

GROUPLINK 1

UPCOMING EVENTS | NEWS & ANNOUNCEMENTS | DISCUSSION TOPIC | PARKINSON'S AWARENESS **APRIL 2017**

UPCOMING EVENTS

Parkinson Society British Columbia (PSBC) endeavours to make attendance at events accessible to all who may benefit. The Society may be able to subsidize attendance fees for those who require financial assistance. Please contact Stacey at sdawes@parkinson.bc.ca or 1-800-668-3330 for more details.

STEP BY STEP

The goal of this program is to help motivate people to become physically fit to combat the symptoms of Parkinson's disease. We hope to encourage people to continue a regular exercise routine following the program. Read about a Step by Step success story [here](#).

Start Date: Tuesday, April 11, 2017
 Location: Various locations across the province. Find your nearest location [here](#).
 Fees: Free

Contact Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330 to learn more.

ASK THE EXPERT WEBINAR: REHABILITATION FOR PARKINSON'S DISEASE

With the recent surge of physical fitness and exercise programs offered to people with Parkinson's disease (PD) there seems to be greater awareness of the need for access to physiotherapy. This presentation will review communication and swallowing issues associated with PD, approaches to treatment for these symptoms and accessibility to speech pathology treatment and services in British Columbia.

Date: Tuesday, April 18, 2017
 Time: 10:00am – 11:00am
 Location: Via webinar. Instructions on how to access the presentation will be sent out 24 hours before the event's start time.
 Fees: Free
 Capacity: 150
 Registration: <http://bit.ly/Rehab4PD>
Registration closes Friday, April 14

ANNUAL GENERAL MEETING

PSBC will hold its Annual General Meeting featuring a panel of researchers from Pacific Parkinson Research Centre (PPRC) at UBC. The researchers and topics are as follows:

- Dr. Silke Appel-Cresswell: The microbiome of the gut
- Stefano Cataldi: Repairing the transportation system within brain cells
- Matt Sacheli: New findings and an update on exercise research
- Sun Nee Tan: Effects of exercise and music on brain plasticity

Date: Saturday, April 22, 2017
 Time: 9:45am - 12:00pm (registration opens at 9:00am)
 Location: Great Hall in Building SE2 at BCIT
 3700 Willingdon Avenue, Burnaby, BC ([map](#))
 Fees: Free for members. [Become a PSBC member today](#), it's not too late!
 Registration: <https://www.parkinson.bc.ca/events/education-events/agm/>

DEBRIEFING THE CAREGIVER ROLE WORKSHOP

Losing a loved one is one of life's most difficult experiences. Parkinson Society British Columbia is committed to honouring our slogan, "You are not alone. We are here to help," and that's why, in collaboration with Elaine Book, MSW, at the PPRC, we are offering a grief support group session to help those who have recently lost a loved one to PD.

Date: Thursday, April 27, 2017
Time: 12:30pm – 2:30pm
Location: Oakridge Branch | Vancouver Public Library
191 - 650 West 41st Avenue, Vancouver, BC ([map](#))
Registration: <https://www.parkinson.bc.ca/events/education-events/caregiver-workshop/>

COMMUNICATION AND SWALLOW WORKSHOP – VICTORIA

This full day workshop will focus on the communication and swallowing challenges faced by people with Parkinson's (PwP). The interactive and participatory format will allow attendees to practice treatment techniques and gain insight from a registered speech-language pathologist. This year, participants will be required to watch a pre-workshop webinar prepared by Sherri Zelazny to introduce the topic of communication and swallowing challenges in Parkinson's. This workshop is open to those already experiencing communication & swallowing challenges, as well as those who wish to be proactive in their treatment.

The pre-workshop materials will be sent to participants via e-mail upon registration. A catered lunch will be provided.

