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Epilepsy News is
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Celebrating Purple Day 2019

Epilepsy Newfoundland and Labrador is proud to report another successful Purple Day. Each year we are thrilled to see Purple Day participants all across the province, and this year was no different. The Kavanaghs of Burin wore their purple and had a reading and activity day at their local library. Schools wore purple and learned about epilepsy. Play Learn and Grow Daycare participated in our Bunny Hop again this year, raising \$704! The support shown on social media this year was outstanding. Many people throughout NL

wore their Epilepsy NL Purple Day t-shirts and took to social media with a photo, shared their epilepsy stories and shared epilepsy facts. This contributes greatly to raising awareness and decreasing stigma. Businesses showed support, including a fundraiser at Lawtons Mt. Pearl, a fundraiser at Marystown Dental, and a purple macarons fundraiser at Rocket Bakery. Thanks to all those who wore purple, took to social media, held fundraisers, and raised epilepsy awareness in a way that is unique and meaningful to you. Your participation truly makes



all the difference in a continually successful Purple Day. If you would like to participate in Purple Day 2020 or have an idea for an event, contact Sarah at info@epilepsynl.com or 722-0502.



Purple Day Ambassador 2019

Epilepsy NL's 2019 Purple Day Ambassador Lisa Pack did an amazing job this year. She attended proclamation signings, held a fundraiser, shared her story, conducted interviews with the media, spoke as a panelist at the 2019 Epilepsy Public Forum, and much more. Efforts such as these ensure that the topic of epilepsy remains a point of conversation and increases epilepsy awareness significantly. Well Done Lisa!



I would also like to acknowledge the 2019 Purple Ambassador, Lisa Pack, a young woman from Hermitage, who says epilepsy has never and will never own her life.

-The Honourable John Haggie
Minister of Health and Community Services.

www.epilepsynl.com

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Purple Day at Jack Axes and Bespoke Cycle

This March Alyson Hale led an Epilepsy Awareness campaign in honour and memory of friend Jenn Lahey, and chose to donate the proceeds to Epilepsy Newfoundland and Labrador. The event included a ride for Epilepsy and Purple Power Hour at Bespoke Cycle, and an axe throwing event at Jack Axes, complete with prizes and draws. All together the events raised a grand total of \$2500! Purple Day events such as these help reach so many people. Thank you to Alyson, Jack Axes, Bespoke Cycle and all involved.



Friends and Family Campaign

We would like to extend our sincerest appreciation to all those who participated in our Family and Friends Campaign. People throughout the province donated their time and resources to collect for Epilepsy Newfoundland and Labrador, and we are truly thankful. This campaign is successful due to the dedicated volunteers in this province, your support truly makes all the difference. Fundraising Coordinator, Elaine Potte, would like to thank everyone for all of their hard work during this campaign. If you are interested in participating in the Friends and Family Campaign next year please contact Elaine at 709-722-0502 or 1-866-Epilepsy.



Paper and Feathers Purple Day Fundraiser



The team at Paper and Feathers organized Purple Day at the St. John's Farmers Market to raise epilepsy and SUDEP awareness. They chose to donate the proceeds of the sales of their beautiful cards to Epilepsy NL. Carolyn Dwyer, Tracy Dwyer and Melanie Dwyer presented ENL with a donation of \$1216! The donation was made in honor and memory of Melissa Delaney. Thank you for raising awareness of epilepsy and SUDEP for the more than 10,000 people living with epilepsy in NL.

Raising Awareness in Hant's Harbour

Valerie Butt and the staff at Home Hardware held a Purple Day at Work event in Hant's Harbour this year. They ordered Epilepsy Newfoundland and Labrador Purple Day t-shirts and wore them to raise awareness of epilepsy in their town, along with distributing epilepsy information, creating a great poster board and hosting a fundraiser for ENL that raised \$247!



Disclaimer

The materials contained in the Epilepsy Newfoundland and Labrador Newsletter are to provide general information about epilepsy to the public. The information presented is not intended as medical or legal advice. Epilepsy Newfoundland and Labrador, its employees, board members, medical advisers, volunteers, agents and sponsors do not assume responsibility for inaccuracies or omissions or for the consequences from the use of the information obtained in this newsletter. Epilepsy Newfoundland and Labrador is not liable for any outcome or damages resulting from information in either a direct or indirect form. We recognize that each individual's experience of epilepsy is different. Consult your physician and/or neurologist with any questions you may have. Attention: People with epilepsy should never discontinue anti-seizure medications or make changes in activities unless advised to do so by an attending physician.

