

April 2018

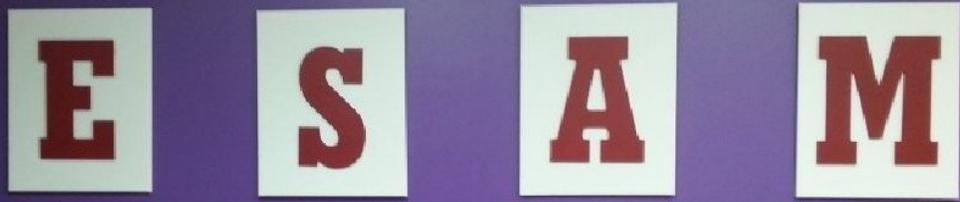
Spring Edition



EPILEPSY AND SEIZURE ASSOCIATION OF MANITOBA

Epilepsy Educator

News from



Once again, Winnipeg Transit donated advertising space on the Community Bus for the month of March 2018. ESAM information was placed on the side of the bus, and on two spaces inside as well.

What an amazing opportunity for promoting awareness of ESAM, epilepsy/seizure disorder and Purple Day. We are so very grateful for the continued support of Winnipeg Transit! ♥




 Epilepsy and Seizure Association of Manitoba

A SEIZURE WILL STRIKE 1 IN 10 MANITOBANS 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

Please accept our apologies, we know we the newsletter is a wee bit late. Fundraising season has been keeping us very busy!

Purple Day At St. Vital Centre



Laura and Frances, Purple Day St. Vital Centre

ESAM staff and volunteers were on hand at the Community Booth at St. Vital Centre for Purple Day 2018.

We would like to thank all the volunteers who came out and helped for the day. As we were setting up, we had people stopping by to share their experiences and pick up Purple Day bracelets and resources!

Thank you to St. Vital Centre for the amazing opportunity for promoting awareness!

Purple Day In Space

As shared by Epilepsy Simcoe County:

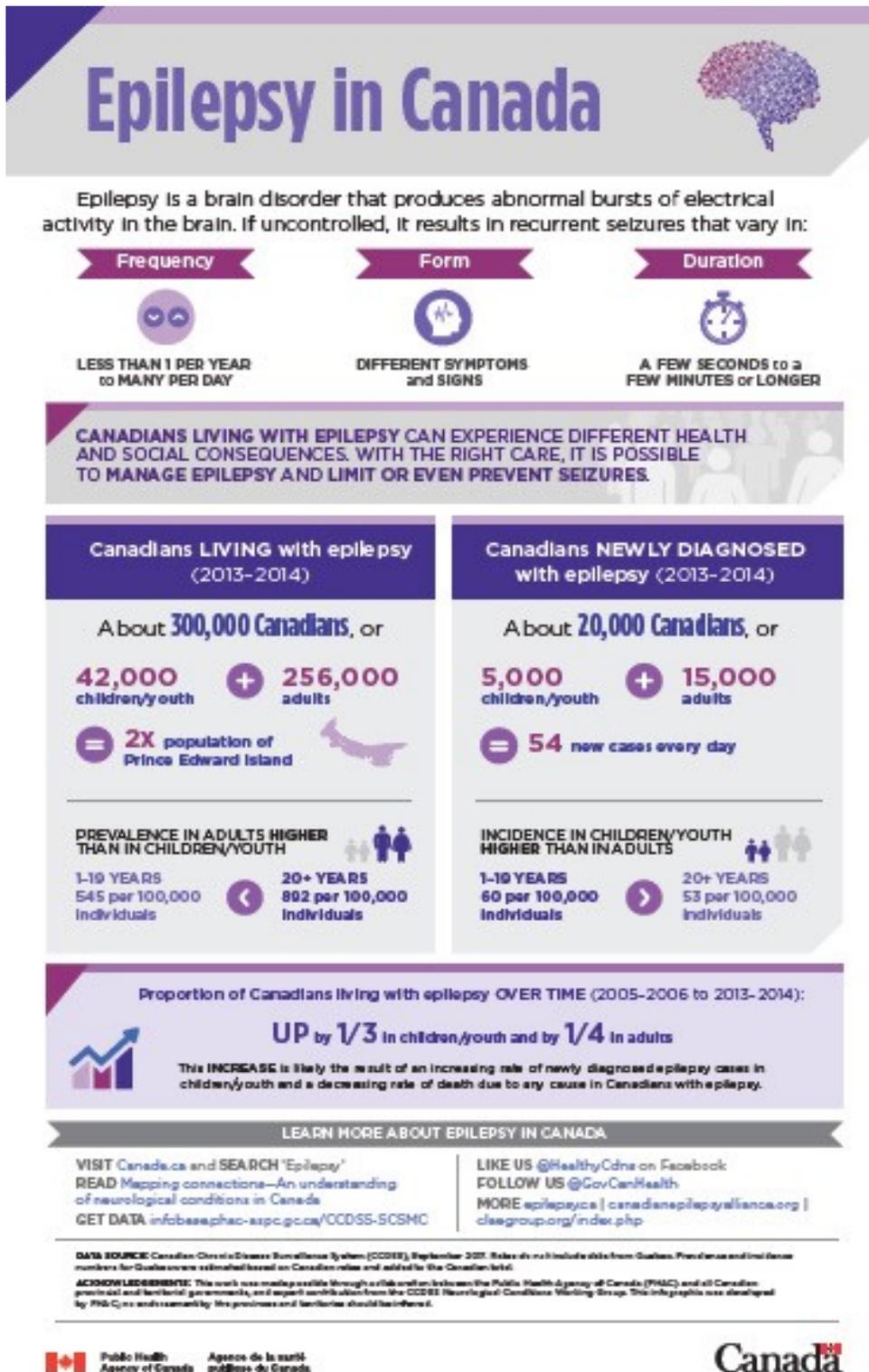
Purple Day was out-of-this-world this year! Part of NASA's Expedition 55/56 crew were donning their purple shirts on March 26th! Most of the members of Mission Control at NASA also sported Purple that day.



