



Victoria Epilepsy & Parkinson's Centre

BRAIN WAVE

The Magazine of the Epilepsy Program

Vol.45, Spring, 2018

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Transformations



A Message from Deirdre



Hello everyone! Thank you for the warm welcome I received from everyone I met so far. If we haven't met yet, I look forward to meeting you or chatting with you over the summer. My main focus is to connect with as many members as possible to get an idea of how we can support those that need it, and how the community can support each other. One common request is that we connect people living with epilepsy with each other at social events. As a member living with epilepsy myself, I love to meet others who know what life is like without the need to explain it.

It's a very special thing. To begin fulfilling this request, we have arranged for HeadWay's first Paint Nite

to be hosted by one of our clients, Liv Wigen-Carsell on May 26, 2018 from 1-4 here at HeadWay. This is open to all clients and their families. Please let us know if you can make it so we know how much paint to buy! We look forward to seeing you there!



There is also great interest for those who have lived with epilepsy for a while to share their successes and life hacks with those who are newly diagnosed, or who are facing a new experience (such as having children). This can be a particularly meaningful way for those people with questions to get real-life answers from those who have lived it. I am excited to know so many people at Headway who are so willing to help. After my daughter was born, I reached out to Headway and was offered the names and phone numbers of a variety of members who were ready and willing to assist me with whatever I needed. What an amazing community! If you are interested in joining our list of people who are actively helping those in our community, please let me know. Also, if you would like to connect with some of these amazing people because you have questions or are facing a new experience (or even thinking about facing a new experience), please get in touch with me and we will make those connections happen!

I am very interested in other services or events our community (that's you guys!) thinks HeadWay could provide for us and our families. What is important to you – education, help with transportation, meditation, family support, tutoring, music therapy, presentations to schools, police officers and bus drivers, meeting others with epilepsy, helping others with epilepsy, socializing, or something else? Please let me know your thoughts. I look forward to speaking with you soon!

Deirdre Syms

Feature

My story

by Deirdre Syms

Epilepsy is a part of my life. It always has been and always will be, I imagine. I accept that, but that does not mean I intend to stop living.

As people with chronic conditions often discover, adversity can make you stronger and more determined. I was diagnosed with absence seizures at the age of six. Being a very active child (there was no sitting around for me!), I was determined to continue all the activities that I loved – swimming, climbing the trees at our cottage at the lake, playing ringette, and skating.

Because I was diagnosed with absence seizures (where you “zone out” for a brief period of time), my parents – in consultation with my doctors – decided I could continue doing most things. These seizures, when diagnosed in someone so young, have an excellent chance of going away on their own, so my condition was seen as temporary. That was not the case for me though. Although there have been periods in which I was seizure-free, my absence seizures remained, and in 2002, I had my first tonic clonic seizure. My seizures were getting worse...

Being allowed to do most of the activities I loved did not mean that the way in which I did them stayed the same. A family member, usually mom, was always with me, either sitting poolside during my swimming lessons, watching the practices and games of whichever sport I was playing, or simple accompanying me to and from school. This “Guided Support” created in me a desire and determination to find ways to safely do the things that I wanted to do in my life. Despite my very healthy level of fear, I endeavoured to create a fun and colourful life. I’ve danced as a member of a belly dance troupe: Bashirah Middle Eastern Dance Troupe (photo taken at the Dragon Boat Festival – I am wearing the green skirt), travelled to amazing places all over the world, and had a child.



Photo by John Gardner

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Feature



This last adventure has been the most challenging as well as the most rewarding. The decision to have a child is often a difficult and emotional one. There was a lot of fear and anxiety about inadvertently hurting my child when I fell, not to mention the possibility of passing my seizures onto her. I consider myself extremely fortunate to have known a woman who was also a mother who had seizures, while I was growing up. To have someone in my life who provided successful examples of living well with seizures had a profound and positive effect on me.

I truly credit Headway with giving me the education and support I need to live my best life – a life I love! It was at an epilepsy conference featuring preeminent epilepsy expert, Dr. Robert Mittan, that I learned everything I had control over in my personal life that could affect the frequency of my seizures. I followed his instructions (based on years of research), and was able to decrease my medication to the point where I was not experiencing many of the negative side effects that often accompany anti-seizure medications. After Sophia was born, I reached out to help manage my anxiety. I was offered a network of support to assist me. It was truly amazing. Now I am giving back.

Article

Catamenial Epilepsy

by Inas Dobba

According to WebMD “For some women, the pattern of epileptic seizures is directly affected by the normal hormonal cycles they experience throughout their lives.” Catamenial epilepsy is when seizures increase by two-fold because of hormonal fluctuations of the menstrual cycle.

So how do hormones and epilepsy interact?

All routes lead to the brain! Epilepsy is associated with abnormal electrical activity in the brain. Similarly, hormones have a direct effect on brain cells, and they control various functions in the brain. According to the Epilepsy Foundation, “sex hormones can influence the excitability of nerve cells in the brain and thus influence seizure control.”

