



Victoria Epilepsy & Parkinson's Centre

TRANSMITTER

The Magazine Of The Parkinson's Program

Vol. 36, April 2015

Parkinson's Awareness Month

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Spring is in the air! The days are getting longer, we have been blessed with some beautiful sunny days, and the flowers are blooming all around us. April is Parkinson's Awareness Month and I invite you to join us in our HeadWay initiatives that we have on the go. There are several incredible ways to show your support and take part in raising awareness for Parkinson's.



- What better way to celebrate the arrival of Spring with a bouquet of tulips? For every tulip purchase, Browns The Florist will be donating \$1 to HeadWay Parkinson's program and services.

Locations:

Downtown: 757 Fort Street Victoria, BC

Sidney: 2499 Beacon Ave W Sidney, BC

Westshore: 2972 Jacklin Road Victoria, BC

Website: <http://www.brownsflorist.com>

Contact

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

- This April, donate 1% of your tax return to HeadWay and your donation will go towards Parkinson's programs and services.
- HeadWay member, Leslie Hodgkinson, will be coordinating a Bottle Drive on April 25th, 2015 from 9AM to 1PM at Lambrick Park Church, 1780 Feltham Road. Spread the word, drop off your empties, or come volunteer and help out!

Help us make this Parkinson's Awareness Month a huge success.



The Power of Collaboration to Serve You

By Maureen Matthew, BSW

We work for you. So, providing the services you most value is our bottom line. Our strength continues to be our availability for individual and family consultations throughout your journey with Parkinson's. We have ongoing working relationships with countless numbers of physicians and health care professionals as we partner together to serve our Parkinson's community.

Another area of excellence is our quality workshop programming in Victoria, Sidney & Westshore both for anyone to attend and some specific to family care partners. Our effective team exercise programs continue to maintain mobility, function and social support to a great many locals. And, the many self help support groups we coordinate are glowing examples of the power of people coming together to connect and support one another. You will also hear more from us on a new thread of service we are working on, which is unique to our area. Local psychiatrist Dr Mohamed Gheis will be working with us to provide mental health educational events and support services starting this May.

We are pleased to announce a new partnership with Parkinson Society British Columbia (PSBC) to enhance local services. PSBC is particularly skilled in a few domains that will now begin to supplement our services in CRD. It's important to note that while our HeadWay agency is dependent on donations to survive, we no longer charge a membership fee. PSBC has a different financial structure, so they have an annual membership fee. They have a fabulous newsletter which we will begin to profile through this newsletter. You will see on page 8 and 9 the main components of a recent article in Viewpoints, PSBC's quarterly publication. The article about deep brain stimulation (DBS) surgery by neurosurgeon, Dr Chris Honey describes access to the only surgical specialist in BC who practices this technique. Please note the long waitlists for consultation and follow up surgery in Vancouver, so anyone who is considering this option needs to discuss eligibility with their neurologist and seek a referral well in advance.

Another component, which PSBC is gifted in, is their quality information and brochures. I highly recommend that you visit their website (www.parkinson.bc.ca) and link to some of the best Parkinson's educational materials available in Canada. For example, many with Parkinson's experience low blood pressure problems that may trigger falls, so reviewing the PSBC website of resources is a wise way to pick up practical strategies.

Parkinson Society BC has been hosting regional conferences throughout BC for over a decade. We wish to give you a 'heads up' that PSBC will now begin coordinating a Parkinson's regional conference in Victoria as well. Our next newsletter in August will give you the details of a full day event they are planning for our area fall 2015.

Last, but definitely not least, our new HeadWay/PSBC partnership will re-kindle the Parkinson's SuperWalk in our area in September 2015. This national event brings people together to raise awareness, raise funds for research & PSBC and provide the powerful foundation of being part of something large and meaningful. Stay tuned for details in August!

Hugs, Maureen Matthew

Parkinson's Wellness Workshops

Group sessions are facilitated by Maureen Matthew, Parkinson's Program Coordinator. Meetings are on a drop in basis at The Salvation Army Citadel 4030 Douglas St (North of McKenzie). Suggested donation is \$10 each to cover expenses or at your discretion.