<https://www.facebook.com/epilepsysimcoecounty/posts/1450030811775746>

Updated Public Health Agency of Canada Epilepsy Infographic

On March 23, 2018, The Public Health Agency of Canada released an updated infographic on epilepsy in Canada.



<https://www.canada.ca/en/public-health/services/publications/diseases-conditions/epilepsy.html>

Into the light: Chiara Sparks emerges from the darkness of epilepsy with first book

Cam Fuller, Saskatoon StarPhoenix-Published on: March 15, 2018 | Last Updated: March 15, 2018 1:14 PM CST



Chiara Sparks fell so far behind in her Grade 12 English class that only a huge assignment would let her graduate on time: writing a 100-page book.

That was hard. The topic choice wasn't — her life with epilepsy.

"I figured, I'm going to write a book with my personal experiences so that other people with epilepsy and illnesses like mine will at least have something to relate to and be, like, okay I'm not alone," Sparks said recently.

Today, the almost-19-year-old isn't just a high school graduate but an author. Her debut book is *Just Like the Lotus: A Remarkably Honest Account of a Young Girl's Battle With Epilepsy*.

"Lotuses grow from mud. You can't have the beauty without the gross," Sparks says. "The lessons I've learned from epilepsy, it's turned me into a better person — wiser, more knowing, more compassionate, more empathy."

She can say that now but what she's gone through has been daunting. Her seizures started when she was 12 and turned her life upside down. The first medication she took stripped away every emotion except anger. There was so much of that, her mother Jennifer had to call the police on occasion because she feared for her own safety. When one officer dismissed her behaviour as a tantrum, she almost went after him.

She would sleep 20 hours a day. She suffered anxiety and depression. She had to live with a webcam in her room so her mother could keep an eye on her. When her mom left her alone in the house, she took the bathtub drain plug with her in case Chiara tried to have a bath, lost consciousness, and drowned.

"The thing is that a lot of people who have epilepsy, all this personal stuff is locked up inside and we can't express it because no one understands," Chiara said.

Perhaps her most public seizure came in the last 10 minutes of the last performance of an adaptation of *Romeo and Juliet* she was acting in with Persephone Theatre's Young Company in front of a full house including her mom. Production personnel were prepared and reacted perfectly, Jennifer said. But that wasn't much consolation for Chiara.

"When I woke up from that and realized I had a seizure on stage, I thought I ruined everything, a year's worth of practise," she said.

"When happiness started coming back I didn't know what happiness was. I got scared of it."

In reality, it inspired the cast to press on with even greater emotion to support her.

<http://thestarphoenix.com/entertainment/local-arts/into-the-light-chiara-sparks-emerges-from-the-darkness-of-epilepsy-with-first-book>

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“We’ll still discuss it and I’ll say, you didn’t ruin it, you didn’t ruin it,” her mom says.

