

A MONTHLY NEWSLETTER BY PARKINSON SOCIETY BC SEPTEMBER 2019 ISSUE

CELEBRATING 50 YEARS OF SERVICE!



Since 1969, Parkinson Society British Columbia has been proud to empower people with Parkinson's across the province, through education, support services, advocacy, and fundraising. This year, join us as we celebrate the strength of our community, and the many milestones we have reached together. We hope to extend our reach wider and impact stronger than ever before – within the Parkinson's community and beyond.

Throughout the year, we will be sharing inspirational stories from the people with Parkinson's, carepartners, and advocates in our community. If you have a story to share about your life with Parkinson's, we would love to hear it! For more information, email us at info@parkinson.bc.ca.

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 us at info@parkinson.bc.ca or 1-800-668-3330 for more details.

COMMUNICATION & SWALLOW WORKSHOP | KELOWNA & WHITE ROCK

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. It is open to those already experiencing communication and swallowing challenges, as well as those who wish to be proactive in their treatment.

Date: Saturday, September 28 Date: Saturday, November 16 Time: 10:00am - 2:30pm Time: 10:00am - 2:30pm

(check-in begins at 9:30am) (check-in begins at 9:30am)

Location: Ramada Hotel & Conference Centre Location: Hazelmere Golf & Tennis Club

2170 Harvey Ave, *Kelowna* [map] 18150 8th Ave, *Surrey* [map]

Cost: Members: \$25 | Pair \$40 Cost: Members: \$25 | Pair \$40

Non-members: \$35 | Pair \$60 Non-members: \$35 | Pair \$60

Registration: www.parkinson.bc.ca/kelowna-cs Registration: www.parkinson.bc.ca/kelowna-cs

WORLD PARKINSON CONGRESS 2019 HIGHLIGHTS | WEBINAR

World Parkinson Congress (WPC) is a triennial international Parkinson's meeting that brings together people with Parkinson's, caregivers, medical practitioners, and scientists to learn and share scientific discoveries, medical practices, advocacy work, and caregiver initiatives.

The fifth WPC took place in Kyoto, Japan in June 2019. Parkinson Society BC (PSBC) proudly funded scholarships for 10 attendees, including people with Parkinson's, carepartners, and healthcare professionals, to attend the event. In this webinar, we will share some of the highlights and key takeaways from this year's WPC.

Instructions on how to access the presentation will be sent our 24 hours before the event's start time.

Date: Monday, September 30 Time: 10:00am - 11:00am

Cost: Free

Registration: <u>www.parkinson.bc.ca/wpc-webinar</u>

COMMUNITY TALK: Q&A WITH CHERYL DANIELS | CRANBROOK

On October 7, join Parkinson Society BC for a community talk with Cheryl Daniels, Registered Nurse from the Kelowna Multiple Sclerosis and Movement Disorders Clinic. This session will allow for attendees to bring forth their own questions to Cheryl on Parkinson's medication and management. Come prepared for an hour of Q&A!

Date: Monday, October 7 Time: 7:00pm - 8:00pm

Location: Heritage Inn Hotel & Convention Centre

803 Cranbrook St N, Cranbrook [map]

Cost: Free

Register: <u>www.parkinson.bc.ca/cranbrook-ct-oct</u>

COMMUNITY TALK: MENTAL HEALTH & PARKINSON'S | SUNSHINE COAST

On October 7, join us on the Sunshine Coast for a talk with the Society's own Registered Clinical Counsellor, Tricia Wallace. Tricia will review the symptoms of Parkinson's with a focus on the non-motor aspects of the disease, especially depression, anxiety, and apathy. We will explore the compounding nature of non-motor symptoms and their impact on overall functioning. Treatment options will also be discussed. Group participation and feedback will be welcomed.

Date: Monday, October 7 Location: To be determined

Cost: Member \$5 | Non-Member \$10

Register: www.parkinson.bc.ca/sunshinecoast-ct

ASK THE EXPERT: HOUSING AND SUPPORT FOR OLDER ADULTS I WEBINAR

As individuals age, the ability to manage a home may evolve. When one lives with Parkinson's, or has a loved one affected by the disease, there may be other factors to be considered in care. Changes in the progression of the disease and/or aging, may result in the need for in-home support with tasks such as housekeeping and bathing, or require a move to a smaller living space, assisted living, or a long-term care home.