Pre-Registration Required:

Keys to Successful Management of Parkinson's with Neurologist Dr. Parbeen Pathak

Date: Wednesday, April 29, 2015 **Time:** 1:30pm-3:30pm

Description: Dr. Pathak will discuss the elements of managing Parkinson's that can enhance your function and quality of life. Half of his session will be a Q & A, so please bring your questions understanding that he cannot address individual treatment issues.

Drop-In Session:

Addressing Anxiety & Parkinson's with Neuropsychiatrist Dr. Mohamed Gheis

Date: Tuesday, May 26, 2015 **Time:** 1:30pm-3:30pm

Description: 70% of people with Parkinson's have tremor as a symptom. Most, tell us that tremor increases in times of stress or even during times of positive excitement. Whether you have tremor or not, an anxiety form of depression is a common non motor symptom of Parkinson's. Feeling more able to manage anxiety naturally decreases it. Dr. Gheis will host a discussion regarding the varied forms of anxiety seen in Parkinson's and practical medical and self management strategies.



Upcoming Programs

Parkinson's Support Groups

Session: Sidney & Westshore Parkinson's Support Groups

Group sessions are facilitated by Lindsay Beal, Parkinson's Outreach Coordinator. Drop-in basis.

Sidney Group - Meets 1st Tuesday of every month (Sept-June)

Time: 1:30-3:30pm **Location:** Saanich Peninsula Presbyterian Church, 9296 East Saanich Rd. Suggested donation of \$4.

Westshore Group - Meets 3rd Tuesday of every month (Sept-June)

Time: 1:30-3:30pm **Location:** Alexander Mackie, 753 Station Ave.

Description: Group discussions are introduced through topics of interest and relevance to living well with Parkinson's. Sessions are rich with personal life experience, caring respect for one another and a wealth of practical information and wisdom. In May we'll have Kaitlyn Roland, PhD speaking. Kaitlyn will go over the differences in cognition: including thinking processes (reaction time, speed of processing), mood and memory. We will learn where these functions occur in the brain and how they can change with Parkinson's. We will explore ways to challenge or adapt to these changes in cognition with programs and therapies such as exercise and brain training, etc. In June we'll have our end of season potluck, and sessions will resume in September.



Exercise Programs

Regular exercise is an essential component in the management of Parkinson's. While exercise is important for everyone's health, it is particularly important for people with Parkinson's. Exercise plays a major role in maintaining muscle strength, balance, flexibility, ability to walk safely, and ability to carry out activities of daily living. It can also help with some other Parkinson's symptoms, including constipation, sleep problems and anxiety or depression.

WHEN:

Monday and Thursday: 1pm-2pm

Standing and seated exercises with free weights, balls, and bands.

Tuesday and Thursday: 11:30am - 12:30pm

Seated only exercises with free weights, balls, and bands.

While an attendant and volunteer assistants are on hand to provide additional attention, these programs are designed for those who can follow through on exercises independently. The cost per class will be \$10.00. The Centre is happy to help organize HandyDart transportation for those who qualify.

Please call Lindsay Beal, Exercise Program & Outreach Coordinator, to determine your eligibility to register for these programs, at 250-475-6677, or email lbeal@vepc.bc.ca

Upcoming Programs



Motionways

For more information or to register, contact Lindsay Beal, Parkinson's Outreach Coordinator at 250-475-6677 or lbeal@vepc.bc.ca

Description: Motion Ways is a movement meditation class. Using music and various attentiveness exercises, Lindsay Beal

facilitates a process of exploration, creativity and mindfulness. This is an opportunity to dance without steps, to go at your own pace, and to follow your physical needs. It runs one hour each week.



Thank you to our incredible volunteers!

Volunteer Appreciation Week was April 12-18, 2015 and we could not be more thankful for our incredible volunteers. We would not be where we are today without you!

Parky's Peddlers

By Alf Todd



In June of 2012, 15 cyclists and I left Victoria for a two week bike ride down the coast to San Francisco, to raise money for Parkinson's research; that effort formed the "Parky's Peddlers".