Chiara’s horse Whisper has been a huge part of her life through it all. Even if she could only visit with her, it made a difference. Once while barrel racing, Chiara started having a seizure. Whisper stopped and carefully walked her back to her mom.

“I definitely don’t think I would be here if it wasn’t for horses,” she said.

Things have improved drastically since Chiara started seeing Dr. Jose Tellez-Zenteno and taking a new drug. Her last seizure was about five months ago.

She says when she started feeling normal emotions again, it was almost overwhelming

“When happiness started coming back I didn’t know what happiness was. I got scared of it. I would actually start crying because I didn’t understand what was going on.”

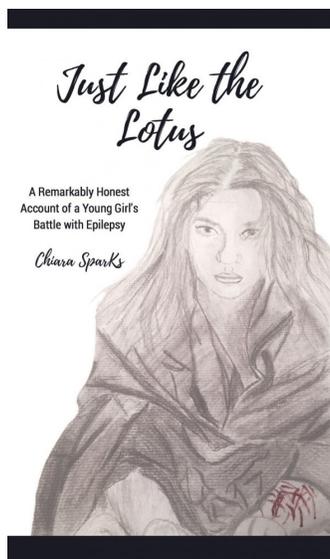
Out of necessity, the mother-daughter bond has been very strong. Chiara gets tears thinking about it.

“When I was too tired to do things, she was my motivational speaker, she was there to hold me when I was crying. When I was angry, she tried to understand me as best she could.

“We’re both fighting epilepsy and both our lives are hard but it’s different kinds of hard. She has to watch her daughter suffer and I have to suffer with it.”

Re-reading the book recently, Chiara realized there could have been even more in it. So a literally new chapter seems to be starting as well.

“I think there will be another one,” she said.



[Just Like the Lotus is available on Amazon](#) and locally at McNally Robinson. The book launch at McNally is March 22 at 7 p.m., coinciding with Epilepsy Awareness Month. A portion of proceeds will go to the RUH Foundation, Saskatchewan Epilepsy Program, to support the research of Dr. Tellez. Chiara will also be on hand at Purple Day for Epilepsy on March 23 at RUH, SaskTel Theatre.

Purple Day Bunny Hop 2018

PURPLE DAY BUNNY HOP!

We were privileged to have 18 day care centres across Manitoba sign up to participate in the Purple Day Bunny Hop. ESAM would like to thank the following daycares

Heritage Park Children's Programs

Military Family Resource Centre Childcare Centre

South Park Child Care

St. Maurice Daycare

Tiger Hills Resource Centre

Carter Early Learning Centre

Tache Community Day Care

Little Skippers

Fairlane Children's Centre

The Pas Preschool

Anishinabe Headstart

Dream Catcher & Jean McDonald

Morning Star Daycare

Pembina Valley Child Care Centre

Kidi-Garden

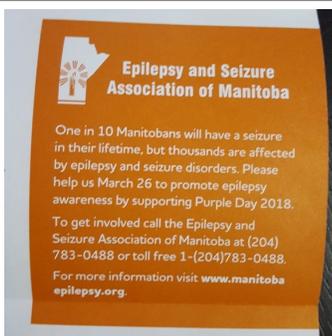
Morrow Avenue Child Care

Morden Community Child Care Centre

Carpathia Children's Centre



Manitoba Hydro Energy Matters Newsletter



Did you receive the Manitoba Hydro Energy Matters newsletter? ESAM is always excited about any opportunity for raising awareness of epilepsy/seizure disorder. The blurb about ESAM, and Purple Day was in the January 2018 Energy Matters newsletter.

Maurice Dumontier Memorial Golf Tournament

We know summer is on the way when ESAM starts gearing up for The Moe!



Join us for the 26th annual Maurice Dumontier Memorial Golf Tournament (a.k.a. : The Moe).



Tournament Date: Saturday June 16, 2018

Tournament Location: Transcona Golf Club, 2120 Dugald Road

Tournament Fee: \$100.00 per golfer

WIN GREAT PRIZES!



To register an individual or a team, contact us at ESAM offices:

Phone: 204-783-0466

Toll-free: 1-888-780-3726

By email: epilepsy.seizures@gmail.com or esam@manitobaepilepsy.org



Player's Choice Raffle held the night of the event.

Membership Renewal

April 1 2018-March 31 2019

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 2018-March 31 2019. 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 2018-March 31 2019**

Please send my newsletter to me:

_____ By regular post, to the address I listed above

_____ By email. My email address is _____

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