

Viewpoints

Parkinson
Society
British
Columbia



A quarterly newsletter for the Parkinson's Community of British Columbia

SPRING
2015

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OUR MISSION Parkinson Society British Columbia exists to address the personal and social consequences of Parkinson's disease through education, outreach, scientific research, advocacy and public awareness.

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Your support is essential!

PSBC would not exist without the generosity of its members, donors and volunteers since it receives no government support.

The following are the many ways you can support your society:

Membership—\$25 annual fee

Monthly or Quarterly Donation

United Way

Remember PSBC when giving through United Way

Special Events

Your participation in our special events makes a difference

Planned Giving and Bequests

Consider **PSBC** as a beneficiary in your Will

Editorial Statement

The views and opinions expressed within the pages of *Viewpoints* are not necessarily those of Parkinson Society British Columbia. The intention is to provide the reader with a wide range of material. Parkinson Society British Columbia welcomes submissions for the newsletter. The editor reserves the right to edit material and to withhold material from publication.

Articles contained in *Viewpoints* are for information only. PSBC does not guarantee nor endorse any product or claim made by an author. In matters of medical treatment or therapy, patients should consult their physicians.

Self-Help Support Groups

100 Mile House, Abbotsford, Burnaby, Campbell River, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox Valley, Courtenay/Comox Caregivers, Cowichan, Cranbrook, Creston, Elk Valley (formerly Sparwood), Fort St. John, Kamloops, Kelowna, Kelowna Caregivers, Ladner, Langley, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Mission, Nanaimo, Nelson, New Diagnosis 1 & 2 (Vancouver), New Westminster, North Shore, North Shore Caregivers, Osoyoos, Parksville/Qualicum, Parksville Caregivers, Penticton Caregivers, Powell River, Prince George, Quadra Island, Richmond, Shuswap/Salmon Arm, Shuswap/Salmon Arm Caregivers, South Sunshine Coast (Sechelt), Surrey, Terrace, Trail/Castlegar, Tri-Cities, Tri-Cities Caregivers, Tsawwassen, Vancouver Arbutus, Vancouver Caregivers, Vancouver West Side, Vernon, White Rock

We're starting a movement. The Parkinson's Movement

April is Parkinson's Awareness Month!
Help us spread the word about the benefits of exercise and raise funds for exercise programs designed specifically for people living with Parkinson's.



Here's how to join The Movement:

- 1** **Commit** to doing your favourite form of exercise from now until the end of Parkinson's Awareness Month, April 30th.
- 2** **Register** online (www.parkinson.bc.ca) and create your own personal profile detailing your exercise commitment.

Example: I'm committing to walk a total of 50km from March 10th to April 30th. Please support me as I walk and raise funds for much-needed exercise programs for people living with Parkinson's.

- 3** **Ask** for pledges from family, friends, co-workers, neighbours, that woman you wave Hi! to when you walk your dog, the bank teller, the grocery store clerk, everyone on Facebook, and of course, the server at your local coffee shop!
- 4** **Feel good.** If regular exercise is new to you, feel good that you've made a lifestyle change. If you're already breaking a sweat regularly, feel good that you've raised money to improve someone's life.

More and more research supports the theory that exercise is one of the best non-medical options to manage Parkinson's symptoms. Help us improve the lives of those living with Parkinson's.

Go to www.parkinson.bc.ca to register or donate to **The Parkinson's Movement** today!

Other ways you can participate in Parkinson's Awareness Month:

- Organize an event or information day at your favourite place to exercise, a shopping mall, community centre or church and distribute PSBC brochures and information materials.
- Become a **Champion for Parkinson's** and organize a fundraiser – it could be a garage sale, pub night or hosting a dinner in your home. Contact Betty Hum bhum@parkinson.bc.ca for your planning guide, materials and event kit.
- Deliver information to general practitioners, neurologists, hospitals, and residential care facilities in your community.
- Spread the word through Facebook and Twitter. Remember to "like" our Facebook page to share our posts!

ask an expert

NINA BLOOMFIELD

answers your questions about
Physiotherapy



Nina Bloomfield currently works for Fraser Health in pulmonary rehabilitation as well as part time in private practice focusing on neurological physiotherapy. In 2014, she led PSBC's PWR pilot project in Burnaby, BC. Throughout Nina's 30 years of experience as a physiotherapist, her interest in PD has led her to work with both individuals and groups teaching exercises to enhance movement and maintain functional mobility.



