

Epilepsy News

Winter 2019

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Epilepsy News is
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Purple Day 2019

Here at Epilepsy Newfoundland and Labrador we are excited to be preparing for March 26th Purple Day 2019. This March we want to paint the province purple, and we need your help. We welcome all members and supporters to help raise epilepsy awareness at their work places, children's classrooms, community centres, libraries and more. Last year schools wore purple, had bake sales, and learned about Epilepsy First Aid. Businesses pledged to wear purple and hold an event, and day cares participated in our Bunny Hop. The wonderful thing about Purple Day is that it is a day to raise epilepsy awareness in whatever way is meaningful for you. Everyone can participate in their own way, all over New-

foundland and Labrador and the world!

We have posters, tattoos, information pamphlets and ribbons for your event, to help make your corner of the island merry and purple. Join us and the many people around the globe who are helping end stigma associated with epilepsy by giving a better understanding of this neurological disorder. Bring on the purple and be as creative as you can! Throughout the day we share stories on social media and our website, don't forget to share your Purple Day online using #PurpleDay2019 / #EpilepsyNL, and tag us on Facebook and Twitter!

Contact Sarah at
info@epilepsynl.com for
more information.



Lisa Pack: Purple Day Ambassador 2019

Each year Epilepsy Newfoundland and Labrador selects a Purple Day Ambassador, one who helps raise epilepsy awareness and celebrates Purple Day in their area. A Purple Day Ambassador shares their story to let others know they are not alone. A Purple Day Ambassador inspires. Epilepsy Newfoundland and Labrador is proud to announce the 2019 Purple Day Ambassador, Lisa Pack of Hermitage, NL. Lisa is a

member with Epilepsy NL, an advocate for epilepsy awareness and has shared her story through ENL and the Canadian Epilepsy Alliance. Purple Day, created by Cassidy Megan of Nova Scotia, was created in an effort to raise awareness and let people living with epilepsy know that they were not alone. Lisa certainly encompasses that spirit. Congratulations Lisa and thank you.



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Epilepsy Public Forum 2019: March 23 2019

On March 23rd, 2019, in partnership with Memorial University Faculty of Medicine's SIGN (Student Interest Group in Neurology) Epilepsy Newfoundland and Labrador will be co-hosting the 2019 Epilepsy Public Forum. The event will be held at the Health Sciences Centre, and features Keynote Speaker Dr. A. O. Ogunyemi, Epileptologist. Dr. Matthew Parsons will discuss Epilepsy Newfoundland and Labrador funded research that is happening right here in our province.

The conference will also feature a panel discussion lead by individuals with lived experience with epilepsy, as well as a number of break out sessions on topics such as seizure first aid, Neuroanatomy, and EEG/MRIs. The breakout sessions will be recommended for either the general public or medical students, however all sessions are open for registration.

Further schedule and registration details will be available

on Epilepsy Newfoundland and Labrador's website (www.epilepsynl.com) as well as social media (Facebook and Twitter: @EpilepsyNL) shortly. Check in for updates and save the date for this excellent opportunity to both learn and share information about epilepsy, and bring epilepsy awareness to the public.

**PUBLIC FORUM
2019****2018 Epilepsy NL Family Scholarship Winner**

Congratulations to Rachel Spicer, winner of the 2018 Zach Rowe Memorial Scholarship. Rachel has been involved with Epilepsy Newfoundland and Labrador for many years, and has been a tireless advocate for Epilepsy Awareness over the years. She has arranged Purple Day education days and fundraisers throughout her time at school in Pasadena, contributed her story to ENL's Epilepsy Newsletter and worked together with her family to educate and raise awareness of epilepsy. We have no doubt she will continue to advocate.



Rachel is currently attending the University of New Brunswick and we wish her the best of luck in her future endeavors.



**Epilepsy
Newfoundland
and Labrador**

Purple Day

SUPPORT EPILEPSY AWARENESS WEAR PURPLE ON MARCH 26

1 IN 10 PEOPLE WILL HAVE A SEIZURE

**March 26
2019**

WWW.EPILEPSYNL.COM

Purple Day 2019: Get Involved!

Wondering how you can get involved in Purple Day 2019? Check it out!

