



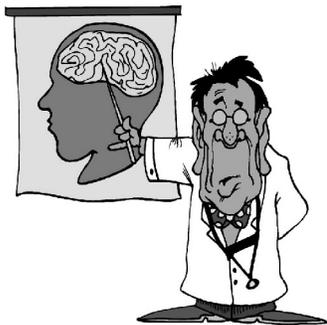
Ask The Doctors! A Question & Answer Forum for Everyone

Have epilepsy questions you have always wanted to ask an expert?

Want to share the stories and experiences of others who struggle with epilepsy?

WE HAVE YOUR OPPORTUNITY!

On **Thursday, March 21st**, Epilepsy Newfoundland and Labrador will be hosting our annual province-wide **Ask The Doctors** Forum on Epilepsy. Once again we are very pleased to have two of this province's foremost authorities on epilepsy and seizures:



Dr. A. Ogunyemi,
Epileptologist

and

Dr. D Buckley,
Pediatric
Neurologist

Come join two of Newfoundland and Labrador's most knowledgeable neurologists on epilepsy and seizure disorders, in a province-wide Question and Answer Forum. Ask Dr. Ogunyemi and Dr. Buckley the questions that are important to you, and find out even more about epilepsy.

**Participation is open to anyone in the province.
REGISTRATION FOR THIS EVENT IS FREE**

This will be our 24th year for this event! During all that time, there have been so many thought provoking questions, with something new to learn each year.



Participants are welcome to ask questions pertaining to their specific circumstances, or more general questions. Some past questions have included:

- Seizures and memory loss
- The decision to wean off meds after years of being seizure-free
- Nocturnal Seizures
- Non-epileptic seizures and treatment options
- and many others.

Don't feel comfortable speaking up? No problem! Just by listening to the other questions, you can learn a great deal that might help you too.

If you live in St. John's and the surrounding areas the conference will be held on March 21st at 7:00pm, at the Epilepsy NL offices, 351 Kenmount Road (next door to VOCM Radio).

If you live outside of St. John's, we are pleased to be able to include everyone in the province who wishes to participate in this annual forum via teleconference. If you have access to a phone, you can join us!

Make sure you don't miss out.
Please register in advance to save your place.

For more information or to register, contact
PAM ANSTEY, Information Officer
Epilepsy Newfoundland and Labrador
(709) 722-0502 or toll free at 1-866-EPILEPSY
info@epilepsynl.com

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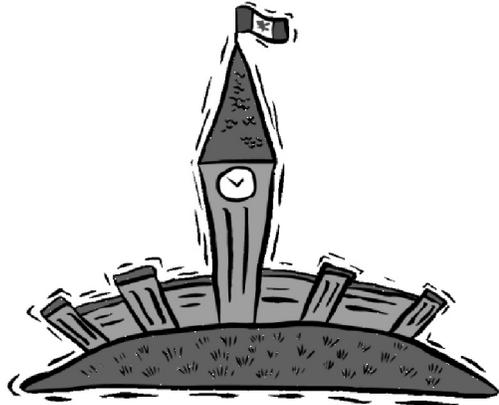
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Purple Politics!



On March 26th there will be a very special Gala in Ottawa for all Members of Parliament and Senators to honour and celebrate Purple Day for Epilepsy.

Is your representative going? If you think your MP or Senator should be there, email or call them! Let's make sure that all the Newfoundland and Labrador representatives are present and purple for the Gala in support of Epilepsy Awareness.

If they would like more information about the event, have them get in touch with us here at the office.

Our Executive Director, and President of the Canadian Epilepsy Alliance, Gail Dempsey will be there to help educate and spread understanding of the realities of living with epilepsy.

Let's bring epilepsy out of the shadows and into the light of the national view, starting right at the top of Canadian Government.

Closer to home, check to make sure your town or community will be proclaiming March 26th as Purple Day. Notices have been sent to every city, town, and community in the entire province. Take a moment to call your town office today and ask them to proclaim March 26th Purple Day for Epilepsy in your community.