What is physiotherapy? Isn't it just for people who are injured?

Physiotherapy is treatment performed by a registered physiotherapist aimed at enhancing or restoring movement and function. Trained in movement science, physiotherapists are experts in assessing and treating movement. Therapists often specialize in specific areas including orthopedics and sports injury, respiratory health, neurology, women's health and pediatrics or geriatrics. A common misconception

is that physiotherapists can only help after an injury or mobility issue has arisen, but they can also work with you on preventative measures for potential movement problems.

What Parkinson's symptoms can physiotherapy help?

We all have unique bodies and movement patterns but a diagnosis of Parkinson's can bring additional movement problems such as rigidity, slowness of movement, balance and posture issues, as well as general de-conditioning from lack of exercise. A physiotherapist can make general recommendations and educate you on the kinds of exercises that are important to address and prevent common physical issues from PD. In addition, an individual assessment will address your unique concerns to ensure that you are functioning optimally.

Can physiotherapy help even if I have "freezing of gait" or balance and posture issues?

Absolutely. A physiotherapist can educate you and recommend specific exercises that allow you to better understand and manage your challenges.

Can I do physiotherapy if I'm in a wheelchair or use an assistive aid such as a cane or a walker?

The human body has great capacity to adapt and change. Regardless of your level of ability and use of assistive devices, exercises and new movement strategies can be used to improve your function. Sometimes a carepartner can be shown how to assist you in your exercises and mobility.

Do you need a referral from your doctor to see a physiotherapist?

Physiotherapists in BC are direct care professionals and do not require a doctor's referral. If you are see-

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ing a physiotherapist in the public system, such as in a hospital outpatient department or through home care, a doctor's referral may be helpful or required.

? What is LSVT® LOUD? What is PWR!? Are there specific exercise programs for people with Parkinson's?

There has been a significant increase in research exploring the effect of exercise for Parkinson's symptoms over the past few years. Exercise in general has been shown to have a positive effect.

LSVT® was one of the first exercise programs specifically designed, studied and proven to help people with Parkinson's – in particular those who have bradykinesia, or slowness of movement. Dr. Becky Farley, a physiotherapist from Arizona, developed the research and exercise program for LSVT® but then went on to develop the Parkinson's Wellness Recovery Program, or PWR!.

PWR! is aimed to help with a variety of issues at all levels of Parkinson's and uses whole body movements. It is offered in both group and individual settings and can be tailored to specific needs. For more information about PWR! see www.PWR4life.org.

In an effort to promote the benefits of exercise for those living with Parkinson's and extend our range of services, in 2012, PSBC helped fund PWR! training. If you're looking for PWR! in your area, we can help. Contact Caroline Wiggins at cwiggins@parkinson.bc.ca or 604 662 3240 | Toll Free: 1 800 668 3330

There are other programs that have been developed for people with Parkinson's such as dance, boxing programs and yoga.

? Are there physiotherapy exercises that I can do at home if I'm in a remote area of BC and cannot access a physiotherapist easily?

More research is showing the importance of exercise for Parkinson's disease – specifically exercises such as tai chi, yoga, dancing and treadmill training. The difference between general non-specific exercise and physiotherapy exercises is simply that physiotherapy exercises follow an assessment and the prescription of exercise is specific to you. Becky Farley has written a book called, "A PWR! Guide to a Parkinson-specific Exercise Program" that can be used as a guide to begin exercises. Combining general exercise with exercise designed for people with Parkinson's is an excellent way to stay active and address symptoms when a physiotherapist is not available.

? If I'm too tired or in too much pain how can I do physiotherapy?

Fatigue and pain are a common cause of a vicious cycle of inactivity. A physiotherapist can advise you on how to gradually build up an exercise program to help reverse this cycle. It is also important to be sure that your general health and wellness is ad-

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ASK AN EXPERT

continued from page 5...



dressed including optimal medication, good nutrition, sufficient rest and participating in social activities you enjoy. The important thing to remember is that every bit of activity and exercise counts.

Why should I go to physiotherapy?

Exercise is now considered an important part of treatment of Parkinson's disease and should be started as soon as possible. A physiotherapist can help direct you in starting an exercise

routine, or make sure that the exercises you are doing address your unique situation.

