

A MONTHLY NEWSLETTER BY PARKINSON SOCIETY BC APRIL 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.

ANNUAL GENERAL MEETING I VANCOUVER

We invite you to join us for our Annual General Meeting on Saturday, April 13, featuring guest speaker, Dr. Matthew Farrer. Cited as one of the most influential researchers in the field of Parkinson's disease, Dr. Farrer and his lab have played a role in the discovery of every major gene in typical late-onset Parkinson's, as well as some atypical and early-onset forms.

Light refreshments will be served.

Date: Saturday, April 13

Time: 9:45am - 12:00pm (check-in begins at 9:00am)

Location: Library Square Conference Centre | Alice MacKay Room

350 West Georgia Street, Vancouver [map]

Cost: Free for members. Non-members interested in attending must sign up and pay \$25 annual membership fee.

Register: <u>www.parkinson.bc.ca/agm2018</u>

DEBRIEFING THE CAREGIVER ROLE | ONLINE WORKSHOP

Parkinson Society British Columbia (PSBC) is committed to honouring our slogan, "You are not alone. We are here to help," and that is why, in collaboration with the Pacific Parkinson's Research Centre (PPRC), we are offering an online grief support group session to help those who have recently lost a loved one to Parkinson's disease.

We invite you to join us for a webinar led by Elaine Book, Social Worker at the PPRC, and Courtney Doherty, Clinical Counsellor at PSBC.

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

Date: Thursday, May 2 Time: 10:00am - 12:00pm

Cost: Free

Register: <u>www.parkinson.bc.ca/caregiver-debrief-workshop</u>

COMMUNICATION & SWALLOW WORKSHOP | QUESNEL & PRINCE GEORGE

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: Friday, May 10 Date: Saturday, May 11 Time: 10:00am - 2:30pm Time: 10:00am - 2:30pm

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

Royal Canadian Legion Branch 94 Spruce Capital Senior's Recreation Centre Location: Location: 262 Kinchant St, Quesnel [map]

3701 Rainbow Drive, *Prince George* [map]

Cost: Free. This workshop has been sponsored Cost: Members: \$25.00 | Pair \$40.00

by Coralee Oakes, MLA Cariboo North Non-members: \$35.00 | Pair \$60.00

www.parkinson.bc.ca/princegeorge-cs Registration: www.parkinson.bc.ca/quesnel-cs Registration:

COMMUNITY TALK: MEDICATION MANAGEMENT | CRANBROOK

On May 13, join PSBC for a community talk with Cheryl Daniels, a nurse from the Kelowna MS and Movement Disorders Clinic. Cheryl will be speaking about medication management for Parkinson's disease.

Date: Monday, May 13 Time: 7:00pm - 8:00pm

Location: Heritage Inn Hotel & Convention Centre

803 Cranbrook St N, Cranbrook [map]

Cost: Free

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

ASK THE EXPERT: BALANCE & FALLS | WEBINAR

Postural instability and falls are very common in people with PD, and have great effect on quality of life. Unfortunately, current treatments are unable to alleviate postural instability, and while research is currently being done on this topic, the mechanisms underlying balance deficits and falls in PD are still not well understood.

On May 21, Eveline Pasman, PhD Candidate at thte University of British Columbia in the School of Kinesiology, will join Parkinson Society BC for the first time to share an overview of our current knowledge about Parkinson's-related postural instability and falls.