Housing and support options are available; however, they can be confusing and overwhelming to navigate. On October 8, Marjahn O'Connor, Snezana Ristovski, and Rebecca Frederick from EngAge BC will join Parkinson Society BC for a webinar about Route 65, a new online platform designed to help older adults meet their housing and wellness needs. This will include how to use Route 65 as a tool to find suitable housing, and an overview of the different types of living and wellness options available for older adults.

Instructions on how to access the presentation will be sent our 24 hours before the event's start time.

Date: Tuesday, October 8 Time: 10:00am - 11:00am

Cost: Free

Registration: <u>www.parkinson.bc.ca/route65-webinar</u>

TIME OUT FOR CAREPARTNERS WORKSHOP | PARKSVILLE

Parkinson Society British Columbia recognizes the efforts made by carepartners and caregivers every day. On Friday, October 18, we invite all carepartners/caregivers to join us for an afternoon of education, socialization, and relaxation. Guest speakers will share experiences and strategies for coping with the complexities that arise as a result of Parkinson's disease. Light refreshments will be provided.

Special notice: An adjacent room will be available for people with Parkinson's (PwP) to partake in activities (e.g., light exercise, dancing, singing), while their carepartner/caregiver participates in the sessions. We ask that PwP coming to the event respect this room divide, and not attend sessions unintended for them. This room will be managed by volunteers who will provide companionship and light exercise activities. The volunteers will not be medical professionals.

Date: Friday, October 18

Time: 1:00pm - 4:30pm (check-in begins at 12:30pm)

Location: Parksville Community Centre

123 Jensen Ave E, Parksville [map]

Cost: Member: \$30 | Pair \$45

Non-member: \$40 | Pair \$55

Register: <u>www.parkinson.bc.ca/tofc-parksville</u>

EXPRESS YOURSELF: A WRITING WORKSHOP TO HELP YOU COPE AND THRIVE I VANCOUVER

This 10-part writing workshop is for people with Parkinson's and carepartners. No writing experience is necessary! Together, participants will complete simple, fun, and meaningful writing exercises, as well as take part in guided meditations and mindfulness exercises. We will tap into your inherent creativity and inner wisdom as sources of healing, strength, and community building. Come share your story and help yourself and other folks who understand what you're going through move through challenging times.

The workshop is led by Rebecca Gifford, partner in Parkinson's with her husband, Larry. She is an author, blogger, marketing writer, and writing coach with more than 20 years' experience helping people and organizations navigate the creative process and tell their stories. Rebecca also is a homeschooling mom to her 10-year-old son and a weekly contributor to her husband's podcast, *When Life Gives You Parkinson's*.

Workshops for this series have been scheduled for: October 24, November 14, November 28, December 12, December 19, January 9, January 23, February 13, February 20, and March 5. *Please mark your calendars as reminders will not be sent to registrants*.

Date: Beginning Thursday, October 24

Time: 7:00pm - 9:00pm

Location: Moberly Arts & Cultural Centre

7646 Prince Albert St, Vancouver [map]

Cost: Free

Register: <u>www.parkinson.bc.ca/writingworkshop-19</u>

YOUNG ONSET PARKINSON'S DISEASE | WEBINAR SERIES

Young Onset Parkinson's Disease (YOPD) is generally defined as a diagnosis of Parkinson's before the age of 60. Because of the age of diagnosis, the needs of those with YOPD will differ from those with later-onset Parkinson's. Elaine Book, social worker at Pacific Parkinson's Research Centre, joins Parkinson Society BC for this webinar series aimed at addressing some of the specific issues faced by people affected by YOPD.

We encourage participants to bring their questions to each session as there will be time set aside for Q&A and discussion. We welcome all individuals with YOPD to this webinar series as well as their spouses and/or carepartners/caregivers, as they may benefit from learning more about the disease to assist in supporting their loved one.

Instructions on how to access the presentations will be sent our 24 hours before the event start time.

Self-Management

Self-management refers to the tasks that an individual must undertake to live well with one or more chronic conditions. It is particularly important for people with YOPD as Parkinson's is a lifelong progressive neurological illness. This session will go over self-management techniques to help you live well and thrive.

