

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, 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.

UPCOMING EVENTS

Debriefing the Caregiver Role

When a loved one is lost, it is one of life's most difficult experiences. You may find yourself struggling with many intense and frightening emotions leaving you feeling isolated or alone. Having someone to lean on in this time is important in helping you through the grieving process.

In collaboration with the Pacific Parkinson's Research Centre, PSBC offers this workshop to those who have recently lost a loved one with Parkinson's disease. Grief, coping, and recovery will be discussed. Elaine Book, Social Worker at the Pacific Parkinson's Research Centre, and Tricia Wallace, Clinical Counsellor at PSBC will facilitate.

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

Date: Thursday, December 12
 Time: 10:00am – 12:00 pm
 Cost: Free
 Registration: www.parkinson.bc.ca/debriefing-the-caregiving-role

Communication & Swallow Workshop, Nanaimo

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, January 25
 Time: 10:00am – 2:30pm (check-in begins at 9:30am)
 Location: Vancouver Island Conference Centre | Dodd Narrows Room A/B
 101 Gordon St, Nanaimo
 Cost: Member: \$25 | Member Couple/Pair \$40
 Non-member \$35 | Non-member Couple/Pair \$60
 Registration: www.parkinson.bc.ca/nanaimo-cs

Ask the Expert Webinar: Mindfulness

What does it mean to be mindful? How does one practice mindfulness, and why is it beneficial?

Join us on Wednesday, January 29, as Parkinson Society British Columbia's own clinical counsellor, Judy Zhu, discusses mindfulness, and leads a meditation practice via webinar. Judy is a registered doctor of Traditional Chinese Medicine and has been practicing Zen meditation

for over 10 years. In this webinar, she will share the researched benefits of mindfulness on our body and mind, from reducing anxieties, stress, and pain, to improving cognitive function, emotional regulation, and overall quality of life. She will also talk about how mindfulness can be applied to daily life to help manage the many stressors that people with Parkinson's disease, their families, and carepartners face.

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

Date: Wednesday, January 29
Time: 10:00am – 11:00am
Cost: Free
Registration: www.parkinson.bc.ca/mindfulness-webinar

Better Together: Intimacy & Parkinson's

Approximately half of all men and women with Parkinson's disease will experience problems with intimacy and sexual functioning. These symptoms can be difficult to talk about, but are important to address. The sexual functioning and wellbeing of people with Parkinson's and their partners can be affected by many factors, including motor symptoms, non-motor symptoms, medication effects and relationship issues.

This webinar, led by Elaine Book, Social Worker at the Pacific Parkinson's Research Centre, and Tricia Wallace, Clinical Counsellor at Parkinson Society BC, will discuss challenges with sexual intimacy and will explore options to address emotional distance influenced by physical limitations and role transitions brought on by Parkinson's disease.

We strongly encourage couples to participate in this webinar together. The content is focused on relationships, sharing and communication, so the exercises in the webinar are geared toward couples. Registration is required by all participants to access the event. However, registrants will have the opportunity to be anonymous during the webinar presentation.

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

Date: Thursday, February 13
Time: 7:00pm – 8:30pm
Cost: Free
Registration: www.parkinson.bc.ca/intimacy-webinar

UPCOMING FUNDRAISING EVENTS

Champions for Parkinson's

- Donate a Car Canada: Ongoing (read more: bit.ly/2ORTuJn)
- Naturally Urban Pet Food Delivery Sales: Ongoing (read more: bit.ly/2MLasvX)

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! Contact Caroline Wiggins at cwiggins@parkinson.bc.ca or 1-800-668-3330.

NEWS & ANNOUNCEMENTS

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

We're hiring a full-time Education & Support Services Coordinator

Reporting to the Manager, Education & Support Services, the Education & Support Services Senior Coordinator will lead efforts in the execution of the Society's largest yearly education event, *Moving Forward, Together*, in addition to planning regional and community events across the province for people with Parkinson's, carepartners, and healthcare professionals. The successful candidate will also be responsible for providing and/or supporting the delivery of information, education and resources to the Parkinson's community; this includes researching and maintaining information resources.

For more information, visit: bit.ly/PSBC-ESS-Coordinator.

We're looking for a new Board Treasurer

We're seeking a new Board member for the role of Treasurer to join us in our mission of empowering the Parkinson's community in BC. The right candidate will be well versed in understanding financial statements and best practices.

For more information: bit.ly/PSBC-Treasurer.

