Inside...

<table>
<thead>
<tr>
<th>Section</th>
<th>Pages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy Coordinator message</td>
<td>2</td>
</tr>
<tr>
<td>Inclusive School Environments</td>
<td>3-5</td>
</tr>
<tr>
<td>Announcements</td>
<td>6-7</td>
</tr>
<tr>
<td>Programs</td>
<td>8-10</td>
</tr>
<tr>
<td>Community Events</td>
<td>11-12</td>
</tr>
<tr>
<td>Survey Results &amp; Open Road</td>
<td>13</td>
</tr>
<tr>
<td>Golf Tournament Photos</td>
<td>14</td>
</tr>
<tr>
<td>From the Executive Director</td>
<td>15</td>
</tr>
</tbody>
</table>

Contact

202-1640 Oak Bay Avenue
Victoria, BC V8R 1B2
Phone: 250-475-6677
Fax: 250-475-6619
Email: help@vepc.bc.ca
www.headwayvictoria.com
A Message from our Coordinator

This issue of the Brain Wave is likely arriving just at the start of the school year. Are you preparing children for a new teacher or a new school? Are you leaving home for college or university, or continuing education with community courses? These events can be both exciting and stressful, and if you’re managing epilepsy as well, planning and preparing is especially important. A high percentage of people with epilepsy will experience more than the average challenges in the school setting. (See our LINKS page 5)

Learning is a complicated feat that can be fostered and supported or limited and hindered in many ways. Everyone learns, but what supports learning, and what hinders it? Learning is a way of life for me. From the time I quit high school (yes, I left school early) I have declared my commitment to growth through learning. I want to grow as a person – to develop not just skills and knowledge, but personal qualities and characteristics as well. I since received my high school diploma, but I understood back then, that learning can happen in a wide variety of settings. Indeed, some learning might not contribute to my growth or development as a person. Stressful settings can cause us to learn adaptive behaviors specifically for these stressful settings. For example, in an environment where people make hurtful or shaming comments, one might learn how to lay low, thereby forgoing opportunities to try new things. If I’m aiming to learn public speaking, then this environment hinders this learning, but it’s really good for learning how to hide. In stressful environments the sympathetic nervous system is activated making us ready to fight or flee. When stress passes the threshold of coping, we cannot focus with our higher thinking, and learning new concepts is impossible. Stress is a well-known trigger for seizures in people with epilepsy. (See page 5) I often hear about children with epilepsy being accused of having an “attitude problem” when really they have entered an environment where learning is hindered. What’s more stressful than going to school everyday to struggle and be misunderstood? Piling on the stresses increases the likelihood of breakthrough seizures, which in turn creates fatigue and concentration problems. Thankfully, there are some ways to de-escalate the stress cycle.

The article, Creating Inclusive School Environments, on the following page looks at ways to address some of the learning challenges in schools. Supportive learning opportunities also exist at the Centre for Outreach Education (CORE), a tutoring program for children that runs out of University of Victoria and the Learning Curve with personalized programs and workshops. (See page 12)

Another supportive learning environment is the Inclusive Leadership Cooperative (ILC), fostering the practice of soft skills, such as deep listening, self-awareness and communication. We’ve invited Dr. Linda Hill, co-founder of ILC, to conduct a short workshop for us in November. Dr. Hill has been guiding diverse groups of adults, youth, and children to build inclusive, welcoming and respectful schools, neighbourhoods, work-places and communities for over forty years. (see page 10)

Learning can also occur in less formal settings. For example the garden project described on page 8 provided an inspirational learning experience for one of our members.

If you have learning goals, choosing the skills, knowledge, even qualities you seek to develop is the first step and the next step is finding the best learning environment or co-creating it!
Epilepsy is one of the most frequently diagnosed neurological conditions affecting children. It is characterized by recurrent seizures and often presents with neurobehavioral comorbidities including excessive fatigue, cognitive impairments, psychiatric disorders, and social and behavioral problems. These complications have vast implications for a child’s development, daily functioning and school adjustment. This article reviews literature examining the challenges associated with epilepsy and the implications the challenges have for school experiences. This article then clarifies how schools can best support, accommodate, and prepare for these children and families based on the authors’ previous qualitative research.

