatives.

Huntsman says some of the parents of his own patients tell him their children have improved since they began using the oil. "It is something I'm hearing fairly often in my clinic. We're not sure why that is. Could it be just the cannabidiol? Could it be the very minute amounts of THC? We're not sure," he said.

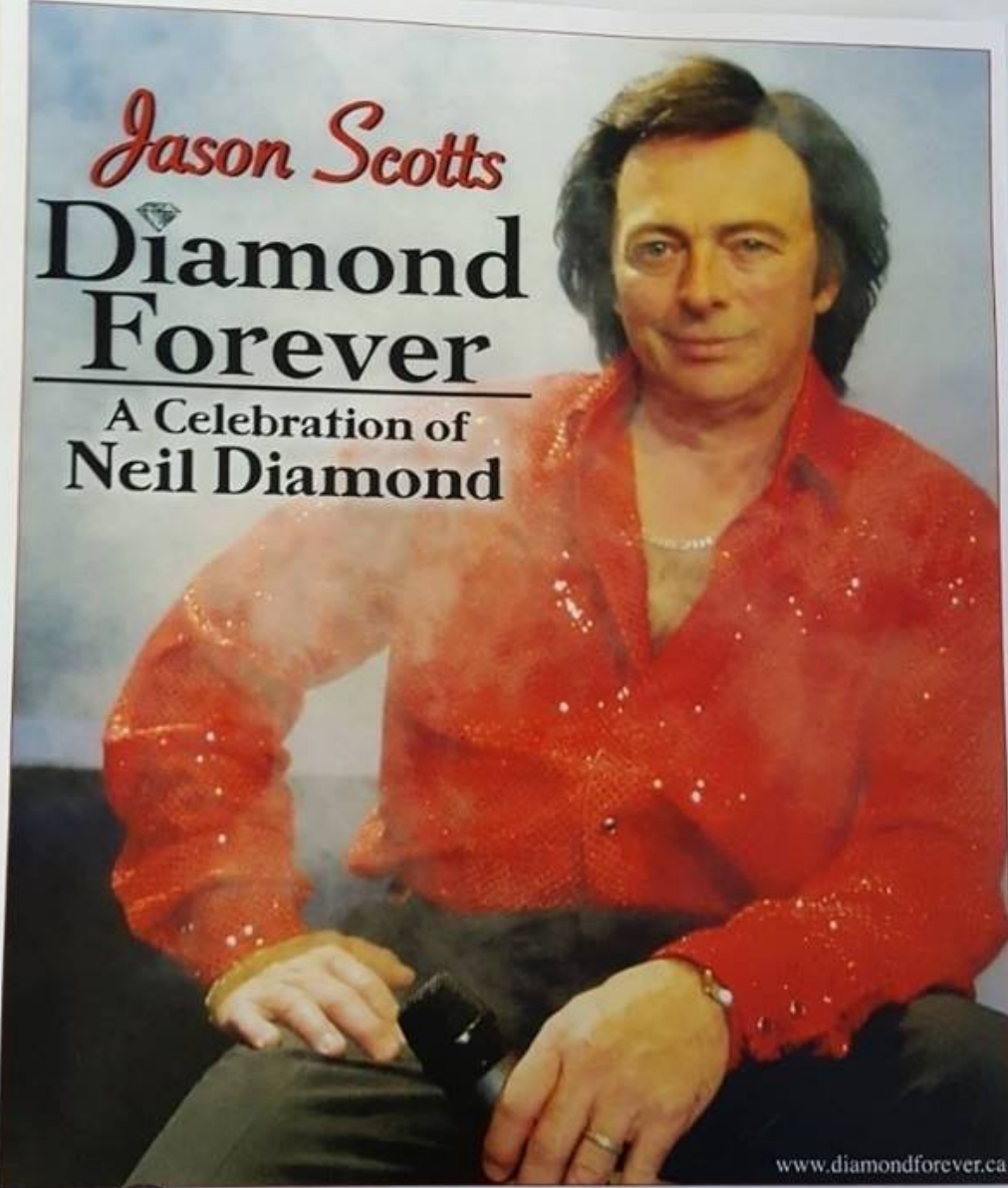
Huntsman says it will take the children in his study seven months to complete the study. The children will be monitored by a team of experts in pediatric neurology, pharmacology, clinical biochemical analysis, psychology and biostatistics. He and his team then hope to have data available for presentation in the next year to year and a half.

