

A MONTHLY NEWSLETTER BY PARKINSON SOCIETY BC OCTOBER 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.

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: St. Hilda's Anglican Church

5838 Barnacle St, Sechelt

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

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

ASK THE EXPERT: HOUSING AND SUPPORT FOR OLDER ADULTS | 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 out 24 hours before the event's start time.

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

Cost: Free

Registration: www.parkinson.bc.ca/route65-webinar

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: www.parkinson.bc.ca/tofc-parksville

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.

Registration information is available at www.parkinson.bc.ca/yopd-webinar-series.

Instructions on how to access the presentations will be sent out 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

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

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

COMMUNICATION & SWALLOW WORKSHOP I 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, November 16

Time: 10:00am - 2:30pm (check-in begins at 9:30am)

Location: Hazelmere Golf & Tennis Club

18150 8th Ave, *Surrey* [map]

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

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

Registration: <u>www.parkinson.bc.ca/white-rock-cs</u>

ASK THE EXPERT: HOSPITALIZATION & PARKINSON'S I 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 | BURNABY

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: www.parkinson.bc.ca/movingforward

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



- 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.

NEWS & ANNOUNCEMENTS

Note: The listings below may include events not organized by Parkinson Society BC. Any listing of third-party event(s) should not be considered an endorsement. The Society cannot be held responsible or liable for any loss or damage suffered as a result of participation in third-party events.

NEW SUPPORT GROUPS

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

VA (*111*

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 information!
(Wellness Studio)	(Education Room)	
7191 Granville Ave	98 Ridgewood Drive	

Online Advanced Parkinson's Carepartners

This new monthly online support group is geared for individuals who care for someone with advanced Parkinson's disease, which can be characterized by complex medical needs and/or changes in cognition that require help in almost all areas of daily life.

Whether you are a spouse, partner, adult child, or friend, Parkinson Society BC invites you to join our growing online community, fostering connection with others who share similar experiences. To register, please contact Tricia Wallace at pwallace@parkinson.bc.ca or 1-800-668-3330.

Date: 4th Thursday of every month, beginning October 24

Time: 9:00am - 10:00am

Location: Via webinar. A valid internet connection will be required to participate.

D.:..

Login instructions will be sent out 24 hours before the meeting.

Cost: Free

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.

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

SONGSHINE PROGRAM | NORTH VANCOUVER

Songshine is an effective music-based vocal program for persons whose speech has been affected by Parkinson's disease, stroke, other neurological disorders or aging voices. The program builds voices with a holistic approach that integrates breath awareness and body alignment, "vocalizes" (singing exercises), singing in the community, diction and articulation exercises, creative imagination, role-playing, and emotional engagement.

These classes are led by instructor Joani Bye: joanibye@shaw.ca | 604-202-9784

Date: Thursdays, from September 26 – December 12, 2019

Time: 1:00pm - 2:00pm

Location: John Braithwaite Community Centre | Anchor Room

145 W 1 St, North Vancouver [map]

Cost: \$35 course fee
Registration: bit.ly/nvansongshine

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 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

For helpful movement tips for Parkinson's, watch this video released by Singapore General Hospital, available on YouTube: youtu.be/qo7kXKgo2AE. Be sure to consult your healthcare team before trying these tips yourself.

DISCUSSION: EXERCISE FOR PARKINSON'S

DISCUSSION QUESTIONS:

- 1. What is your Parkinson's exercise routine?
- 2. Which exercises, classes, or programs do you find most helpful for Parkinson's?
- 3. What changes do you notice in your symptoms, mental health, and your overall well-being when exercising regularly?

At the 5th World Parkinson Congress, held this June in Kyoto, Japan, exercise was discussed as a key part of treatment for Parkinson's disease (PD), helping to manage symptoms and increase confidence. Exercise is associated with beneficial changes in brain structure, increased blood flow, and improved neuron function (Ellis & Rochester, 2018). Scientific evidence links exercise with clearer cognition, better posture and gait, improved mobility, and slower PD progression (de Carvalho et al., 2018). Endurance exercise 2.5 days per week has also been studied by Symth et al. for its benefits on mental health, improving mood and lowering anxiety in people with Parkinson's (Pena, 2019). Along with the physical movements of exercise, the social connections it offers are also known to be beneficial for overall health.

EXERCISE TIPS

It is important to confirm which type of exercise best suits your needs, taking into consideration cost, time spent, and access to programs. Your healthcare team can help you determine which exercises may be beneficial, and which ones may be unsafe for your condition. Adaptations for exercise regimens are typical, so clearly communicate your needs and health status to instructors and group leaders. For example, many exercises like Tai Chi, PWR! (Parkinson's Wellness Recovery), and Rock Steady Boxing can be done in a chair.

While there are benefits noted for many forms of exercise in PD, it's important to find something that fits your level of ability and lifestyle, so that you can uphold a regular routine. For those with mild to moderate symptoms, exercise is generally recommended 5 days per week, starting with a regimen that is tolerable, adding intensity over time. Routine is important, so that you can grow comfortable enough with your workouts to perform them as vigorously as possible. In advanced stages of PD, exercise can focus on helping you maintain your mobility, using movement, auditory, and visual cues to lessen the risks of lung infection and falls (Kaseda et al., 2017).

Exercise programs should include four key elements: flexibility (stretching), aerobic activity, resistance/strength training, and balance. Large amplitude body movements (i.e. large and fast movements that require the greatest amount of acceleration and power) are proven to be beneficial for Parkinson's (Manley, 2016). However, the nature of these movements should be tailored to your needs. The duration of your exercise sessions can also make significant impact on their effectiveness; a minimum of 30 to 45 minutes per session is generally suggested.

Since motivation can vary, a cornerstone of exercise is routine, which can be thrown off with appointments, or changes in weather. For support, seek external reminders, like an exercise partner who can help hold you accountable to your schedule.

ADDITIONAL RESOURCES

Physical Activity Guidelines | <u>bit.ly/PDPhysicalActivity</u>
Active Living Resources | <u>www.parkinson.bc.ca/activeliving</u>
Community Exercise Programs | <u>www.parkinson.bc.ca/exercise</u>
Parkinson's Exercise Video Series | <u>youtu.be/TCIUh9KshDs</u>

SOURCES

de Carvalho, A. O., Sá Filho, A. S., Murillo-Rodriguez, E., Rocha, N. B., Carta, M. G., & Machado, S. (2018). Physical exercise for Parkinson's disease: Clinical and experimental evidence. Clinical practice and epidemiology in mental health: CP & EMH, 14, 89.

Ellis, T., & Rochester, L. (2018). Mobilizing Parkinson's disease: the future of exercise. Journal of Parkinson's disease, 8(s1), S95-S100. Retrieved from https://content.iospress.com/articles/journal-of-parkinsons-disease/jpd181489

Kaseda, Y., Ikeda, J., Sugihara, K., Yamawaki, T., Kohriyama, T., & Matsumoto, M. (2017). Therapeutic effects of intensive inpatient rehabilitation in advanced Parkinson's disease. Neurology and clinical neuroscience, 5(1), 18-21.

Manley, E. R. (2016). Large-amplitude group exercise training programme for individuals with mild to moderate Parkinson's Disease: A pilot intervention study. Retrieved from https://epubs.rcsi.ie/cgi/viewcontent.cgi?article=1125&context=mscttheses

Pena, A. (2019). Endurance exercise may help manage cortisol levels in Parkinson's patients, study suggests. Parkinson's News Today. Retrieved from https://parkinsonsnewstoday.com/2019/05/24/endurance-exercise-helps-manage-cortisol-levels-parkinsons-patients