



Victoria Epilepsy & Parkinson's Centre

# BRAIN WAVE

The Magazine Of The Epilepsy Program

Vol.37, September 2015

## Announcing Brainstorm for Health

### Inside...

**Making the most of your neurological care.**

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Staying healthy is a worthwhile goal for anyone and is especially important for those with neurological conditions, such as acquired brain injury or epilepsy. Staying healthy when you have a neurological condition can become a full-time job.

#### Ever have questions like these?

Who is on your healthcare team?  
How do you make the most of a short neurologist visit?  
What if you want to explore alternative therapies?  
What are the different medications that might work for you and what role does your pharmacist play?

Join us for an investigation of these and more questions with our expert keynote speaker and panelists. This workshop will be of interest to those with a neurological condition, family members, and healthcare professionals.

Register by phone at 250-475-6677 or by e-mail at [help@vepc.bc.ca](mailto:help@vepc.bc.ca)  
Stay tuned to [www.headwayvictoria.com](http://www.headwayvictoria.com) for more details.

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**Presented by:**

HeadWay

Victoria  
Brain Injury  
Society



# On Being a Mom with Epilepsy

By Julie Audette



I was diagnosed with an idiopathic nocturnal seizure disorder in 1997. I experience tonic-clonic seizures while I sleep or shortly after waking. The diagnosis took considerable time as many tests came back negative and I have no warning (aura). It took a number of medication trials to find the right prescription to manage my condition. I have been well controlled on medication for a number of years so long as I manage stress and take my medication as scheduled. Early on I was cautioned about pregnancy citing birth defects, miscarriages, and conception difficulties.

Fast forward two decades and I found myself pregnant grappling with the decision to stay on the medication or taper off. Each choice is fraught with risks: stay on the medication and chance birth defects or go off and risk having seizures. My partner and I did not take the decision lightly. I am fortunate enough to have an excellent neurologist who follows current research and has had many patients in similar situations. With a research background, I felt it necessary to do my own investigation and was surprised to find little North American information regarding birth defects, miscarriages, and seizures during pregnancy. European research did show a low incidence of birth defects on my particular medication so I chose to remain on the prescription with close monitoring. My inquiries led me to discover a study out of the University of Massachusetts in conjunction with Harvard Medical School called the AED Pregnancy Registry. They are compiling research on the risks of malformations in babies born to women with seizure disorders both on and off medication. The participation only required a couple of phone interviews and a focused medical release. I would strongly encourage women to sign up for this study to help practitioners and patients make more informed decisions surrounding pregnancy and epilepsy.

I was referred to an obstetrician through my neurologist who also has experience with epilepsy/seizure disorders. I had multiple tests and careful monitoring throughout my pregnancy. Rather than worry about the factors I could not control (birth defects) I chose to focus on those things that I could control (diet, exercise, and stress management). These skills and discipline became even more important post partum. You will hear many times over that you, as a mother, have to take care of yourself first to take care of others. I believe this is even more important when you are living with a medical condition. I cannot emphasize enough how important it is to have a strong support network of medical professionals, family, friends, and support groups. Ask for and accept help for yourself and your family. I personally struggled with breastfeeding, perhaps due to a post partum infection that left me hospitalized. The stress of not being able to feed my baby tore me apart. I cannot say enough about the La Leche League who supported me through a very difficult and frustrating experience. I was able to successfully breastfeed my baby which allowed a slower withdrawal of medication for him after experiencing it in utero. Although most medications caution against breastfeeding, I learned that a lower volume passes through breastmilk than the placenta. Information like this is extremely important to new mothers that require daily medications.

There are a number of support groups for mothers in the Greater Victoria area that are extremely useful

and beneficial. I attended many meetings and benefitted greatly but I did find that there was a lack of help for mothers struggling with their own medical issues. I am looking forward to the support group being set up through the Victoria Epilepsy and Parkinson's Centre. I hope that it will fill the gap for these mothers. Balancing motherhood and a seizure disorder while working full time has been tricky but two years in with a happy healthy son has been an adventure worth taking! I wouldn't change a thing.