The study is being funded with support from the Children's Hospital Foundation of Saskatchewan and the Saskatchewan Health Research Foundation, among others. Information on how to enroll can be found on ClinicalTrials.gov. At the same time, researchers at Toronto's Hospital for Sick Children are beginning [their own study](#) on the use of cannabis extracts to treat children with severe epilepsy. That study will enrol 20 children aged one to 18 with Dravet syndrome, a rare and debilitating form of epilepsy that begins in infancy. The condition, caused by a genetic mutation, accounts for about one per cent of all cases of epilepsy.

In December 2015, the Canadian Paediatric Society issued a statement warning parents against using medical marijuana to treat their children's health conditions.

[The statement said](#) that while cannabis is increasingly being used to treat certain kids' illnesses, "evidence is lacking about the overall effect on children."

<http://www.ctvnews.ca/lifestyle/canadian-researchers-to-study-cannabis-oil-to-treat-kids-epilepsy-1.3321008?autoplay=true>



Jason Scott's
**Diamond
Forever**
A Celebration of
Neil Diamond

www.diamondforever.ca

LIVE IN CONCERT
MARCH 25 - 7:00 PM
ACCESS EVENT CENTRE
111 Gilmour St. Morden, Manitoba

<p>All Net proceeds are donated to Epilepsy and Seizure Association of Manitoba!</p>	<p>\$25 Tickets available at the door Red's Café & Convenient Store in Manitou Call Anna Martens 204-312-0082 The Winkler Times in Winkler 204-325-4771 The Olive Tree in Morden 204-822-3981</p>
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Research using Apple watch links epileptic seizures to stress and missed sleep



Epilepsy Society- The ten-month study showed that stress was the most common trigger, linked to 37 per cent of seizures. Participants also identified lack of sleep as a trigger for 18 per cent of seizures, menstruation for 12 per cent and over-exertion for 11 per cent. Other reported triggers included diet, missed medications and fever or infection.

Seizure triggers did not vary by the type of seizure people had. The study found that stress was more commonly reported as a trigger for participants who worked full-time, at 35 per cent, compared to those who worked part-time, 21 per cent, were unemployed, 27 per

cent, or were disabled, 29 per cent.

Recording seizures

The preliminary study released today will be presented at the American Academy of Neurology's 69th Annual Meeting in Boston, April 22 - 28, 2017. A total of 598 people signed up to track their seizures with an app called EpiWatch built using ResearchKit, a software framework designed by Apple to make it easy for researchers to gather data more frequently and more accurately.

When participants felt a seizure aura starting, they opened the app. Using the Apple Watch's sensors, EpiWatch recorded participants' heart rate and movements for 10 minutes. The app asked them to perform tasks to test responsiveness.

Saving lives

After the seizure ended, participants were given a brief survey about seizure type, aura, loss of awareness and possible seizure triggers. "The data collected will help researchers better understand epilepsy, while helping people with epilepsy keep a more complete history of their seizures," said study author Gregory Krauss, MD, of Johns Hopkins University in Baltimore, and a member of the American Academy of Neurology.

"The app also provides helpful tracking of seizures, prescription medication use and drug side effects — activities that are important in helping people manage their condition."

Focal seizures only

Epilepsy Society's medical director Professor Ley Sander commented: "It is interesting to see results coming through from wearable technology that is simple and easy to use. This is certainly the way forward in terms of data collection and hopefully in the future it may help us to predict seizures and give people better control over their lives.

"However, at the moment the technology is only able to gather data from people who have an aura before their seizure and have time to open up the app on the watch. So the research will only be relevant to those with focal seizures."

In all, 40 percent of the group tracked a total of 1,485 seizures, with 177 participants reporting what triggered their seizures. "Seizures are very unpredictable," said Krauss. "Our eventual goal is to be able to use wearable technology to predict an oncoming seizure. This could potentially save lives as well as give people with epilepsy more freedom. The data collected in this study helps us take a step in that direction." The study was supported by Johns Hopkins University.

<https://www.epilepsysociety.org.uk/news/Research-using-Apple-watch-links-epileptic-seizures-stress-missed-sleep-22-02-2017#.WMmmPPKvSV5>

Community Presentations

ESAM executive director has been busy delivering epilepsy and seizure awareness education sessions.