Now into my eighth year of dealing with the struggles of Parkinson's Disease, I am still able to ride my bike but the "long" rides will have to be memories and the torch will be passed on.

On June 13th of this summer (2015), my good friend, Walter Schnetzler, will lead up a ONE-DAY ride from Victoria (B.C.) to Tofino, a distance of 320 kilometers. This is not a ride for the average rider. Not only is 320 km a huge-one day ride, the terrain will challenge the best.

Why are we doing this? To raise support for the Victoria Epilepsy and Parkinson's Centre (VEPC). All donations will be tax-deductable and will be kept in Victoria. If you're interested in participating, contact us at the phone number and email below.

Contact:

Phone: 250 4787-8623 (Alf Todd) or 250 474 4479 (Walter Schnetzler)

Email: Todds50@telus.net

Calendar of VEPC Programs Events

April to June 2015					
Date	Time	Topic	Venue	Register (R) Drop-In (DI)	Cost
Tuesday, April 21	1:30 - 3:30	Westshore Support Group - Discussion: Efficiency at the Dr's Office	Westshore	DI	Don.
Wednesday, April 29	1:30 - 3:30	Keys to Successful Management of Parkinson's with Neurologist Dr. Parbeen Pathak	S.A. Citadel	FULL	Don.
Tuesday, May 5	1:30 - 3:30	Sidney Support Group - Guest: Dr. Kaitlyn Roland on Cognitive Changes in PD	Sidney	DI	Don.
Tuesday, May 19	1:30 - 3:30	Westshore Support Group - Guest: Dr. Kaitlyn Roland on Cognitive Changes in PD	Westshore	DI	Don.
Tuesday, May 26	1:30 - 3:30	Addressing Anxiety & Parkinson's with Neuropsychiatrist Dr. Mohamed Gheis	S.A. Citadel	DI	Don.
Tuesday, June 2	12:00 - 2:00	Sidney Support Group - Potluck	Sidney	DI	Don.
Tuesday, June 16	1:30 - 3:30	Westshore Support Group - Potluck	West Shore	DI	Don.
Mondays until June 1	11:15-12:15	MotionWays	GH Rec.	R	\$10

For registration:
Call 250-475-6677

Gordon Head Rec. (GH Rec)

4100 Lambrick Way

Sidney

Saan. Pen. Presbyterian Church
9296 East Saanich Rd.

Sally Ann Citadel

4030 Douglas St.
(Turn North off McKenzie)

West Shore

Alexander Mackie
753 Station Avenue

Anxiety and Parkinson's

Like other chronic conditions, people with Parkinson's often struggle with mental health difficulties. While the illness is known to impair many aspects of movement, research has found that two non motor symptoms —depression and anxiety — play a key role in Parkinson's as well. While anxiety is less well-studied than depression, it may be just as common. In fact, up to 40 percent of people with Parkinson's will experience some form of anxiety during the course of their illness. This is important because left unchecked anxiety can worsen a person's overall health condition.



What Causes Anxiety?

Anxiety is a mood disorder characterized by a general feeling of nervousness and agitation, and a looming sense that something bad is about to happen. Sometimes this emotional state can become so overwhelming that it interferes with the PWP (Person with Parkinson's) ability to lead a normal life. In people with Parkinson's, anxiety can be caused by a combination of factors, including changes in the brain's structure and natural chemistry as well as ongoing, stressful experiences that occur as a result of living with a progressive disease. Here are some common psychological and biological factors that may contribute to the development of an anxiety disorder:

Psychological Factors

There are many common fears and worries that go along with Parkinson's which may trigger anxiety. One is a fear of being unable to function independently, particularly during a sudden "off" period (the time of day when medication is not working). Sometimes this can lead to a fear of being left alone. Another is a concern about being embarrassed—often related to interacting with others in public and not wanting to be watched or judged because of this illness.

Biological Factors

Many of the brain pathways and chemicals affected by Parkinson's are the same as those affected by anxiety and depression. People with Parkinson's have abnormal levels of the brain chemical GABA. Similarly, anxiety and depression are linked to low levels of this neurotransmitter as well, and can be treated with one class of anti-anxiety medications designed to increase these levels. In some cases, anxiety is directly related to changes in motor symptoms. Specifically, PWP who experience "off" periods can develop severe anxiety during these states sometimes to the point of full-blown anxiety attacks.