It is best to see a physiotherapist who has a special interest in treating people with neurological conditions. Many private clinics specialize in sports and orthopedics, but there are more clinics that now specialize in neurology. UBC's Pacific Parkinson's Research Centre has a physiotherapist you can consult with if you are being seen there. Some hospital outpatient physiotherapy clinics have specific neurology physiotherapists. If you are home bound, a home care physiotherapist may be able to see you in your home through home health services.

How often should I see a physiotherapy?

This will depend on your needs, goals and the resources and services available. What is most important is that you are provided with the tools, education, movement strategies and exercises that you can follow on your own on a regular basis. A routine will help you get the best results.

Are there any specific questions I should ask the physiotherapist when I visit them?

You will want to know about what kinds of exercises or other treatment that can be offered to help to improve your mobility and address any specific concerns you have related to your physical function.

How much does physiotherapy cost?

Physiotherapy services offered in public health settings such as hospitals, home health and the UBC Movement Disorder Clinic have no fee. Private physiotherapy costs will vary and it is best to contact the therapist or clinic directly. The Physiotherapy Association of BC has a website with a 'find a physio' feature where you can search for services in your community. If you have extended health benefits some or all of the costs may be covered. Otherwise, physiotherapy is a medical expense that may be applied to your tax return.

West Coast College of Massage Therapy

613 Columbia Street
New Westminister, BC

(Near 6th Street, one block from Columbia Skytrain Station)



West Coast College of MASSAGE Therapy

For the third year in a row, the College is holding a special massage clinic for people with Parkinson's, caregivers and support workers.

The clinic is on **Thursdays from 4:00 p.m. to 7:45 p.m.** The cost is \$13 for people with Parkinson's and \$22 for carepartners and support workers.

We have received excellent feedback from those who have attended the clinic. If you are interested, please call the clinic receptionist at **604 520 1830**.

Access is through the back entrance on Clarkson Street and is wheelchair accessible.



Exercise as Treatment

WITH MATTHEW SACHELI



Neuroscientist Matthew Sacheli was working as a personal trainer to help put himself through university when he noticed that one of his patients, who had Parkinson's disease, had fewer symptoms when engaging in calisthenics and resistance training.

By the end of the workout, however, Sacheli could see his client's tremors and stiffness return.

"It was really an eye-opener to me to see that exercise could be beneficial for these patients," Sacheli remembers.

That experience inspired Sacheli, now a graduate student in neuroscience at the University of British Columbia, to marry his love of sports and exercise with research into exactly why exercise helps people with Parkinson's disease. Although doctors and researchers have learned that dance, Tai Chi, or other forms of exercise reduce both motor and non-motor symptoms of Parkinson's, they don't know how frequently or how intensely people need to exercise to get the benefits, or precisely what part of the brain exercise stimulates to affect these changes.

Sacheli is using two types of imaging to investigate whether exercise triggers a release of dopamine within the brain, and if it does, what specific regions of the brain are involved. If he can identify the mechanisms involved, that knowledge could open up new treatment avenues.

Sacheli is using Positron Emission Tomography (PET) to scan the brains of people with Parkinson's before and after they have participated in three months of a regular exercise routine, to see if dopamine levels increase. He will also use functional Magnetic Resonance Imaging (fMRI) to chart the activity in his participants' brains as they play a card game that

■ Research Project

Investigating the therapeutic mechanisms of exercise interventions for the treatment of Parkinson's disease.

■ Pilot Project Grant

\$30,000 over two years

■ Project Description

If we can show that it doesn't necessarily matter what type of exercise you are doing, but that all exercise is beneficial, I think it will help motivate people who are not able to go out and run a marathon, but can walk their dog for 20 minutes.

mimics the brain's response to rewards, like the pleasurable feeling a workout delivers.

By correlating the data from the two, Sacheli hopes to pinpoint the brain structures that exercise affects. Eventually, he hopes doctors will be able to write accurate prescriptions for the kind and type of exercise people require to improve their symptoms. Sacheli's goal is to inspire a more holistic approach to treating Parkinson's disease.

"The future of clinical care is a multiple and comprehensive health approach, especially for a complex disease like Parkinson's disease," he says.