Date: Saturday, May 13, 2017
Time: 10:00am – 2:30pm
Location: Orchid Room | Sandman Hotel Victoria | 2852 Douglas Street ([map](#))
Fees: Member \$40.00 | Member (Couple/Pair) \$70.00
Non-Member \$50.00 | Non-Member (Couple/Pair) \$90.00
Facilitator: Sherri K. Zelazny, MA RSLP
Registration: <http://bit.ly/VictoriaCS>



MOVING FORWARD, TOGETHER

Please join us for the *Moving Forward, Together* conference, which will bring together members of the Parkinson's community from across the province in Richmond, BC. The return of this much-anticipated event will feature prominent local, national and international presenters who will speak to topics related to the treatment and management of Parkinson's and its associated challenges. Its purpose is to foster an educational and inspirational space for enriching the connection between people with Parkinson's, carepartners, friends and healthcare professionals.

Nominate an outstanding member of the Parkinson's community for the [Above and Beyond](#) awards. PSBC will be recognizing volunteers who have committed valuable hours and exceptional efforts to help the Society and community in a variety of ways. To nominate someone, please use our [Above and Beyond nomination form](#).

Moving Forward, Together Travel Grants

To maximize the benefit of the Provincial Conference to British Columbia's Parkinson's community, PSBC is offering a limited number of [scholarships](#) for people with Parkinson's (PWP) and family care partners who would be unable to attend the conference without financial assistance.

The scholarships will be awarded with great discretion. Scholarship recipients are expected to pay associated expenses and submit receipts for reimbursement after the conference. Receipts must be received by July 31, 2017.

Date: Saturday, June 3, 2017
Time: 9:00am – 3:15pm
Location: Sheraton Vancouver Airport Hotel | 7551 Westminster Highway | Richmond, BC ([map](#))
Fees: **Early Bird registration ends April 30!**
Member \$40.00 | Member (Couple/Pair) \$70.00
Non-Member \$60.00 | Non-Member (Couple/Pair) \$100.00
Registration: <https://www.parkinson.bc.ca/moving-forward/>

For a listing of all upcoming education events, visit our [events calendar](#).

Champions FOR PARKINSON'S

- Shifting Gears for Parkinson's: March 13, 2017 – October 31, 2018 ([read more](#))
- Wholey Fit Spin Class Fundraiser: Tuesday, April 11 ([read more](#))
- Spring Online Auction: April 11 - 25 ([read more](#))
- Me-n-Ed's 10th Annual Charity Golf Tournament: May 23 ([read more](#))
- Champions for Parkinson's Raffle: Draw date is May 23 ([read more](#))
- Shakin' the Rock for Parkinson's: June 11 – 16 ([read more](#))
- Cotswolds Walking Holiday: August 31 – September 8 ([read more](#))

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! Please contact Mirela at mdzaferovic@parkinson.bc.ca or 1-800-668-3330.

NEW! PORT ALBERNI SUPPORT GROUP

This group is intended for anyone who affected by Parkinson's disease (carepartners, friends and family members welcome).

Date: 3rd Monday of each month
Time: 10:30am – 12:00pm
Location: Smitty's Restaurant
3426 3rd Avenue, Port Alberni, BC ([map](#))

NEW! VANCOUVER WORKING PROFESSIONALS WITH PARKINSON'S

This group aims to connect people with Parkinson's who are still active in the work force. The lunch provides an opportunity to discuss issues common to those who are still working. **Attendees are asked to purchase their own lunch. Pre-registration is mandatory.**

Date: Every second Tuesday of the month
Time: Varies
Location: Law Courts Inn Restaurant, downtown Vancouver, BC ([map](#))
Registration: Contact Floris at fvanweelderen@gmail.com

NEW! RICHMOND CAREPARTNERS SUPPORT GROUP

Are you caring for a person with Parkinson's disease? Are you a concerned family member or friend? Are you interested in speaking to others in similar situations? Join the new Richmond carepartners support group. **Please note that you may be asked to pay the Minoru Seniors Activity Centre Membership fee of \$22/person per year, or a one-time drop-in fee.**

Date: 3rd Wednesday of each month
Time: 2:00pm – 3:30pm
Location: Minoru Place Activity Centre, M1 Meeting Room
7660 Minoru Gate, Richmond, BC ([map](#))

UPDATED SCHEDULE! NORTH VANCOUVER SONGSHINE

Vocal exercises and group singing to strengthen voices.