**Physical Challenges**
Children with epilepsy experience a number of physical problems that interfere with daily functioning and school adjustment. These problems can stem from recurrent seizures and/or effects of anti-epileptic drugs (AED’s). The most frequent complaint is excessive fatigue following a seizure, or as an effect of AED’s. Often extra sleep is essential, resulting in frequent absenteeism from school. Impairments in memory, concentration difficulties, headaches and visual disturbances also interfere with functioning. These challenges may be misinterpreted by teachers as distractibility, absentmindedness, or a lack of interest, and lower teacher expectations for academic performance, which can compromise achievement.

**Emotional Challenges**
Many children with epilepsy experience intense emotional distress and intermittent sadness, and show high rates of suicidal ideation. Although AED's can increase sadness and anxiety, so does coping on a daily basis with the unpredictability of epilepsy. Unexpected loss of body control during a seizure and the potential harm or social embarrassment can be extremely anxiety provoking. Depressive and anxious thoughts can also hinder the ability to concentrate and process information. Negative feedback from teachers and peers regarding poor focus and underachievement can produce additional feelings of inadequacy and interfere with school adjustment and academic success.

**Behavioral Challenges**
Children with epilepsy often have significant problems with attention and vigilance. The high incidence of ADHD may be related to recurrent seizures and the use of AEDs that can also have stimulating effects on behaviour. Children with epilepsy often display higher rates of aggression. This can be partially linked to the occurrence of seizures. Aggressive behavior may elicit negative reactions from teachers and peers, and create a rejecting social environment. These children are subsequently deprived of opportunities to learn appropriate social skills that would help them interact with peers and adapt to school environments.
Creating Inclusive School Environments cont’d

Social Challenges
Children with epilepsy often experience profound social isolation. They tend to feel different from their peers and lack self-confidence. They often experience bullying and social exclusion after having a seizure in front of peers who are unfamiliar with the condition. Parental monitoring and imposed restrictions can limit a child's ability to fully engage in social activities and diminish their sense of autonomy. Children who internalize negative concepts about themselves are likely to withdraw, which has negative implications for school performance.

Recommendations

Education
Identification of epilepsy is often a difficult process, particularly for non-stereotypical seizures, such as absence seizures. Teachers are frequently the first to observe behaviours that indicate the development or worsening of epilepsy. Unfortunately, these professionals often lack the knowledge required to recognize and intervene appropriately when such behaviours occur. Families receive false interpretations about these symptoms, which can exacerbate confusion. Professional development for educators should provide contextualized information about the prevalence and nature of epilepsy in school settings. To reduce mislabelling, teachers must be educated on how children with epilepsy may present physically, cognitively, emotionally, and behaviourally, as well as understanding the side effect associated with the treatment. Children should also be informed about epilepsy as an anti-stigma strategy. Having a plan at school ensures teachers and peers know how to react in the event of a seizure and creates a secure environment where children with epilepsy can engage in social and academic activities.

Academic, Emotional, and Behavioral Support
Children with epilepsy, who display a lack of progress or a decline in academic performance, may require additional educational support and encouragement. These children may also benefit from psycho-educational testing to help confirm the presence of impairments and facilitate the development of an individualized education plan (IEP). Children with epilepsy may require modifications at school (i.e., frequent breaks during tests and extended time for assignments).
Inclusion and Allied Service Delivery

Teachers often feel ill-equipped to manage the exceptional needs of children with epilepsy. As a result, educators experience stress and burnout, which impairs teaching style and student-teacher relationships and creates negative classroom environments. To prevent burnout, teachers should be taught instructional approaches that support inclusion, and have access to an allied approach.

In conclusion, negative school experiences can be mitigated by educating school communities about epilepsy, and ensuring children with epilepsy obtain the academic and social supports they need; stigma reduction programs, resilience training, school adaptations, IEPs, and psychosocial assessments may be particularly beneficial. Findings emphasize the need for an allied approach to the provision of support services to ensure that the needs of both students and faculty are met.

Even Controlled, Epilepsy May Still Cause Problems for Kids


THURSDAY, March 31, 2016 (HealthDay News) -- Even when their seizures are well-controlled, children with epilepsy can still have learning and behavioral disorders that lead to social and educational problems when they're young adults, a new study finds.

Researchers discover why stress leads to increased seizures in epilepsy patients

http://mediarelations.uwo.ca/2016/06/14/researchers-discover-stress-leads-increased-seizures-epilepsy-patients/
June 14, 2016
Sarah Crespi

Around the world 50 million people have epilepsy. Stress can make people with epilepsy have more seizures, but how stress and seizures are related has been a mystery. Now researchers have found that an epileptic brain may respond differently to stress hormones. In a non-affected rodent brain a stress hormone (corticotrophin releasing factor – CRF) calms activity. In rodents with engineered epilepsy, the brain reacts differently. The same hormone increases excitability. These different responses to stress hormones could explain why stress makes epilepsy worse.
Announcements

Art Show in March 2017

Artist’s with epilepsy or who are affected by epilepsy start to get your art ready for the Second Annual Art show in support of people with Epilepsy. This year’s theme is, “Epilepsy in My Life.”