There are many different strategies to manage anxiety. Effective treatment can lead to a better quality of life. Feeling a sense of personal control is an antidote to managing anxiety. The first step is to share concerns with loved ones and the physician about symptoms. Receiving support and discussing treatment options can offer new avenues of hope.

Source: Excerpt with edits from <http://www.parkinson.org/Parkinson-s-Disease/Living-Well/Anxiety> & <http://www.parkinson.org/Parkinson-s-Disease/Living-Well/Anxiety/What-Cause-Anxiety->

Special Note: Local neuropsychiatrist Dr Mohamed Gheis will be discussing anxiety at the Victoria Parkinson's workshop hosted by Maureen Matthew on May 26, 2015 at the Sally Ann Citadel. Please see page 3 of this newsletter.

Deep Brain Stimulation

Dr. Honey is Associate Professor of Neurosurgery at the University of British Columbia. He is on the Board of the World Society of Stereotactic & Functional Neurosurgery and the Canadian Neuromodulation Society. Currently, Dr. Honey is the only neurosurgeon in British Columbia qualified to perform Deep Brain Stimulation.

What is DBS?

Deep Brain Stimulation (or DBS) is a new way of “turning off” or neuromodulating a small area of the brain. It involves placing a small platinum electrode or wire into the abnormal area of the brain. Instead of destroying the area (like we used to do), we use high frequency electrical stimulation to “turn it off”. The electrode is connected by a subcutaneous wire to a pacemaker which sits under the skin, usually in the chest. When electrical pulses are produced by the pacemaker and sent to the tip of the electrode, the brain cells in the region of the electrode are “turned off”.

How does Deep Brain Stimulation (DBS) work?

In summary, there are a number of medical conditions where symptoms in the body occur because of an abnormal activity of the brain. Epilepsy is the most obvious example - abnormal bursting electrical activity in a small area of the brain causes seizures in a patient. If that abnormal area of the brain is deliberately destroyed by a neurosurgeon then the seizures stop and the patient's life can be improved. The difficulty for the surgeon arises in predicting if that area of the brain can be destroyed without hurting the patient. In many cases it can. The pacemaker can then be adjusted to maximize the benefits (turning off the malfunctioning area) and minimize the side effects (turning off adjacent important areas). That is the greatest strength of DBS - it can be adjusted to maximally benefit an individual patient and if there are unwanted side effects, it can be turned down.

Patients with Parkinson's (PWP) have areas of their brain that are overactive and a DBS electrode can be placed in those areas to correct the brain activity. This may be a confusing concept for some because everyone has been told that Parkinson's is due to a loss of dopamine brain cells. Loss of this cell can result in overactivity (or underactivity) depending on whether the dopamine cell was working as a stimulating or inhibiting cell.

When should one consider DBS?

We reserve DBS surgery for those patients who are having unacceptable side effects with their medications. If you are doing well on your medications, don't have surgery.

What makes a patient a good candidate for DBS?

We are looking for 3 motor symptoms that do not respond to optimal medications:

- i) Motor fluctuations
- ii) Dyskinesia, or
- iii) Tremor

What is the wait time for DBS in British Columbia?

There are two waiting lists. The first (W1) is the time from when your neurologist puts in a referral for surgery until the time of your neurosurgical appointment. W1 is approximately 3 years. The second (W2) is the time from deciding you want surgery to the day of surgery. W2 is approaching one year.

Deep Brain Stimulation (Cont'd)

Is DBS covered by health insurance?

Yes.

What are the benefits of DBS?

The benefits of DBS are directly related to the surgical target. Targeting the thalamus will reduce tremor approximately 80-100%. Targeting the pallidum will reduce dyskinesia approximately 80-100%. Targeting the subthalamic nucleus will reduce motor fluctuations. The details are best reviewed with your neurosurgeon and, of course, vary from patient to patient.

Does DBS improve non-motor symptoms?

