



Victoria Epilepsy & Parkinson's Centre

# BRAIN WAVE

The Magazine Of The Epilepsy Program

Vol.42, Spring, 2017

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# Test your limits & Reach New Heights



# A Message from our Coordinator



## Epilepsy Program Coordinator's Message

I have a friend who is completely content with his life the way it is, and he is not interested in growth or developing his character. With a few friends, we were listening to music one night, and he said “What song is this? It’s no good. I don’t know it. Let’s change it.” I asked him “It’s not familiar?” He confirmed. I asked him, “So, if something is familiar it’s good, and if you don’t recognize it, it’s not good?” “That’s right!” he agreed wholeheartedly. He asked another friend of mine about her profession. His reply, “I don’t know what you’re talking about.” And that was the end of that conversation, he didn’t want to know about her work because it was something new to him. These self-limiting behaviours certainly keep my friend feeling comfortable. His life is everything he dreamed of and he wants to keep it safe from anything that will change his life unpredictably. I can certainly appreciate the tidiness of his life and choices.

Something new can be exciting, challenging or a combination of both. It heightens our awareness and engages attention. For many people though, this is an uncomfortable experience; something new requires more energy than the familiar, more effort to assess and understand. Why would we want to seek something new, when the rut of familiarity is “easier”? I can think of two motivators for trying something new: growth and change. Some people are motivated by growth and development. They want to explore new potential, new horizons, and new ways of being. People venture to the edge of their known lives, and step into the unknown in order to learn and make it known. Alternatively (and not so different) change can be a motivator. Perhaps what is known does not fit one’s ideal, and there is strife, or suffering. People seeking improvement must then venture to the edge of their known lives, and step into the unknown, dedicated to a new path – likely one that is recommended by a trusted guide.

In this issue the article Healthy Mental Well-being (page 4) discusses physical and mental benefits of novel experiences. Spring is a great time of year to step out, and try something new. The weather gets gentler, and newness abounds; bulbs are sprouting, birds are hatching and HeadWay is running a new Guided Breath & Relaxation program (page 7) which by the way is a great skill to ready you for novel experiences.

The Epilepsy Program at HeadWay has been partnering with the Inclusive Leadership Cooperative (ILC). Last autumn we co-created and co-facilitated the workshop De-stressing the Learning Environment, which was very well received by 30 educators and parents of children with epilepsy. Just this past February two young adult members of the agency attended a weekend workshop with the ILC (page 8). Being inclusive and creating an inclusive environment will inevitably bring people together who are very different – much like the social gathering I described above. As an agency, we bring people together over two commonalities, epilepsy and Parkinson’s – yet members come from various walks of life and may be very different from one another. Connecting with Differences is one of the four pillars of Inclusive Leadership and Relaxing About Differences is a skill for connecting. So we come full circle – trying new things, meeting new people and managing the challenges with Breath & Relaxation skills. You might want to try our new program because being with others who are practicing this skill is reassuring, supportive, and fun! Stay tuned for future Inclusive Leadership opportunities through HeadWay!



## Psychosomatic Disorders and PNES

By Rachel Coneys

Rachel is a third year Neuroscience student studying at UVic and has been volunteering at HeadWay since October 2016.

Psychosomatic disorders have long been seen as frustrating and challenging disorders. With no apparent physical abnormalities, psychosomatic disorders are characterized by the involvement of both mind and body – physical manifestations of psychological disturbances. ‘Physical’ diseases like epilepsy are vulnerable to mental states such as anxiety and stress which have been known to worsen the disorder. Psychogenic non epileptic seizures (PNES) are attacks which present as epileptic seizures but are not caused by abnormal electrical discharges. Approximately 20-30% of patients with intractable seizures are diagnosed with PNES. Many people with PNES have undergone psychological distress, traumatic events or death of a loved one. It is these psychological conflicts which are thought to lead to the physical symptoms seen in PNES.

Researchers traced neural networks (the pathways between our nerve cells) in the brain and found connections between the higher thinking areas of the brain (the cerebral cortex), and the adrenal medulla (implicated in emergency situations via the autonomic system) and other organs. This research may help provide some biological basis behind PNES and help explain why emotional states such as stress can manifest itself into physical non epileptic seizures.