Get your school involved: Are you or your family members attending school? Talk to a teacher, guidance counselor or principal about making your school a Purple Day School on March 26th. Once your school is on board contact us and we will send along some supplies. Primary, elementary, secondary, post-secondary, all schools are welcome to partake!

Join the Purple Day Bunny Hop: Day Cares across the province celebrate Purple Day by learning about epilepsy, dressing in Purple and bunny hopping throughout the day. Ask your child's centre about joining the fun on March 26th. We will send Bunny Hop packages to registered children's centres, including temporary tattoos, bunny ear templates and colouring sheets.

Get your work involved: Organize a Purple Day event or fundraiser that speaks to you to join in raising Epilepsy Awareness at work. Ideas include a Purple Bake Sale, Wacky Purple Accessory Day or Purple Sock Party (everyone donates a loonie or toonie to wear purple socks-be sure to get a photo!) We will post pictures online and on Social Media throughout the week.

Attend Ask The Doctors: Every year Epileptologist Dr. Ogunyemi and Pediatric Neurologist Dr. Buckley join us for an Ask The Doctors Forum. Two Doctors are available for your questions. People can call in or come in person. The session will be at our offices @ 351 Kenmount Road near the end of March. Call us for more details 709-722-0502. Don't miss out on this amazing opportunity to get your questions answered.

Buy a T-Shirt or Pen: We have Purple Day Pens for \$2 and Purple Day T-Shirts for \$12.50-\$16.00. Orders must be made before March 6th, or before February 20th if shipping is required. Show your Purple colours this March with a pen or t-shirt with all proceeds going to ENL! *shipping costs will apply

Volunteer: Want to participate in Purple Day in another way? Contact Sarah at info@epilepsynl.com / 709-722-0502 to chat about it! Great options are volunteering to share Epilepsy NL's Epilepsy Awareness posts on Twitter and/or Facebook, volunteering to host a bake sale at your school/workplace, volunteering to help distribute Epilepsy Awareness packages in the St. John's and surrounding areas, or another idea that speaks to you!



*"I never let my
condition
control what I
can or cannot
do."*

-Edward

Pilgrim-Turner

(Epilepsy NL

2018 Purple Day

Ambassador)





Epilepsy NL Halloween Bingo Night

On October 25th members and epilepsy community supporters gathered together at the Epilepsy Newfoundland and Labrador offices to play Halloween Bingo. The event was a great success with refreshments, fun and prizes, along with the grand prize draw of an official Epilepsy Newfoundland and Labrador Purple Day t-shirt. A big thank you to members and supporters for coming out! Stay tuned for upcoming events.



"Seeing the positive impact of the funds we donate to the numerous organizations that help strengthen the communities where we all live and work is truly inspiring."

-NLCU CFC

Chairperson,

Allison Chaytor-

Loveys

NLCU Charitable Foundation Annual Charities Reception

On Friday, November 16, 2018, at The Best Western Plus St. John's Airport Hotel and Suites, Epilepsy Newfoundland and Labrador's Information Officer Sarah Mercer accepted a donation on behalf of ENL, at the Newfoundland and Labrador Credit Union Charitable Foundation Corporation's Annual Charities Luncheon. This year's efforts resulted

in approximately \$72,500 being distributed to 84 provincial charities, and Epilepsy NL is proud to be one of the chosen supported charities. Representatives from a number of charities from the metro area attended the luncheon to accept their donations from funds raised by the NLCU CFC in 2018. NLCU Branch Managers from across the Province

were in attendance as well to receive cheques for charities in their respective communities.



Cape St. Francis Elementary Fundraiser

The staff and students at Cape St. Francis elementary took initiative to organize a walkathon fundraiser. They chose three charities to donate the proceeds to, Epilepsy Newfoundland and Labrador being one of them. Community Information Officer Sarah Mercer was happy to stop by the school for an assembly held in the gym, with the entire student body!

We'd like to extend a big thank you to students and staff at Cape St. Francis. Your donation will go a long way in providing essential programs and services to the members of Epilepsy Newfoundland and Labrador, and it is truly inspiring to see such generosity in a student body of such a young age.



