



## Epilepsy NL Scholarship Winners 2013-2014

**C**ongratulations to our winners! The ENL scholarships have been awarded for 2013-2014. Each year ENL proudly offers \$1000 scholarships to post secondary students with epilepsy to assist them with continuing their education and pursuing their dreams.

### The Zach Rowe Memorial Scholarship

The **Zach Rowe Memorial Scholarship**, valued at \$1000, and supported by the fundraising efforts of the Rowe family, is awarded to a student with epilepsy in their first year of Post Secondary studies after High School. It honours Zach Rowe, recipient of the ENL scholarship in 2006, who passed away as a result of his seizures in 2009.



*Cassie Singleton receives her scholarship from ENL Executive Director Gail Dempsey*

This year's winner is **Cassie Singleton of Clarenville**. Cassie has just begun her first year at Memorial University with the goals of pursuing a medical career.

*Most people had me convinced that I wasn't capable of passing high school, let alone*

*making it into university or becoming a doctor one day. I blew everyone away, including myself.*

### The Jim Hierlihy Memorial Scholarship

The **Jim Hierlihy Memorial Scholarship**, also valued at \$1000, honours a mature student with epilepsy who has taken the initiative to return to studies to advance in their present job or train for a new career. It honours one of ENL's incredible volunteers, Jim Hierlihy, who was on the Executive of the ENL support group in Gander and a great supporter of all those living with seizures.



*Staci Blandford receives her scholarship from Gail Dempsey*

**Congratulations to Staci Blandford of St John's.** Staci is currently studying to become a CPA at the College of the North Atlantic.

*Epilepsy does not define me, nor does it control my daily life, but it is a part of who I am*

*and has certainly impacted my outlook on life in a positive way.*

### Epilepsy NL Family Scholarship



*Heather Spicer with her father Tim, after being presented her scholarship by board member Patsy Lush*

This year ENL is pleased to present a brand new scholarship. Valued at \$1000 it is awarded to a student whose parent or guardian has epilepsy.

The winner of the first ever Epilepsy NL Family Scholarship is **Heather Spicer of Pasadena**. Heather's

Father, Tim has been a long-time member of ENL and has lived with seizures for many years. Heather has just begun her first year at Sir Wilfred Grenfell in Corner Brook with a goal to work in psychology.

*My father is very close to my heart and ultimately I want him to lead a happy life. I have learned to accept my father for whom he is and that having epilepsy is just another part of him. While I may not be the one who has seizures, I am still living with epilepsy every day.*

## Epilepsy News

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## Follow Your Dream



**M**ona Earle is a previous winner of the Jim Hierlihy Scholarship in 2011. Since then she has graduated with Geomatics Engineering Technology at College of the North Atlantic. Currently she is working as an Offshore Hydrographic Surveyor in the Gulf of Mexico as well as off Newfoundland.

*"Your assistance has helped me accomplish a lot of goals and graduate to a position I love."*

**Congratulations Mona on your new and exciting career.  
All the best from  
Epilepsy  
Newfoundland and Labrador!**

Set your sights high, the higher the better. Expect the most wonderful things to happen, not in the future but right now. Realize that nothing is too good. Allow absolutely nothing to hamper you or hold you up in any way. - Eileen Caddy

## 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-seizure medications or make changes in activities unless specifically advised to do so by an attending physician.**

## Needs of Families: Research Shines Rare Spotlight on Fear, Depression and Clinical Chaos

*This is the second of two feature articles from the IEC Congress Report, July 2013, as prepared by Helen Leask PhD*

The International Epilepsy Congress (IEC) was held in Montreal last month, the first time this huge global gathering of epilepsy researchers and advocates has been held in North America. The big themes were: technical advances in diagnosis, medicine and surgery; new ways to organize the healthcare system; psychological and social issues; and the fight against stigma.

### **A Cry for Help**

A study from McMaster Children's Hospital in Hamilton subtitled *A Cry for Help* showed the high levels of stress and anxiety suffered by parents around the time their children were diagnosed with epilepsy. "Parents said they were 'living with a knot in their stomach every day'", said study author Dr Ramachandran Nair who leads the epilepsy service at the hospital. He said that his service "emphasizes 'family-centred care, not just patient-centred care.'"

Mothers suffered significant levels of depression, anxiety, fear and exhaustion, while fathers expressed feelings of worry, anger and concern about their families. Terror that their children would die resulted in high levels of vigilance, with everyone around them giving conflicting advice. Many parents admitted that their children slept with them in an effort to keep them safe.

Challenges with the medical system added to the misery, said Dr Nair. "Many parents received misinformation and misdiagnosis before seen by the specialist and they felt their concerns were not validated by the non-specialist," he said. "Parents were concerned that without a firm diagnosis appropriate investigations to identify the underlying cause of seizures, clear management plan or discussion on prognosis wouldn't be possible. All these resulted in a high level of anxiety and frustration among parents."