The common treatment for PNES is CBT (Cognitive Behavioral Therapy), which helps patients control symptoms by providing them with new ways to think about, and respond to their symptoms. A recent study by Dr. Tolchin showed patients who were compliant with therapy had a 50%+ reduction in their seizure frequency and reported a better quality of life after therapy (as opposed to patients who were non-adherent with therapy). Sticking with, and engaging in CBT lead to clear improvements in these patients. Recent research shows patients with PNES are not inclined to follow through on this therapy. One theory being studied now is that patients who drop out, are not concerned about their illness. Therefore improvement is not a motivator for adopting a new therapeutic lifestyle.

Despite no obvious physical causes, PNES should not be overlooked as it can be a serious and extremely debilitating disorder, which fundamentally needs more awareness and understanding. These findings shed light and are the first step in helping explain how psychosomatic disorders and PNES arise and offer new therapeutic approaches for these disorders

### References

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## Healthy Mental Well-being

*By Rachel Coneys*

Leading healthy lifestyles through diet and exercise has long been known to contribute to good physical health. Psychological well being as well as physical is just as important for our general health. It is not as obvious how we can keep our minds healthy as it is to keep physically well. So how can we keep our brains healthy? Increasing our exposure to new experiences and challenges and limiting the impact stress has on us are some of the ways which we can.

### **New Experiences**

Travelling to new places, starting new hobbies and joining new clubs all help keep the brain stimulated, which increases our resilience (our ability to recover quickly from difficulties) to physical and psychological stressors. The constant mental stimulation that change brings is thought to keep the brain 'switched on' and engaged. So how does this work and why do we need this? Neurons in the brain (the brain's nerve cells) communicate with other nerve cells by sending electrical and chemical messages between each other. These messages relay a vast range of information – from our heart and breathing rates, to our memories and emotional states. It is important that the connections between these neurons stay strong for us to function well both mentally and physically - when the communication between these neurons starts to breakdown, problems arise. There are many ways that we can help strengthen these connections. The vibrancy and challenges of new experiences are acknowledged by the brain, which responds by creating new and re-enforcing old connections between neurons. This experience-dependent process alters the structure of the brain and is known as synaptic plasticity. Plasticity (changeability and flexibility) can increase and strengthen communication between neurons, enhancing our mental ability and resilience. New ventures, activities and challenges all play their role in engaging and strengthening the brain, ultimately leading to a healthy mental well-being.

### **Reducing Stress**

Active lifestyles not only contribute to physical well-being, but also psychological. Participating in every day leisure activities such as walking has been shown to relieve stress, increase life span and contribute to neural plasticity. Active lifestyles can help reduce the impact of epilepsy in some individuals – regular aerobic exercise has been shown to reduce the number of seizures patients' experience. Meditation and mindfulness are another proven way of relieving stress on the brain. Mindfulness, a form of mental meditation can help clear the mind. A recent study showed how mindfulness can reduce anxiety in epilepsy by encouraging self-awareness and acceptance of emotions, rather than using energy fighting one's fears.

Improving our overall health in small yet significant ways can have a big effect on both our physical and psychological well being, be it starting new hobbies or taking up new leisure activities, it is better late than never.

## References from page 4

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[http://www.medscape.com/viewarticle/852133#vp\\_1](http://www.medscape.com/viewarticle/852133#vp_1)

## Research Links: Waves and Cycles

### Text messaging generates a new type of brain wave rhythm

A new study used brain imaging techniques to view the brain wave activity of patients with epilepsy whilst they were text messaging. A distinctive 'texting rhythm' was found whilst people were using their smart phones.

<https://www.sciencedaily.com/releases/2016/06/160627095322.htm>

### Genes influence the sleep/wake timing of seizures

Members of the same family with epilepsy are more likely to experience seizures at the same time throughout the night. An interesting study (link below) found genetics are likely factors in determining the timing of seizures during sleep.

<https://www.sciencedaily.com/releases/2016/03/160307144456.htm>

### Rhythmic breathing modulates brain activity

New research has shown the rhythm of breathing can help organise electrical activity in our brains and boost their functioning. Breathing patterns (especially inhalation through the nose) and brain wave activity were shown to be in synchrony with each other. Though this is not unique to people with epilepsy, it does indicate that breath in some ways can influence our mental functioning in any given moment. Perhaps taking the Guided Breath & Relaxation Course offered through HeadWay will engage you in a practice that can positively affect your mental function – who knows?