2 at Imagine Ability in February



2 at Brandon Support Services
(formerly WeCare) in March



Com-Span in February and
March

Zebrafish models may hold key to epilepsy drugs

Feb. 10 (UPI) --By Amy Wallace - A new study from the National Institutes of Health, or NIH, used a drug found in a zebrafish model of epilepsy that is showing promising results.

"This is the first time that scientists have taken a potential therapy discovered in a fish model directly into people in a clinical trial," Vicky Whittemore, Ph.D., program director at the National Institute of Neurological Disorders and Stroke, or NINDS.

"These findings suggest that it may be possible to treat neurological disorders caused by genetic mutations through an efficient and precision medicine-style approach."

Researchers used a zebrafish model of Dravet syndrome, a severe form of pediatric epilepsy, to test the drug lorcaserin and found it suppressed seizure activity in the fish. Dravet syndrome is caused by a genetic mutation which researchers were able to introduce into the zebrafish to cause epilepsy. Lorcaserin was then tested in five children with Dravet syndrome who were resistant to other anti-epileptic drugs. The Lorcaserin was associated with a decrease in seizure frequency in all of the children. Some of the patients in the study became seizure-free for two weeks but after three months, seizure activity increased, though not at the level of multiple seizures daily that they had been experiencing before the trial.

A prior study by Scott Baraban, Ph.D., the William K. Bowes Jr. Endowed Chair in Neuroscience Research and professor of neurological surgery at the University of California San Francisco and co-author of the study, used an automated drug-screening method to identify anti-epileptic therapies and found clemizole was effective in decreasing seizure activity in zebrafish as well.

"Using zebrafish, we can greatly reduce the time between identification of a potential treatment and getting it to individuals who desperately need help," Baraban said in a press release.

The study was [published in the journal Brain](#).

http://www.upi.com/Health_News/2017/02/10/Zebrafish-models-may-hold-key-to-epilepsy-drugs/1351486752367/

Purple Day Bunny Hop! Putting the fun in fundraiser!

We have had an amazing response for the Purple Day Bunny Hop this year. In 2017, 23 daycares and child care centres signed up to participate in the Bunny Hop. Over 1200 people will receive Purple Day bracelets this year, promoting awareness of both epilepsy/seizure disorder and of ESAM!

For the event, daycare centres pick a day close to Purple Day to run the Bunny Hop. As 1 in 100 people will develop epilepsy in their lifetime, children are asked to hop 100 times throughout the day, to show that even little kids can show support for epilepsy!

Purple Day Bunny Hop 2017 Participants



Fort Garry Child Care Centre-Waterford
MFRC Community Child Care Centre
Thompson Children's World Daycare
South Park Child Care
Jean McDonald Treasures of Hope Day Care
Happy Feet Learning Centre
Fuzzy Bears Inc
CPEF St. Joachim
Carpathia Children's Centre
Dream Catchers Head Start Preschool Program
Teekinakan Daycare
Tiger Hills Community Resource Centre
Treasure Keepers Children's Centre
Beautiful Savior Lutheran School
Fort Garry Child Care-Oakenwald
Les Boutons d'or Inc
Seven Oaks Child Daycare Centre
Fort Garry Child Care Centre-Pembina

Ashworth Children's Centre Inc
Growing Minds Child Care Centre
Tots of Love Early Learning Centre
Winkler Day Care
Winnipeg Beach Tiny Tots Inc.

Thank you from E.S.A.M.

Membership Renewal Time!

April 1 2017-March 31 2018

Membership – Epilepsy and Seizure Association of Manitoba

4 – 1805 Main Street Winnipeg, Manitoba R2V 2A2

Name: (Please Print)

Address: _____

Postal Code: _____ **Telephone:** _____

_____ **I would like to renew my membership to the Epilepsy and Seizure Association of Manitoba for the year April 1 2017-March 31,2018. Cost is \$10.00.**

_____ **I am a new member and would like to join the Epilepsy and Seizure Association of Manitoba for the year April 1 2017-March 31 2018**

Please send my newsletter to me:

_____ By regular post, to the address I listed above

_____ By email. My email address is _____

Thank you for showing your support of ESAM through membership! Each membership helps to show the commitment to epilepsy awareness in Manitoba.

EPILEPSY AND SEIZURE ASSOCIATION OF MANITOBA

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Email: esam@manitobaepilepsy.org, epilepsy.seizures@gmail.com

<http://www.manitobaepilepsy.org>,

<https://www.facebook.com/epilepsy.seizures>