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 advisors, 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 have.

People with epilepsy should never discontinue anti-epileptic medications or make changes in activities unless specifically advised to do so by an attending physician.

Purple Day - March 26th, 2013

It's March, and that means **Purple Day 2013** is only a few more days away! We have so many things happening; from hopping bunnies to quizzing doctors, we're working hard to get the word out, and to let anyone who lives with epilepsy know that they are not alone.

Purple Day Bunny Hop

We're turning the province's pre-schools purple with our Any-Bunny can Have Epilepsy Purple Bunny Hop.

Daycares and Preschools all over the province have been invited to hop along with us on Purple Day in support of Epilepsy Awareness.

Every 'bunny' that hops for Epilepsy on Purple Day will be eligible to win prizes, and everyone who participates will get information all about seizures.

Positively Purple Schools

We're sending out the call to all schools, inviting them to become one of our Positively Purple Schools for Epilepsy. Invitations have gone out to every school in the province and we want to see a province of purple from coast to coast!

2012 saw many schools show their purple with events and activities to bring awareness to their school about what life is like with seizures. It was awesome! If you're school hasn't signed on yet, it's not too late. We can rush all the information, handouts, and fun bits to make your school a Positively Purple School for Purple Day 2013.

Purple Day Proclamations

Last year, the Government of Newfoundland and Labrador, along with cities and towns all over this province proclaimed March 26th as Purple Day for Epilepsy.

This year we are hoping for even more proclamations. We want to encourage all MHAs, MPs, and Municipalities to be active supporters. Sign the proclamation, wear Purple on March 26th, light up your town hall with purple lights, or participate in any creative way you choose.

Paint the Province Purple

Many individuals, businesses, organizations, and workplaces across the province go purple for Purple Day. Do you? Let's get even more places involved this year to show just how much support there truly is for people living with seizures across Newfoundland and Labrador.

Want great ideas for things you can do at your workplace or in your community? Check out the next page of this newsletter for fun and creative ways YOU can help paint the province purple for Purple Day 2013.

Let us know, and we will send you information and promotional goodies you can use to make your event even more purple.

The Purple Day Puzzler

Want an easy way to save a little extra money on your next purchase at our thrift store **Previously Loved Clothes & Things**?

Visit our thrift store and pick up the **Purple Day Puzzler** - a flyer filled with information about Epilepsy and Purple Day, as well as a fun puzzle. Complete the puzzle and return it to our store at 351 Kenmount Road to receive 50% off any one item of clothing!

(While supplies last. Certain conditions apply. See in store for all the details)

Purple Day

Founded in 2008, by nine-year-old Cassidy Megan of Nova Scotia, Canada, Purple Day is an international grassroots effort dedicated to increasing awareness about epilepsy worldwide. On March 26th, people from around the globe are asked to wear purple and spread the word about epilepsy.

*Join with us in turning the province purple on **Purple Day!** On Tuesday, March 26th, wear purple and encourage others to do the same. (Let us know and take pictures!)*



How Will You Proclaim Your Purple?

Want to participate in Purple Day but not sure what to do?

We have lots of ideas.

Check them out and find one that's perfect for you.

- ★ Wear Purple!
- ★ Purple outfit day - The more outrageous the better
- ★ Purple pizza day - to make and share, or sell for lunch as a fundraiser
- ★ Purple shirt day - paint or dye plain white t-shirts purple, decorate with words of support
- ★ Purple cupcake/cookies/muffins/cake sale
- ★ Seizure education day - Information and awareness shared with everyone
- ★ Purple balloon launch
- ★ Purple face painting

- ★ Positively Purple Tea Party
- ★ Purple Pancake breakfast
- ★ Pedal for Purple - Grab your bike and pedal for Epilepsy Awareness. Get donations and turn it into a fundraiser.
- ★ Purple Photo or Scavenger Hunt - How many things can you find?