Movapo (Apomorphine) now available under the Limited Drug Coverage Program

As of November 26, 2019, Movapo has been made available under BC PharmaCare's Limited Drug Coverage Program. For more information, visit: bit.ly/Movapo-Announcement.

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.

Online Advanced Parkinson's Carepartner Support Group

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

Time: 9:00am – 10:30am

Location: Via webinar. *A valid internet connection will be required to participate. Login instructions will be sent out 24 hours before the meeting.*

Cost: Free

Information Kiosk at the Pacific Parkinson's Research Centre!

Every Thursday, Parkinson Society BC will be available 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

Website: parkinsons.ubc.ca

TIP JAR

If you receive home and community services, it is important to update the healthcare team assigned to you. Make contact every three to six months (or sooner if you encounter a big change), outlining changes to your health and environment. This should include updates on your support network and services you access, and your new or ongoing needs. Parkinson Society BC can provide information about PD care for you to share with your healthcare team.

DISCUSSION TOPIC: November is Fall Prevention Month**Discussion Questions**

1. What does self-advocacy mean to you?
2. How do you self-advocate for your healthcare needs?

December 10th is International Human Rights Day, commemorating the establishment of the Universal Declaration of Human Rights (UDHR). Patient rights around the world draw on the UDHR, noting every person, no matter their standing or status, has inherent dignity, and is deserving of privacy, confidentiality, information, bodily integrity, and non-discrimination to attain the highest possible standard of health. Further, each person has the right to participate in public policy regarding healthcare (Cohen & Ezer, 2013).

In the context of Parkinson's disease, advocacy may be hampered by physical limitations, emotional imbalance, low motivation, and isolation. Additionally, those in carepartner/caregiver roles may be tired or have competing priorities, making it difficult to assert healthcare rights. Parkinson Society BC (PSBC) aims to enhance the voices of all who are affected by Parkinson's disease (PD), by providing opportunities for knowledge development and connection, while sustaining a platform for advocacy issues to be addressed.

Tools offered by PSBC that can assist with self-advocacy include:

- **Consultations & Counselling:** As a person with Parkinson's, or a carepartner/caregiver, you may experience emotions related to symptoms, medications, or life changes that make advocating for your healthcare needs challenging. Our support services team can provide you with resources to help navigate these issues. Furthermore, you may benefit from speaking with a clinical counsellor on staff to discuss, and work through, more complex concerns.
- **Support Groups & PDLINK:** Participating in one-on-one or group support opportunities offered through the Society will allow you to better understand the issues that impact individuals affected by Parkinson's disease through the sharing of stories and experiences. Knowing that you're not alone can help build confidence and reduce shame or embarrassment one may have. These supports also provide a safe space to share information about care, while developing a sense of community.
- **Aware in Care Kits:** These kits are designed to protect, prepare, and empower people with Parkinson's and their carepartners before, during, and after a hospital visit. Each kit includes a bag, tools (eg. a medical alert bracelet), and many information sheets outlining personal needs to plan for the next hospital stay – whether it is a scheduled visit or an emergency.
- **Advocacy Network:** The Society maintains a network of advocates across the province to assist in drawing attention to the often complex and pressing issues faced by people affected by Parkinson's disease.

- **Membership:** Our members assist in gathering information about key issues affecting the Parkinson's community in the province of BC. Your voice helps us identify advocacy priorities and impacts the outcomes in healthcare for Parkinson's patients.

PSBC has outlined a five-point Advocacy plan with the following goals:

1. Add specialized staff to existing PD programs.
2. Fund PD-specific training for allied healthcare professionals.
3. Expand the Deep Brain Stimulation program.
4. Expand medication coverage.
5. Increase support for carepartners.

Additional Resources

5-Point Advocacy Plan | bit.ly/psbc5pointplan

Aware in Care Kits | www.parkinson.bc.ca/awareincare

PSBC Resources | www.parkinson.bc.ca/resources

PSBC Advocacy | www.parkinson.bc.ca/advocacy

Family Caregivers of BC Advocacy | bit.ly/caregiversadvocacy

Office of the Senior's Advocate | www.seniorsadvocatebc.ca

Source

Cohen, J. and Ezer, T. (2013). Human rights in patient care: A theoretical and practical framework. Health and Human Rights Journal. Retrieved from: www.hhrjournal.org/2013/12/human-rights-in-patient-care-a-theoretical-and-practical-framework