Matthew Sacheli Biography

Born and raised in Calgary, Alberta, Matt attended the University of Ottawa, obtaining a Bachelor of Science Honours degree in Human Kinetics and gaining his certification in exercise physiology (CSEP-CEP). He continued his education at Wilfrid Laurier University receiving a Master of Science in Kinesiology. During his graduate studies he researched sensory based exercise interventions for the treatment of Parkinson's disease at the Sun Life Financial Movement Disorders Research and Rehabilitation Centre.

Matt is currently attending the University of British Columbia pursuing a PhD in Neuroscience at the Pacific Parkinson's Research Centre (PPRC) under the supervision of Dr. A. Jon Stoessl. The focus of Matt's research is investigating the therapeutic mechanism of exercise in Parkinson's disease. Apart from his research Matt enjoys spending time on the golf course, coaching baseball and snowboarding. Matt would like to thank the doctors and staff at the PPRC for their educational support.

The Griffiths family: supporters of Parkinson Society BC for 35 years

The Griffiths family's first contact with the Parkinson Society British Columbia (PSBC) was nearly 35 years ago. Chuck and Ena Griffiths, parents of Lynda and Helen, led busy, active lives. As vice-president of a large international chemical company, Chuck was looking forward to retirement and spending time in the outdoors, visiting their off-the-grid cabin and playing golf.



Lynda and Helen recall that things started to change in the early 1980s when their father was first diagnosed with Parkinson's disease. Instead of feeling defeated, Chuck demonstrated grace in the acceptance of his diagnosis and recognized early on that continuing to participate in activities he enjoyed was greatly beneficial. He left appointments at the BC Neurodegenerative Disorders Centre with Dr. Calne feeling positive about his situation, and soon

began attending PSBC meetings where treatment options and research advances were often discussed. Later on, Chuck served on the Board of Directors of the Society.

The family regularly participated in April's annual Tulip Sale as part of *Parkinson's Awareness Month* at Pacific Centre mall and, when *SuperWalk* started, continued their involvement with PSBC by having fun walking together. As time passed, Chuck's dyskinesia worsened making it more difficult to participate in such activities. Lynda says, "Every once in a while Lois, Executive Director of PSBC at the time,

would call to see how things were going with dad. Lois and the PSBC team were always quick to offer support so that we could continue selling tulips."

Chuck Griffiths passed away in 2001 at the age of 86. To honour her husband, Ena Griffiths had her will rewritten to include a Legacy Gift to PSBC as she felt so strongly about making a gift to the organization that provided hope and encouragement to the entire family.

Ena passed away nearly 10 years after Chuck, and as her Executrices, Helen and Lynda gave great thought to how their parents would have wanted the gift to benefit the Parkinson's community. Knowing their father's passion for exercise and enthusiasm for research, these were two areas they felt their parents would be proud to support.

When asked what their advice would be to other families affected by Parkinson's, Lynda says, "You just need to carry on and look for opportunities to be positive. One of the ways that we decided to do this is by getting involved in our community – specifically PSBC. Certainly one of the things that our parents taught us, and has stuck with us, is the importance of contribution. It feels good to do good, and involvement not only helps others, but helps you too."

If you are considering a **Legacy Gift** to Parkinson Society British Columbia please direct your inquiries to Cecilia Tupper: Phone 604 662 3240 | Toll Free: 1 800 668 3330 ctupper@parkinson.bc.ca

CRA Charitable Business Number: 11880 1240 RR0001

Exercising your need to communicate

First-hand Accounts of Using Voice Applications

Parkinson's disease can affect many aspects of life. Up to 90% of people with Parkinson's disease experience difficulty with communication. However, like the disease, the progression and severity of communication issues will differ between people. When communication is impaired, quality of life suffers and isolation grows. Despite these challenges, your desire to communicate can be rewarded with the right tools. Tony Burrows and Val Swannell, members of the PD community, both utilize high tech solutions in their day-to-day lives. To help make the right choices for you, they've both agreed to share their stories hoping that it will provide some insight into available solutions. You may also consider:

- Environmental management recommendations such as eliminating background noise when possible, and acquiring eye contact with your communication partner before you start speaking;

- Lee Silverman Voice Treatment® for Parkinson Disease – the gold standard voice therapy treatment; and
- Assistive and Augmentative Communication – these devices can range from a simple picture board to a computer program that synthesizes speech from text

Don't wait until communication difficulties are interfering with your quality of life. Sherri Zelazny, Registered Speech Language Pathologist, recommends that you and your communication partners begin with a formal hearing assessment performed by a Registered Audiologist. Additionally, it is valuable to have early contact with a Registered Speech Language Pathologist for support in all aspects of communication.



