

A MONTHLY NEWSLETTER BY PARKINSON SOCIETY BC MAY 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: 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 the 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.

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

Cost: Free

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

LAB TOUR: CENTRE FOR APPLIED NEUROGENETICS | VANCOUVER

Join Dr. Matthew Farrer and his team on a tour of their laboratory at the Centre for Applied Neurogenetics (CAN) at the University of British Columbia. Research at the CAN is focused on deciphering the underlying causes of Parkinson's disease, and testing therapeutic interventions.

This half-day event will include a tour of the lab, presentations showcasing current research projects being done at the CAN, and an opportunity for individuals to ask questions.

Date: Wednesday, May 22 Time: 2:00pm - 5:00pm

Location: Djavad Mowafaghian Centre for Brain Health

2215 Wesbrook Mall, Vancouver [map]

Capacity: 40 Cost: Free

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

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, 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 Coguitlam [map]

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

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

Register: www.parkinson.bc.ca/time-out-port-coguitlam

REGIONAL CONFERENCE | KELOWNA

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. The conference does not include a meal, however light refreshments will be provided.

Topics covered at this conference will include:

- New and Advancing Therapies | Dr. Daryl Wile, Movement Disorder Specialist in Kelowna
- Sleep and Parkinson's | Dr. Ron Cridland, MD with the Canadian College of Family Physicians and Fellow at the American Academy of Sleep Medicine
- · Living with Purpose & Resilience "I Am Not My Disease" | Debra Coffey, Registered Professional Counsellor

Date: Saturday, June 22

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

Location: Ramada Hotel & Conference Centre

2170 Harvey Ave, Kelowna [map]

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

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

Register: <u>www.parkinson.bc.ca/kelowna-rc</u>

FUNDRAISING EVENTS



- Method Tattoo Sales: Ongoing until July 15 [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.

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.

50TH ANNIVERSARY VIDEO SERIES: THE BENEFITS OF JOINING A SUPPORT GROUP

With help from members of the Parkinson's community, as part of our 50th anniversary celebration, we have been working on producing a series of videos. These videos are intended to generate awareness of the Society's programs and services, as well as the realities of life with Parkinson's disease.

The first two videos in this series discuss the benefits of joining Parkinson's-specific support groups. Parkinson Society BC has a network of over 50 support groups across the province.



LEARN MORE

WATCH OUR VIDEOS

NEW! NORTH SHORE SUPPORT GROUP

This group is intended for anyone affected by Parkinson's disease. Carepartners, friends, and family members are welcome. Please note that visitor and street parking is available, but limited. Carpooling is encouraged.

Date: Starting Thursday, May 16

3rd Thursday of each month

Time: 10:00am - 11:00am Location: Amica Lions Gate

701 Keith Rd, West Vancouver [map]

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.

PARKINSON'S SINGING GROUP: JOIN THE TREMBLE CLEFS!

People with Parkinson's, carepartners, family, and friends are all invited to join The Tremble Clefs, an informal singing group led by members of the Maple Ridge/Pitt Meadows Parkinson's Support Group. Singing is a great tool for strengthening memory, exercising vocal cords, expressing yourself, and socializing. The Tremble Clefs are a friendly, non-judgemental group of peers, and they welcome anyone who would like to stop in and sing a few songs with them.

For more information, please contact Chris Olsen at 604-463-1242 or chrisolsen@live.ca.

Date: Every 2nd, 3rd & 4th Thursday of the month

Time: 11:00am - 12:30pm

Location: Fraserview Village Community Centre | Fireside Lounge

22610 116 Ave, Maple Ridge [map]

BC POVERTY REDUCTION STRATEGY

Last fall, the provincial government passed the Poverty Reduction Strategy Act, which aims to achieve a 25% reduction in BC's overall poverty rate, and a 50% reduction in the child poverty rate by 2024.

The strategy's four guiding principles include affordability, opportunity, reconciliation, and social inclusion. These four principles focus the strategy on lifting communities up and out of poverty and creating an environment that allows people to learn, work, support their family, and create the future they want for themselves and future generations. For more information, and to see the full strategy report, visit bit.ly/bcpovertyplan.

SAVE THE DATE: PROVINCIAL CONFERENCE — MOVING FORWARD, TOGETHER

Our provincial conference is back this year, with a new stream for healthcare professionals. Speaker and session information coming soon. Stay tuned to our website for upcoming details.

Date: Saturday, October 26

Location: Hilton Vancouver Metrotown

6083 McKay Ave, Burnaby [map]

PARKINSON'S COMMUNITY NEEDS SURVEY

We are currently conducting a survey of those affected by Parkinson's disease (PD) in BC. If you are a person with Parkinson's, carepartner/caregiver, or family member of someone living with PD, your opinion matters and is valued.

The feedback from this anonymous survey will serve as a guide for us in determining priorities for the future of our programs, services, and advocacy efforts.

We appreciate all responses and thank you for your participation in advance.

TAKE THE SURVEY

DISCUSSION: YOUR HEALTHCARE TEAM

DISCUSSION QUESTIONS:

- 1. Who are all the professionals on your healthcare team, and what do they do?
- 2. Which healthcare professionals do you feel have helped you most, and how?
- 3. How do you ensure you are getting the best possible care?