As a person with Epilepsy, last year’s art show Joy and Hope, showed me I was not alone. Many people came to the opening reception – sharing stories about friends or relatives that have epilepsy, sharing information and being drawn to buy some beautiful works.

Partial proceeds from the sale of the art will go to Headway Victoria Epilepsy and Parkinson’s Centre. It will be up to the artist to decide how much of the purchase price will be donated to Headway. It does seem like March is a long time from now, but this gives you plenty of time to start working on your pieces. The Second Annual Art show will bring awareness about epilepsy and raise funds at the same time. What a great way to spend part of Purple Month in March – in the little fernwood gallery with friends. Watch for further details in the next newsletter, or for more information you can contact Terri Beaton at: volunteer@vepc.bc.ca

Quote

“I told a Facebook friend I was entering a work of art in the Joy & Hope show in support of people with epilepsy. Then she disclosed to me, after all this time, that she has epilepsy. It struck me how important it is to say ‘I care and I want to understand’. It helps make relationships deeper and more meaningful.”

~ Z.F., artist.
Announcements

ANNOUNCING A NEW SERVICE:
New Parkinson’s & Epilepsy Medication Review & Education Consult Service

Medication management of neurological conditions can be complicated and lead to unanswered questions. We are pleased to advise that neuropsychiatrist, Dr Mohamed Gheis is volunteering his time to offer a one-time consult medication review and education service to our agency clients. Amy Tran, volunteer pharmacist, will be assisting with this project.

You are eligible for this service if:
- You would like a one-time session with Dr Gheis to help you to understand your Epilepsy or mood-related treatment options better
- You have a treating physician who will both authorize this service and be responsible for any follow up treatment ideas.
- You are not currently experiencing a mental health crisis.

Process:
- This pilot program will commence in September.
- We will require your treating physician's authorization.
- Eligible clients will receive one appointment only.
- One hour appointments will be booked on one Wednesday each month.
- You will be scheduled for an appointment at HeadWay's office 202-1640 Oak Bay Ave.
- You will be asked to bring a list of your current medications
- During the meeting with Dr Gheis, volunteer pharmacist Amy Tran will supply you with summary notes from the session.
- Dr Gheis will send a follow up report to your physician directly
- To request an appointment or if you have any questions, please contact Lindsay Beal, the project coordinator, at 250-475-6677 or via email to lbeal@vepc.bc.ca.

Clobazam Shortage

Reprinted with permission from the Centre for Epilepsy and Seizure Education

Many people who require clobazam (Frisium) for seizure control have been having an increasingly difficult time filling their prescriptions. There has been a shortage of the drug since December and projected dates for the end of the shortage have been unreliable. There should be a supply of the generic product in pharmacies by the time this newsletter is published. If you are still having a difficult time locating clobazam, see this document for patients published by the Canadian Epilepsy Alliance.

Or call us for help in locating a supply.

By next year it will be mandatory for pharmaceutical companies to announce drug shortages. Please write to your MP and MLA to let them know how drug shortages affect you and that beyond notifications, it is of utmost importance to enforce strategies to avoid shortages in the first place.
The Garden Project

Last Spring, the Esquimalt Unitarian Church (EUC) offered a garden bed for the use of our HeadWay members. Interested members collaboratively plant and tend the veggie patch on a regular basis. There was not much to do in early spring while the new plants were setting their roots and spouting, so during this time our members were introduced to the EUC’s The Rainbow Kitchen. The kitchen provides a nutritious, tasty hot lunch to 125-140 people a day. Over 36,000 meals a year are served in a safe and supportive environment to the poor and marginalized. There is a strong sense of community among those who visit The Rainbow Kitchen as it is a welcoming, non-judgmental place for guests and volunteers where everyone is treated with respect and valued as “part of the family”.

Contact Lindsay if you want to be involved with our garden project. 250-475-6677 lbeal@vepc.bc.ca

Blog

Cultivating Community by Deanna Schneider, an active participant of the Garden Project.