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

Tuesday, May 21 Date: 10:00am - 11:00am Time:

Cost: Free

www.parkinson.bc.ca/balance-and-falls-webinar Register:

TIME OUT FOR CAREPARTNERS WORKSHOP | PORT COQUITLAM

Parkinson Society British Columbia (PSBC) recognizes the efforts made by carepartners and caregivers every day. On May 25, 2019, we invite all carepartners/caregivers to join us for an after 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: Saturday, May 25 Time: 1:00pm - 4:30pm

Location: PoCo Inn and Suites Hotel & Conference Centre

1545 Lougheed Highway, Port Coquitlam [map]

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

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

Register: <u>www.parkinson.bc.ca/time-out-port-coquitlam</u>

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

FUNDRAISING EVENTS



- Method Tattoo Sales: Ongoing until July 15 [learn more]
- Shaken, Not Stirred: April 27 [learn more]
- Full Throttle: May 26 [learn more]
- Donate a Car Canada: Ongoing [learn more]
- Naturally Urban Pet Food Delivery Sales: Ongoing [learn more]
- Tea Parky: 35% of proceeds from every sale on <u>TeaParky.com</u> go to Parkinson Society BC. Special: Use promo code PSBC at checkout for 10% off your purchase

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.

SAVE THE DATE: PARKINSON SUPERWALK IN BC

Registration for this year's Parkinson SuperWalk opens April 4, on a new and improved website — stay tuned! Walks will be taking place on September 7 and 8.

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.

STEP BY STEP

Starting Thursday, April 11, Parkinson Society British Columbia is bringing back the Step by Step program for a fifth consecutive year! Step by Step is a 12-week walking program aimed at incrementally improving the number of average daily steps an individual takes. The first week will determine each walker's baseline, and then each week they will be encouraged to increase their steps based on a personal goal. While participants are encouraged to walk and track their own steps, a community group leader will organize a weekly walk allowing walkers to meet, socialize, and help support one another.

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.

Interested in joining a Step by Step program in your community? We currently have six communities participating this year: Brentwood Bay, Comox Valley, Kamloops, Maple Ridge/Pitt Meadows Prince George, and Vernon/Coldstream. Contact Caroline Wiggins at cwiggins@parkinson.bc.ca to learn more.

NEW SURREY SUPPORT GROUP

This group is intended for anyone affected by Parkinson's disease. Carepartners, friends, and family members are welcome.

Date: 2nd Monday of each month

Time: 6:00pm - 7:00pm

Location: Amenida Seniors' Community | Downstairs Activity Room

13855 68th Ave, Surrey

SAVE THE DATE: WORLD PARKINSON CONGRESS 2019, KYOTO

The 5th World Parkinson Congress will be held in Kyoto, Japan from June 4th–7th, 2019. Are you interested in attending? Registration is open now. Full information on registration categories is available at www.wpc2019.org/page/RegFees.

WORLD PARKINSON DAY AT UBC

On April 11th the Centre for Brain Health at UBC will be promoting brain wellness through music and art. There will be opportunities to purchase art made by individuals with Parkinson's disease, create paintings, buy baked goods, listen to music, and learn more about the disease!

Date: Thursday, April 11 Time: 10:00am - 2:00pm

Location: Djavad Mowafaghian Centre for Brain Health | First floor lobby

2215 Wesbrook Mall, Vancouver [map]

ONLINE SUPPORT GROUPS

Interested in joining an online support group? A valid internet connection will be required to participate. You must register to attend. Please contact us at 1-800-668-3330 or info@parkinson.bc.ca for more details.

Carepartners 3rd Wednesday of each month

9:00am - 10:30am

This group is for those who care for someone with PD, including spouses, partners, adult children, or friends.

New Diagnosis

4th Thursday of each month

9:00am - 10:30am

This group is available to help individuals who have been diagnosed with PD in the last two years.

Young Onset Parkinson's Disease 2nd Tuesday of each month

7:00pm - 8:30pm

This group is meant for individuals diagnosed with PD under the age of 60.

NEW RESOURCES

- Self-Management as Self-Care Webinar | John Murphy [video] [presentation slides]
- Managing Advanced Parkinson's Disease [helpsheet]
- Medical and Recreational Cannabis and Parkinson's Disease [helpsheet]
- Wills & Estate Planning [helpsheet]

All of our educational materials, including helpsheets, brochures, pamphlets, and booklets, are available for download online at www.parkinson.bc.ca/resources. To view recordings of our past webinars, workshops, or conference presentations, visit our YouTube channel at www.youtube.com/ParkinsonSocietyBC.