## Treatment Update: Fycompa



According to a press release from Eisai Inc., the US Food and Drug Administration (FDA) has approved Fycompa (generic name perampanel) to help manage primarily generalized tonic-clonic seizures. Tonic-clonic seizures (also called grand mal seizures) are a common type of seizure. In fact, when people hear the term “seizure” they most commonly think of a tonic-clonic seizure. When a person has a tonic-clonic seizure, his/her muscles will stiffen (usually causing him/her to fall to the floor) and then the muscles will start to jerk.

A seizure refers to excessive electrical activity in the brain. If you have tonic-clonic seizures, your neurologist likely refers to them as primarily or secondarily generalized. A primarily generalized tonic-clonic seizure involves your whole brain as soon as it starts. Someone having a primarily generalized seizure gets no warning of an impending seizure; the seizure happens out of the blue. On the other hand, tonic-clonic seizures that are secondarily generalized start in one small part of the brain (a partial seizure) and involve more of the brain over time. Someone who has a secondarily generalized seizure might first experience a twitch in their leg or a very strong feeling of déjà vu, and then, after a few seconds, that person would have a tonic-clonic seizure.

Different anti-epileptic medications work for different types of seizures and they can be very effective. Up to 70% of people with seizures become seizure-free by taking these medications. Fycompa is a newer anti-epileptic medication and was first approved as an adjunctive therapy (meaning it is to be used with another anti-epileptic medication) for partial seizures that may become secondarily generalized tonic-clonic seizures. On June 22, 2015, it was announced that Fycompa can now be prescribed as an adjunctive therapy for primarily generalized seizures, as well. This means more people with seizures may benefit from taking Fycompa. The decision to approve Fycompa for primarily generalized seizures was made based on the results of a study in which people with epilepsy added Fycompa to the medications they were already taking to treat primarily generalized seizures and 64% experienced a significant reduction in seizures and 31% of those who added Fycompa to their existing treatments were seizure free at the end of the study. The most common side effects reported by those who started taking Fycompa were dizziness, headache, fatigue, somnolence, and irritability.

If you have uncontrolled tonic-clonic seizures, you may want to talk to your neurologist about options to manage your seizures, including Fycompa or other medications or alternative therapies.

### Source:

News Release No.15-43: U.S. FDA APPROVES EISAI'S ANTIEPILEPTIC AGENT FYCOMPA® AS ADJUNCTIVE TREATMENT FOR PRIMARY GENERALIZED TONIC-CLONIC SEIZURES. Eisai Co., Ltd. June 22, 2015. FDA Okays New Indication for Perampanel (Fycompa) in Epilepsy. Medscape. Jun 22, 2015.

# Epilepsy Around the World



**World Health  
Organization**

Delegates of the World Health Organization endorsed a resolution urging Member States to strengthen their ongoing efforts in providing care for people with epilepsy. Although affordable treatment for epilepsy exists, up to 90% of people with the condition may not be properly diagnosed or treated

in resource-poor settings. The resolution highlights the need for governments to formulate, strengthen and implement national policies and legislation to promote and protect the rights of people with epilepsy. It also stresses the need to reinforce health information and surveillance systems to get a clearer picture of the burden of disease and to measure progress in improving access to care.

Delegates emphasized the importance of training of non-specialist health-care providers, such as family physicians, as key to reducing the epilepsy treatment gap. In low- and middle-income settings, strategies to improve access and affordability of antiepileptic medicines should be a priority. Countries are encouraged to undertake public awareness activities to reduce misconceptions about epilepsy and encourage more people to seek treatment.

Between wait-lists and MSP payments, it's easy to forget that we have it pretty good in Canada. Purple Day is nationally recognized and more people are aware of what to do and what not to do when witnessing a seizure. That doesn't mean there's nothing left to do. Let's follow the WHO example and continue to educate our families, friends, and neighbours about epilepsy!

## ...And in Our Own Backyard

### **Canada and Victoria see new developments in medical marijuana.**

On May 7, 2015, Victoria News reported changes to the way doctors prescribe medical marijuana that may reduce individual's access to it. Doctors have been encouraged not to prescribe medical marijuana to anyone under the age of 25, those with psychosis or a substance abuse disorder, those with cardiovascular or respiratory illnesses, or those who are pregnant or nursing. Further, medical marijuana should only be prescribed with the consent of a doctor who has an ongoing "treating relationship" with the patient. That means an individual has to have a family doctor prescribe medical marijuana, rather than going to a walk-in clinic.