I visit the garden twice a week, usually Mondays and Fridays sometime between 10:00 and 2:00. Just being there feels good. I’ll spend ½ an hour pulling weeds, but can easily spend up to 2 hours there enjoying the company of the other gardeners. By working on our little raised garden bed I have been able to get to know Leslie McGrath, who does most of the Rainbow Kitchen coordination, and much of the gardening on the church property. Leslie is so knowledgeable, and generous with information and resources. I’ve learned so much from her – we’ve talked about the healing qualities of herbs and a number of other garden topics. I love the community environment and the Rainbow Kitchen with the diversity of people who come there. I’ll do some weeding and have lunch and meet people who I would never have met otherwise. I met a woman in a wheelchair who talked about how helpful people are at the Rainbow Kitchen, and about how being on disability has really helped her too. I could really relate to what she had to share, but would never have known that if I hadn’t sat down beside her and chatted during my lunch.

When I go to the garden, I often help Leslie with other gardening projects on the property. Leslie always offers us the use of tools, seeds, and pretty much anything else we need to grow our little garden. There is usually food available as well – always bread, sometimes fruits and vegetables, and grocery items.

I’ve had nothing but good experiences, not only in the gardening realm, but I have had the opportunity to meet new people from different walks of life. The exchange of resources, work and social time is very positive too.
In an atmosphere of experimentation and fun, people can reduce stress and improve flexibility and balance. **Motion Ways** is a custom created exercise class incorporating music and dance, tailored for those individuals with neurological conditions such as Parkinson’s, epilepsy, peripheral neuropathy, multiple sclerosis or an acquired brain injury. Enrich your well-being; join Lindsay Beal as she leads you in a relaxing self-paced, creative session, where the benefits will keep you coming back to this weekly class. So dance yourself to better balance, improved posture and overall function.

**How to Register?**
Register with the Gordon Head Recreation Centre at 250-475-7100
Session: Mondays, Sept. 26 - Dec. 19, 2016, Cost: $9/$77
Drop-in Fee: $9 plus tax Time: 11:15am-12:15pm
Location: Gordon Head Recreation Centre, 4100 Lambrick Way
Programs

Connections with Peers
HeadWay has a number of ways for people to connect with peers. Share tips, and strategies and know that others are in similar situations managing epilepsy with everything else.
Register with Lindsay 250-475-6677  email : lbeal@vepc.bc.ca

Adults Group
Runs the second Tuesday each month from September to June.

Youth & Young Adults Group
Runs monthly.
First time attending?
Register with Lindsay for one of the following sessions:
Tuesday September 13th, 2016
Tuesday December 13th, 2016
5:00 – 7:00
Light buffet supper provided.

Moms with Epilepsy Peer Support Group
Moms with epilepsy are gathering a few times this fall to share and support each other. This group is a casual, “fluid” group, to accommodate individual needs; babies and breast feeding friendly, etc. This is an opportunity to discuss balancing your own health with the needs of your child /children. Dates and times will be determined by those interested in attending. Contact Lindsay to participate in a Doodle Scheduling Poll.

De-Stressing the Learning Environment
With Dr. Linda Hill, Psychologist
A workshop for educators, assistants and parents of children with epilepsy
Children with chronic health conditions have several things in common. Fatigue and reduced tolerance for stress are typical and impact the ability to concentrate and learn. Healthy children also undergo times of stress that surpass the threshold of learning academics. In a room full of people, some will be having a great day, and some will not. The larger the class, the greater the diversity of needs there will be among individuals. How can classrooms be, not just integrated, but inclusive – where differences are viewed as gifts to exchange instead of problems to be eliminated? How can the collective task at hand (classroom learning) remain in focus and be achieved by all? This is an experiential workshop focusing on health, stress, and learning. More information will be available in September.
Community Events

Dance Without Limits

This program provides an opportunity for children and youth with various disabilities to have fun while exploring dance, creative movement and games.

September 20th – November 15th
(Tuesdays)
5:15pm-6:00pm

MOVE Adapted
Fitness and Rehabilitation Society of BC
302-531 Yates Street Victoria, BC V8W 1K7

This is a free inclusive program. Drop-ins, parents and caregivers are welcome!