Epilepsy Public Forum 2019

On Saturday, March 23, Epilepsy Newfoundland and Labrador (ENL) along with the Student Interest Group in Neurology (SIGN) hosted the 2019 Epilepsy Public Forum. The event brought together people living with epilepsy, their families, the general public, health professionals, researchers, and medical students to better understand epilepsy from multiple perspectives. Presentations included opening remarks from ENL Execu-

tive Director Gail Dempsey, a keynote address from Dr. Ogunyemi, Newfoundland and Labrador's only neurologist that specializes in epilepsy, a presentation from Dr. Matthew Parsons, a leading researcher in the science of epilepsy, and a panel discussion of patient stories. There were also breakout sessions for seizure first aid, anatomy of the brain, and an introduction to EEG (electrical recordings of the brain).

The forum was free to the general public with space for 125 people to attend. All the spaces were filled, in addition to a waitlist of approximately 30 people. It is encouraging to see so many members of the public take an interest in learning more about epilepsy. Let's keep that going and continue to raise awareness of epilepsy in NL all year round.



"Epilepsy has never, and will never, own my life."

-Lisa Pack, 2019 ENL Purple Day Ambassador



NLWIC Information Session

On Thursday, March 28, Epilepsy Newfoundland and Labrador attended an NL Workforce Innovation Centre (NLWIC) meeting, hosted by InclusionNL and Susanne Dawe, NLWIC Stakeholder Engagement Coordinator. NLWIC provides a co-ordinated, central point of access to engage government, career and employment ser-

vices providers, skills development organizations and stakeholders in the business and community sectors throughout the province. The Centre's goal is to support the research, testing, and sharing of ideas and models of innovation in workforce development that will positively impact employability, entrepreneurship, and attachment to the workforce in

Newfoundland and Labrador. The meeting detailed the centre's current projects and highlighted future available funding opportunities for research proposals focused on innovation in the workplace. You can keep an eye out for new calls for proposals on their website at: www.nlwic.ca.



Faith Atkins: Don't Fear the Purple



For the last five years the JAC team have put so much effort into celebrating Purple Day and raising Epilepsy Awareness with Epilepsy Newfoundland and Labrador. JAC is an award winning marketing agency providing professional web design, web development, social media, marketing and advertising services in St. John's. Team member and long time Purple Day Ambassador Faith Atkins created the campaign "Don't Fear the Purple" as a way to raise awareness of epilepsy. This amazing initiative shares epilepsy facts and information via social media, has held many special events, fundraisers and contests for Purple Day, and has donated greatly to Epilepsy NL. This year the JAC team fundraised for Epilepsy NL. For each donation made the donor's name would be entered to win a fabulous sports prize package as a thank you. The initiative raised \$455, which was matched by JAC, making a grand total of \$910! JAC also held their annual clothing drive for Previously Loved Clothes and Things and Facebook Live feed, to highlight Purple Day for epilepsy awareness.

"Greatly appreciated! Answering so many of my questions and helping me learn so much."
-Facebook Live Viewer

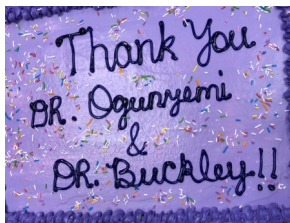


Ask the Doctors Anniversary

2019 marked a very special anniversary for Epilepsy Newfoundland and Labrador's annual Ask the Doctors Forum, a free March Awareness event where individuals can get their epilepsy related questions answered. Each year two amazing doctors participate, Dr. Ogunyemi (Epileptologist) and Dr. Buckley (Pediatric Neurologist). This year we celebrated the 30th anniversary of Dr. Ogunyemi's participation and the 27th year of Dr. Buckley's participation! We are beyond thrilled to have had 30 years of shared knowledge from these incredible doctors. The doctors held a very informative Q & A session, both in person and on our first Facebook Live event, providing opportunity for those who could not attend to listen and

ask questions. Sharon Penney and Bernadette Azizan, who were also present at the first Ask the Doctors 30 years ago, attended the event as a surprise and presented the doctors with gifts of appreciation on behalf of Epilepsy Newfoundland and Labrador. Bernadette spoke about Dr. Ogunyemi, and Sharon spoke about Dr. Buckley, whom she worked with for many years as his Nurse Coordinator at the Jane-way. Christopher Dempsey, who videotaped the very first Ask the Doctors Forum 30 years ago, was also in attendance and videotaped the event once again, capturing this very special occasion.

