

GROUPLINK 1

UPCOMING EVENTS | NEWS & ANNOUNCEMENTS | DISCUSSION TOPIC | CAREPARTNER'S CORNER APRIL 2018

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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 Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330 for more details.

STEP BY STEP

Spring is here and it's time to re-energize your exercise program! If you cut back on exercise or need some help to get started, walking is an easy way to start or add in some movement to your day.

Step by Step is a 12-week walking program aimed at incrementally improving the number of average daily steps taken by an individual. The resources help you determine your walking baseline, and then each subsequent week you will be challenged to increase your steps based on your personal goal. While participants are encouraged to walk and track their own steps, we are also looking for community group leaders to organize a weekly walk for walkers to meet, socialize and support one another.

The goal of this program is to help motivate you to become physically fit to combat the symptoms of Parkinson's disease. It is designed to encourage you to continue exercising regularly following the program.

Interested in becoming a Step by Step leader in your community? As a team leader you would be responsible for organizing a weekly walk, selecting walking locations and motivating your team! Contact Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330 to learn more.



ALLIED TEAM TRAINING FOR PARKINSON'S (ATTP)[™] COMMUNITY TALKS

Designed by the Parkinson's Foundation and the International Parkinson and Movement Disorder Society (MDS), the Allied Team Training for Parkinson's[™] (ATTP) comes to Vancouver, BC April 4-6, 2018. Offered for the first time in Canada, this three day on-site course was developed for healthcare professionals to increase their knowledge of Parkinson's disease and build capacity for comprehensive inter-professional care.

While the ATTP takes place in Vancouver, Parkinson Society British Columbia (PSBC) has arranged for several of the world renowned experts to present Community Talks for the general public. We invite you to join us for one of the talks in Abbotsford or Richmond.

ATTP[™] COMMUNITY TALK: MILD COGNITIVE IMPAIRMENTS AND NON-MOTOR SYMPTOMS, ABBOTSFORD

Lucie Lachance, RN, is one of the leaders of the Movement Disorders Program at the McGill University Health Centre as well as a lecturer at McGill University. She has been involved as a director on the board for Parkinson Canada from 2004–2010 and 2011–2014. Additionally, she was involved as faculty on the program for the World Parkinson Congress in 2013 in Montreal and 2016 in Portland Oregon. Currently, she acts as the Program Director of the Neurology Residency Training at McGill University.

In this community talk, she will be speaking about mild cognitive impairments and non-motor symptoms of Parkinson's disease.

Date: Tuesday, April 3, 2018
Time: 1:30pm – 3:00pm (registration opens at 1:00pm)
Location: Nikkel Hall at Central Heights Church
1661 McCallum Road, Abbotsford ([map](#))
Cost: PSBC Member \$5.00
PSBC Non-member \$10.00
Registration: www.parkinson.bc.ca/abbotsford-community-talk

ATTP[™] COMMUNITY TALK: LIVING WELL WITH PD AND PREVENTING FALLS, RICHMOND

Julia Wood, MOT, OTR/L received her Bachelor of Science in Exercise Science and Wellness from Ball State University and her Masters in Occupational Therapy from the University of Minnesota. As an outpatient occupational therapist, Julia specializes in treating neurological movement disorders and neurodegenerative diseases.

Heather Cianci, PT, MS, GCS is a Geriatric Clinical Specialist and founding therapist at the Dan Aaron Parkinson's Rehabilitation Center (Good Shepherd/Penn Partners) at Pennsylvania Hospital in Philadelphia, PA – part of the University of Penn Health System. She has been a physical therapist since 1994, with the majority of those years dedicated to working with patients with Parkinson's disease (PD) and atypical parkinsonisms.

Date: Friday, April 6, 2018
Time: 6:30pm – 8:00pm (registration opens at 6:00pm)
Location: Multipurpose Room 1 at City Centre Community Centre
Unit #105, 5900 Minoru Boulevard, Richmond ([map](#))
Cost: PSBC Member \$5.00
PSBC Non-member \$10.00
Registration: www.parkinson.bc.ca/richmond-community-talk

COMMUNICATION AND SWALLOW WORKSHOP, PENTICTON

This interactive and participatory workshop, led by Registered Speech Language Pathologist Sherri Zelazny, will focus on the communication and swallowing challenges faced by people with Parkinson's (PwP). It is open to those already experiencing communication and swallowing challenges, as well as those who wish to be proactive in their treatment.