The city of Victoria may impose new fees and restrict the age of those who enter marijuana dispensaries. On May 7, 2015 The Globe and Mail reported that from April 2014 to April 2015, the number of marijuana dispensaries in Victoria increased from four to 18, causing citizens have expressed concerns.

At the same time, the Supreme Court of Canada ruled that medical marijuana can be available in alternate forms. On June 11, 2015 the National Post reported that the Supreme Court overturned an appeal to keep cannabis-infused cookies, brownies, oils, and teas illegal because medical marijuana users have a right to a range of products containing the drug. And medical research into the possible benefits of medical marijuana continue.

## ...And in Our Own Backyard (Cont'd)

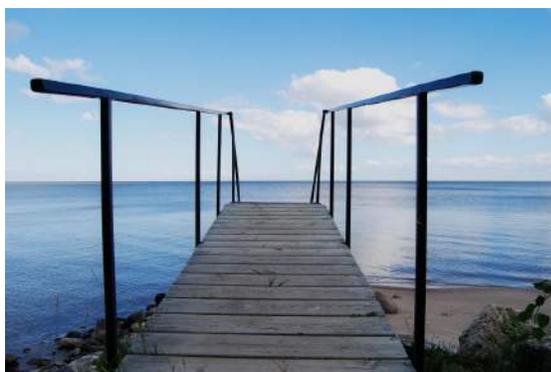


The American Academy of Neurology (AAN) stated in a press release on April 13, 2015 that a liquid form of cannabidiol (the non-psychoactive component of marijuana) is showing promise in reducing seizures for those with Dravet and Lennox-Gastaut syndromes. These are severe forms of epilepsy that often fail to respond to anti-epileptic medications. Two hundred and thirteen people with Dravet, Lennox-Gastaut, and other forms of rare and severe epilepsy were treated with cannabidiol and one hundred and thirty-seven completed the trial. For those who completed the trial, the number of seizures they experienced decreased by 54%. Twelve people stopped taking cannabidiol due to unpleasant side effects and side effects were reported by 10% of study participants and included drowsiness, diarrhea, tiredness, and decreased appetite. This is an initial study and more research is needed to explore the effect of cannabidiol on seizures.

The controversy over the safety and efficacy of medical marijuana continues. The good news is: more research is on the way to answer questions around its usefulness and availability. As always, be sure to communicate with your doctor and follow your doctor's recommendations in managing epilepsy.

**Please note:** HeadWay does not endorse medical marijuana as an epilepsy treatment. Although more research is available regarding the use of medical marijuana as a form of epilepsy treatment, it is still controversial. Anti-epileptic medication remains the treatment of choice for epilepsy. Always follow

### HeadWay's Very First Health Fair!



**Date:** Saturday, February 27, 2016

**Time:** 10am-4pm

We are looking for community organizations that would be interested in taking part in the health fair! This is a great opportunity to promote your organization, share resources, and connect with the community. If this is of interest, please contact Lynn Fanelli, our Development Coordinator, at [lfanelli@vepc.bc.ca](mailto:lfanelli@vepc.bc.ca) or call 250-656-2871

# What's Happening at Headway

There's a lot going on at HeadWay this fall!

To register or learn more about any of the programs listed here, contact Jennifer Morgan at (250) 475-6677 or e-mail [jmorgan@vepc.bc.ca](mailto:jmorgan@vepc.bc.ca)

## Workshops

### Session: Living a Healthy Life with Chronic Conditions

*Pre-registration required.*

**Dates:** Wednesdays, September 16-October 21, 2015 **Cost:** Free **Time:** 1PM-3:30PM

**Location:** HeadWay Boardroom

**Description:** This is a six-week program; each week, meet with your peer leaders and group members for 2 ½ hours and learn about how your epilepsy symptoms may be influencing your emotions, energy levels, or stress levels and gain the tools to break this cycle! The next workshop runs Wednesday afternoons from 1:00-3:30 starting September 16 until October 21. You must be registered to attend this program. This workshop is open to those with epilepsy or Parkinson's as well as family members.