Find a speech pathologist and audiologist at www.bcaslpa.ca or www.cshhpb.org



TONY BURROWS was diagnosed with Parkinson's on March 26, 2012 and subsequently identified as having Parkinson's Plus, also known as Multiple System Atrophy (MSA). At this time there is no treatment to slow the progression of MSA, a progressive brain disorder, and Tony's diagnosis means he now has a life expectancy of between three and six years. This life-altering disease has led to diminishing handwriting skills and a failing voice. To assist him in communicating, Nicole Armstrong, Speech Pathologist at Lions Gate Hospital, recommended an app called Verbally (<http://bit.ly/VerballyApp>) – which has a free version and a premium upgrade available for \$99.99.

Tony refers to this as a life-changing app because, “when you think about it all, what are two of the main ways that we, as humans, communicate? Writing and speech – and unfortunately I have been robbed of both”. What's great about this app, he says, is that it allows you to type what you want to say and play it out loud using a number of different accents and male or female voices. Furthermore, it has a predictive text, or prompt screen, on the side of the app that can often guess the next word you may want to use – saving you time.

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More than a carepartner: redefine your role, reclaim your identity

WHO ARE YOU?

Three words; so simple to read, so difficult to understand. People spend decades trying to respond to this question before they eventually realize that it's unanswerable—who we are is always changing.

So we come up with a stopgap. We describe ourselves by pointing to the most prominent role we play at any given point in time. For people taking care of a loved one, this role is often as a carepartner.

This way of thinking, while convenient, has its drawbacks. It doesn't take long to feel pigeon-holed, trapped within the narrow confines of the very definitions we helped create. Because it can be an all-consuming role, it's easy for carepartners to feel as if that's all they are. It's hard for them to envision an identity beyond this.

“People are fluid,” says Janice Taylor, author, columnist and life coach for Virtual Shoulder.com, and we need to start seeing ourselves that way. “We are not defined by one role,” she says, “We think of ourselves as nouns—but we are really verbs. We are beings.”

Being a carepartner is not a definition

It should be easy for a carepartner to see themselves as a verb—they're always doing something.

People taking care of a loved one constantly bounce between dozens of daily tasks: driving to doctor's appointments, cooking dinner, working a day job and making sure pills are taken on time.

Taylor, a carepartner herself, talks about how exhausting it can be just to make simple daily decisions for her mother. What she should eat for dinner? Which

of her outfits should be kept and which should be thrown away?

When faced with this never-ending series of tasks, a person's sense of self is often the first thing that gets sacrificed.

She knows how difficult it can be for people taking care of someone to connect with their true selves. “Society tells you what you're supposed to do and how you're supposed to feel,” but it doesn't have to be this way.

The wisdom in cliché advice

Set boundaries, put on your own oxygen mask first, ask for help.

These statements form the basis of the informal carepartner creed. They also highlight the vital importance of staying true to yourself while taking care of another human being.

Before you can set meaningful boundaries with a loved one, you must decide how much you're willing to give. Before you can ask others for help, you must first be able to recognize (and accept) that you've reached the end of your proverbial rope.

“It's okay to express that you're completely overwhelmed,” Taylor says, “You need to define your role as a carepartner and know how much you're comfortable with based on your own sense of self.”

Know yourself. Know your feelings and your limits and don't be afraid to voice them.

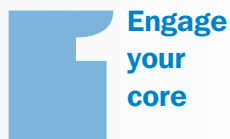
Portrait of a whole person

How do you temporarily subtract carepartner from your resume and tap into the person you really are?

It can be tricky, particularly if you've been looking after a loved one for years, but Taylor offers some advice for re-connecting with and getting to know your true self:

continued on next page...

No, it's not an argument for taking an extra Pilates class. An important part of the re-definition process is thinking about your core set of inner resources. Define yourself by the things you like to do. For example, you may be a creative person who enjoys writing, singing and practicing yoga. You may also be a wife, mother and a daughter who's taking care of her elderly mother but, as Taylor points out, those labels describe your relationship to other people, not your relationship with yourself.