Date: Friday, April 13, 2018
Time: 10:00pm – 2:30pm
Location: Days Inn & Conference Centre
152 Riverside Drive, Penticton ([map](#))
Cost: PSBC Member \$25.00 / PSBC Members (couple/pair) \$40.00
PSBC Non-member \$35.00 / PSBC Non-members (Couple/Pair) \$60.00
Registration: www.parkinson.bc.ca/penticton-communication-workshop

COMMUNICATION AND SWALLOW WORKSHOP, VERNON

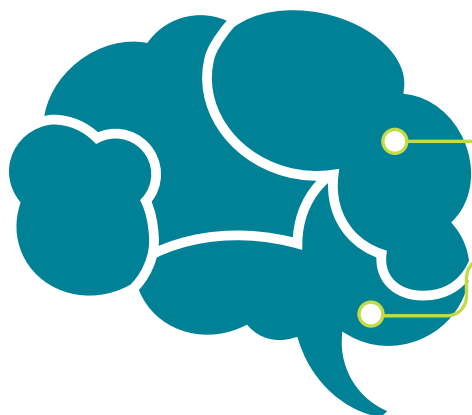
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Date: Saturday, April 14, 2018
Time: 10:00pm – 2:30pm
Location: Vernon Lodge & Conference Centre
3914 32 Street, Vernon ([map](#))
Cost: PSBC Member \$25.00 / PSBC Members (couple/pair) \$40.00
PSBC Non-member \$35.00 / PSBC Non-members (Couple/Pair) \$60.00
Registration: www.parkinson.bc.ca/vernon-communication-workshop

PSBC ANNUAL GENERAL MEETING

We invite you to join us for our Annual General Meeting (AGM) on Saturday, May 5th featuring guest speaker Dr. Martin J. McKeown. Dr. McKeown will discuss new understandings and research in relation to Parkinson's disease. Additionally, he will provide updates on the Pacific Parkinson's Research Centre (PPRC). Light refreshments will be served.

Date: Saturday, May 5, 2018
Time: 9:45am – 12:00pm (Registration opens at 9:00am)
Location: Lower Auditorium at Broadway Church
2700 East Broadway, Vancouver ([map](#))
Cost: **FREE for PSBC members only**
Non-members interested in attending must pay the \$25.00 membership fee
Registration: www.parkinson.bc.ca/agm



ANNUAL GENERAL MEETING

Broadway Church

May 5, 2018

with guest speaker Dr. Martin McKeown

ASK THE EXPERT WEBINAR: WILLS AND ESTATE PLANNING

Statistical reports show that 48% of Canadians don't have a will or estate plan. For those aged 35–54, that figure jumps to 55%. Becoming well-informed about wills and estate planning is necessary to secure the financial future of your loved ones.

In this webinar, estate planning lawyer Mary-Jane Wilson explains:

- why preparing a will is important
- powers of attorney
- representation agreements

Speaker: Mary-Jane Wilson is a partner at the law firm Wilson Rasmussen LLP. She regularly provides advice to individuals, families and organizations in the areas of: real estate and financing, estate planning, wills and trusts, powers of attorney, estate administration and probate, and representation agreements. She is also the author of the British Columbia Probate Kit.

Date: Tuesday, May 8, 2018

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.

Registration: www.parkinson.bc.ca/wills-estate-webinar



SAVE THE DATE: REGIONAL CONFERENCE, KELOWNA

Parkinson's disease is a unique and complex condition. Our regional conferences are immersive and interactive opportunities for people affected by the disease to learn from leading experts while connecting with the Parkinson's community.

Date: Saturday, June 16, 2018

Time: TBD

Location: Kelowna Ramada Hotel & Conference Centre
2170 Harvey Avenue, Kelowna ([map](#))

Champions FOR PARKINSON'S

- Wholey Fit Spin Class: April 11 ([read more](#))
- Shake, Shake, Shake: May 25 ([read more](#))
- Shaken, Not Stirred: April 28 ([read more](#))
- Me-N-Ed's Charity Golf Classic: May 22 ([read more](#))
- Full Throttle: May 27 ([read more](#))
- Shifting Gears for Parkinson's: Continuing until October 31 ([read more](#))
- Donate a Car Canada: Ongoing ([read more](#))
- Naturally Urban Pet Food Delivery Sales: Ongoing ([read more](#))
- Tea Parky: 35% from every sale on TeaParky.com will go to PSBC, ongoing. Special: Use promo code PSBC at checkout for 10% off your purchase.