### Volunteer Opportunity: Living a Healthy Life with Chronic Conditions

*Pre-registration & previous participation of the program required.*

**Dates:** November 18, 19 & 25, 26 (participants must attend all 4 sessions) **Cost:** Free **Time:** 10AM-4PM

**Location:** HeadWay Boardroom

**Description:** We're seeking volunteers to lead future sessions of "Living a Health Life with Chronic Conditions." If you are interested in supporting people with chronic conditions, want to learn new skills, have taken this course and enjoyed the philosophy then we welcome you to acquire certification as a workshop facilitator. Training sessions are interactive and fun, and are provided at no cost. Participants are required to attend all four training days. Facilitators who complete the training will be asked to co-lead at least one workshop.

### Session: The Child with Epilepsy: A Practical Guide for Parents

**Date:** Saturday, October 24, 2015 **Cost:** \$10.00 (subsidies are available) **Time:** 10AM-3PM

**Location:** HeadWay Boardroom



**Description:** Parenting is an exciting and challenging chapter in life. Having a child with a chronic health condition brings additional challenges. It can feel like you're navigating an impossible maze- from finding the best treatment option to keeping your child safe to optimizing school experiences. The workshop is intended for parents of children with seizures. If you're a parent of a newly diagnosed child, you are likely not sure where to go next. Even if you're a parent of a child who has had seizures for a number of years, you may still have questions about how to best support your child. This workshop will inform, inspire and prepare you to explore options, ask questions, share ideas and learn about resources available here in Victoria.

# What's Happening at Headway

## Support Groups

To register or learn more about any of the programs listed here, contact Jennifer Morgan at (250) 475-6677 or e-mail [jmorgan@vepc.bc.ca](mailto:jmorgan@vepc.bc.ca)

### Supporting Adults with Epilepsy

*Drop-in but initial consult required. Contact Jenn Morgan*

**Date:** 3rd Tuesday of every month **Cost:** Free **Time:** 12PM-1:30PM **Location:** Headway Boardroom  
**Facilitator:** Ron Truswell



**Description:** This group is available to anyone with epilepsy who feels as though they would benefit from some peer support. Whether you have had epilepsy since you were a child or are newly diagnosed, sharing your story and hearing from others can have a significantly positive impact on your life and on the lives of those you touch. Even if you are presently seizure-free or if you are having active seizures, it does not matter. This group provides a safe space for individuals to discuss epilepsy-related issues, such as medications, relationships, sleep, and lifestyle.

### Young Adults with Epilepsy

*Drop-in but initial consult required. Contact Jenn Morgan*

**Date:** 2nd and 4th Tuesday of the month, September-June **Time:** 6:00pm-7:30pm **Location:** HeadWay Boardroom **Cost:** Free **Facilitators:** Megan Carrigan and Garrett Appleton

**Description:** Whether you've had epilepsy all your life or started having seizures in adolescence, issues rise up whenever your life changes- and changes are bountiful in adulthood! Come out and meet other adults who have epilepsy. Talk about anything from school and jobs to relationships to medication management. The group meets on the second and fourth Tuesday of every month at HeadWay.

### Moms/Future Moms

*Drop-in but initial consult required. Contact Jenn Morgan.*

**Date:** 1st Monday of every month **Cost:** Free **Time:** 6:30PM-7:30PM **Location:** Headway Boardroom **No Faciliator.**

**Description:** Becoming a mom is a momentous occasion. It brings lots of smiles and lots of challenges, including lack of sleep and emotional stress, which can be triggers for seizures. All moms experience worry and can benefit from sharing these with other moms. Moms with epilepsy or women who want to become mothers are welcomed to this support group. HeadWay's support group for moms provides an opportunity to share happy thoughts, worries, and strategies with other moms.