**Engage
your
core**



**Talk
about
yourself**

It may sound unusual, but engaging in some third-person self-talk can help you come up with alternative definitions of who you are. For example, you could say to yourself, "(Your name) is a quilter, attorney, and unabashed romance novel nerd." Taylor says this method creates a sense of inner spaciousness and freedom that may clear your head and help you plug into your true self. "It puts you in a place where your mind isn't hijacked by what's going on, where you're more than your thoughts," she says.

Re-tooling your self-definition doesn't mean that you have to spend hours sitting alone, meditating on the mysteries of life. Taylor suggests taking a few minutes right after you wake up to connect with your inner being. "Remember who you are before you get out of bed," she says.



**Connect
under the
covers**



**Talk
about
strangers**

There's perhaps no better way to re-invent yourself than by being around people you've never met before. Look for groups and clubs in your area that are focused on things you're interested in. That way, you can explore a personal passion while introducing yourself to people who have no preconceived opinions about who you are. They won't know you're carrying a car full of carepartner baggage unless you tell them. Which can offer a refreshing change of pace if your day-to-day interactions constantly seem to revolve around one question: "How's mom doing today?"

Most people shelve their own ambitions once they start looking after their loved ones. But, setting personal goals can be a great way to explore and re-ignite your passions. According to Taylor, the most important thing about goal setting is consistency. Take ten minutes a day to work towards your target, whether it's writing the next great American mystery novel or growing an herb garden in your backyard.



**Set
some
goals**



PSBC has a network of carepartner support groups across British Columbia. This year, the Society is also piloting a Carepartner Series that involves six weeks of support meetings driven by participants' needs. A facilitator will present topics and manage discussions, but the series will focus on the personal experiences of group members.

A list of carepartner support groups is available on the inside cover of Viewpoints. For more information please contact Caroline Wiggins at cwiggins@parkinson.bc.ca, 604 662 3240 or 1 800 668 3330.

Source: Article adapted from Aging Care (<http://www.agingcare.com/Articles/more-than-a-carepartner-152745.htm>).

Make an impact

Do you want to help fund research, grow support networks and improve quality of life for those living with Parkinson's?

Become a **Champion for Parkinson's** and plan your own independent community fundraising event! From bake sales, birthday parties and beer tastings, to sports tournaments and car shows, no event is too big or too small. Take the lead, get creative, build awareness, raise funds and don't forget to have fun!

We are here to help you plan a successful event. We provide:

- Friendly support
- Step-by-step planning
- Website & social media support
- Event kits



FOR MORE INFORMATION Contact Betty Hum
 bhum@parkinson.bc.ca | 604 662 3240 | 1 800 668 3330
www.parkinson.bc.ca/Champions

Your actions have an impact. Start planning your event today!

March

28

Regional Conference – Surrey

Parkinson's is a journey with different stages and challenges. This March, join us in Surrey to learn from leading experts in the field – helping you to live well at every stage.

This year's speakers include Dr. Claire Hinnell, Matthew Sacheli, Nina Bloomfield and Joanne Taylor. Lunch and refreshments will be provided and there will be plenty of free parking nearby.

Date: Saturday, March 28, 2015

Time: 10 am – 4 pm
(registration opens at 9:30 am)

Place: Comfort Inn & Suites
8255 166 Avenue, Surrey

Cost: \$30 Members
\$40 Non-members

Registration deadline is March 23, 2015.

April

11

New Pilot Program! Step by Step

As a part of PSBC's continued effort to bring you more services and programming, we're offering a new pilot program in communities across BC! Set to take place from April 11th to July 4th, Step by Step is a 12 week walking program aimed at incrementally improving the number of steps an individual takes per day. In participating communities a group leader will organize a weekly group walk which will allow participants to meet, socialize, and help motivate one another.

The following communities have already confirmed their participation: Abbotsford, Chilliwack, Comox Valley, Cowichan, Kamloops, Maple Ridge/Pitt Meadows, Parksville and Prince George.

If you or someone you know would be interested in leading a Step by Step group or participating in your community, please contact Caroline Wiggins at cwiggins@parkinson.bc.ca, 604 662 3240 or 1 800 668 3330.

29 & 30

Voice & Swallow Seminar – Kelowna*

This two-day event will focus on the voice and swallowing challenges faced by people living with Parkinson's. It will be an interactive and participatory format and all levels of voice and swallow disorder will be included.