WE'RE LOOKING FOR MORE CHAMPIONS THIS YEAR!

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.

NEWS & ANNOUNCEMENTS

ABOVE AND BEYOND VOLUNTEER RECOGNITION AWARDS ARE BACK

Parkinson Society British Columbia (PSBC) recognizes people with Parkinson's and their caregivers who have gone above and beyond with others in their communities and who demonstrate a passion to celebrate each day with joy, compassion and understanding. These individuals are true examples that people affected by Parkinson's can live rich, full lives. They make an effort to open up new opportunities and foster relationships they had never imagined possible before their diagnosis. We have been very fortunate to meet and work together with these individuals, but we know that there are many more inspiring stories. PSBC would like to highlight these dedicated individuals.

At our upcoming Annual General Meeting on May 5th in Vancouver, PSBC will recognize individuals and share their inspiring moments, as well as highlight the Top 10 who receive the most nominations. Please nominate someone from your community who embraces the "Above and Beyond" philosophy in their life.

Nominations must be received by Friday, April 20th, 2018. Visit <http://bit.ly/aboveandbeyond2018> to nominate an outstanding volunteer today!

AVAILABLE NOW! RECORDINGS FROM ASK THE EXPERT WEBINARS

PSBC offers webinars to help make Parkinson's resources more readily available to all British Columbians, regardless of geographic location. We understand that, sometimes, life gets in the way of attending webinars during their scheduled times. Thankfully, guest speakers have given us permission to record their webinars for you to watch at a time that is convenient for you. The following webinars are newly available:

- Duty to Accommodate and Disability Insurance ([view video](#))
- Vision Issues in Parkinson's ([view video](#))

CONTINUING EDUCATION SCHOLARSHIP PROGRAM FOR EXERCISE INSTRUCTORS & HEALTHCARE PROFESSIONALS

PSBC aims to provide opportunities for individuals who wish to pursue a career involving Parkinson's disease (PD) specific training through our Continuing Education Scholarship Program for exercise instructors & healthcare professionals. This scholarship was established to assist people who are passionate about assisting the BC PD community. Scholarships are open to any professional interested in working with this population. The panel will choose applicants who demonstrate a strong commitment to supporting those with PD through long-term community engagement and programming.

Six scholarships, valued up to \$1000, will be awarded in 2018. Three applicants will be chosen for each deadline. Deadlines for scholarship applications are:

- March 31, 2018
- September 30, 2018

For more information, please visit www.parkinson.bc.ca/continuing-education-scholarships or contact Caroline at cwiggins@parkinson.bc.ca or 1-800-668-3330.

COMPREHENSIVE CARE PLAN CHECKLIST

In collaboration with Vancouver Coastal Health, Providence Health and Fraser Health Authority, PSBC developed a checklist to help people with Parkinson's and carepartners monitor symptoms and request specific health services. This self-management tool enables you and your healthcare professionals work together to obtain the best care possible. The final version of the checklist is available [here](#).

COMING SOON: CAREGIVER BOOKLET

A Comprehensive Guide for Parkinson's Caregivers will be available this April. It was written by Kaitlyn Roland, PhD, with support from other members of the PD community. Kaitlyn's father was diagnosed with Parkinson's in 2002. She has completed a Masters in Health and Rehabilitation Sciences, focusing on new ways to moderate caregiver burden. Currently, her work at the Institute on Aging and Lifelong Health looks at cognitive changes in Parkinson's disease, associated care needs and caregiver experiences.

The book includes information about:

- Parkinson's disease
- Living well day-to-day
- Developing a care plan, including planning for the future
- Building a care support team and communicating with healthcare professionals
- Support options
- Self-care

PSBC will be announcing the publication of this guide via email, web and social media. If you have questions about caring or any of PSBC's resources, please contact Jaclyn Willems at jwillems@parkinson.bc.ca or 1-800-668-3330.

PILOT! KAMLOOPS CAREGIVER SUPPORT GROUP

PSBC and MS Society of Canada – BC & Yukon division are partnering to offer a special Kamloops Caregiver Support Group. This monthly volunteer-led support group is intended for individuals caring for a loved one with Parkinson's disease or Multiple Sclerosis. Stop by and try out this new opportunity to share and support others! If you have questions, please contact Caroline Wiggins at cwiggins@parkinson.bc.ca or 1-800-668-3330.