The Facebook Live of the forum is archived on our Facebook page (@EpilepsyNL).



Purple Day Proclamation 2019

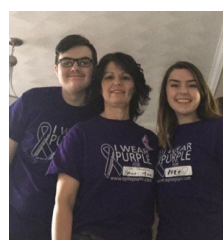
Each year it is so inspiring to see cities and towns all around the province sign the Purple Day Proclamation, declaring March 26th as Purple Day. Epilepsy Newfoundland and Labrador attended a meeting with The Hon. John Haggie, Minister of Health and Community Services, to have the proclamation signed on behalf of Newfoundland and Labrador. ENL also had towns volunteer to sell t-shirts at their office, take Purple Day photos with members around NL, and had councils send in donations to show support. Signing the proclamation is an excellent opportunity to show support for those living with epilepsy in your area, raise awareness of epilepsy, and fight against stigma. Pictured below: Province of NL, Pasadena, Wabush, Flatrock, Rencontre East, Hermitage-Sandyville, Mt. Pearl, Paradise, Torbay.



**"It's time to end
the stigma."
-The Hon. John
Haggie,
Minister of
Health and
Community
Services**



Purple Day Around the Province Submitted Photos



Epilepsy NL Membership

We invite you to become a member of Epilepsy Newfoundland and Labrador. **Membership is free of charge.** By becoming a member you gain access to a wide range of benefits, services and information such as:

- Access to support programs and advocacy services
- Invitations to special events, teleconferences and information sessions on various social and medical aspects of epilepsy
- Quarterly Newsletter
- Three Scholarships exclusively available to members
- Support: Strength comes in numbers. The more members we have the more support ENL will receive for research, proposals etc.
- Voting privileges at the Annual General Meeting
- Notification of changes in seizure medications or treatments that matter to you

If epilepsy is important to you and you want to make it important to others, please apply for membership by emailing info@epilepsynl.com, calling (709) 722-0502/ 1-866-Epilepsy, or mailing in the form found below.

**Your
Membership
Matters**



I Would Like to Become a Member with ENL

Name:	Email:
Address:	
Phone:	Would you prefer email or postage?
Do you or a loved one have epilepsy?	What type of seizure/seizures are present?
Additional Comments and Suggestions: Are there any issues regarding epilepsy you would be interested in learning more about?	

Please clip and mail this form to Epilepsy Newfoundland and Labrador— 351 Kenmount Rd. St. John's, NL A1B 3P9 or you can email all your information to info@epilepsynl.com to save on postage. You can also submit your form online (www.epilepsynl.com). If you would like to make a donation you can donate through our website by visiting epilepsynl.com and clicking the DONATE button.

9 Year Old Girl First Child in Canada to Undergo DBS for Epilepsy

It started when Andi Dreher was only three years old. Her head slumped over, her face went blank. It was the first of many epileptic seizures that the Ontario child would endure. At the beginning, Andi would have a couple of seizures a year, but the condition slowly progressed. By the time she turned seven, she was having up to 150 seizures a day. The seizures make it difficult for Andi to do even the simplest tasks, such as walking, talking and eating. "She knows she used to play soccer and she used to do cheerleading — that she used to do these things and now she can't. That's hard," her mom said.

Among serious neurological conditions in children, epilepsy is the most common. For most, the condition can be controlled by medications. "But about one-third of children who have epilepsy don't respond to medication. A subset of them can potentially be helped by a variety of surgical treatment," said Dr. George Ibrahim, the pediatric neurosurgeon at the Hospital for Sick Children who operated on Andi.

Before meeting Ibrahim, Andi and her family had already tried countless medications, had two surgical procedures, and even tested out the ketogenic diet — a high-fat, mid-protein, low-carbohydrate way of eating that's sometimes used to try to control seizures in children with epilepsy. Running out of options, Ibrahim and his team decided they needed to try something different.