Date: Tuesdays | April 4 – June 6, 2017
Time: 12:45pm – 1:45pm
Location: North Shore Neighbourhood House
225 East 2nd Street, North Vancouver, BC ([map](#))
Fee: \$12 per session for non-members of the NSSRC; discount for NSSRC members
Contact: Joani Bye | joanibye@icloud.com | 604-202-9784
Penelope Bacsfalvi | slp@nssrc.org (SongShine Certified instructors)

EXERCISE

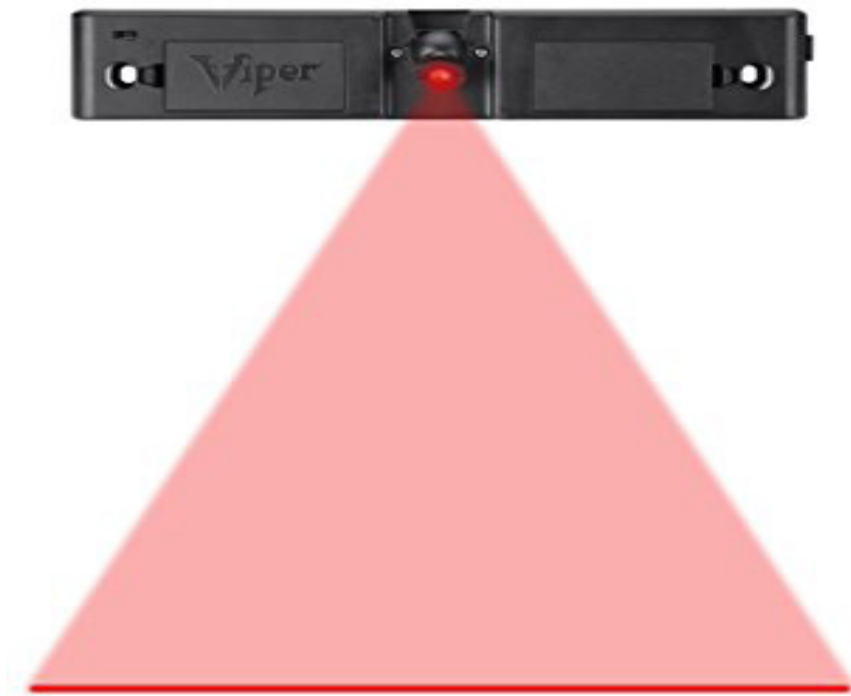
Our website includes an up-to-date list of all of the Parkinson's-specific community exercise programs across the province - there may be one near you! <http://www.parkinson.bc.ca/exercise>

Note: Any listing in the aforementioned documentation should not be considered an endorsement of the third party event(s). As such, the Society cannot be held responsible or liable for any loss or damage suffered as a result of participation.

TIP JAR

This month's Tip Jar contribution comes from a fellow whose wife with Parkinson's uses a laser dart line on her walker. While it may seem odd to fasten a laser to a walker, it could help you or your loved one walk more effectively. Like music to the ear, a laser creates a (visual) cue that can help individuals with Parkinson's walk with fewer freezing episodes. If this is something that interests you or a loved one, be sure to consult a healthcare professional, such as an Occupational Therapist or Physiotherapist, before implementing this strategy.

Laser dart line machines come in all shapes and sizes; [the Viper](#) is one example and can be found and ordered online.



Do you have any tips or tricks that you would like to share with your PD community? These can be tips from something that works well, to eating and dressing, to getting out of bed or travelling! All tips and tricks are welcome! Please share your ideas with Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330.

SUBSCRIBE TO GROUPLINK!

If you wish to receive personal copies of GroupLink please connect with Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330 and your name will be added to our GroupLink email distribution list.