A supportive healthcare team is an integral part of life with Parkinson's disease (PD). Some may only consider doctors or nurses to be a part of their healthcare team, but there are so many other healthcare professionals that people with Parkinson's can benefit from seeing.

Having a holistic approach to your health is a great way to ensure that you are getting the most out of your treatment. There are many trained healthcare professionals involved in the delivery of health or related services pertaining to the identification, evaluation, and prevention of diseases and disorders, outside of the fields of medicine and nursing (ASAHP, 2018). These workers are typically referred to as allied healthcare professionals (AHCP), and include occupational therapists, physiotherapists, dietitians, speech language pathologists, counsellors, social workers, chiropractors, massage therapists, and others.

AHCP provide a wide range of roles and responsibilities including:

- Designing programs to improve functions like balance, movement, or communication
- Identifying, evaluating, and preventing diseases and disorders
- · Educating individuals, families, and communities on their diagnosis and best treatment options
- Providing emotional, financial, and other supports to individuals and families

Parkinson Society BC believes it is valuable to have an interdisciplinary approach to your healthcare. Management of PD includes the diagnosed individual, their carepartners/family, and a team of allied healthcare professionals. When limiting ourselves to one medical professional, we are obtaining only one perspective on our health and treatment. Someone with PD may have multiple complex needs, which may include additional diagnoses of other physical or psychological conditions. It is therefore important to find support from a team of professionals with various areas of expertise so you can receive the most holistic support and treatment from a medical, psychological, and social perspective.

CHOOSING YOUR HEALTHCARE TEAM

A crucial part of building your healthcare team is finding professionals who are able to provide the kind of care that is most important to you. Communicate openly with your healthcare team to ensure that your needs, preferences, and values are all taken into account when establishing a care plan or receiving treatment. This sometimes involves heavy topics, like advance care planning, so it is important to find practitioners with whom you feel comfortable. Those who are responsible for your care can make arrangements to provide you with the best options available within your established boundaries, whether that includes religious accommodations, financial barriers, or other preferences and values you communicate.

Person-first healthcare that prioritizes the values of the patient is sometimes referred to as the palliative care approach. In the past, palliative care was reserved for end-of-life, when professionals focus on providing comfort, rather than curative treatment, to their patients. Now, according to Kathleen Yue at the BC Centre for Palliative Care, all holistic care for chronic, life-altering conditions can be considered to be provided with a palliative care approach from the point of diagnosis (2019). This type of care does not seek to cure the individual, but rather support them to live well and comfortably for the rest of their life. Palliative care for Parkinson's can include any conventional healthcare, alongside emotional and spiritual support, social work, or assistance from carepartners, family, friends, volunteers, or assisted living facilities.

To receive healthcare services with a palliative care approach, a person with PD should be highly involved in their own disease management and advance care planning. Healthcare professionals need support from their clients in order to do the best work they can. Alongside open communication about your values, one of the best ways you can help your healthcare team support you is by tracking your symptoms, and communicating any changes you experience.

SOURCES

Association of Schools of Allied Healthcare Professions (ASAHP). 2018. What is Allied Health? Retrieved from http://www.asahp.org/what-is/

Parkinson Society British Columbia. 2019. Kathleen Yue Discusses Palliative Care for Parkinson's. Retrieved from https://www.parkinson.bc.ca/media/176835/viewpoints-spring-2019.pdf#page=6

ADDITIONAL RESOURCES

Your Healthcare Team and How to Access It | Helpsheet | bit.ly/pdhealthcareteam
Talking to Your Healthcare Professionals | Helpsheet | bit.ly/paceframework
Comprehensive Care Plan Checklist | Symptom Tracker | bit.ly/pdsymptomchecklist
Preparing for a Medical Appointment | Helpsheet | bit.ly/pdappointmentprep
Healthcare Decision Making | Helpsheet | bit.ly/pdadvancecareplan
Wills & Estate Planning | Helpsheet | bit.ly/willsandestatesplanning
Advanced Parkinson's Disease | Helpsheet | bit.ly/advancedpdmgmt
Aware in Care Kits | www.parkinson.bc.ca/aware-in-care
Exercise & Active Living Programs | www.parkinson.bc.ca/activeliving

SAVE THE DATE: PARKINSON SUPERWALK IN BRITISH COLUMBIA



this September!

REGISTER TODAY FOR PARKINSON SUPERWALK!

Join us for Parkinson Society British Columbia's largest fundraising event of the year, Parkinson SuperWalk!
Beginning the weekend of September 7 & 8, incredible British Columbians in over 20 communities throughout the province will walk together to help give hope to approximately 13,000 people in BC living with Parkinson's.

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.

Participating communities include:*

100 Mile House Pitt Meadows/Maple Ridge Burnaby Port Alberni Castlegar **Powell River** Chilliwack Prince George Comox Valley Richmond Cranbrook (Virtual Walk) Salmon Arm Terrace Kamloops Kelowna Vancouver Langley Vernon Nanaimo Victoria Oliver White Rock

Don't see your community listed? Sign up to become a Virtual Walker to fundraise and walk in any community outside of the organized walk locations at a time that works for you. Your location can be anywhere in or outside Canada.

PARKINSON.BC.CA/SUPERWALK

Parkinson SuperWalk in British Columbia is operated by Parkinson Society British Columbia under license from Parkinson Canada

^{*} Locations are subject to change. Visit our website to learn more.