IN-SERVICE PRESENTATION, KELOWNA

In-service presentations are public opportunities for individuals to learn more about Parkinson's disease. Presentations are facilitated by PSBC staff or Speaker's Bureau volunteers who provide information on Parkinson's symptoms and treatments. They are held across the province in care facilities, libraries, community centres and other spaces.

- On Tuesday, April 24th, a PSBC Speaker's Bureau Volunteer, Mary De Souza, will be holding a presentation on Parkinson's at the Kelowna Public Library (located at [1380 Ellis Street](#), Kelowna) from 12:30pm – 2:00pm. Feel free to show up and listen in!

Note: Any listing above 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

Maintaining a sense of humour is important! Many members of our community are experts at finding the humour in any situation, as Robert Emberley, from Nova Scotia, exemplifies in his YouTube videos: https://youtu.be/sp2tbPTi_QI



Do you have any tips or tricks that you would like to share with the 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 Jaclyn at jwillems@parkinson.bc.ca or 1-800-668-3330.

DISCUSSION QUESTIONS:

1. How are you recognizing Parkinson's Awareness Month? What have you done to help raise awareness about Parkinson's in the past?
2. What makes your Parkinson's experience unique to you? How is it similar to others you know?

Talking about Parkinson's is not always easy, whether it be to your spouse, children, friends, family or employer. While most people have heard of Parkinson's disease (PD), the range of symptoms experienced, and the ripple effect the disease has on friends, family and the healthcare system is less understood. This is why Parkinson's awareness is so important. Everyone's Parkinson's journey is different and unique, which makes sharing personal experiences so valuable.

April is Parkinson's Awareness Month, and this year Parkinson Society British Columbia is encouraging you, your family and friends to share your experiences from across the province through our #PDANDME (PD and Me) campaign.

This year's campaign seeks to expand the public's understanding of Parkinson's disease by highlighting:

- **The complexity of the disease.** While tremors are a common symptom, people with Parkinson's experience a range of both motor and non-motor symptoms.
- **The diversity of the PD community.** Although PD is slightly more prevalent in men than women, it impacts people across a range of age groups and ethnicities. The diversity of the disease has been the cornerstone of our This is Parkinson's disease campaign in 2016 – 2017.
- **The community impact of the disease.** We recognize that Parkinson's has an impact on those diagnosed, as well as their family and friends. We also know that the current healthcare system is often ill-equipped and too overburdened to assist patients with timely and effective disease management. With the aging population, the number of people in BC diagnosed with the condition is expected to increase, which will place further financial and social strains on families, institutions and organizations. It is for these reasons that Parkinson Society BC has been advocating for improved care and continuing the search for a cure by investing in promising research.

WHAT IS PSBC DOING FOR APRIL AWARENESS MONTH?

"What I Wish People Knew about Parkinson's" Star Cards

Star-shaped cards have been distributed to some of PSBC's support groups and brought to the Society's education events. These postcards have space for individuals to write down what they wish the public knew about PD. Submissions will be kept anonymous, but space is available on the back of the cards for participants to include their information in the event that they are willing to speak to the Society further about their experiences. These cards will help us establish priorities for PD awareness, as well as direct future campaigns and initiatives.



Publicity & Media Coverage

We are continuing our long-standing relationship with Global BC and several other media outlets, including print news and radio stations. We invite you to review our plan more in-depth at: www.parkinson.bc.ca/pdandme.

Parkinson's Art Exhibition

This exhibit will feature work from people with Parkinson's disease. This August, we'll be showcasing the selected pieces at the Vancouver Public Library's Georgia Street branch in "the Moat"!

We'd love to see your artistic side, and are currently seeking submissions for this project until June 1, 2018. Send us your photographs, paintings and/or sketches. Unfortunately, due to limited space, we are only able to accept 2D art (no sculptures or pottery).

For full details, and submission forms, please visit: www.parkinson.bc.ca/art-exhibit.

HOW YOU CAN HELP

Use your voice to help expand the reach of our #PDANDME (PD and Me) campaign! You can do this by sharing your experience with Parkinson's disease via Twitter, Facebook and Instagram using the hashtag #PDANDME. The more people that participate, the louder we will be heard!