Lunch and Learn: Fostering the Next Wave of Disability Leaders

On October 12th, 2018, Epilepsy Newfoundland and Labrador Executive Director Gail Dempsey and Information Officer Sarah Mercer attended a Lunch and Learn session hosted by the Coalition of Persons with Disabilities Newfoundland and Labrador. The Lunch and Learn, entitled “Fostering the Next Wave of Disability Leaders” featured Mario Levesque of Mount Allison University, who presented his research on disability nonprofit leadership.

Levesque, an Associate Professor in Politics and International Relations, conducted research on the key skills, tasks and responsibilities of Executive Directors (ED's) of disability nonprofits, in order to increase understanding of nonprofit leadership and foster the

next wave of disability leaders.

Mario conducted a series of interviews with both ED's of nonprofits and government disability program officials, as well as nonprofit Boards of Directors. The skills and top priorities held by ED's were found to be similar to those working in government disability. While ED's identified contract implementation, board relations and relationship building as their top three tasks, government disability officials also identified relationship building, with focus on senior management and frontline staff/operations. The research also showed that both ED's and government officials possess both people and management skills. ED's demonstrated advanced emotional intelligence,

budgeting, organizational and collaborative skills in comparison with officials.

The research compiles a profile of Atlantic Canadian disability leaders for reference, in the hopes of ensuring the current strength in leadership is able to be carried on in the next wave of disability leaders.

Information credited to: Mario Levesque, Mount Allison University, *Disability Nonprofit Leadership in Turbulent Times – An Atlantic Canadian Profile*, Presentation to the NL Network of Disability Organizations October 12, 2018, St. John's, NL.



SHARE Education Summit 2018

On October 11th, 2018, Epilepsy Newfoundland and Labrador Community Information Officer Sarah Mercer attended the SHARE (Science, Health and Research Education) Summit held by Memorial University's Faculty of Medicine. The SHARE summit was a showcase for applied health research in Newfoundland and Labrador, held with the intent of showing how that research is improving the lives of patients in our province. The summit was a free, one day event, led by a keynote speech from Dr. John Haggie, Minister of Health, who spoke on priorities for health care in Newfoundland and Labrador, and the role of research in addressing the needs of the people of our province. SHARE featured concurrent educational sessions, panel discussions, quick-fire rounds and a plain language poster contest. Following is a summary of several sessions at-

tended.

Session 1: “Who Helps the Helpers? Managing Post-traumatic Stress Disorder in the Public Service Personnel” This session addressed the health of public safety personnel (911 dispatchers, firefighters, paramedics and others) and available options to deal with the emotional fallout of the trauma of others. Dr. Rose Ricciardelli from Memorial University's Dept. of Sociology discussed new, innovative ways of providing much-needed mental health supports for the responders we depend on.

Session 2: “No Place Like Home: Helping Older Adults with Complex Mental Health Needs Age in Place” Dr. Roberta DiDonato of Memorial University's Department of Psychology unveiled her project in partnership with Stella's Circle to identify and address the best way to help people with complex needs stay safely

in their community for as long as possible.

Session 4: “Your Genes, Your Call...” Epilepsy Newfoundland and Labrador Vice President Patti Bryant sat on a panel discussion regarding large volumes of patient data becoming available to physicians and the potential ability to tailor treatments to individual patients, according to their genes.

Session 6: “Nothing About us Without Us: Engaging Patients as Partners in Research” Patient engagement was highlighted as the best way to ensure that research is addressing the needs of the people it aims to help. Dr. Holly Etchegary, NL SUPPORT's Academic Patient Engagement Lead, and a member of the Patient Advisory Council office spoke about the importance of and lessons learned in engaging patients as partners in research.

**“Nothing about
us without us:**

**Engaging
Patients as
Partners in
Research”**



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.

“Pacemaker for the Brain” Could Help People with Epilepsy

A new neurostimulator developed by engineers at the University of California, Berkeley, can listen to and stimulate electric current in the brain at the same time, potentially delivering fine-tuned treatments to patients with diseases like epilepsy and Parkinson's. The wireless, artifact-free neuromodulation device (WAND) works like a “pacemaker for the brain,” monitoring its electrical activity and delivering electrical stimulation if it detects something amiss, according to the researchers.