Need even more ideas? Want freebies and information to hand out on Purple Day?

Contact us at info@epilepsynl.com
or call 1-866-EPILEPSY (866-374-5377)



2013 Door to Door Campaign

Our 2013 Door to Door Campaign is well underway across Newfoundland and Labrador. With the help of many generous and caring people just like you, I am sure that this year will be a success once again.

It's because of our volunteers and the generosity of those who give even a small donation that we can continue to bring numerous programs and services to individuals, family and friends who are influenced by the effects of epilepsy.

Will you give just a little time to help? If so, perhaps you could collect a street or small area in your hometown, or perhaps you would be willing to collect among your friends and family?

If you are able to help for even an hour or two, please call me at 722-0502 or toll free at 1-866-EPILEPSY (374-5377).

Elaine Pottle, Campaign Coordinator

Understanding SUDEP

It's one of those topics in epilepsy that many never talk about, or if they do, only lightly glance over because it is scary stuff - SUDEP, or sudden unexplained death in epilepsy.

It's controversial for certain. Even most experts can't really agree on how prevalent it is. The latest statistics from the World Health Organization put the total number of epilepsy related deaths per year around 220 in Canada, and researchers feel that anywhere between 7 and 17% of those may be related to SUDEP.

But what is SUDEP really, and more importantly, are there any steps that people with epilepsy can take to reduce their risk?

In technical terms, SUDEP is defined as:

"the sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in patients with epilepsy, with or without evidence for a seizure, and excluding documented status epilepticus, in which post-mortem examination does not reveal a toxicological or anatomic cause for death." Nashef L, *Epilepsia* 38 (Suppl.11): 56-8

In plain English, SUDEP is when a person with epilepsy dies suddenly and no other cause of death is revealed.

While no one has yet to determine an actual cause, research has shown some people seem to be more at risk than others.

- Having frequent changes of anti-epileptic drug dosage .
- Experiencing nocturnal seizures (during sleep).
- Being alone at the time of the seizure.
- Being a young adult, particularly male.
- Uncontrolled or poorly controlled epilepsy
- Severe epilepsy and learning difficulties
- People with a long history of tonic-clonic seizures
- People who take 2 or more anti-epileptic drugs (especially if combined with psychiatric agents)
- Poor compliance with anti-epileptic medications
- Alcohol abuse (definite links found)

When considering the risk factors, remember that just because some or more of these may apply it does not mean that someone will die from SUDEP.

However if several of the factors do apply, it may be worthwhile to consider making some changes to minimize the risk.

- Controlling seizures seems to be most important, discuss your management plan with your doctor
- Keep appointments so your doctor can monitor any changes, and adjust your medications accordingly.
- It is vital to take all medications at the time prescribed and in the correct manner every day.
- Avoid sudden drug withdrawal, or dosage changes
- Adopt a healthy lifestyle including regular sleep, exercise, nutritious meals, and stress reduction.
- Avoid alcohol and street drugs
- Stay with company whenever possible so that someone can help during seizure
- Nocturnal seizures seem to have a higher incidence of SUDEP. Preventive measures could include having the bed near the floor, changing from a regular to a corrugated foam pillow to reduce the possibility of suffocation, and having a monitor to alert others when a seizure occurs.

"People with epilepsy have the right to know that SUDEP exists, and they have the right to be responsibly counselled about how to reduce the risk," says SUDEP Aware's Dr Elizabeth Donner.

If you would like more information on SUDEP, visit www.sudepaware.org or call the Epilepsy NL office.

Disability Tax Credit & the RDSP Are You Getting the Benefits?

Are you getting all the benefits you deserve? Many people who might be eligible for the Disability Tax Credit or the Registered Development Savings Plan never take full advantage. That's like giving your money away!

Check to see if you might be eligible for a little more money in your pocket.