<https://www.theguardian.com/science/neurophilosophy/2016/dec/23/breathing-modulates-brain-activity-and-mental-function>

# Feature Story

## **THANK YOU PENINSULA CO-OP!**

It's the silver anniversary of the HeadWay Charity Golf Classic Tournament this year. To date, \$650,000 has been raised during our most successful fundraiser. And Peninsula Co-op is the Title Sponsor of our Tournament again, as it has been for the past 25 years, stepping up to the plate or pin, if you will, to give back to our community so generously. Community giving is a big part of the core principles of Peninsula Co-op since opening its' doors in 1977. So, what drives Peninsula Co-op's philanthropic involvement and spirit? Tom Humphreys, Peninsula Co-op's Petroleum Operations Manager explains *"We are in business to support our members and support our community and keep all the money in Victoria. It's just the core of how we operate. And I think it always will be."* This falls in line with Peninsula Co-op's Mission: "We work together to build strong communities and benefit our member-owners." How fortunate was HeadWay when Peninsula Co-op decided to come on board as a sponsor back in 1992! But why were we chosen to receive the gift of Peninsula Co-op's generosity? Simply put says Tom *"It's a partnership with HeadWay, who has the strength of the administrative machinery to look after things. And the money we raise and the good things we are doing is going to a good place, HeadWay."*

There is also another connection. Parkinson's has a familiar face to Tom. His father passed away from the condition in 2006 so the realities of this disease are palpable. There is nothing like personal experience to *"drive things home"*.

Tom was the chair of the golf committee from 2004 to 2008, the hay days of the tournament with over 220 sponsors, and a 1 million dollar Hole in One prize! Poor economic times hit in 2009, and the tournament saw losses in sponsorship and participation in the years afterward. HeadWay is extremely grateful for Peninsula Co-ops' dedication to our cause and community through its continuing financial support.

Words of advice from Humphreys: "The Education component is very important." *"If you are supporting a cause you better bring the cause to the show."* *"And make the event FUN, make it a BIG party!"*

In previous years, during Tom's rein as chair, themes for the tournament were the trend. Check out this photo:



Tom Humphreys and friends from the south.

So let's make this Silver Anniversary a BASH to remember! Please celebrate with us and help raise much needed funds for our agency, so we can continue our mission of supporting and enhancing the lives of those who live with Epilepsy and Parkinson's! Take advantage of our early bird special and book your spot by May 1 to be eligible to win a trip for 2 to see the Toronto Blue Jays in Seattle for 3 Games including Accommodation and Travel. Valued at \$1600! Let's PARTY!

*Article by Shannon Oatway*



# Programs

## Guided Breath and Relaxation Program

Anxiety, stress, and frustration are common terms we use to describe our state of being when we are dealing with chronic health concerns ourselves or supporting a loved one who does. The good news is that we can develop skills to nurture ourselves when we feel a sense of dis-ease.

Most of us are shallow breathers, particularly when we are stressed. Yet, deepening the breath is a practice that can impact our lives with countless blessings. Inducing the relaxation response is one of the most powerful ways to enrich a calm sense of wellbeing.

We are pleased to continue offering this 7 week course conducted by Kyeren Rowena. Kyeren is a local wellness practitioner with years of experience leading relaxation training sessions. As her website describes, "Breath is our most immediate and natural tool for letting go of stress, worry, panic, anxiety and negative self talk. Breath patterns become ragged and shallow when we lose our calm, but conscious breath work returns us to equilibrium. In this weekly class you will learn how to incorporate and rely upon powerful, easy-to-use breath tools and other helpful techniques in your daily life." So whether you have epilepsy or are a loved one seeking a greater sense of control and peace in your life, we welcome you to register.

### Eligibility:

Open to anyone with epilepsy, Parkinson's or family members for stress management benefits.

When: Two seven week programs for you to choose from:

Mondays from April 24-June 19, 2017 from 1-2:30pm. No class May 1st.

Or Thursdays from April 27-June 15, 2017 from 10:30am-noon. No class May 4th.

Where: HeadWay Victoria Epilepsy & Parkinson's Centre 202-1640 Oak Bay Ave. (Parking is on Morrison Street in gravel lot – use stalls "for clients".)

Cost: \$70 pre-paid for the 7 week series. Subsidized rates are available if requested. Advance registration fees can be made by cash, cheque or credit card.

What to bring: You are welcome to bring a pillow, blanket or other aids to ensure your warmth & comfort during this seated program

How to register: Space is limited for these small group programs. Please contact the agency at 250-475-6677 to register or for more info, call/email Lindsay Beal lbeal@vepc.bc.ca



**HeadWay**  
Victoria Epilepsy & Parkinson's Centre  
*Charity Golf Classic*  
OUR SILVER ANNIVERSARY

25 Years

REGISTER BEFORE MAY 1<sup>st</sup> TO QUALIFY  
TRIP FOR 2 TO SEE THE TORONTO BLUE JAYS IN SEATTLE  
SPONSORED BY HARBOURCATS  
Incl: 3 Games, Accommodation & Transportation

### Come golf with us!

On June 8th 2017 join us at Olympic View Golf Course as we celebrate the 25th Anniversary of the HeadWay Charity Golf Classic!