Families said that the situation improved once they were referred to a top epilepsy centre, with a firm diagnosis bringing a significant sense of relief. However, the pressures did not go away with diagnosis, said Dr Nair: "Epilepsy in their children continued to impact parents' emotional and mental health heavily due to different reasons, such as unpredictable seizures, cognitive effects, fear of death and so on."

### **Parents Need More Information**

A Dutch study focused on the educational needs of parents. Top of the list for the 174 families were: how the epilepsy would progress (76%); learning problems (71%); and specific information on their own child's seizure type (66%). Many parents in the study also wanted information on behavioural problems, consequences of epilepsy such as death or brain damage, anti-epilepsy drugs and school supports. For many parents, information was even more important than social support.

Mieke Daamen, the nurse practitioner who headed the education survey, said counseling at the clinic itself was very effective: "Previous consultations with a nurse practitioner led to a lower need for information and psychosocial support." Ms Daamen also expressed a wish that organizations providing information to parents would take on board the results of her study: "The needs [we have identified] could offer a guideline when giving information".

### **Treating Depression May Help Marriage Problems**

Turning to spouses, a study from China measured the pressure on a marriage from epilepsy. A researcher from Sichuan University analyzed 'marital adjustment' - a formal measure of how happy a marriage is - in 136 people with epilepsy compared to 145 people without epilepsy.

Dr Jiani Chen found that there was more marital discord in the marriages coping with seizures. However, the challenge was not the seizures themselves, but the emotional pressures of having epilepsy; depression, in particular, had a measurable impact on the relationship between the couple. "They said their partner became more bad-tempered and more depressed and this affected their marriage," said Dr Chen.

Treating the depression improved matters. Dr Chen suggested that control of depression in a spouse with epilepsy "may be considered a treatment to improve marital adjustment."



## Farewell from Pam

You and I will meet again, When we're least expecting it, One  
day in some far off place, I will recognize your face,  
I won't say goodbye my friend, For you and I will meet again.

~ Tom Petty

**G**ood-byes are always bittersweet. After more than ten years with Epilepsy Newfoundland and Labrador, I will be leaving my position on December 20<sup>th</sup>.

It has been an incredible ten years. I have been honoured to be a part of so many people's lives and journeys with epilepsy. I have talked with thousands of students about the brain and seizures; I have laughed with people and cried with people. I have seen hope even in the darkest of places, and I have seen the strength and resilience of the spirit; determined to fight and never, ever give up.

When I started with ENL back in 2003, I knew so little about epilepsy, or the ways that seizures can affect every part of someone's life.

Through you all, I have learned so much more than I could have ever hoped.

To every person I have worked with over the years, **thank you** for letting me into your lives, and for letting me help where I could. Your stories have touched me deeply and I will be leaving here changed because of them.



**Never forget that you are so much more than your seizures.**

## Hello from Susan

**H**ello to you all! I am the new Information Officer with Epilepsy Newfoundland and Labrador. I am very excited and eager to begin my journey helping in the lives of others who live with seizures.

I have a background in Public Relations as well as Education. Given my teaching experience I will say that, **making a difference** is something I have always lived by. The more we educate people about seizures, the better quality of life for those who are living with them.

I am here to talk with those of you who want to know more, walk with those of you who suffer and to help in any way I possibly can to make life easier.

This will be a new venture for me and I am sure it will be a wonderful and rewarding experience.

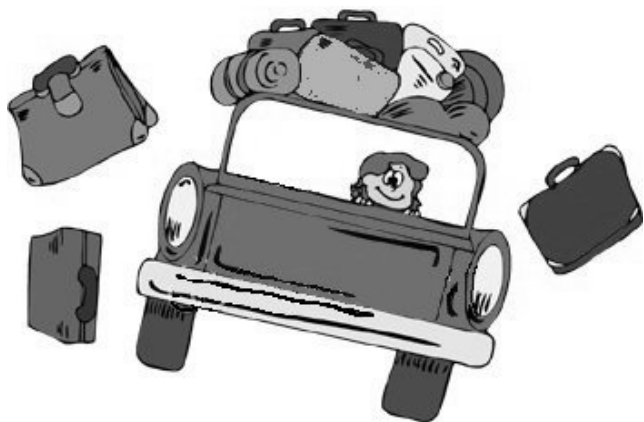
I look forward to meeting and working with all of you in the new year. Have a safe and Happy Holiday!