Deep-brain stimulators currently on the market either stop recording while delivering electrical stimulation or record at a different part of the brain from where the stimulation is applied because the electrical signals from the brain are overwhelmed by the large pulses of electricity delivered by the stimulation, the researchers said. They likened the work of these stimulators to measuring small ripples in a pond at a different point from which the splash that creates the ripples takes place. Also, the electrical signatures that precede a seizure or tremor can be quite subtle and the frequency and strength of electrical stimulation required to prevent them must be precise. It can take years of small adjustments by doctors before the devices provide optimal treatment. “The process of finding the right therapy for a patient is

extremely costly and can take years. Significant reduction in both cost and duration can potentially lead to greatly improved outcomes and accessibility,” said lead researcher Rikky Muller of Cortera Neurotechnologies and an assistant professor of electrical engineering and computer sciences at UC Berkeley. “We want to enable the device to figure out what is the best way to stimulate for a given patient to give the best outcomes. And you can only do that by listening and recording the neural signatures.”

WAND's custom-integrated circuits were designed to record the full signal from both the subtle brain waves and the strong electrical pulses. This chip design allows WAND to subtract the signal from the electrical pulses, resulting in a clean signal from the brain waves.

“Because we can actually stimulate and record in the same brain region, we know exactly what is happening when we are providing a therapy,” said Muller, in a statement. WAND is both wireless and autonomous, meaning that once it learns to recognize the signs of a tremor or seizure, it can adjust the stimulation parameters on its own to prevent the unwanted movements. And because it is closed-loop — meaning it can stimulate and record simultaneously — it can adjust these parameters in real-time.

WAND can record electrical activity over 128 channels, or from 128 points in the brain, compared to eight channels in other closed-loop systems. To demonstrate the device, the team used WAND to recognize and delay specific arm movements in rhesus macaques. The device is described in a study that appeared today in *Nature Biomedical Engineering*.

The research team built a platform device with wireless and closed-loop computational capabilities that can be programmed for use in a variety of research and clinical applications. In experiments, subjects were taught to use a joystick to move a cursor to a specific location. After a training period, the WAND device was capable of detecting the neural signatures that arose as the subjects prepared to perform the motion, and then deliver electrical stimulation that delayed the motion.

Muller said. “In the future, we aim to incorporate learning into our closed-loop platform to build intelligent devices that can figure out how to best treat you, and remove the doctor from having to constantly intervene in this process.” Cortera Neurotechnologies has filed a patent application on the integrated circuit used in this work.

*Article via
www.medicaldesignandoutsourcing.com



**“Significant
reduction in
both cost and
duration can
potentially lead
to greatly
improved
outcomes and
accessibility”**

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.

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New App Available on Google Play Store for Seizure Detection

Amir Helmy was in the seventh grade when he heard a family friend talking about the expensive monitoring equipment people with epilepsy had to rely on to monitor their seizures. The year was 2012, five years since the launch of the first smartphone. Amir had a simple thought. Our smartphones have accelerometers that can detect motion. Why not use the smartphone to better aid people living with epilepsy, their families and caregivers in managing their daily lives? With this question, the concept of the mobile application Seizario was born. The Seizario app includes both automatic detection of several emergency scenarios through motion detection and easy and immediate communication of critical information to family members and caregivers. In 2014, Amir presented his Seizario concept at the Epilepsy Foundation Shark Tank competition. He won \$75,000 to develop a free phone app for detection of motor seizures. As of August 2018 the app has been released for Android and is available to download for free (with in-app purchases) from the Google Play App Store.



As per seizario.healthappytech.com, note that using Seizario is not a substitute for calling for medical help or calling 911 in case of life-threatening emergencies.

** via Epilepsy Foundation Research Quarterly Issue 7*



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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.

Epilepsy
Newfoundland & Labrador



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WWW.EPILEPSYNL.COM



Asked and Answered

Q: Can I drive if I have epilepsy?

A: It is important to note that having epilepsy does not automatically disqualify you from being legally permitted to drive. However, if your seizures are not controlled, there are restrictions to driving. Each province and territory has its own regulations. Driving is not allowed until you have been seizure free for at least 6 to 12 months and you are under a doctor's care. A shorter period may be considered upon a favourable neurologist's recommendation.

If your seizures return, contact your doctor. For more information visit: www.epilepsynl.com/driving.

**If you have further questions speak to your doctor and go from there. Via Epilepsy Education Series.*