There are three patterns of Catamenial epilepsy that align with the three phases of menstrual cycles and show the hormonal fluctuations as a fertile soil for inducing seizures:

- Premenstrual phase: This is the most common pattern where the sex hormones, estrogen and progesterone, closely related to each other, and both witness a fall in their levels. The reduction of the anti-seizure effects of Progesterone leads to a drop in Anti Epileptic Drugs (AEDs) levels, which in its turn stimulates the Catamenial seizures.
- Preovulatory phase: A pattern that shows a surge in Estrogen unaccompanied by an increase in Progesterone's, but with varying proportions. The resultant elevation of the Estrogen / Progesterone ratio is what induces seizures.
- Luteal phase: High Estrogen levels and low Progesterone levels detected in the second half of the cycle which facilitates an increase in seizures.

Therefore, it is important to chart menstruation and seizures on a calendar to establish a pattern. If a Catamenial exacerbation is established, treatment is based on the pattern.

There are several methods for treating Catamenial Epilepsy. Hormonal therapy, is one of them; to either suppress hormones or supplement them. In the latter case, natural or synthetic Progesterone is taken, especially in the first and last phases mentioned above. Progesterone has anticonvulsant properties and reduces neuronal metabolism and electrical discharge rates of the brain cells, which makes it preferable for treatment.

Overall, approximately one third of women with epilepsy are classified under the designation of Catamenial epilepsy, in which seizures are exacerbated by their menstrual cycle.

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Article

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Community Corner

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. Call 250-475-6677 or email epilepsy@vepc.bc.ca

Hope Air

Sometimes your healthcare needs cannot be met in Victoria and you will have to travel off the island. If you need to travel for medical care, Hope Air makes flights available Canada wide. Once you have your medical 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. Call toll-free 1-877-346-4673.



2018 Golf Tournament Sponsors

*There is still room to join us for our Charity Golf Classic on June 7th
Book a foursome or come on your own. Fun will be had rain or shine!
For further details visit www.headwayvictoriagolf.com*

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Programs & Workshop

Support Groups

HeadWay has a number of ways for members to connect with each other. There is no substitute for real-time, person to person interactions. We have an amazing community that supports and celebrates one another. Register in advance with Deirdre 250-475-6677 or email epilepsy@vepc.bc.ca for any of the following groups.

Adult's Peer Support Group

Runs monthly on the second Wednesday, 12:30 p.m. – 2:00 p.m.

This is a support group to encourage the sharing of personal stories that empower and give encouragement to individuals to move forward in their lives with hope and optimism.

Facilitated by Ilyanna Weeks.

Youth & Young Adults Peer Support Group

Runs monthly on the second Wednesday, 6:30 p.m. – 8:00 p.m.

Moving away from the traditional style of support group, we are focusing on creativity and fun.

Parents Peer Support Group

Runs monthly on second Wednesday, 6:30 p.m. – 8:00 p.m.

Starting May 9th and continuing throughout the summer.

For parents with children with epilepsy, *AND* for parents who have epilepsy.

Neuropsych and Medication Review Clinic

One time private consults with Dr. M. Gheis

Do you feel social anxiety, have episodes of panic, or find your thinking and emotions are interrupting your day? It is very difficult to discern the difference between symptoms of stress, seizures/postictal symptoms or medication side effects.

To request an appointment or if you have any questions regarding the referral process, please contact Ilyanna Weeks at 250-475-6677 or email ilyanna@vepc.bc.ca.

Cognition & Learning in Children with Epilepsy by Dr. Sare Akdag

Sometimes children who have epilepsy experience problems with thinking and learning because of the seizures or the underlying brain abnormalities that are causing seizures. Please join Dr. Sare Akdag, Psychologist at the Queen Alexandra Centre for Children's Health, in this small group seminar to learn more about common thinking and learning problems children with epilepsy can have and the ways to best support them at school and in other settings. To register call 250-475-6677 or email: help@vepc.bc.ca

Date: Thursday, May 24, 2018

Time: 6:30 p.m. - 8:00 p.m.

Location: HeadWay - Fee is \$20. A discretionary rate for limited income is available.

Programs

Approximately 5% of people with epilepsy have photosensitive epilepsy and the onset peaks around age 12. Seizure triggers include television viewing, video games, computer screens and natural flickering light, such as sunlight on water. People with pure photosensitive epilepsy should view television from a distance 5 times the diagonal measurement of the screen in a well-lit room. Some people find that eyeglasses with “blue blocker” lenses help reduce seizure frequency. If you would like to trial these eyeglasses, please book an appointment with Deirdre. Child size glasses are also available. There is funding if you decide to purchase a pair.



