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Epilepsy News is
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Spring 2018

Purple Day 2018

Epilepsy Newfoundland and Labrador is proud to report another successful Purple Day! Every year we have so many fantastic participants, and this year was no different. The Spicers of Pasadena wore their Purple and had a reading program at their local library. ENL's 2018 Purple Day Ambassador, Edward Pilgrim-Turner, visited hospitals, took to social media and successfully raised Epilepsy Awareness in Labrador. Many people throughout NL wore their official ENL Purple Day T-shirts with pride, including Kristina Squires and Juanita Stamp who took initiative to organize T-shirt sales amongst family, friends and co-workers. Surrounding businesses showed support, including an Epilepsy Awareness at Work Day at Medigas in Paradise, and an Epilepsy Awareness Day and

fundraiser at Lawtons Mt. Pearl. Schools across the province held bake sales/Purple Shirt Days and set up information booths, and daycares Bunny Hopped for the more than 10,000 people living with epilepsy in NL. 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 2019 or have an idea for an event, contact info@epilepsynl.com or 1-866-Epilepsy.



2018 Purple Day Ambassador



Epilepsy NL's 2018 Purple Day Ambassador Edward Pilgrim-Turner of Happy Valley-Goose Bay was diagnosed with epilepsy in the summer of 1993, when he had just turned 20. He has faced adjusting to medication side effects, challenges with epilepsy at work and has worked to stay active and healthy.

He has chosen to share his story as despite the challenges brought forth by epilepsy Edward has never let his diagnosis define who he is or what he is capable of accomplishing: "No

matter how often I had a seizure, I never let my condition control what I can or cannot do."

As ENL's 2018 Purple Day Ambassador, Edward's perseverance inspires others: "To be the Purple Day Ambassador means so very much; being able to spread awareness about Epilepsy to people in both my community, and through social media."

Edward attended the signing of the Proclamation with Mayor Wally Anderson, and had a busy and successful day visiting the local hospital, distributing pamphlets, fundraising and taking to social media.

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Dr. A.O. Ogunyemi,
M.D., FRCP ©

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Sarah Mercer

Evan's Bookmarks

Every year Evan Newhook of Dildo creates a piece of art and sells it in his hometown on Purple Day, with the proceeds going to Epilepsy Newfoundland and Labrador. Evan was the 2015 Purple Day Ambassador and his ambitions and passion have remained consistent ever since. He is dedicated to spreading awareness in his school and throughout his community: "I want people to know how to help others and

what to do when someone has a seizure. I am going to make a difference every year." This year Evan designed a beautiful bookmark, and his efforts raised over \$200! Evan's family runs Active Printing located in Dildo, which helped design and print our Purple Day t-shirts with all proceeds going to ENL. Thank you to Evan and the Newhooks!



Evan presenting the cheque to Sarah Mercer.

Silly Squad Raising Epilepsy Awareness

The Silly Squad and teacher Greg Woolgar presenting the cheque to Sarah.

Epilepsy NL reaches out to schools in Newfoundland and Labrador to participate in Purple Day, increasing awareness of epilepsy for individuals of all ages. This year in St. John's, a group of hard working and conscientious students at St. Matthew's took initiative to help raise Epilepsy Awareness at their school. St. Matthew's School has a volunteer based group known as the Silly Squad, who work together to organize and facilitate fundraisers throughout the year. This year the Silly Squad once again par-

ticipated in and fundraised for Purple Day. The squad, along with teacher Greg Woolgar, dressed in Purple and greeted their fellow students in the morning in the school's foyer on Purple Day, letting all know that it was time to Go Purple for Epilepsy. St. Matthew's had temporary tattoos, ribbons, and informational pamphlets on hand, and raised over \$200.00! Thank you St. Matthew's staff and students for your dedication, and a special shout out to the Silly Squad!

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 re-

sponsibility 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 Research Backed by ENL Grant 2018

Last year Epilepsy Newfoundland and Labrador donated \$25,000 to The Faculty of Medicine at Memorial University. That gift supported Dr. Matthew Parsons' research project, "Understanding and Preventing the Disregulation of Excitatory Neurotransmission in Epilepsy". This year, Epilepsy Newfoundland and Labrador is continuing to support integral epilepsy research in our province by awarding an additional \$25,000 research grant.