# What's Happening at Headway

## Tools For Success



To register or learn more about any of the programs listed here, contact Jennifer Morgan at (250) 475-6677 or e-mail [jmorgan@vepc.bc.ca](mailto:jmorgan@vepc.bc.ca)

**Date:** Wednesdays, September to May **Time:** 4:30pm-6:00pm **Location:** UVic CORE, MacLaurin Building A347  
**Cost:** \$200 **Coordinator:** Stefani Lowes

**Description:** The tutors in the **Tools For Success** program will help you:

- Identify learning challenges
- Build on strengths
- Develop learning strategies that are personal and effective

Tutors work with children in small groups and yet the program is highly individualized. Weekly tutoring sessions involve a variety of approaches, and interactions, so that learning is a fun experience. SPACE IS LIMITED and pre-registration is required. Payment plans and subsidies available. A waiting list is being taken for the 2015/2016 school year; please contact Jenn Morgan for details.

**We need a couple more tutors for September.  
Do you know any teachers who might be interested?  
Contact Jenn Morgan at the contact info listed above!**

## Epilepsy Advisory Committee

*We are looking for members to represent different groups within our membership- those with different seizure types, those who are working and those who are not, parents, seniors, etc. If you are interested, contact Barb Gilmore (250-475-6677; [bgilmore@vepc.bc.ca](mailto:bgilmore@vepc.bc.ca))*

**Date:** One meeting each quarter **Location:** Headway Boardroom **Cost:** Free

**Description:** The Epilepsy Advisory Committee meets four times per year to help plan the epilepsy services which best reflect the needs and interests of our members. We believe that it is people such as you, who understand the day-to-day experience of epilepsy, who can help us ensure that our services are on track. Meetings are informal— members bring a lunch, and we provide beverages.

# What's Happening at Headway

## Motion Ways: A Movement Meditation Program



*Pre-registration required: Register with Gordon Head Rec Centre at (250) 475-7100*

**Date:** Mondays, September 14-December 14, 2015 **Time:** 11:15AM-12:15AM **Location:** Gordon Head Recreation Centre, 4100 Lambrick Way **Cost:** \$100 for 12 classes or \$10 drop-in fee

**Description:** Using music and movement, Lindsay Beal will facilitate a process of exploration, creativity, and mindfulness. This is an opportunity to dance without steps, go at your own pace, and follow your physical needs.

## The Brainwave

Want to share an experience, tip, or trick to dealing with epilepsy? Then contribute to the Brainwave; send a letter, poem, artwork, interesting web link, or anything of interest! Plus: We're going greener! You can now access the Brainwave online as soon as it is produced. This will reduce the amount of paper required and help our environment. By default, we will keep you on our paper mailing list but if you would like to access the Brainwave in electronic form, please e-mail your name and address to [help@vepc.bc.ca](mailto:help@vepc.bc.ca) with "Green Brainwave" in the subject line.

## HeadWay Blog

As a person with epilepsy or a loved one of someone with epilepsy, you've seen it all and you've learned along the way. HeadWay would like you to have the opportunity to share with others in our online blog. Check out what others have shared at <http://www.vepc.bc.ca/epilepsy-blog/>. You can submit to the blog by contacting Amanda Ng, Community Awareness Coordinator, at (250) 475-6677 or [ang@vepc.bc.ca](mailto:ang@vepc.bc.ca).

# Get it? Got it! Puppet Troupe

## Q&A with Puppet Coordinator Shannon Oatway: Looking back at the 1st year of this awareness project



### 1. For those who don't know about the Puppet Troupe- what is it and who are the partners involved?

“Our pilot project: Get It? Got It! The Community Awareness Puppet Project helps raise awareness and educate children through puppetry about Autism Spectrum Disorder, Fetal Alcohol Spectrum Disorder, epilepsy and seizures, and Immigrant and Refugee newcomer issues. Headway Victoria Epilepsy and Parkinson's Centre, Pivot Point Family Growth Centre, Victoria Native Friendship Centre and the Victoria Immigrant and Refugee Centre Society gathered together to create the program and were funded by the Victoria Foundation.

Our puppet troupe consists of 4 puppets, each representing one of the disorders/issues. Hannah is our puppet who has epilepsy. We perform at schools in the Greater Victoria area; typically we put on two short performances and then have a question and answer period with the children afterwards. The whole event would run about 30 - 40 minutes. The puppet skits are suitable for 6 - 10 year old children.”