Cookies and Conversation Social

The aroma of homemade freshly baked goodies will be wafting through our agency offices in anticipation of your visit to our Cookies and Conversation Open House which we will be hosting the 1st Monday of every month from 12 – 1pm, starting on June 4th. We would love to get to know our clients better, in a relaxed, social atmosphere. Our welcome mat is out.

Fundraising Ideas

You got JUNK? Host a Garage Sale in support of HeadWay.

To kick off this DIY (Do It Yourself) fundraising idea, our E.D. Zuzanna Szkudlarek is hosting her own garage sale on June 16th. Spring is typically the time people de-clutter their homes and as the saying goes “one person’s junk is another person’s treasure”. If you would rather contribute some of your well loved items to Zuzanna’s sale please phone the office and let us know.

Pickup and drop off can be arranged.

Volunteer Corner

National Volunteer Week celebrates the value of volunteering every year for the week of April 15th to April 21st. And this year’s theme was: “Celebrate the Value of Volunteering – building confidence, competence, connections and community.”

From opportunities to develop new skills, to finding deep and meaningful personal connections, the magic of volunteering is that it creates social and economic value for all.

Here at HeadWay we give a heartfelt thank you to our amazing dedicated volunteers!! We value each one of you for the contributions that you make to HeadWay.

As Volunteer Coordinator I welcome new aspiring volunteers to connect with me to discuss a future with HeadWay.

Talk soon, Ilyanna Weeks

ilyanna@vepc.bc.ca



Events

PAINT NITE

Announcing HeadWay's 1st Paint Nite to be hosted by one of our clients, Liv Wigen-Carsell. It's open to all clients & their families.

Please reserve a spot so we know how much paint to buy!

Contact the office: 250-475-6677 or help@vepc.bc.ca

Date: Saturday, May 26th

Time: 1pm – 4pm

Location: HeadWay - #202 – 1640 Oak Bay Ave.

By Donation

Release your inner Picasso!



Farewell BBQ for Maureen Matthew

Please join us to celebrate our Maureen to wish her well on her new path.

Wear purple to show your love!

Hotdogs, Burgers, Beverages & Snacks generously provided by

Please RSVP to help@vepc.bc.ca or call the office



Date: Friday, June 1, 2018

Time: 4:00 pm - 6:00 pm

Location: Centennial Park - Central Saanich [map link](#)

Requests for transportation please contact: help@vepc.bc.ca or call 250-475-6677

Executive Director's Message

After 28 year of dedication to HeadWay and the Parkinson's community, Maureen Mathew is setting her sights on a much deserved retirement. Although we anticipated this announcement, it doesn't make it any easier and she will be greatly missed by her colleagues and Parkinson's community alike.

I met Maureen last August, and in our short time together she has become an unofficial mentor to me. I'm in awe of her kindness and work ethic, what Maureen can do in two days, most people accomplish in a full week. I will carry that with me as we move ahead. I know I speak for the entire staff when I say we will miss her happy purple outfits, her awesome laugh and healing hugs. With gratitude, love and appreciation, please join me in wishing her the best in the next steps of her journey. This is a big milestone, and we will honor Maureen with a proper send-off June 1st. We are hosting a BBQ at Centennial Park from 4 p.m. to 6 p.m., please join us, wear something purple!

I'm so pleased to welcome Deirdre Syms to our team. Her energy and warmth is inspiring! I hope you get a chance to connect with her this summer as she needs your input to envision the future of our epilepsy programme. Living with epilepsy herself, Deirdre can relate to our clients and understands first-hand, the issues involved with epilepsy. Based on her conversations with you, Deirdre is taking this time of transition to evaluate what sort of peer support groups you need and will encourage you in reaching the best quality of life for yourselves, your family and friends.

I want to also acknowledge all the support we received during Purple Month. Our community really came together. Country Grocer, a great HeadWay supporter, held a fundraiser on behalf of HeadWay. Our newest Board Member Tessa Hawkins and her family baked delicious treats in support of epilepsy programming and her bake sale raised \$412! Also, a group of you met with several Mayors and leaders in the CRD for a very thoughtful conversation about living with epilepsy in an urban setting. The legislature lit up the fountain in purple and the city of Esquimalt shone purple lights around City Hall. Our small team of 9 dedicated volunteers spread epilepsy awareness throughout various Victoria communities to over 90 local businesses and stores who participated by decorating their establishments in purple. Truly a team effort, love it – thank you!

Something new happening at the HeadWay office is our monthly get together we are calling Cookies and Conversations. Starting in June, on the first Monday of each month from 12-1pm, pop by our office to join us for some homemade cookies and some stimulating conversations, however...fair warning... we are doing the baking ourselves! Some of our most meaningful interactions have been with our clients who have stopped by to visit our library or just to drop something off. These casual visits are wonderful opportunities to spend time getting to know each and every one of you.

With gratitude,

Zuzanna

P.S Tania and I are hosting a garage sale June 16th to support HeadWay services – call us to find out how we can help you host your own!

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