Following is a brief outline of the research conducted via ENL's 2017 grant, as prepared by Dr. Parsons: As per the hypothesis, a particular drug was tested for benefits. The drug was ruled out due to the number of side effects, however, Dr. Parsons was able to uncover other mechanisms for potential beneficial drug treatments. The funding was used to assist with ongoing operational needs of biomedical research lab, such as the purchase of drugs for the experiments, animal housing costs, and graduate student

support.

The grant had great positive impacts in the field, including increasing student and researcher interest in pursuing epilepsy research, and an addition of epilepsy content to courses for students at the graduate level. Lectures on epilepsy were given to neurology residents, and the data captured during this study can be used to leverage federal funding opportunities, allowing for further research.

On May 7th, 2018, ENL representatives attended a meeting with Researchers Dr. Matthew Parsons and Dr. Gary Paterno, as well as Memorial University Faculty of Medicine Senior Development Officer Jillian Gibson, to discuss research being funded by Epilepsy NL's 2018 grant, and award the grant itself. In attendance were ENL President, Ron Stone, Vice President Patti Bryant, Executive Director Gail Dempsey and Information Officer Sarah Mercer. The awarded

grant will fund the research project entitled "A Role for the MEIRI Gene in the Aetiology

of Epilepsy". MIERI is a gene that was discovered by Memorial University's Faculty of Medicine. In the current research project, Dr. Paterno, with a background in stem cell, genetics and cancer research, and Dr. Parsons are collaborating on investigating the epigenetics (the study of changes in organisms caused by modification of gene expression rather than alteration of the genetic code itself) that impact epilepsy by using the regulatory gene MEIRI in relation to neuron creation and stimulation. Following the meeting ENL President Ron Stone presented the \$25,000 grant to Drs Parsons and Paterno. This grant not only allows for further research but also contributes to the study of epilepsy on a continuing basis, by providing opportunities for more graduate students in our province to become involved and interested in research, of epilepsy in particular.



(R-L) Dr. Parsons, Dr. Paterno, ENL President Ron Stone, Vice President Patti Bryant, Executive Director Gail Dempsey, Information Officer Sarah Mercer.

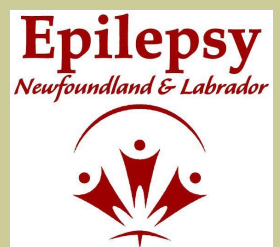


ENL President Ron Stone presenting the grant to Dr. Paterno and Dr. Parsons.



Faculty of Medicine

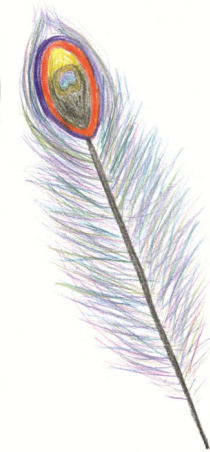
"I am truly grateful for this opportunity, and know that this would not have been possible without funding from Epilepsy NL."
-Dr. Parsons



Previously Loved Clothes & Things



Show Your
Support!



Wear Purple
March 26


Don't Fear the Purple

For the last four 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 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 held a clothing drive for Previously Loved Clothes and Things. The

team arrived at Previously Loved at 10:00 am on March 26th Purple Day with many bags of items they had collected.

Executive Director Gail Dempsey and Information Officer Sarah Mercer joined JAC members Faith and Anna during a Facebook Live feed, to highlight Purple Day for awareness and JAC's contributions. JAC and Don't Fear the Purple also held a bake sale with purple goodies at their office, raising \$250.00, an amount that was matched by JAC!



JAC Team dropping off donations



ENL would like to extend our sincerest thanks to the JAC team and Faith Atkins for their valuable contributions in raising epilepsy awareness and for their continual support.