### 2. Shannon, you've been so passionate and wonderful in your role as coordinator. What drew you to this position and what did you enjoy most?

“I thought teaching children about sensitive issues that they may encounter in their own classrooms using puppetry as a tool was a fantastic idea. And the fact that this was a pilot project that I would essentially be responsible for getting up and running was very attractive to me. I enjoyed the whole evolution of the project, idea to execution. Growing from little but an idea and moving it forward to where the troupe was performing.”

### 3. When the puppet troupe performs at a school what are some of the reactions you get from students? What reactions do you get from the teachers and school staff?

“The overall reactions to the performances were very positive. Teachers saw the value in the performances and saw it as a great learning opportunity for their students. The overall reaction from the students was positive; they enjoyed the puppets and frequently had a number of questions regarding the skit although they were very enamored with the puppets in general. They enjoyed it



when the puppets responded to their questions, as did the teachers. We were often very kindly praised and appreciated, citing that our work is ‘important.’”

#### **4. What were the outcomes of the program- what did students learn?**

“Students learned some important facts about being different and also that those who experience different challenges are really just like everyone else in that they want to be accepted and understood. The students also became aware of their own abilities to be compassionate and caring. In some cases I’m sure it started conversations that carried on afterwards in the classrooms.”

#### **5. Did you learn or gain anything this year?**

I gained valuable experience in managing volunteers and being the project coordinator in general, insuring that ALL the “parts” were working in sync. I had a fantastic time with this project. I am especially grateful that I had an executive director that trusted my ideas and vision for the project and supported me 100%.

**HeadWay, PivotPoint Family Growth Center, Victoria Native Friendship Center, and Victoria Immigrant and Refugee Center would like to extend our sincerest thanks to Shannon and the fabulous puppeteers she gathered!**

## Get to know **Tools for Success** Coordinator Stefani Lowes



### **1. Hi Stefani. You’re in school right now- tell us about that.**

Hi! Yes, I’m in the Special Education Master’s thesis program at UVic, and I’m in my second year. Before coming to UVic I was in Vancouver and got my Bachelor’s degree in Applied Behaviour Analysis.

### **2. Stefani, what do you bring to Tools for Success and what are you excited for this year?**

I feel that, as a behaviour therapist, I bring a unique set of skills to Tools for Success. I’ve been working with children and youth diagnosed with autism for the last 7 years. I’m excited to see some familiar faces as well as welcome new ones this fall.

### **3. What do you do when you’re not at school or working?**

I love watching movies and documentaries as well as tv series! In my spare time I’m usually watching something or I’m out enjoying the nice weather.

# Upcoming Fundraisers

## The Goodlife Fitness Marathon



Every year GoodLife Fitness chooses twenty local non-profit organizations to benefit from the fundraising and awareness of the Victoria Marathon. HeadWay has benefited the last two years and we're looking to top our efforts in 2015! This is a great way to support HeadWay and raise awareness of epilepsy in our community.

Not a marathon runner? Why not sign up to walk 8k or be a cheerleader? There's a children's run too!

**Sunday, October 11th, 2015**

Starts on Menzies St at Kingston St  
(beside the BC Legislative Buildings)

Marathon race begins @ 8:45am

Check out the marathon website at <http://runvictoriamarathon.com/> for details and stay tuned to the HeadWay website at [www.headwayvictoria.com](http://www.headwayvictoria.com) to register for our team or direct pledges to our agency.

## “Night of the Lights” Fundraiser

As a fundraiser this year we are doing the Hillside Centre's "Night of Lights" This will be a private shopping opportunity with appetizers, door prizes, and one night only retail specials. The cost per ticket is \$5. We keep the entire proceeds from the tickets. There is no cost to Headway. This event will be held on Sunday, November 22, 2015, from 6-9:30 pm. Remember only those with tickets will be admitted. Get those Christmas presents early. These tickets will be available in the office starting the first week of September.