Disability Tax Credit

The Disability Tax Credit is a non-refundable tax credit used to reduce income tax payable for eligible individuals. To be eligible, you must meet all three of the following conditions:

- You must have a severe impairment in physical or mental functions.
- Your impairment must be prolonged - which means it has lasted or is expected to last for a continuous period of at least 12 months.
- A qualified practitioner certifies that your impairment is severe and prolonged and completes Form T2201, Disability Tax Credit Certificate, detailing the effects of the impairment applicable to the basic activities of daily living.

If you are eligible for this credit but are unable to use all or part of it because you have no taxable income, you can transfer it to your spouse, common-law partner, or other supporting person.

A supporting person may be able to claim all or part of a dependant's Disability Tax Credit providing that both the supporting person and the dependent were residents of Canada during the tax year.

Registered Disability Savings Plan

The Registered Disability Savings Plan (RDSP) is a savings plan designed specifically for people with disabilities in Canada. The first of its kind in the world, this new tax-deferred savings program will assist families in planning for the long-term financial security of their relatives with disabilities.

Over time, the RDSP will provide billions of dollars to supplement income, enable home ownership, and enhance quality of life for as many as 700,000 Canadians with disabilities.

In addition to the RDSP, some individuals may also be eligible for the Canada Disability Savings Grant and Bond.

Highlights of the Registered Disability Savings Plan

- Funds can be invested tax-free until withdrawal
- Anyone eligible for the Disability Tax Credit may set up an RDSP
- In the case of a minor child, a parent or guardian can establish and direct the RDSP
- A \$200,000 lifetime contribution limit
- Contributions by individual, family or friends
- No annual limit on contributions
- Contributions grow on a tax deferred basis
- No restrictions on when/why the funds are used
- Upon withdrawal, the income, the Grant, and the Bond are taxed in the hands of the beneficiary, and are likely to be taxed at a much lower rate

Highlights of the Canada Disability Savings Grant

- The CDSG will provide a federal contribution to assist families in saving for the future
- When annual net income is less than \$83,088 the grant will contribute:
 - \$3 for every \$1 contributed on the first \$500
 - \$2 for every \$1 contributed on the next \$1,000
- When annual net income is over \$83,088, the grant will contribute:
 - \$1 for every \$1 contributed up to \$1,000
- The Grant can be received for 20 years, until the beneficiary turns 49.

Highlights of the Canada Disability Savings Bond

- When annual net income is \$24,183 or less, **the Canada Disability Savings Bond will provide \$1,000 per year whether or not contributions are made to the plan**
- The RDSP thus becomes accessible to persons with disabilities whose family does not have the resources to make contributions
- Like the Grant, the Bond can be received for up to 20 years until the person's 49th birthday

The Registered Disability Saving Plan is exempt from the calculation of Income Support benefits in Nf & Lab!

For More Information

Disability Tax Credit:

- Contact Canada Revenue Agency at 1-866-741-0127

RDSP

- Contact your bank or financial institution

Epilepsy Drug Linked To Increased Risk Of Autism

Children born to mothers who took the antiepileptic drug sodium valproate during pregnancy are at significantly increased risk of autism and other neurodevelopmental disorders.

The finding came from new research published in the *Journal of Neurology, Neurosurgery and Psychiatry*

The research involved kids born to 528 pregnant women in England between 2000 and 2004. Fifty percent (243) of the moms had epilepsy, only 34 of those women did not take antiepileptic drugs while pregnant.

Carbamazepine was taken by 59 of the women, valproate was taken by another 59 women, lamotrigine was taken by 36, forty-one of the females took a combination, and 15 took other medications.

The researchers evaluated the physical and intellectual development of the kids at 12 months, three years, and 6 years of age.

The mothers also provided the scientists with information on whether they ever had to seek professional advice concerning their child's development, behavior, health, or educational progress.

There were 415 kids who had complete data on all 3 evaluations. A neurodevelopmental disorder was diagnosed in 19 kids by the time they were 6 years old, three of those children were affected by a physical abnormality.