Rocket Bakery: Purple Cupcakes

Each year on Purple Day, Epilepsy Newfoundland and Labrador teams up with Rocket Bakery. Beautiful Purple Cupcakes are made and decorated with care, and sold on March 26th. With 50% of the proceeds of the Purple Cupcake sales benefiting Epilepsy NL. The Purple

Cupcakes are always a favourite, and this year they were a huge hit, selling out in hours! ENL would like to extend a big thank you to Rocket Bakery and Fresh Foods for their continual support in raising Epilepsy Awareness in Newfoundland and Labrador. Rocket Bakery is located in Downtown



Purple Cupcakes 2018

St. John's, if you are in the downtown area stop by and grab yourself a treat!

We Want to Hear From You

Epilepsy NL is a proud member of the Canadian Epilepsy Alliance (CEA), and as part of the CEA's 20th Anniversary, we would like to highlight individual stories of epilepsy this year.

Sharing stories lets us know we are not alone and can inspire others.

Do you have a story that you would like to share? We would love to help you get it out there. Email info@epilepsynl.com or call 709-722-0502 to talk about submitting your story to Epilepsy Newfoundland and Labrador and for consideration to be placed on the CEA website.

There are many faces of epilepsy-let's show some from Newfoundland and Labrador!

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 Pottle, would like to thank everyone for all of their hard work during this campaign. If you are interested in partici-

pating in the Friends and Family Campaign next year please contact Elaine at 709-722-0502 or 1-866-Epilepsy.



Purple Day in Pasadena

Purple Day was started in 2008 by Cassidy Megan of Nova Scotia to let those who live with seizures know that they are not alone. Epilepsy Newfoundland and Labrador is proud to have participants who have been involved in Purple Day for many years, and Rachel Spicer, along with her family, have been participating in Purple Day since 2009! Rachel has led Purple Day at her high school each year, and this year marks her final year of high school. Epilepsy NL Community Information Officer Sarah Mercer spoke with Rachel via email and she had the following to say about her experiences with Purple Day and ENL.

In 2009, my sister Heather Spicer and I started participating in Purple Day. We learned about Purple Day from Epilepsy NL and we wanted to do our part. At the elementary school level starting in grade 3, I encouraged my classmates and school to wear purple. I continued to do this through all of my years of high school until grade 12. My father, Tim, was diagnosed with epilepsy when Heather was an infant. I have seen how epilepsy has affected his life and

our family life and I wanted to do my part to help support/raise awareness. My cousin Adam has also lived with epilepsy his entire life. To me there were too many stereotypes of epilepsy. Being that all seizures were grand mal (tonic-clonic) seizures and lead to convulsions on the floor. My dad has Focal Impaired Awareness seizures so his type of seizure is completely different to that stereotype. I wanted others to be aware and to become educated.

In the past few years, my school has always been a supporter of Purple Day. The majority of students wear purple and have been supportive of the students in the school with epilepsy. I always set up a table with information and ribbons where people can come ask me questions and learn a little more about epilepsy. A few years ago we had the paint your thumb purple activity where you could paint your nail purple with nail polish. Surprisingly, this went over well with



Pasadena Academy 2018

the boys in the school! When I was 12 years old I created a small business I called FoamRaising for Epilepsy. I created small foam creations and donated 100% of the sales to Epilepsy NL. I sold these creations at school and to friends and family. This has always been my favourite way to support Purple day and Epilepsy. It wasn't something that was too difficult for me to do but I was able to help out some others who live with epilepsy.

Thank you, Rachel and family for your support and dedication over the years, and we wish you all the best in your future endeavors!

"I wanted others to be aware and to become educated."
-Rachel Spicer



"Foamraising" 2011

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.



Purple Day Commitment

Each year Epilepsy Newfoundland and Labrador asks MHAs, MPs, Mayors and Council to sign a Purple Day Commitment. This commitment simply asks them to wear purple and take advantage of their social media presence to spread awareness about epilepsy. This year we had such a great response. Almost all government

officials wore Purple in the House of Assembly on March 26th, and Mayors as well as many councilors wore Purple and Epilepsy Awareness ribbons during Proclamation Signings. Thank you for your support of Purple Day. Executive Director Gail Dempsey, CIO Sarah Mercer

and Epilepsy Newfoundland and Labrador members were invited to the House of Assembly to hear Ministerial Statements about Epilepsy and ENL, and we are happy to share some excerpts from each parties' statements.