Dates: Wednesday, April 29 & Thursday, April 30, 2015

Time: 10 am – 3 pm
(registration opens at 9:30 am)

Place: Ramada Hotel & Conference Centre
2170 Harvey Avenue, Kelowna

Cost: \$40 Members
\$50 Non-members

*Voice & Swallow Seminars will be offered in other locations throughout the year. Check PSBC's website for the latest updates.

SATURDAY

SATURDAY

WEDNESDAY & THURSDAY





PAT GALLAHER

We are saddened by the passing of Pat Gallaher, aged 65, who passed away from complications during surgery. Pat was the founder of BC Playthings, a toy and preschool supply store in Edgemont Village, North Vancouver. After being diagnosed with Parkinson's in 1997, he joined PSBC's Board of Directors in 2006 and maintained an active family and professional life.



BARBARA HODSON

Parkinson Society British Columbia wishes to acknowledge the passing of Barbara Hodson, aged 68 from complications of Parkinson's disease. Diagnosed in 1991, Barbara was a profes-

sional librarian, a Board Member of PSBC and contributed to the editing of Viewpoints for over eight years.

We are grateful for the support and service of these individuals. Our deepest condolences go out to their families and loved ones.

May

June

SATURDAY

23

Regional Conference – Kelowna

Dates: Saturday, May 23, 2015

Time: 10 am – 4 pm
(registration opens at 9:30 am)

Place: Ramada Hotel and Conference Centre
2170 Harvey Avenue, Kelowna

Cost: \$30 Members
\$40 Non-members

TUESDAY

9



Me-n-Ed's 8th Annual Charity Golf Tournament

Proceeds will support programming, services and research for Parkinson's disease.

Time: 1 pm Shotgun Start

Place: Riverway Golf Course
9001 Bill Fox Way

For more information and to purchase tickets, please contact Cris at 604 931 2468

THURSDAY

11

Regional Conference – Vancouver

Dates: Thursday, June 11, 2015

Time: 10 am – 4 pm
(registration opens at 9:30 am)

Place: Italian Cultural Centre
3075 Slocan Street, Vancouver

Cost: \$30 Members
\$40 Non-members



More details on upcoming events will be available soon at www.parkinson.bc.ca

EXERCISING YOUR NEED TO COMMUNICATE: FIRST-HAND ACCOUNTS OF USING VOICE APPLICATIONS

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If you have a planned conversation coming up, for example with a doctor or Neurologist, you can pre-type or prepare a conversation and save it under a category name. It will also save a history of your conversations, which can be turned on or off. Jokingly, Tony notes that his “wife hates this history function as when it comes to proving a point, I have proof of what I just said right under my fingertips”.

In addition to providing him with a vehicle to effectively communicate with his family and friends, the app has given him the necessary typing skills to complete two books, “*From a Hotelier to Parkinson’s Disease*” which is now available from Amazon or Indigo, and “*The Journeys. A Positive Approach to Living with Parkinson’s Disease*” which is set to be available at the beginning of May 2015.

VAL SWANNELL was diagnosed with Parkinsonism in March 2010 by Dr. Jon Stoessl. Despite the news, having experienced worsening symptoms of speech, writing and balance, she was pleased to have a diagnosis and options for treatment.



In November 2010 she joined the Board of Parkinson Society British Columbia (PSBC) to affect positive change for others living with PD. Val’s key focus

now is to “build awareness of Parkinson’s disease (PD), and fundraise to find a cure.” In an effort to work towards her goals, she actively participated in **The Parkinson Movement** (which last year included cycling in the Penticton Grand Fondo 92 km Mediofondo) and *SuperWalk* in September. Val says, “I have learned to ask others for help and have been very surprised and delighted by their positive responses – I must thank many of my friends, colleagues and family for their incredible support.”

Despite having taken and practiced LSVT Loud, her speech has worsened and it has become very difficult for most people to understand her.

To assist Val in communicating, her speech language therapist at Lion’s Gate Hospital recommended the Delayed Auditory Feedback (DAF) application (<http://bit.ly/DAFApp>). Val has since installed the \$10 app on a number of her mobile devices. The app has saved expending thousands of dollars on purchasing a specialized DAF device which would normally cost between \$1,000–\$5,000.



Initially Val said that the Bluetooth compatible app was a “lifesaver”, but it did pose some challenges. She notes that, “some Bluetooth devices are difficult to use with this as they only have one earpiece. I have found one that is fairly good called the Plantronics Backbeat Go 2, which has two earphones and a microphone. It’s available at Amazon.ca for about \$80.”