Thank you to Peninsula Co-op for sponsoring a pre-golf BBQ lunch. After a day of golfing there will be a champagne reception sponsored by Enrico Wineries, followed by a gourmet dinner. There will also be a fabulous silent auction and lots of great prizes.

**CO-OP PENINSULA CO-OP**

**EVENT DETAILS**

**Location:**  
Olympic View Golf Course

**Date:**  
Thursday, June 8, 2017

**Time:**  
11:00 - 1:00 pm Registration  
1:30 - 6:30 pm Golf  
6:30 - 7:00 pm Reception & Silent Auction  
7:00 pm Dinner

**Details:**

- 18 holes of Golf
- BBQ lunch sponsored by Peninsula Co-op
- 144 Golfers, 175 Dinner Guests
- Entertaining on-course activities
- Champagne reception sponsored by Enrico Wineries
- Dinner & Silent Auction

**Cost:**  
\$180 per person or \$600 for a team of four

Register early, or for more information, visit:  
[HeadWayVictoriaGolf.com](http://HeadWayVictoriaGolf.com)

# Programs

## Connecting with Other Members

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. There is no substitute for real-time, person to person interactions. Positive social connections bolster health and reduce the effects of stress. Days and times are subject to change; as well special events might come up, so get connected to be informed. If you are interested in any of the following groups, make an appointment with Lindsay, 250-475-6677 lbeal@vepc.bc.ca

### Adults Peer Support Group

- Focusing on personal empowerment and wellness strategies.

### Moms with Epilepsy Peer Support Group

- Focusing on supporting one another, and sharing stories, including through Facebook.

### Parents of Children & Adult Children with Epilepsy

- Currently in the wings, and occasionally invited into the fold of Moms with Epilepsy

### Youth & Young Adults Peer Support Group

- Focusing on developing and sharing Inclusive Leadership skills.

Recently two members participated in a weekend workshop called Cultivating Inclusive Leadership. They shared what they learned with the group, and we realized these skills will really strengthen our group, and make it easier for new people to join. We want to bring one of these workshops to Victoria in the autumn so more of our members can learn these leadership skills.

## VOLUNTEERS WANTED

### TIME ON YOUR HANDS?

Would you have time to volunteer for HeadWay? Or know anyone who would be interested in volunteering for us? Do you or someone in your network have a special skill that would benefit our agency? If so, please contact our new Volunteer Coordinator, Tania Fritz. We would love to have you on board!





# Programs

## Neuropsych and Medication Review Clinic

One time private consults with Dr. M. Gheis and Pharmacist

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.

We are offering one-time consultations with Dr. Gheis, neuropsychiatrist, and a pharmacist to help you understand and address the complexities you experience.

You are eligible for this service if:

- You would like a one-time session with Dr Gheis to help you better understand your Epilepsy or mood-related treatment options.
- 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.

To request an appointment or if you have any questions regarding the referral process, please contact Lindsay Beal, the project co-ordinator, at 250-475-6677 or email lbeal@vepc.bc.ca.

*"Motion Ways is a great class, a great gathering! The music is always so lovely. We dance! We release! We make sure that we are not gripping on to anything that our afflictions may promote! It is a tremendously positive space! ~ participant*

## Motion Ways

*This class combines creativity, dance and mindfulness for those with any neurological conditions (e.g. Epilepsy).*

*Activate the sensory-motor systems while having fun. Bring awareness to your position, movement and balance.*

*Set your own pace and enjoy the rhythms.*

*Instructor: Lindsay Beal*



### How to Register?

***Mondays, April, 24 - June.12, 2017, Cost : 7/\$58***

***Registration Pin Required: 826405***

***Drop-in Fee: \$9 plus tax Time: 11:15am-12:15pm***

***Location: Gordon Head Recreation Centre,  
4100 Lambrick Way***

## Are you subscribed to E-Blasts from HeadWay?

Periodically we send out notifications of programs and events that might have missed the newsletters. Occasionally we'll send reminders of the most popular upcoming programs and events to be sure you don't unintentionally miss out.

Some subscribers have stated that they don't receive the HeadWay messages. The program we use to send out the email messages keeps track of how many were successfully delivered, and how many messages were opened. We have noted that most messages arrive, and many are not opened. The program also shows how many messages bounced and these are usually only a few in number.