You can share your images and stories with PSBC in one or more of the following ways (don't forget to use the hashtag #PDANDME where applicable):

1. Like our page on Facebook: www.facebook.com/ParkinsonSocietyBritishColumbia
2. Follow us on Twitter: [@ParkinsonsBC](https://twitter.com/ParkinsonsBC)
3. Follow us on Instagram: [@ParkinsonsBC](https://www.instagram.com/ParkinsonsBC)
4. Send an email to Amanda McCulley at amcculley@parkinson.bc.ca
5. Mail can be forwarded to:
Parkinson Society British Columbia
Suite 600 – 890 West Pender Street
Vancouver, BC V6C 1J9

Throughout the campaign, we will be sharing the stories of real British Columbians affected by Parkinson's disease, some of whom you may have seen in our previous awareness initiatives. These individuals come from a variety of personal and professional backgrounds and they all have unique Parkinson's experiences. Their stories will seek to demonstrate the diversity of the Parkinson's community.

Are you looking for a resource to help open up conversations about PD? We suggest sharing a copy (or the link) of Parkinson Society British Columbia's [Understanding and Moving Forward booklet](#). This booklet is easy to read and understand. It is our "PD 101" resource that everyone in the family and support circle can reread many times over. If you would like a physical copy of this booklet, please contact Jaclyn Willems at jwillems@parkinson.bc.ca.

HOW HAS PARKINSON'S DISEASE IMPACTED YOU?

JOIN THE CONVERSATION #PDANDME



DISCUSSION QUESTIONS:

1. How has Parkinson's disease changed your life?
2. Who have you turned to for support? What activities or resources have supported you as a carer?

Carepartners/caregivers play a critical role in the life of those living with Parkinson's disease, which is why drawing attention to their experiences is a critical part of creating greater Parkinson's awareness. This year, our awareness activities aim to shed light on how the disease affects those diagnosed, as well as surrounding family, friends and loved ones. Like Parkinson's, the stages of caregiving can change drastically over time.

Similar to your loved one who has been diagnosed with Parkinson's, it is important to make sure you, as a carepartner, are receiving the care and help you need to live a healthy life. Your own health can also be supported by your loved ones, healthcare professionals and communities that you belong to. Support begins with doing all you can for yourself, and then learning to accept help when needed.

Some ways of gaining support are by connecting with other carepartners/caregivers through a support group or peer-to-peer program such as PDLink. Our support groups and PDLink program may be something to consider if you haven't already done so. Having peers with whom you can share information and experiences with, can significantly improve your coping capacity. It can also create a sense of togetherness and community.

Feeling alone and isolated can be avoidable; when you reach out to others, you open the door for others to reach out to you. By connecting with others, they become more aware of your situation and of the complexity and diversity of Parkinson's. Please, don't be afraid to ask family and friends for the following methods of support. Here are some examples of how to ask for social support:

- A listening ear: "I have a lot on my plate right now. Would you be available for a chat over coffee or tea sometime soon?"
- Asking a trusted family member or friend to stay with the individual you are caring for in order to provide you with a break: "I could really use a break from the day-to-day. Would you be able to help me with [blank] next week?"
- Asking a friend on an outing: "I truly enjoy your company. Would you like to have lunch, or go to a movie?"
- Asking for help with specific tasks, such as shopping, yard work or making a meal: "I'm finding it challenging to prepare for Easter Dinner. Would you be available to help?"

Are you looking for a welcoming space to share your PD experience? PSBC has several carepartner specific support groups across the province: www.parkinson.bc.ca/supportgroups.

We also have an online carepartner support group so you are able to connect with others all across BC! For more information please contact Myriame Lepine Lyons at mlepinelyons@parkinson.bc.ca or 1-800-668-3330.

Use your voice to help expand the reach of our **#PDANDME** (PD and Me) campaign! You can do this by sharing your experience with Parkinson's disease via Twitter, Facebook and Instagram using the hashtag **#PDANDME**. The more people that participate, the louder we will be heard!

Visit www.parkinson.bc.ca/pdandme to learn more.

Sources

Parkinson Society British Columbia. (2016). *Caring in the Family*. Retrieved from <https://www.parkinson.bc.ca/media/31461/caring-in-the-family.pdf>

Parkinson Society British Columbia. (2016). *Asking for and Accepting Your Own Support: A Carepartner/Caregiver Resource*. Retrieved from <https://www.parkinson.bc.ca/media/48893/asking-for-and-accepting-your-own-support.pdf>