Date: Thursday, November 7 Time: 7:00pm – 8:00pm

Cost: Free

Registration: <u>www.parkinson.bc.ca/yopd-selfmanagement-webinar</u>

Coping as a Carepartner

This session will be co-facilitated by a carepartner of a YOPD individual and will cover some of the feelings and challenges that a carepartner of someone with YOPD may experience. Methods for coping will also be discussed.

Date: Thursday, November 14 Time: 7:00pm - 8:00pm

Cost: Free

Registration: <u>www.parkinson.bc.ca/yopd-carepartners-webinar</u>

Parenting

One of the unique challenges of YOPD is that those diagnosed are often parents to young or adolescent children. In this session, co-facilitated by a YOPD parent, we will discuss how children may be affected by a Parkinson's diagnosis in the family and how parents are able to support their children in this journey.

Date: Thursday, November 21 Time: 7:00pm - 8:00pm

Cost: Free

Registration: <u>www.parkinson.bc.ca/yopd-parenting-webinar</u>

ASK THE EXPERT: HOSPITALIZATION & PARKINSON'S | WEBINAR

People with Parkinson's disease (PD) have unique needs and considerations while in the hospital, and it is not uncommon for healthcare professionals to be unfamiliar with these needs. It is important for people with Parkinson's to be prepared for both planned and unplanned hospital visits, and to know how to self-advocate for their care.

Debra Mayer will be joining PSBC for the first time to discuss hospitalization and PD, share tips for how to best self-advocate in the hospital setting, and how you can make the most out of your <u>Aware in Care kit</u>. Debra is a member of the Aware in Care advisory committee at the Parkinson's Foundation, and is a registered nurse specializing in critical care and emergency nursing. Her areas of practice include chronic and acute care nursing, clinical experiences, and simulation. She also teaches nursing full-time.

Instructions on how to access the presentation will be sent our 24 hours before the event's start time.

Date: Tuesday, November 19 Time: 11:30am – 12:30pm

Cost: Free

Registration: <u>www.parkinson.bc.ca/hospitalization-webinar</u>

FOR A LIST OF ALL UPCOMING EDUCATION EVENTS, VISIT WWW.PARKINSON.BC.CA/EVENTS

PROVINCIAL CONFERENCE



MOVING FORWARD, TOGETHER | VANCOUVER

Parkinson Society British Columbia invites all members of the Parkinson's community in BC to join us for an exciting opportunity to learn about recent scientific breakthroughs and disease management techniques.

Moving Forward, Together will foster an educational and inspirational space for enriching the connection between people with Parkinson's, carepartners, friends, and healthcare professionals. 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. The conference will include two morning plenaries and eight afternoon breakout sessions, which aim to offer a diversified itinerary for all attendees, from researchers to individuals who are at different journey points of Parkinson's.

This year we will be offering a new breakout stream specifically for healthcare professionals to attend and expand their knowledge of Parkinson's disease.

View the agenda for information on topics and speakers: www.parkinson.bc.ca/mftagenda

Date: Saturday, October 26

Time: 9:00am - 3:45pm (check-in begins at 8:00am)

Location: Hilton Vancouver Metrotown

6083 McKay Ave, Burnaby [map]

Cost: Member: \$40 | Pair \$70

Non-member: \$60 | Pair \$100

Registration: <u>www.parkinson.bc.ca/movingforward</u>

PROVINCIAL SUPPORT GROUP FACILITATOR TRAINING

Parkinson Society British Columbia invites support group facilitators to join us for an afternoon of growth and collaboration. Learn new approaches and strategies for effective support group leadership, and connect with facilitators from across the province.

Date: Friday, October 25

Time: 12:00pm – 5:00pm (check-in begins at 11:30am)
Dinner: Facilitator Social Supper to follow at 6:30pm
Location: Hilton Vancouver Metrotown, Tiffany C Ballroom

6083 McKay Ave, Burnaby [map]

FUNDRAISING EVENTS



- Champions for Parkinson's Raffle: May 1 September 30 [learn more]
- Donate a Car Canada: Ongoing [learn more]
- Naturally Urban Pet Food Delivery Sales: Ongoing [learn more]

We're looking for more Champions! 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 Prime at mprime@parkinson.bc.ca or 1-800-668-3330.