DBS does not improve non-motor symptoms of Parkinson's disease. Non-motor symptoms include but are not limited to dementia, depressions, loss of smell, constipation, bladder dysfunction, imbalance (this is complicated and can be improved in some), impulse control disorders (also very complicated and can be potentially be improved), and REM sleep disorders.

Source: Please refer to www.parkinson.bc.ca for further information on DBS. This article was extracted from the Parkinson Society of British Columbia's Winter 2014 Viewpoints newsletter that can be found at:

www.parkinson.bc.ca/publications

Care Partner's Corner

Celebrating Family Caregiver Week in BC May 4-10, 2015

- We at HeadWay send our heartfelt gratitude to all family, friends and volunteers who give of themselves to enrich the lives of others.
- Thank you to Kaitlyn Roland for her workshop offering and understanding Cognitive Changes in Parkinson's. It was so popular that we intend to offer it again. Call Maureen Matthew at 250-475-6677 if you wish to be on the waitlist (or email her at: mmatthew@vepc.bc.ca)
- There are many excellent private home care agencies in Greater Victoria. Maureen Matthew is familiar with many and can help you identify a good agency fit for your needs. One unique service is designed specifically for caregiver respite needs of low income families. Saint Elizabeth, a national home care service provider, has a charitable service called the Caregiver Respite Program. Low income families can access up to 32 hours a month for up to 3 months of respite care by one of their qualified home care staff. For more details, call them at 250-385-0444 or check out www.saintelizabeth.com
- Better at Home may help you with needed chores. This United Way initiative enables access to housekeeping and many other services at a sliding scale based on income. For details, go to www.betterathome.ca and link to your neighborhood.



Free Webinars for Family Caregivers

The Family Caregivers' Network (FCN) hosts excellent FREE Webinars for Family Caregivers.

Register for FREE by calling Care-ring Voice Network at 1-866-396-2433 or register on-line at www.caringvoice.com. Webinars are offered via computer or you can simply listen in by phone. For more information call 1-877-520-3267 and visit www.familycaregiversnetwork.org. Here's what's coming up!

Tues, May 5, 6:30 – 8:00 PM What Don't I Know That I Need to Know? Effective Decision Making in Caregiving by Maureen Grant, RSW Maureen will review the mix of care decisions that need to be made along the way and practical strategies from the basics to more complex matters.

Thurs, May 7, 6:30 – 8:00 PM Creating an Unhealthy Environment for Caregiver Burnout By Allison Reeves, RCC Allison will outline how you can increase your resiliency and hardiness and be proactive in living your life in a way that will not allow caregiver burnout to take root.

Wed, May 27, 6:30 – 8:00 PM Letting Go: A Valuable Lesson in Family Caregiving by Allison Reeves, RCC Learning when to hold on and when to let go helps both you and the person for whom you are caring – whether that involves letting go of expectations, control or trying to maintain life the way it used to be.

Mon, June 15, 6:30 – 8:00 PM Respite: Who Benefits? By Allison Reeves, RCC

In this webinar, Allison will explore what taking respite means to you and the benefits to both you and the person you are caring for.



We offer our compassion to the families who have lost the following loved ones and extend our sincerest thanks to those who sent donations in their memory:

Joyce Albany, Henry Behder, Joseph Dufour, Robert Fiset, Dick Giske, Geoffrey Hallam, Martha Hawthornwaite, Allan M. Hutchinson, Wilfrid Meagher, Bob McLaren, Kathleen Oldale, Stephen Ruff, Patricia Walton, and David Young.



From the Executive Director

Spring...open the doors and welcome.

Welcome to spring 2015! What a beautiful place to have so much happening. The workshops, classes, groups and links to resources that Maureen and Lindsay have referred to in this newsletter are happening with excitement. Please call us about anything you want to become involved in.

Welcome to activities being hosted by our colleagues at ParkinGo and Parkinson Society of British Columbia ...lots of activities in the area for all of you to attend as we each provide services to you in different ways.

Welcome a 9% Parkinson's Membership Growth in a year! 570 in May 2014 and 622 almost a year later.