The app is best used for one-on-one conversations in a quiet environment as it is difficult to properly hear someone with the earphones on. If you are able to hear someone, the noise is hard to understand as the microphone picks up sounds that the app then delays. What you’re left with is overlapping deferred speech with real time speech. In noisy environments a lot of background noise can be picked up through the microphone and deferred, which can be frustrating if you’re trying to focus on listening to someone. Despite these concerns, Val would, “definitely recommend this to someone with Parkinson’s disease to try out as it is a reasonably affordable way to assist with your speech.” Though she’s not tried it yet, Val has heard that some headsets use bone conduction which may be a help to users. Stay tuned!

SUPPORT GROUP NEWS

New Support Group: 100 Mile House

We are pleased to announce that there will be a new support group meeting in 100 Mile House. The meeting times have yet to be determined. If you are interested in attending, please contact Caroline Wiggins at cwiggins@parkinson.bc.ca or 604 662 3240 | 1 800 668 3330.

PSBC STAFF CHANGES

New Staff

We are pleased to introduce two new staff members to Parkinson Society British Columbia (PSBC) to cover maternity leave for Laura Darch, Marketing and Communications Manager and Stacey Dawes, Information and Programs Manager.

Alicia Wrobel joins the team as Manager of Marketing & Communications, Interim, covering for Laura Darch. Alicia holds a Bachelor of Arts in Communication, Honours and brings her experience of working with over twenty non-profit associations as the lead on marketing and communications initiatives. She also has considerable experience in providing technology support to non-profits including full cycle web development and database implementation and design.

Currently completing her Masters of Arts in Counselling Psychology at the Adler School of Psychology, **Myriame Lépine Lyons** joins the PSBC team as Education and Support Services Coordinator, Interim to provide support during Stacey Dawes' maternity leave. Myriame completed her internships at Harbourside Family Counselling Centre and Alderwood Family Development Centre and her community service practicum at West Side Family Place. She brings with her a wealth of experience in research, as well as program development and implementation.



Raise your voice for Parkinson's!

Parkinson's disease (PD) is one of the most treatable of all neurological conditions. Medical treatment increases longevity and allows most people with PD to remain active and productive for many years. The medical treatment of PD, unfortunately, is not always simple.

Join us in our advocacy campaign to raise awareness of the challenges of the disease and lobby for much needed extra support.

Contact Jean Blake at jblake@parkinson.bc.ca or 604 662 3240 if you are willing to add your voice, meet with your MLA and become an Advocacy Ambassador for Parkinson's.

DO YOU HAVE PARKINSON'S RELATED LEGAL ISSUES?

Through a partnership with PSBC, the law firm of **Blake, Cassels & Graydon LLP** offers free of charge legal services to people with Parkinson's in British Columbia.

The Litigation Support Program from Blakes addresses legal issues such as discrimination against individuals with Parkinson's in the workplace; discrimination in accommodations, services or facilities that are generally available to the public; and, wrongful denial of disability insurance or denial of government services.

If you have a legal problem relating to Parkinson's disease, please contact Jean Blake, CEO at jblake@parkinson.bc.ca for more information.

Blakes
LAWYERS

notice of annual general meeting

Saturday, April 11, 2015

9:45 am—12:30 pm

BROADWAY CHURCH
2700 East Broadway, Vancouver
(entrance on Slocan Street)

Join us as the Board Chair provides a summary of 2014 and Dr. Jon Stoessl shares highlights of the latest PD research. Later, get moving by participating in an interactive session on *Dance for PD*® led by Jo-Ann Gordon (from New York's Mark Morris Dance Group).

Please be advised that this is a members only event and registration is required for attendance. If you are a non-member interested in attending the AGM and educational sessions, membership with the Society is offered at an annual fee of \$25. This fee allows you and your household to take advantage of all benefits until December 31, 2015.

Free parking is available on site and the venue is wheelchair accessible. Light refreshments will be provided.

Go to our website at www.parkinson.bc.ca to register or to become a member of the Society.



 Parkinson Society British Columbia
Soci t  Parkinson Colombie-Britannique
In Partnership with Parkinson Society Canada
600-890 West Pender Street, Vancouver, BC V6C 1J9

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