PARKINSON SUPERWALK IN BRITISH COLUMBIA

Join us for Parkinson SuperWalk, beginning the weekend of September 7 & 8! Funds raised in BC through this event help to provide valuable support services and education offered by Parkinson Society British Columbia throughout the province, as well as fund research efforts. Learn more and register today at www.parkinson.bc.ca/superwalk.

NEWS & ANNOUNCEMENTS

Note: The listings below should not be considered an endorsement of any 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.

CONTINUING EDUCATION SCHOLARSHIPS

Parkinson Society British Columbia aims to provide opportunities for individuals who wish to pursue a career involving Parkinson's disease (PD) through our **Continuing Education Scholarship Program for Exercise Instructors & Healthcare Professionals**. This scholarship was established to assist people who have a passion to gain PD-specific training and bring these benefits to the BC PD community.

The program is open to any professional interested in working with this population. Scholarships will be awarded to applicants who demonstrate a strong commitment to supporting those with PD through long-term community engagement and programming. Special consideration will be given to applicants living in communities with limited resources for people with Parkinson's.

Six scholarships up to \$1000.00 will be awarded in 2019.

For more information: www.parkinson.bc.ca/continuing-education-scholarships

SURVEY RESULTS: SINEMET VS. GENERIC LEVODOPA DRUGS

We recently conducted a survey with the intent of better understanding the patient's perspective in achieving symptom control with brand name (Sinemet) vs. generic forms of levodopa. Read our findings and conclusions here: bit.ly/psbcsinemetsurvey.

PARKINSON WELLNESS PROJECT: GRAND OPENING | VICTORIA

Parkinson Wellness Project (PWP) offers a place for people living with Parkinson's to exercise, share, and be supported. Visit their grand opening on September 18 for a day of tours, exercise demos, and networking with the local Parkinson's community! Victoria movement disorder specialist, Dr. Kieran Tuck, will be speaking, along with UK neuroscientist and member of the Cure Parkinson's Trust, Dr. Jon Stamford, and representatives from the Island Health Authority.

For more information about PWP, visit www.parkinsonwellnessproject.org/new-facility or call 250-360-6800.

Date: Wednesday, September 18 Location: Parkinson Wellness Project

202 - 2680 Blanshard St, Victoria [map]

INFORMATION KIOSK COMING TO THE PACIFIC PARKINSON'S RESEARCH CENTRE!

Starting on October 3, Parkinson Society British Columbia will be available every Thursday to provide information and consultations to those visiting the Movement Disorders Clinic at the Pacific Parkinson's Research Centre. Our friendly and knowledgeable staff can offer educational resources, give referrals, and connect you with the support services you need. Find us in the private side room, just off the waiting area.

Location: Movement Disorders Clinic | Pacific Parkinson's Research Centre

UBC Hospital, 2221 Wesbrook Mall, Vancouver [map]

Website: <u>parkinsons.ubc.ca</u>

NEW SUPPORT GROUPS

These groups are intended for anyone affected by Parkinson's disease. Carepartners, friends, and family members are welcome!

Richmond Princeton Williams Lake Sunday, September 8 1st Thursday of each month This is an informal group that meets 1:00pm- 2:00pm 3:30pm-4:30pm irregularly. Minoru Centre for Active Living Princeton General Hospital Please contact PSBC to find out more (Wellness Studio) (Education Room) information! 7191 Granville Ave 98 Ridgewood Drive

IMPACT PARKINSON'S EVENTS | NEW WESTMINSTER

ParkArt: Join IMPACT Parkinson's for a new arts and crafts program fostering creativity, expression and connection with others while also addressing Parkinson's-specific symptoms. Available to people living with Parkinson's, their family members and friends. Options include:

- Exploring Creativity using collage/mixed media with Tatiana A. Bobko September 21
- Poppy felting with Anne Whitmore of "The Poppy Project" October 15
- · Introduction into Neurographica with Alina Smolyansky November 16

Healthy Eating for Parkinson's: Join IMPACT Parkinson's with Founder, Robyn Murrell, Dr. Caroline Coombs, ND, and Wendy Wells, Dietician, RHN, BSc, MSc for a 3-part practical series on healthy eating for people with Parkinson's. Registrants must sign up for all three sessions.