## Want to support HeadWay?

HeadWay is a non-profit organization that runs on donations. Many people have supported us through third party fundraisers; that is, people stage a fundraising event and donate the proceeds to HeadWay to help us run the programs and services so many rely on. Examples of past events include bottle drives, bake sales, information tables at local libraries and schools. If you are a creative person and have an idea- go for it! HeadWay staff can support you by advertising the event in newsletters and on the website.

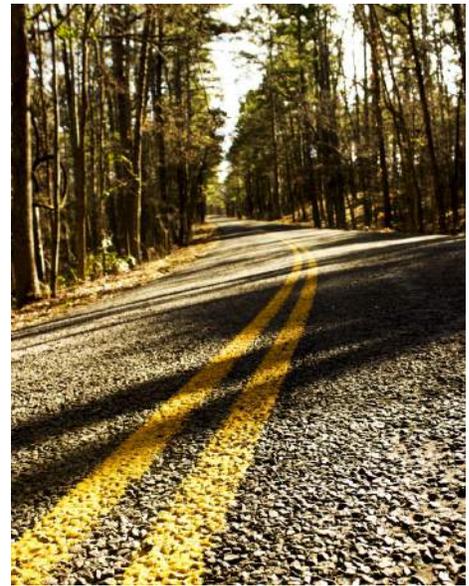
# The Open Road: Travel Assistance

## Community Travel Training

BC Transit offers free training to anyone who needs assistance in learning how to use the bus system. If seizures interfere with communication you may also benefit from an emergency bus card to inform drivers of the stop you need. Call (250) 384-7723 for further information.

## Bus Tickets Available from our Office

For people who do not have a bus pass, and are in financial need, a limited number of bus tickets are available to help you get to doctor's appointments, employment interviews or to look after children's needs. Contact Jennifer Morgan for tickets.



## Hope Air

Sometimes your healthcare needs cannot be met in Victoria and you will have to travel to Vancouver or farther. Unfortunately, MSP and Pharmacare will not help you pay for travel expenses. If you need to travel for medical care, Hope Air makes flights available around the country. Once you have an appointment booked you can contact this non-profit organization and book a trip for yourself and one travel companion. Only round trip flights can be scheduled and a \$50

processing fee is charged for the ticket. Call toll-free 1-877-346-HOPE or [www.hopeair.org](http://www.hopeair.org).

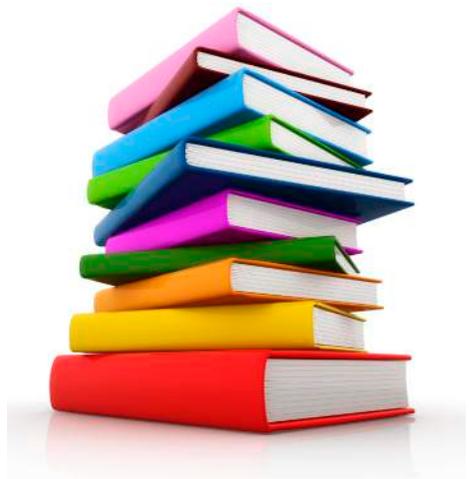
## Seizure Investigation Unit, Vancouver General Hospital

If you're travelling to the Vancouver General Hospital, HeadWay's updated "Off Island" booklet is full of helpful information, such as how to get there, where family members or companions can stay, and what to expect while on the unit. Contact Jennifer Morgan for your free copy.

# Education Assistance

## Don't forget to apply for your bursary at Camosun College!

The new school year is upon us and for post-secondary students that means tuition fees will be due. If you attend Camosun College and have a diagnosis of epilepsy you can apply for a bursary to help fund your education. The bursary is managed by Camosun Financial Aid and you can visit their website <http://camosun.ca/services/financial-aid/> or e-mail [financialaid@camosun.ca](mailto:financialaid@camosun.ca) for information.



# Research Update

## Epilepsy education supports successful management



As Epilepsy Program Coordinator, my role is support, care, and knowledge. It has always been my belief that knowledge- about epilepsy, treatment options, and about oneself- is the key to living well with epilepsy. That's another reason we have support groups; when people with epilepsy come together to support and educate each other, it's been my experience that they feel better equipped to manage their epilepsy and feel supported by a community of peers.