*Each one of us can  
make a difference.  
Together we make  
change.*

~Barbara Mikulski



## Fall Excursion - What an Amazing Week!



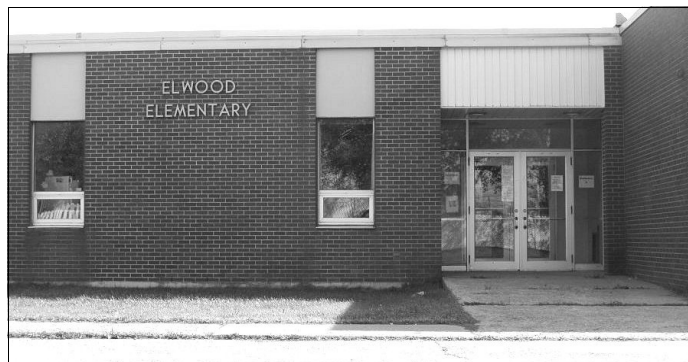
**W**hen I set out to plan the Fall Excursion this year, I did so with the goal of going at least a few places I had never been, and hopefully being able to meet with some of our more remote members. Fortunately I was able to do both.

My plan was to begin in Pasadena then work my way east to Buchans. Given the bureaucracy of getting School Board approval last year, I was a little apprehensive. However, the beginning of September marked the launch of the new English School Board, being headed by the former Eastern School District staff. We had a great working relationship with the Eastern School Board, and getting approval for the excursion was fortunately simple and quick.

Sadly, I wasn't able to begin in Pasadena, as the school was not interested. Instead, I began in Deer Lake, then travelled to Pollard's Point and Hampden on Tuesday. Wednesday was La Scie, Thursday saw me in Baie Verte and Springdale, and I concluded the week in Buchans and Badger.



I was thrilled to be able to connect with two different members of ENL; a family from Pasadena, and an individual from Corner Brook. Both of them took it upon themselves to drive to Deer Lake so we could meet in person and talk for a while. The impact of face-to-face meetings cannot be underestimated. I had a lovely time with both groups, and was very grateful to be able to have at least one opportunity to talk in person.



The rest of the week was excellent in spite of the miserable weather, and included a mix of school presentations, staff sessions, and daycare workshops. I also got to meet with the Public Health Nurse in Buchans to talk about how best to serve the people of the area given that they are in a relatively isolated area.

Over the course of the week, I did 25 presentations, had two member meetings, one professional meeting, and left behind resources and information in every town I visited. I reached over 600 people, not including the many parents and individuals who will read the information that was distributed.

The weather may have been rainy and foggy, but the response to the presentations more than made up for it. I'm proud of the interactive and high-energy session that we offer, and always gratified to see people respond so enthusiastically.

## Advance Health Care Planning

**E**pilepsy Newfoundland and Labrador are proud and honoured to support the new Advance Health Care Directives education initiative.

The Coalition of Persons with Disabilities-Newfoundland and Labrador want to help people make some difficult choices.

On October 8, 2013 it released a booklet that guides people through advance health-care directives (forms for which are also included in the booklet), urging people to make decisions about the level of health-care and treatment measures they'd want to receive should they ever be unable to communicate those wishes — and who will be allowed to speak for them in that situation.

Michelle Murdoch, the coalition's president, said the information is to help people say what they want to happen to them, rather than letting others make those decisions for them.

"We should be telling the medical system what as individuals we want, not presuming that everybody wants the same thing," Murdoch said after the coalition announced the information booklets at the Fluvium.

Murdoch said people might find it difficult to discuss with loved ones what sort of treatment they'd want, but it's a necessary conversation to have.

"We need to carry the conversations on, to get over that reluctance to talk about it," she said.

Dr. Rick Singleton, regional director of pastoral care and ethics for Eastern Health, said it's important to do it while people are still competent and able to make decisions about what they want to have done.

"The individual can give the direction for themselves, but it gives the direction for those who have to take on the burden of making the decision. And that's a big burden when it's a loved one," he said. "Particularly when it's the burden of having to decide about not continuing treatment."



### Advance Health Care Directives and Substitute Decision Makers



Often, said Singleton, a proxy decision-maker unsure of what his or her loved one would want will decide on more complicated and extensive treatments than they would want.

"Many people will request health services, heroic measures, for loved ones, that they wouldn't request for themselves. Most of us have a sense of when we would see it as reasonable to discontinue (care). But it's much more difficult to make that decision when it's going to bring the end of life to a loved one, and it's certainly much more difficult when there's disagreement among family members about when and what that time is."

Advance health-care directives allow people to ease the burden on family members who have to make those decisions, he said. Advanced health-care directive forms are available online at the coalition's website: [codnl.ca](http://codnl.ca). By Daniel MacEachern, *The Telegram*, October 09, 2013

## 2014 Door to Door Campaign

**O**ur 2014 Door to Door Campaign is searching for people like you to volunteer in your community to help make 2014 the best year ever.

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.