Believing deep brain stimulation (DBS) may be the answer, Ibrahim recruited colleague Dr. Suneil Kalia, a neurosurgeon at Toronto Western Hospital, to assist with the surgery. The procedure is commonly done on adults to treat movement disorders such as Parkinson's, as well as epilepsy and chronic pain. It works by sending electrical impulses to targeted areas deep in the brain to relieve symptoms without harming the surrounding tissue. Performing the procedure on a child, however, is rare — with only 40 known cases — and none in Canada. That all changed on Oct. 1 this year when Andi made her way into the op-

erating room, emerging about eight hours later with electrodes placed deep in her brain and a battery-operated implant in her chest. Her mother Lori Dreher now has control of the implant, adjusting the levels on her programmed device to try to figure out what works best in minimizing her daughter's seizures. "We have hopes that this will work, once we tighten it in," Dreher said. Ibrahim said it will take time, but he, too, is hopeful: "The true effects of the deep brain stimulation can only be known once the device has been turned on for several months. But when we turned it on as a test during surgery, it completely silenced the electrical activity that's causing Andi's seizures, which is what we were hoping to target."

As for Andi, Lori said her daughter was actually excited going into surgery, because she knew it may be the answer to stopping her seizures: "She's an extremely resilient young girl. She has a very severe form of epilepsy and despite that, she loves life."

Via cbc.ca



"She's an extremely resilient young girl. She has a very severe form of epilepsy and despite that, she loves life."



Innovicares

The innoviCares card is a free prescription savings card available to all Canadian residents, and is funded by participating pharmaceutical manufacturers. Present your innoviCares card at your pharmacy and ask for the brand-name medication. Your card will automatically cover a portion of the cost of the original brand.

Your innoviCares card will coordinate with your existing insurance plan(s), or if you don't have insurance, it can be used on its own. Visit www.innovicares.ca to see if your prescriptions may be covered.



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Asked and Answered

Q: Is epilepsy hereditary?

A: Some types of epilepsy have a genetic basis. In certain epilepsies, one or more inherited genes may result in the condition. In other cases, an inherited neurologic disorder that involves structural or chemical abnormalities in the brain can increase the risk of seizures and lead to epilepsy. Another factor associated with a genetic cause of epilepsy is an inherited susceptibility to seizures. Each individual has a seizure threshold that determines the level at which the brain will have a seizure. Some individuals inherit a lower threshold or lower resistance to seizures resulting in a greater risk of having seizures. The risk of a child having unprovoked seizures is one to two percent in the general population and approximately six percent if a parent has epilepsy. **Via Epilepsy Education Series*

Previously Loved ♥
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At Previously Loved Clothes and Things thrift store you never pay sales tax. Because we are a charity, 100% of the proceeds from the sales at our store stay right here in the province and go directly back into the community through the programs and services of Epilepsy Newfoundland and Labrador.

Previously Loved Clothes & Things is a social enterprise owned and operated by Epilepsy Newfoundland and Labrador, and has been successfully contributing to our community since 1998.



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INTERESTED IN A SUPPORT GROUP?

Let us Know!

Contact Sarah at info@epilepsynl.com / 722-0502

Sobeys Merrymeeting Road Donation

The team at Sobeys Merrymeeting Road organize a Jeans Day where each participating employee donates to wear jeans to work. This round they chose to donate the proceeds to Epilepsy Newfoundland and Labrador. Agnes, Kelly, and Paul (the store mascot) presented Info Officer Sarah Mercer with a donation of \$100.00!

Previously Loved Clothes and Things Jewelry Blitz

Previously Loved Clothes and Things held a Mother's Day Jewelry Blitz on Sunday, April 28th. Organized by Fundraising Coordinator Elaine Pottle, the Jewelry Blitz featured a fantastic selection of jewelry of all types for sale. The event was a great success, raising over \$1600 in benefit of Epilepsy Newfoundland and Labrador. Tickets were also available on a beautiful gift basket, free with purchase of jewelry or by individual ticket purchase. Keep an eye on Previously Loved Clothes and Things Facebook page (@PLCAT) for future events!