If you are missing our messages consider these points:

1. Your email program might be blocking messages. Check your spam or junk folder. Add our email address to your "safe sender / safe recipient" list used by the junk email filter
2. Your email program might be automatically blocking pictures. If this is the case you can put your cursor over the message bar and "right" click with the mouse to download pictures.
3. Check the website for events and programs.



Thank you to Jo-Ann at Nuttycake Photography for the use of the photos above.

*Absolute Therapy, Athletic Therapy Clinic – PISE, Acacia Integrative Health Clinic, Arbonne International, Bayshore Home Health, BC Responsible & Problem Gaming Program, Boys & Girls Club Brentwood Bay, Central Saanich Optical, Connect Hearing, Country Grocer, Dr Shelina Babul-Keynote Speaker, Earth's Options Cremation & Burial Services, Hatley Memorial Gardens, Hair Flair, Hearinglife Canada, Home instead Senior Care, In Motion Athletic Therapy, Inner Warriors Yoga, Island Culinary Service, Island MMA Training Cnt, JUSU Bar, Kinnikinnick Foods Inc., Kirby's Source for Sports, Lifestyle Markets, LifeLabs, Marianne Noade - Organo Coffee, MONAT – Victoria, Nikken Wellness Consultant, Norwex Independent Consultant, Panorama Recreation Centre, Peninsula & Brentwood Physiotherapy, Pen Yoga, Ray Dahl Optical and Optometrists, Platinum Naturals and Natures Aid, Reach Health, Remax Camosun, RJ Angels Care Ltd, Sacred Transitions, Seaside Magazine, Shoal Centre, Sidney All Care Residence, Stem to Stern Massage Clinic, Enerex Botanicals, SierraSil, Studio Fitness Victoria, Star Cinema, Vadym Graifer – Author, VI Fitness, Vibes Fitness Sidney, Victoria Brain Injury Society, My Epicure, Victoria Epicure, Viewmont Dental Clinic.*

# Community

A Poem

## Epilepsy

I saw my mother put  
     the small plates on the stairs  
 And wondering looked up and  
     saw my oldest sister collapsing

Action taken by parents  
 Assisting as they were able

My sister and I knew there was  
     something we should know  
 but in those days was not understood

Years later I find good reason  
     to fight stigma first  
                     last and always  
 Because we as people are meant  
     to care for each other as equals

To learn the first aid for seizures  
     if our fellow humans – our neighbours  
                     fall at work, wherever  
 So that life may be carried on  
     as far as possible in the best  
                     interests of everyone

~ Allison Holt, long time member of HeadWay

## 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 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.

*Newsletter support provided by:*





Dear Members,

They say spring is a time for renewal. There has been plenty of “new” happening at HeadWay over the past few months.

We have a new friendly face to greet you when you walk through the door. Tania Fritz has joined our HeadWay family in a Donor Relations/ Office Coordinator role. Tania is in the office from Monday – Friday and happy to answer and help direct your calls. Please join me in welcoming Tania.

As a fairly new Executive Director here at HeadWay, I have relied heavily on the expertise of Lindsay and Maureen for guidance when it comes to client services. Based on their assessments and feedback from our clients, we continue to provide the quality care, support and knowledge that you have come to expect from this agency, and have also integrated some new programs designed to decrease anxiety and to explore nutrition and the brain. These programs have been well attended and well received which lets us know that we are meeting our client’s needs.

It is important to us that our members feel connected to the agency so we have made outreach and engagement a priority. With limited hours Ilyanna was able to make 72 phone calls last quarter to members who are at risk of isolation. Everybody deserves to have someone to talk to.

I have had the honour of connecting with some of our members and look forward to meeting more this spring. Their stories are inspiring and brave. They have spoken about the importance of this agency, the help they received here and the difference it has made in their lives.

It was nice to see so many of our members come out and show their support for the agency at the HeadWay Health Fair, thank-you! Our next big fundraising event is on June 8th the 25th Anniversary of the HeadWay Charity Golf Classic. This is our largest fundraiser of the year and so important to our agency. Please let those golfers in your life know about our tournament and encourage them to register.

We are grateful to all of you who gave a donation, gave some of your time or fundraised for HeadWay recently. Your kindness and generosity play a significant role in the continuation of our services. Gifts of any size at any time are always appreciated.

Thank you for your continued support,

Mira Laurence  
Executive Director



“The Brainwave”  
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Editor: Shannon Oatway

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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.

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