To Register or Inquire:
Call: 1-800-663-0004
Email: admin@bccerebralpalsy.com
Community Events

Celebrating Community
Sunday, September 11, 2016
Noon - 6pm
Victoria High School Plaza

- Giant Silent Auction - to benefit LDABC The Learning Curve
- Vendor & Exhibitor Market
- Community BBQ
- Live Stage Performances (well-known bands)
- Magicians, Clowns, Stilt-Walking
- Science Fair
- Craft Workshops

To celebrate vibrant Fernwood and raise funds for community projects, each year Vining Street host a FAMILY ORIENTED PARTY. One and all are invited! Please join us on Sunday, September 11th, 2016 at our 9th Annual Street Party on the Plaza (VS POP)

LDABC The Learning Curve
The Learning Disabilities Association of BC South Vancouver Island Chapter has changed its’ name to LDABC The Learning Curve. While our vision to live in a community where all learner’s needs are met remains the same, our new name better reflects our belief in all children and their families’ capacity to learn and thrive. For more information, please visit our website: www.ldasvi.bc.ca

Self- Management Program
Free Six - Session Workshops for Adults with a Chronic Disease
www.selfmanagementbc.ca or toll free phone: 1-866-902-3767

SEAPARC Leisure Complex
2168 Phillips Road
Sooke, V9Z 0Y3
Thursdays
Sep 15 - Oct 20
1:00 PM to 3:30 PM
Leaders: Terri Beaton & Dale Patterson
Headway Epilepsy Members Survey -- 8% of membership responded

Of all respondents interested in attending a HeadWay informational event (60%) most want a two hour duration (55%) on a weekend (40%) afternoon (35%).

The top three topics of interest are Education & Learning, Strategies & Treatments for seizure management, and Research & Cutting Edge Treatment. Each was selected by 50% of those wanting to attend an event.

86% feel connected to HeadWay.

53% do not feel connected to any epilepsy community.

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 Lindsay Beal 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.

How to donate your Shoppers DrugMart Optimum points to HeadWay Victoria Epilepsy and Parkinson's Centre. To donate your Shoppers Optimum Points, please visit: www1.shoppersdrugmart.ca/en/optimum-new/donate-transfer

HeadWay’s 2015/16 Annual General Report & Audited Financial Statements available at: www.vepc.bc.ca or for paper copies please call the office: 250 475-6677
2016 Annual Golf Tournament - THANK YOU
A Message from the Executive Director

A Change in Leadership
I wish to express my heartfelt thanks to all of you that contributed to my experience as executive director at the Centre. With a wonderful staff team, Society members, Board of Directors and so many generous volunteers, I felt like some positive changes were accomplished while upholding the reputation and integrity the Victoria Epilepsy & Parkinson's Centre had built over its 30+ years.

Holding the position of executive director since January 2013 involved many transitions. Highlighting: the physical relocation to 1640 Oak Bay Avenue; changes in staff personnel; some reduction in program service hours; changes in board of directors members; financial and funding changes and decisions involving membership; fundraising events and the Peninsula Co-op Golf transition; fund development overall; enhancing relationships with Parkinson's and epilepsy provincial and local organizations; and not the least of all.....identifying as HeadWay.

Over the past two years I have been slowly working to build what I hope will be a long time working role in this community; that of a private practice clinical counsellor and workshop facilitator.

I want to again thank you for your support over the years and the learning, serving, and receiving which we all experienced together. Now, welcome Mira Laurence to the position!

Sincerely,
Barbara Gilmore

Introducing our new Executive Director, Mira Laurence

A sincere thank you to Barb Gilmore, for the leadership and commitment she has given to HeadWay. We wish her much success with her counselling practice.

I would like to take this opportunity to share a bit about myself and tell you all why I am so very proud to be stepping into the Executive Director’s role.

First and foremost, I am extremely passionate about people! I care about building community and relationships. My background is media, public relations and communications. I spent the vast majority of my career in the public eye in television and radio. That is how I first heard of Headway. I was asked to emcee the Headway Charity Golf Classic and I felt an immediate connection to the organization. I joined the Board of Directors soon afterwards.

Media allowed me the opportunity to fundraise and build awareness for many non-profits up and down Vancouver Island. As a result, I was recognized as one of the Top 20 Under 40 Business and Community Leaders on Vancouver Island in 2012. Now, I am fortunate enough to put all my passion and energy into one organization, our organization - Headway.

Finally, I am a big believer in teamwork, and WOW – we have a fantastic team here at Headway. Between our committed staff, our vibrant Board of Directors and our wonderful volunteers, we provide support, care and knowledge to people living with Parkinson’s and Epilepsy and their caregivers. The work being done at Headway is exceptional and necessary. I can assure our members and clients that we will continue to operate with the same honesty and integrity that you have come to expect.

I’m excited!

Please feel free to come by the office or call me.
Mira Laurence
Executive Director
Note from Editor, Shannon Oatway: 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.