**SUBSCRIBE
TO GROUPLINK!**

SHARING YOUR PD STORY WITH FRIENDS AND FAMILY

Discussion questions:

1. What conversation starters have you found useful to share your PD story with friends and family?
2. What information do you often include when explaining the disease to others?
3. How have others responded to your disclosure? Have their responses surprised you in any way?

Since April is Parkinson's Awareness Month, we are asking for help to raise awareness about Parkinson's disease in BC. One easy way you can take part is by sharing your story with friends and family. However, many people with Parkinson's find the decision to disclose and disclosure methods to be added challenges.

Research and Language

In these circumstances, language and knowledge of the disease is so important, which includes finding the words and descriptors that fit with you, the person with PD, and the carepartner. The more you read, think and talk about the disease, the more comfortable you will become deploying your own terms and knowledge of the condition.

Reading about PD can help both people with Parkinson's and people without the disease wanting to learn more. Sharing a written resource can also be an easy way to start a conversation about Parkinson's with the people around you. We suggest sharing a copy (or the link) of Parkinson Society British Columbia's *Understanding and Moving Forward* booklet: <https://www.parkinson.bc.ca/media/31422/understanding-and-moving-forward.pdf>. This booklet is easy to read and understand. It is our "PD 101" resource that everyone in the family and support circle can peruse many times over.

Talking to someone

Talking to someone at PSBC can be an option for learning about the disease, as well as an opportunity to voice your thoughts about living with Parkinson's. Book a consultation with us; short-term counselling as well as information and referral services are free!

Talking to youth and children

Talking to children can be an added challenge because terminology associated with PD can sometimes be hard to understand. Scientific jargon can make our brains go fuzzy. This, compounded with a child's emotional intelligence, can make the PD disclosure process lengthier. Be patient with yourself and them; time will help everyone to process the diagnosis. If you have young children or teenagers, you might want to consider reading through these helpsheets:

- [Talking to Children about PD](#)
- [Information for teens with a parent with PD](#)

Carepartner's Corner

Being a spouse/partner, adult child or friend of someone with PD can also be overwhelming. Learning about the disease and its treatment options can help alleviate such feelings. You may also want to have your own space to discuss how Parkinson's has affected you. Talking with friends and family can also be difficult as they may not fully understand your situation. Remember, as a carepartner to someone with Parkinson's you also have access to information, counselling and support systems. To see if a Carepartner Support Group exists in your area, visit: <https://www.parkinson.bc.ca/resources-services/support-groups/>. Our Caregiving in a Family with Parkinson's help sheet can also help provide some useful information: <https://www.parkinson.bc.ca/media/31461/caring-in-the-family.pdf>

THIS IS Parkinson's Disease

April is Parkinson's Awareness Month, and we need your help! With over 13,300 British Columbians living with Parkinson's disease (PD), it is the second most common neuro-degenerative disorder after Alzheimer's. Due to the aging population, that number is expected to increase more than 60% by 2031.

This year marks the 200th anniversary of the publication of the first paper to describe the symptoms, potential causes and treatment of Parkinson's disease. As we reflect back on the 200 years of disease research, management and public perception, Parkinson Society British Columbia (PSBC) recognizes that there is still work to be done to improve patient outcomes. PSBC is committed to emphasizing the diversity of the Parkinson's community and drawing attention to the issues affecting people with Parkinson's here and now. To help draw attention to these issues, we are continuing to develop our April campaign titled, *This is Parkinson's disease*.

What is the *This is Parkinson's disease* campaign about?

One of the first illustrations of Parkinson's disease was published in 1886, and since then, it has been widely understood as a disease that only affects the senior population, primarily characterized by shaking. The truth is that Parkinson's doesn't discriminate based on age, gender, ethnicity, religion or sexual orientation. It affects people from all walks of life, and at PSBC, we are firm believers that the diversity of our community strengthens us. This campaign brings together the stories of a diverse group of individuals across the province to change the narrative.