Twelve of these kids had a form of autism, one child also had ADHD (attention deficit hyperactivity disorder). Three had ADHD alone and another four had dyspraxia - a condition that causes poor physical coordination and uncontrolled clumsiness.

The experts discovered that neurodevelopmental issues were notably more prevalent among those kids whose mothers had epilepsy - 7.46% vs. 1.87% of those whose mothers did not struggle with the condition.

The children whose moms took valproate by itself or with another drug during pregnancy had a considerably higher chance of being diagnosed with a neurodevelopmental condition, compared to those whose mothers took other medications for their disorder.

After examining all of the figures and adjusting for factors likely to impact the results, the investigators found that kids exposed to valproate in the womb were 6 times more likely to have a neurodevelopmental disorder.

Kids who were exposed to valproate and other drugs were 10 times more likely to have a neurodevelopment disorder than those whose moms did not have epilepsy.

Six out of 50 children (12%) whose mothers had taken valproate alone while pregnant had a neurodevelopmental problem, as did 3 out of 20 (15%) of those whose mothers had taken valproate with other treatments.

The women who had epilepsy and did not take drugs to treat the condition during pregnancy did not have any children diagnosed with a neurodevelopment disorder. However, the experts noted, there was only a small number of females in this group.

Boys had a 3 times higher chance of being diagnosed with a neurodevelopmental disorder. However, no notable links were identified for the mother's age or IQ, epileptic seizure type, or length of pregnancy.

Although further studies are necessary before conclusions can be drawn, the findings of this research support prior reports that have demonstrated that there are potentially negative effects of valproate on the developing fetus.

For example, one study indicated that kids born to moms who took valproate while pregnant tended to score notably lower in IQ tests by an average of 6 to 9 points at age 3, than kids born to moms who took other anti-epilepsy drugs.

The experts concluded: "If sodium valproate is the treatment of choice, women should be provided with as much information as possible to enable them to make an informed decision.

But on no account should pregnant women just stop taking the drug for fear of harming their developing child," the scientists concluded."

The researchers added that kids born to mothers who took the medication while pregnant need to be observed closely.

Sarah Glynn, Medical News Today, February 1st, 2013

Hellos & Good-Byes

On February 1st, 2013, Epilepsy Newfoundland and Labrador bid a fond farewell to a retiring Alice Kendall, who has worked with ENL for nearly fourteen years.

Alice handled the finances and payroll, as well as the confirmations for donation pick-ups with Previously Loved Clothes & Things, the ENL thrift store. While we are sad to see her go, we know that she's got a great retirement ahead.

Stepping into the role of confirmation clerk is Nancy Evans. Nancy has been settling in nicely and getting used to all the details of the job. Have useful things you don't need anymore, give Nancy a call to arrange a pick-up anywhere in the metro area, and be sure to say hello and welcome her aboard.



*Nancy Evans (standing)
and
Alice Kendall (sitting)*

CCRW Scholarship for Students With Disabilities

The Canadian Council on Rehabilitation and Work has scholarships available to assist students with disabilities in their pursuit for post-secondary education and training.



Scholarships in the amount of \$2,500 each are available for the academic year beginning September 2013.

To be considered, scholarship applicants must:

- Be a person with a long-term and recurring disability that restricts the ability of a person to perform the activities necessary to participate in educational activities. This limitation is expected to remain with the person for life.
- Be a high school student entering full-time into the first year of studies in a Canadian post-secondary institution that is recognized by the Association of Universities and Colleges of Canada at the undergraduate level.

Applications are evaluated on a number of factors including:

- Community involvement
- Extra-curricular activities
- Approach to overcoming barriers
- Academic performance
- Educational goals and direction

Applications, along with all supporting documents must be received at The Canadian Council on Rehabilitation and Work no later than 4:30 pm on Friday, April 26, 2013.

Application forms are available through The Canadian Council on Rehabilitation and Work website: www.ccrw.org

For more information, contact:

The Canadian Council on Rehabilitation and Work
One Yonge Street, Suite 1202, Toronto, ON M5E 1E5
Phone: 416 260 3060 Toll Free: 1 800 664 0925
E mail: info@ccrw.org

A Little Time Out

What words are missing?