A study recently published in the academic journal *Neurology* provides some evidence that when people living with epilepsy connect and share experiences, they improve their seizure management and quality of life. Dr. John Hixon and his colleagues (2015) followed adults with epilepsy who participated in an online forum for six weeks.

Over six weeks, study participants engaged in online discussions related to epilepsy. Participants could post comments that anyone on the forum could read and respond to and they could write private messages to other members. This allowed patients to share experiences, knowledge, and tips. The study authors compared participants' reported self-management and self-efficacy skills and found that both skills increased significantly after participation.

We're all in this together so why not join one of our support groups or take the Chronic Disease Self-Management program? Check out pages 6 and 7 of this newsletter for information on our groups. If you prefer an online forum, check out the forums from Epilepsy Foundation at <http://www.epilepsy.com/forum-topics>. You can also check out HeadWay's blog at <http://www.vepc.bc.ca/epilepsy-blog/> and you can share by contacting Amanda Ng at [ang@vepc.bc.ca](mailto:ang@vepc.bc.ca).

### Reference:

Hixon, J.D. et al. (2015). Patients optimizing epilepsy management via an online community: The POEM study. *Neurology*, 85, 1-8.



We offer our condolences to the family of Jane Howland, particularly her husband Bob. Jane was a long-time member of HeadWay and an active volunteer. We'll miss her smile and gentle spirit.

We would like to extend our sincerest thank you to those who sent donations in memory of those with epilepsy, including:

*Jane Howland and Monica Roberts.*



## From the Executive Director

Autumn will soon be in the air and there is lots happening, which is no doubt a reflection of the interest and involvement from our volunteers and membership. Thank you to everyone that supported HeadWay at either the HeadWay Charity Golf Classic on June 12th, the Annual General Meeting on June 30th, or with your generous donation through our annual summer fundraising campaign.

You may not realize that the annual charity golf tournament had its 23rd year of title sponsorship from Peninsula Co-op, and within the 16 other sponsoring businesses, CanPro Construction and Pepsi have sponsored every year as well. Thank you! Along with the priceless fun and memories, \$30,000 was raised for the Centre. Check out the golf website for sponsors and then go to photos....they're good too!  
<http://www.headwayvictoriagolf.com/sponsors/>

The Annual General Meeting in June holds the election for Board of Directors members. What an enthusiastic and active board I have the pleasure of working with! Ross Young will continue as president and new executive positions are: Matt Peulen as vice-president; John Pereira as treasurer; and Katy Fairley as secretary. Dr. Alexandre Henri-Bhargava, Alanna Holroyd, and Fiona Bayliss will continue as members of the board, and welcome to Leslie Hodgkinson. We are all looking forward to a productive year.

The 2014-15 Annual Report and Audited Financial Statements are available to view on our website. Significantly 40% of last year's revenue came from donations, including planned giving such as regular monthly giving and bequests. We have almost 900 members and it is through the membership and the associated donations that we are able to continue services. Please accept my sincere thanks for your continued support!

Thanks to Hannah, one of the Get It? Got It! Community awareness puppets, for sharing her 'Secret' about seizures with her friend Aisha, at a special performance at our AGM on June 30th. Everyone in attendance was impressed with the program and the puppeteers Jay & Martin and program coordinator Shannon Oatway. Check out their facebook page.

I'm practising my cheers for those of you participating in the Victoria GoodLife Fitness Marathon on Thanksgiving Weekend!

Thank you again everyone for your continued support of our Centre.

Barb Gilmore  
Executive director

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“The Brainwave”

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### DIRECTORS:

President - Ross Young

Vice-President - Matt Peulen

Treasurer - John Pereira

Secretary - Katy Fairley

Dr. Alex Henri-Bhargava

Alanna Holroyd

Fiona Bayliss

Leslie Hodgkinson

### STAFF:

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Parkinson Program Coordinator -

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Epilepsy Program Coordinator

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Lindsay Beal, M.Ed

Community Awareness Coordinator -

Amanda Ng, MPH

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Note from Editor, Amanda Ng: Our newsletter and education meetings provide a range of information which does not necessarily reflect the views of our agency. Please use your discretion and consult your physician.

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