Welcome to a new board member in January; Katy Fairley, from here in Victoria. She is currently the business development manager at Kinetic Construction with a BA from Mount Allison University 2005 in International Relations. She is interested in public speaking, public relations, fundraising and communications and is also serving as a director on the Vancouver Island Construction Association (2014-17) and is the Chair of Women in Construction (2013 – ongoing). Welcome Katy! The Society's board of directors expects to bring additional members to this leadership role over the next few months. Please contact me about details. bgilmore@vepc.bc.ca

Welcome to our members on the Parkinson's Advisory Committee. Leadership for the Society and the Centre's programs come from not only the Board of Directors and executive director, but importantly from Advisory Committees for either Parkinson's or epilepsy. The Parkinson's Advisory Committee meets at least 4 times annually and represents the membership concerning the activities of the Centre. The members are representative of various groups and geographical areas and are liaisons between their needs and priorities for program planning at the Centre.

Thanks so much to each one of these volunteers: Barry Gelling, Monica Shepherd, Dale Patterson, Michele and Trevor Thompsett, Jillian Carson, Barbara Warnock and Ralph Klassen, and new member Stan Fox.

Welcome to Lynn Fanelli who is joining our staff team this year as a fund development coordinator. Read more about her on page 11.

Finally, we Welcome you to join us for our Annual General Meeting being planned for Tuesday, June 30th 3- 5pm. Typically the annual general meeting for the Victoria Epilepsy & Parkinson's Centre Society is held the last week of June to review the fiscal audit of the year just ended and reports of the Centre's programs and activities. Members are invited to attend and vote, interact and meet our staff and volunteers. Call to register 250 475 6677 your attendance.



From the Fund Development Coordinator

As a new member to the Headway team, I bring with me 20 years of fundraising experience. My goal over the next year is to tell our stories. Outline how “It’s my life to live” and what impact living with epilepsy or Parkinson’s has on our daily life.

By engaging our community and telling our stories, we can build supporters for Headway. The goal is to make the Victoria Epilepsy & Parkinson’s Centre everyone’s “Charity of Choice”.

“Charity of Choice”

Get involved this year! You, your business and your family have an opportunity to participate in the Headway Charity Golf Classic June 12, 2015 at Olympic View Golf Course, become a business partner by purchasing an ad in this newsletter, donate to Headway through your payroll donation program, or run the GoodLife Fitness Victoria Marathon October 11, 2015. My two teenage daughters will be running 8 km for their Dad. He was diagnosed with Parkinson’s six years ago.

I look forward to working with you over the next year.

Does Your Workplace Support a Local Charity?

Many companies focus their charitable support around employee areas of interest. We encourage you to tell your workplace about Headway, Victoria Epilepsy & Parkinson’s Centre. As you may know, the Centre provides individuals, families and your community with the support and knowledge needed to live well with seizures, epilepsy or Parkinson’s.

A payroll deduction program is a convenient way to contribute to the Centre. As an employee, weekly, bi-weekly or monthly deductions provide you a convenient way to give to your community; as well as provide a year-end charitable tax receipt.

Contact us and we can provide you with additional information, or go directly to your company’s administration and have Victoria Epilepsy & Parkinson’s Centre Society added to the list of qualified charities who receive payroll donations.

Advertising Guidelines

Acceptance of advertising does not constitute an endorsement by the Victoria Epilepsy & Parkinson's Centre of the products or services listed.

Distribution: 800 Victoria & Vancouver Island

Seasonal Issues: Fall, Winter, Spring/Summer

For ad rates, format, deadlines and payment options please contact Della Truitt, VEPC Office Manager, at (250) 475-6677 or email: help@vepc.bc.ca

Confidentiality Guidelines

We respect your right to privacy, so please be assured that our agency does not share our membership list with outside individuals or organizations. Occasionally we may ask you to volunteer some information so that we can better understand our clients' needs and improve our services.

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EDITOR'S NOTE: 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.

Please Note:

Our website is now www.headwayvictoria.com but is being quickly redirected to www.vepc.bc.ca while we change over. We remain the **Victoria Epilepsy and Parkinson's Centre** (not VEPC and not Headway) for any cheque payments.



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