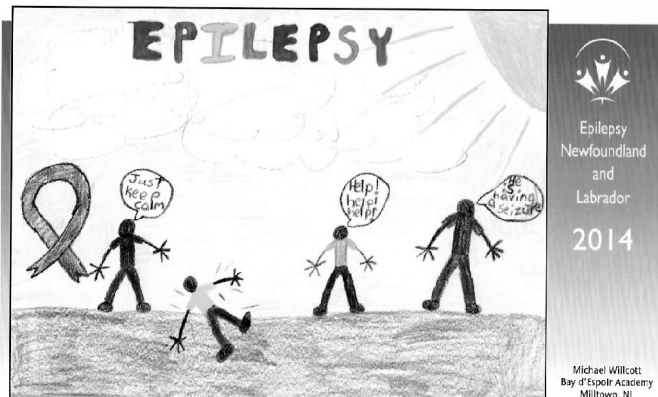
**Will you give just a little time to help?** If so, perhaps you could collect a street or small area in your hometown, or perhaps you would be willing to collect among your friends and family?

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 (866-374-5377).

Elaine Pottle,  
Campaign  
Coordinator



## 2014 Epilepsy NL Pocket Calendars are Here!



**2014 Pocket Calendars are now available.  
Makes a great stocking stuffer!**

**Call 1-866-EPILEPSY**

**O**ur Calendar Campaign is winding down! For each donation of \$20 or more to Epilepsy Newfoundland and Labrador, we are proud to send you a copy of our 2014 Pocket Calendar with artwork by Grade 4 children from all over our province.

Students featured in the 2014 calendar are:

- Michael Wilcott, Bay d'Espoir Academy, Milltown
- Bethany Lambert, Holy Name of Mary Academy, Lawn
- Hannah Doyle, Harbour Grace Primary, Harbour Grace
- Chloe Caroline Fudge, Bay d'Espoir Academy, Milltown
- Lisamarie Slavnwhite, Bishop White School, Port Rexton
- Adailia Earle, Harbour Grace Primary, Harbour Grace
- Clare Molloy, Goulds Elementary, Goulds
- Chloe Osborne, Fortune Bay Academy, St. Bernard's
- Noah Durnford, St. Simon & St. Joseph Academy, Francois
- Hailey O'Connell, St. Peter's Academy, Benoit's Cove
- Ashley Cuff, Bishop White School, Port Rexton
- Teresa Finn, Goulds Elementary, Goulds
- Shawna Edwards, Holy Name of Mary Academy, Lawn

Epilepsy Newfoundland and Labrador would also like to extend sincere thanks to our corporate sponsor



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***UCB Canada supports efforts to identify personalized treatment approach for drug-resistant epilepsy***

"UCB recognizes the important research that Dr. Cossette's team is undertaking to help diagnose and treat drug-resistant epilepsy," said Hervé Lilliu, General Manager, UCB Canada Inc. "We are hopeful that our contribution to this project will help the team reach their goal. The development of personalized diagnostics and treatment will constitute a major advance in preventing brain damage and cognitive impairment in individuals living with epilepsy."

**About UCB Canada Inc.** - Inspired by patients and driven by science, UCB Canada Inc. is a patient-centric biopharmaceutical leader focused on the discovery and development of innovative medicines and solutions to transform the lives of people living with severe auto-immune and central nervous system diseases. For more information, please consult [www.ucb.com/worldwide/canada](http://www.ucb.com/worldwide/canada).



## A Little Time Out



## Light Work

Alex is always getting himself into trouble. One week his teacher gives him detention every day after school. As a punishment he is asked to carry 100 heavy sandbags across the athletics track to the long jump pit. After struggling with the first ten sandbags, Alex has an idea. He realises that if he puts something into each sandbag it will be lighter to carry. What is it?

Answer on Page 10

Goodness is about character -  
integrity, honesty, kindness,  
generosity, moral courage,  
and the like.

More than anything else,  
it is about how we treat  
other people.

- Dennis Prager

## Email or Postal Mail?

**H**elp 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 contact from us, just drop us a line at [info@epilepsynl.com](mailto: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.

## Find Us on Facebook

**A**re you one of the over 400 million people on Facebook? If so, check us out! Our facebook page has all the latest and greatest from Epilepsy Newfoundland and Labrador.



Event pictures, upcoming events, current happenings, bits of news, and medical alerts are some of the things you will find on our corner of the Facebook world.

If there was ever a place to stay up to the minute with ENL, this is it! Just type [www.facebook.com/epilepsynl](http://www.facebook.com/epilepsynl) into your browser and you are sure to find us.

Or go to our website and click on the Facebook "Like" button on our front page.

He puts a hole in each sandbag.

**Puzzle Solution**

## 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:

Address:

Phone:

Would you prefer mail-outs by email or postal mail?:

**To pay by credit card please call 1-866-EPILEPSY or complete the following:**

Account #

Type of card:

Expiry:

**Clip and mail this form to Epilepsy Newfoundland and Labrador - 351 Kenmount Road, St. John's, NL A1B 3P9**