Here's where you come in. We hope to share our message with as many individuals as possible. Included below are some resources developed as a part of our campaign. If you are willing, please do utilize our toolkit to share posts via social media and/or download posters to print and distribute in your community. More information on this campaign can be found at www.parkinson.bc.ca/this-is-parkinsons.

Download and print a copy of a poster:

- Hilary [[download 8.5" x 11" PDF poster](#)]
- Richard [[download 8.5" x 11" PDF poster](#)]
- Wayne & Elaine [[download 8.5" x 11" PDF poster](#)]

Beginning on Monday, April 3, PSBC will be sharing further information and resources about Parkinson's Awareness Month online, via our [website](#) and social media. We encourage you to share this content far and wide, both digitally and in person! If you have any questions about Parkinson's Awareness Month activities, please contact Amanda at amcculley@parkinson.bc.ca or 1-800-668-3330.

Faces of *This is Parkinson's disease* 2017

Wayne and Elaine are part of a team of Parkinson's support group co-facilitators in Courtenay/Comox Valley. They have been married for 52 years, and were diagnosed with Parkinson's within two years of each other. Elaine worked with Revenue Canada, and Wayne had a career in the Alberta oilfields before his Parkinson's symptoms forced him to retire. The couple are now both active retirees with two adult children and six grandchildren.



Wayne and Elaine



Richard

Richard is a 49 year old Vancouver resident. He serves on PSBC's board of directors and is a regular participant in Parkinson SuperWalk. Like many others in the Parkinson's community, he has committed himself to staying active in order to combat the symptoms and the progress of the disease. Rather than exercise at a gym, he prefers to play a variety of sports to help maintain his quality of life. He is a digital designer who also enjoys videography and photography. As his upbringing and values rooted in Buddhism have taught him, he strongly believes in the power of positive thought.

Hilary is 25 years old and lives in Langley with her husband Justin. She began experiencing Parkinson's symptoms at the age of 14 and, after almost a decade, was diagnosed with PD. She credits her faith in God and her strong family support system as her source of strength. Currently, she is nourishing her creative side by working as a freelance graphic designer and website developer. In Hilary's spare time, she takes part in the rigorous exercise program CrossFit and runs her own website and blog. Recently, her neurologist recommended her as a candidate for Deep Brain Stimulation (DBS) surgery and she has since been placed on a three year waitlist for an assessment with Dr. Honey, the only neurosurgeon who specializes in DBS in British Columbia.

Where will you see Parkinson's Awareness Month advertised?

Proclamations

PSBC is pleased to report that the following communities have issued official proclamations in recognition of Parkinson's Awareness Month in 2017:

- [The Province of British Columbia](#)
- [City of Vancouver](#)
- [City of Kelowna](#)
- [City of Prince George](#)

Lights

The following landmarks will light up in PSBC colours to recognize International Parkinson's Awareness Day on Tuesday, April 11, 2017:

- Sails of Light at Canada Place, Vancouver
- Science World, Vancouver

YouTube Videos

Photos only tell a fraction of the story. In 2017, This is Parkinson's disease subjects agreed to share details about their diagnoses and lives in front of a video camera. Short, shareable YouTube videos are now available online:

- [Hilary](#)
- [Richard](#)
- [Wayne and Elaine](#)

Radio

- CISL Boomer Radio Show - April 11, 2017 [time TBD]

Newspaper Ads

Keep an eye out for our ads in the following publications on April 5 and April 7, 2017:

- Abbotsford News
- Chilliwack Progress
- Kelowna Capital News
- Maple Ridge News
- Vernon Morning Star

Transit

Advertisements will be visible on public transit beginning in early April in the following communities:

- Vancouver (Waterfront skytrain wall mural and interior skytrain ads)
- Victoria (interior bus ads)
- Kelowna (interior bus ads)
- Prince George (interior bus ads)



Hilary

Helpful Hashtags:

#ThisIsParkinsonsBC
#UniteForParkinsons

*Thank you for supporting
Parkinson's Awareness
Month!*