When you have found them all, look for those same words in the puzzle. All the leftover letters in the will spell a hidden message.

- An _____ type of seizure looks like staring.
- Seizures start in the _____.
- Type of seizure: _____ Partial.
- Disrupted _____ currents cause seizures.
- Recurrent seizures are also known as _____.
- After a seizure lasts _____ minutes, call an ambulance.
- Convulsive seizures last two to _____ minutes.
- If you have a brain, you can have a _____.
- For first aid, put something _____ under the head.
- Then ask that people give lots of _____.
- One in every _____ people will have a seizure.

T	O	M	O	R	R	E	E	Y
A	B	S	E	N	C	E	L	S
O	C	W	R	A	I	E	E	P
B	T	O	P	U	R	T	C	E
R	F	S	M	U	O	C	T	L
A	O	O	Z	P	T	F	R	I
I	S	I	U	E	L	L	I	P
N	E	D	N	B	E	E	C	E
S	Y	E	V	I	F	O	X	U

Hidden Message:

A lady went to a psychiatrist complaining of a terrible phobia. "Every time I lay down on my bed I get this terrible fear that there is something underneath.

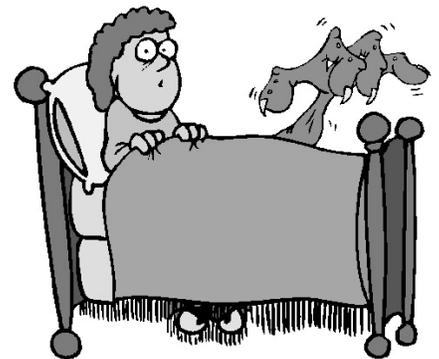
"Wow" responded the psychiatrist "I've never heard of such a phobia, but like all phobias it can be treated, but it will likely take around 20 sessions."

"OK" responded the lady "how much is each session?"

"Oh it's just \$80 a session, but trust me it's well worth it."

When the lady didn't come back to the psychiatrist he gave the lady a call. "How come I didn't hear from you? He asked."

"Well" responded the lady "when I came home and told my husband about the cost he thought he would save some money, he just cut the legs off the bed!"



Email or Postal Mail?

Help us, and help the environment too! Here at ENL, one of the greatest expenses we have is postage. Because of this, and in the interests of being as environmentally friendly as possible, we want to offer our members the option of receiving newsletters and notices by email instead of postal mail.

Privacy is not a concern.

Nobody else will see your email address. And we would never make our email or mailing lists available to anyone else.



If you wish to sign up for e-mail communication from us, just drop us a line at info@epilepsynl.com. If you ever want to change back, just let us know and we will be happy to do so.

If you don't have e-mail, or don't want to receive email newsletters and notifications from us, you don't need to do a thing. We will continue to send you your information through postal mail like always. Have questions? Call us at 1-866-EPILEPSY

Spring is when you feel like whistling even with a shoe full of slush. ~Doug Larson

Harry's mother was expecting, and naturally Harry was very excited about it.

When one day Harry stopped talking about the baby completely.

Concerned, his father asked what was wrong.

"Well", Harry said, "Mom told me she could feel the baby moving in her stomach. Dad... I think she ate it!"



I Would Like To Help in the Fight Against Epilepsy

- I am enclosing a donation of \$ _____
- I would like to become a member of Epilepsy NL. I am enclosing my \$5.00 membership fee.
- I would like to become a volunteer. (We can use volunteers from right across the province)

Name:	Email:
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Address:

Phone:	Would you prefer mail-outs by: email or postal mail?:
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If you would prefer to pay by credit card, please complete the following:

Account #	Type of card:	Expiry:
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Clip and mail this form to Epilepsy Newfoundland and Labrador - 351 Kenmount Road, St. John's, NL A1B 3P9