DISCUSSION: PARKINSON'S AWARENESS

DISCUSSION QUESTIONS:

- 1. Are people generally understanding of your Parkinson's? What sorts of assumptions have people made about you based on your condition (if any)?
- 2. What do you wish more people knew about Parkinson's disease?
- 3. Have you ever been involved with Parkinson's awareness activities?

April is Parkinson's Awareness Month! This is an opportunity to engage the public in expanding their understanding of Parkinson's disease (PD), and the diversity of our community. This year, our April Awareness campaign highlights:

- Inspirational stories from people with PD, their families, and carepartners.
- The history of Parkinson Society BC, and the growth of our programs & services.
- Our Society's mission to ensure all British Columbians living with PD know that they are not alone on their journey.

New this year, we are also celebrating 50 years of service! Parkinson Society BC was established in 1969 with a mission to empower people with Parkinson's in BC through providing resources and services to enable self-management, self-reliance, and self-advocacy. So, throughout 2019, we will be making public awareness a top priority, with the goal of expanding our reach so that all people affected by Parkinson's BC know that we are here to help.



"When we were diagnosed with Parkinson's, it changed our lives. Even simple joys, like dinner with loved ones, are dependent on the effectiveness of our medications."

- Elaine & Wayne | Comox



IT'S MORE THAN A TREMOR

HOW TO GET INVOLVED

Spread the word. To encourage people in the PD community to share their stories, we are bringing back our **#PDANDME** (PD and Me) campaign. By using the hashtag **#PDANDME** on social media, people with PD, and their families, friends, and carepartners can help support the public in better understanding the complexity of PD, and its effects.

Print a poster. No social media? No problem! You can participate in Parkinson's Awareness Month by placing a poster in the window of your home, place of business and favorite local hangout (with permission). Posters are available on our website.

Celebrate with us. For our 50th anniversary campaign, we are building a timeline of the Society's history — and we need your help. Send in your photos from education events, fundraisers, or support group activities you have taken part in over the years for your chance to be featured.

Tell us your story. Every journey with PD is unique, and we want to hear about yours. Be an ambassador for our awareness efforts, and have your story shared in our newsletters, on our website, or as part of our 50th anniversary video series. For more information, contact Jovana Vranic at jvranic@parkinson.bc.ca.

Approach your local news outlet. News coverage about PD and the people affected is considered topical during April Awareness Month. In the past, many people with Parkinson's have been successful in helping to earn media coverage in their communities. Consider sharing our press release with local news outlets, or provide your own interview, or letter to the editor!

Find out more about how you can get involved at www.parkinson.bc.ca/awareness.

WHY AWARENESS MATTERS

While most people have heard of PD, the breadth of symptoms experienced, and the ripple effect the disease has on friends, family, and the healthcare system, are lesser understood. Furthermore, with approximately 13,000 people affected by the condition, making it the second most common neurological disorder after Alzheimer's, the disease receives considerably less attention.

Public misconceptions about Parkinson's disease can have drastic effects on the quality of care and support services offered to the community. When more people are aware of the needs of people with PD, our community gains more advocates who support efforts like government lobbying, fundraising, programs, service delivery, and cutting-edge research.

Parkinson Society BC relies on the generosity of our donors and volunteers to support the PD community. By supporting our awareness efforts, you are helping us to expand our programs and services. With your help, we can:

- Reach people with PD and their carepartners in more remote communities
- Publish more educational materials, such as helpsheets, booklets, brochures, and presentations
- Connect and collaborate with leading Parkinson's experts and researchers
- Put on more educational events such as workshops, community talks, and conferences
- Fund more leading-edge research projects to help find better treatments, and ultimately a cure for PD

All it takes is spreading the word. Together, we can make a difference.

If you have questions or comments about any of PSBC's awareness activities, please contact:

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