- Learn about the diet/microbiome connection, testing available for people with Parkinson's, eating a plant-focused diet, and how diet affects Parkinson's symptoms and medication, on September 28.
- Shop with a Nutrition Consultant at Choices Markets during a 90-minute Parkinson-specific group nutrition tour.
 Various dates in October.
- Create simple healthy dishes with the team from Amaranthus, a plant-focused restaurant, on November 21. You will also share a full meal together (soup, salad, and veggie burger) plus take-home healthy recipes!

To register for IMPACT Parkinson's events, contact:

604-525-2631 | info@impactparkinsons.com | www.impactparkinsons.com

NEW VIDEOS: PARKINSON'S EXERCISE SERIES

This February, we ran a six-week online exercise class led by Naomi Casiro, PWR! Certified Physiotherapist, and founder of Neurofit BC. Due to the popularity of this program, we have teamed up to re-release these exercise videos in high resolution for you to follow along at home, at your own pace. Watch the first video here: youtu.be/TCIUh9KshDs.

TIP JAR

When feeling an 'off' period coming, choose someone to walk with, copying their gait movements. This follows the principle of "entrainment." Ask your physiotherapist for more information and tips. Read more at bit.ly/pdentrainment.

DISCUSSION: COMMUNITY BUILDING & SUPPORT NETWORKS

DISCUSSION QUESTIONS:

- What does community mean to you?
- 2. Who do you count on as part of your support network?
- 3. How has participating in a support group helped you?

.....

It is often said that strong support networks foster good health. However, many of us have not had opportunities to explore the full meaning of social support in our lives. This month's GroupLink will review some key elements of social support networks, and shed light on how connection with others can inspire new directions in healthy behaviour.

Support networks are categorized as informal (community members, family, friends, and coworkers) and formal (human service workers, healthcare providers, and health services). Forms of support we seek are typically emotional (feeling closeness and being understood), instrumental (tangible aid), informational (advice, suggestions and information), and appraisal (constructive feedback) (Glanz, Rimer & Viswanath, 2015). Support networks take shape based on the unique context of each individual, including personal perceptions of what it means to be supported, available services and resources.

FINDING SUPPORT

Social support networks work best when there are many options to choose from in response to shifting needs (Glanz et al.). Parkinson Society BC provides multiple opportunities to build formal and informal elements of support networks through our free counselling, education, and advocacy. Informal elements of support, like support groups and community events, can improve quality of life with Parkinson's disease (Tod et al., 2016).

Support group members are often mentors, advisors, and friends who understand the challenges associated with Parkinson's. Beyond sharing important advice and resources, participating in your local support group can help you form meaningful connections that extend beyond your group's scheduled meetings.

Here are a few suggestions to improve social support networks from Here to Help BC:

- 1. Don't be afraid to take social risks, like meeting new people and trying new things.
- 2. Get more from the support you have, asking for what you need in a balanced way.
- 3. Reach out toward others for social connections.
- 4. Create new opportunities, such as getting involved in an organization or group.
- 5. Examine unhealthy ties with others and explore healthy boundaries to repair relationships.
- 6. Make a plan to attain supports that work best for you.
- 7. Be a joiner; join a support group.
- 8. Be patient with the timelines around building new friendships.
- 9. When making new connections, avoid negative relationships that affect your emotional health.
- 10. Take care of your relationships, offering what you can such as support to others.

COMMUNITY AND CELEBRATION

Across BC, there is a strong community dedicated in our efforts to improve the lives of all those whose lives have been touched by Parkinson's disease. Each year, we come together at Parkinson SuperWalk to celebrate the strength and resilience of our community, and raise funds and awareness for life-changing programs and services.

We hope you will join us at your local Walk, and help inspire hope for over 13,000 British Columbians living with Parkinson's. To learn more and register, visit www.parkinson.bc.ca/superwalk.

ADDITIONAL RESOURCES

Here to Help BC | www.heretohelp.bc.ca

Social Support | Here to Help | bit.ly/hthsocialsupport

SOURCES

Glanz, K., Rimer, B. K., & Viswanath, K. (Eds.). (2015). Health behaviour: Theory research and practice (5th ed.). San Francisco, CA; Wiley and Sons.

Tod, A.M., Kennedy, F., Stocks, A., McDonnell, A., Ramaswamy, B., Wood, B., & Whitfield, M. (2016). Good-quality social care for people with Parkinson's disease: A qualitative study. British Medical Journal Open. Retrieved from dx.doi.org/10.1136/bmjopen-2014-006813