Cities and Towns Across the Province Sign the Proclamation

Each year cities and towns across Newfoundland and Labrador proclaim March 26th as Purple Day by signing the Purple Day Proclamation. There was a great response to the Proclamation this year, and we would like to thank all the cit-

ies and towns who participated for their support. The Province of Newfoundland and Labrador, represented by The Honourable John Haggie, Minister of Health and Community Services, also proclaimed March 26th as Purple Day. Below are

some Proclamation highlights from around Newfoundland and Labrador, for a full listing of participating cities and towns visit www.epilepsynl.com



The Hon. John Haggie with Executive Director Gail Dempsey and CIO Sarah Mercer, St. John's.



Board Member Patsy Lush with Mayor Jim Parsons, Corner Brook



Purple Day Ambassador Edward Pilgrim-Turner with Mayor Wally Anderson, Happy Valley-Goose Bay.



Mayor Paul Pike and Council, St. Lawrence.



"The provincial government gladly joins with schools, businesses and individuals in communities throughout the province today, as well as across Canada, and in other countries, to recognize Purple Day in Newfoundland and Labrador".

The Honourable
John Haggie
Minister of Health and Community
Services



"I am delighted to stand with my colleagues today and offer congratulations to all those organizing Purple Day events, and I too encourage everyone to attend activities in their communities."

The Honourable
Lorraine Michael
Third Party House Leader



"The official opposition joins with government, schools, and communities across the province and the country to recognize Purple Day. It is very likely we all know a family member or friend who copes with epilepsy, so it is important that we use every opportunity, like today, to recognize its' impact".

Mr. David Brazil
MHA Progressive Conservative Party

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Epilepsy NL and the MaxZen Racing Team

MaxZen Racing is a team of drivers who compete in Targa Bambina, which is a rally race of motorsports in Newfoundland and Labrador. The team uses the opportunity to bring awareness to different topics, and this year are partnering with Epilepsy Newfoundland and Labrador to bring awareness to Epilepsy. In December of 2017 ENL Representatives Executive Director Gail Dempsey and Information Officer Sarah Mercer met up with MaxZen Racing Representatives Gordon Maxwell, Mark Noftall, Elizabeth Noftall and ENL's 2012

Purple Day Ambassador Luke Noftall at ENL's offices to discuss design concepts and awareness strategies.

The 2nd annual Targa Bambina competition, held during the Canada Day long weekend in 2018, consists of three days of driving competition, offering 16 competitive stages on the lower Burin Peninsula of NL. Targa NL is owned and operated by Newfoundland International Motorsports Limited, and is one of three internationally recognized motorsports events in the world, held over seven days. Targa Bambina follows the same motorsports event



Epilepsy Newfoundland
and Labrador

outline, and is a compact, three day driving adventure. The competition is an excellent opportunity to reach a wide audience, promote awareness of epilepsy and dispel myths that still surround it. Targa Bambina will start on June 29th and run until July 2nd 2018. Stay tuned to our Facebook and Twitter (@EpilepsyNL) for updates on Epilepsy NL and the MaxZen Racing team's Epilepsy Awareness efforts!

Previously Loved Clothes & Things

LOCATION: 351 KENMOUNT ROAD, ST. JOHN'S, NL.
OPEN SEVEN DAYS A WEEK 9:30 AM - 9:30 PM
HAVE SOMETHING TO DONATE? (709) 722-5571

WHERE YOU'LL FIND HUNDREDS OF TREASURES WITH EXPERIENCE!

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.



@PLCAT @EPILEPSYNL



@EPILEPSYNL

WWW.EPILEPSYNL.COM

Epilepsy
Newfoundland & Labrador



CLAE Scientific Meeting 2018

Epilepsy Newfoundland and Labrador will be attending the 2018 CLAE Scientific Meeting, set to be held in St. John's, NL from September 21st-September 23rd 2018. CLAE is "an organization of medical and basic sciences professionals counting more than 125 members, including physicians, basic scientists, nurses, neuropsychologists, neuroradiologists, students and other health professionals" (*via clae.org*). Neurologists, Researchers, Epileptologists, and Epilepsy Professionals will attend the conference in NL to participate in sessions held by registered speakers. Epilepsy NL looks forward to this opportunity to have such focus on Epilepsy and Epilepsy Research in our province.

