

SPECIAL NOTICE

In response to the global outbreak of COVID-19, Parkinson Society BC (PSBC) staff are working remotely until further notice. We will continue to offer programs and services in alternate formats. For the most up-to-date information, visit this web page: www.parkinson.bc.ca/coronavirus. If you have any questions, please contact us at info@parkinson.bc.ca.

UPCOMING EVENTS

- **Improv: Performance Troupe** | Wednesdays, January 12 – March 30
Learn more & register: <https://bit.ly/performancetroupepd>
 - **Drumming for Parkinson's** | Wednesdays, February 2 – March 9, & March 16 – April 20
Learn more & register: www.parkinson.bc.ca/drumming-classes
 - **SongShine with Joani** | Thursdays, February 3 – March 10, & March 17 – April 21
Learn more & register: www.parkinson.bc.ca/songshine-with-joani
 - **Tai Chi – Beginners' Progression** | Thursdays, February 3 – March 31
Learn more & register: <https://bit.ly/taichipd>
 - **Virtual Gardening Group** | Every 2nd and 4th Thursday, March 10 – September 22
Learn more & register: <https://bit.ly/pdgardeninggroup>
 - **Ask the Expert: Bone Health and Parkinson's** | Monday, March 14
Learn more & register: <https://bit.ly/bonehealthandpd>
 - **Bollywood Dance** | Tuesdays, April 5 – 26
Learn more & register: <https://bit.ly/bollywooddancepd>
 - **Ask the Expert: Eye Health and Parkinson's** | Wednesday, April 6
Learn more & register: <https://bit.ly/eyehealthandpd>
 - **April Challenger** | Thursdays, April 7 – 28
Learn more & register: <https://bit.ly/aprilchallenger22>
 - **Voice Aerobics®** | Thursdays, June 16 – 30
Learn more & register: <https://bit.ly/voiceaerobicspd>
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UPCOMING FUNDRAISING EVENTS

Champions for Parkinson's

- Donate a Car Canada: Ongoing (read more: <http://bit.ly/2ORTuJn>)

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 disease (PD)? 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 ext. 255.

TIP JAR

The Tip Jar is where we share advice from Parkinson's community members. This month, we share advice on oral care.

- A support group member's dentist suggested that his wife with Parkinson's use Xylimelt to prevent dry mouth and to stimulate saliva. It is available over-the-counter at many pharmacies.

Do you have any tips or tricks that you would like to share with the Parkinson's community? These can be tips from something that works well, to eating and dressing, to getting out of bed or travelling! All tips and tricks are welcome! Please share your ideas at info@parkinson.bc.ca.

NEWS & ANNOUNCEMENTS***Updated provincial health orders regarding in-person support group meetings***

As per the updated COVID-19 restrictions, PSBC will resume in-person support groups for those who sign the indoor meeting agreement. Support groups may still choose to access our Zoom accounts if they prefer to remain virtual. For facilitator inquiries, please email Liz Janze, *Education & Support Services Coordinator*, at ljanze@parkinson.bc.ca or call 1-800-668-3330 ext. 228.

Save the date! 2021 Annual General Meeting (AGM)

We invite you to join us for our Annual General Meeting on Saturday, April 23, featuring guest speaker Dr. Lara Boyd. Dr. Boyd is a neuroscientist and physical therapist who is currently a professor at the University of British Columbia. Her research efforts are leading to the development of new and effective therapeutic methods, some of which have applications for

people with Parkinson's, including leveraging neuroplasticity. Neuroplasticity is the brain's ability to grow and "rewire" neural networks based on an individual's learning and life experiences. In this talk, Dr. Boyd will speak about the applications of neuroplasticity in managing Parkinson's symptoms.

Please be advised this is a *member-only event*. Registration will be available shortly at www.parkinson.bc.ca/agm-2021.

Submit your photo to be one of our Faces of Parkinson's Disease

In honour of Parkinson's Awareness Month this April, we will be collecting photos from people with Parkinson's disease in BC to help draw attention to the diversity of the community. To learn more and submit your picture, please visit www.parkinson.bc.ca/facesofpd.

Support the expansion of the Deep Brain Stimulation (DBS) program in BC

In 2019, the BC Ministry of Health promised a second neurosurgeon to help reduce waitlist times for DBS surgeries. The waitlist to see Dr. Christopher Honey for initial DBS assessment is now up to four years. We need the BC Ministry of Health to follow through on their promise. TAKE ACTION and support our letter writing campaign today at www.parkinson.bc.ca/dbs.

Volunteer as a community organizer for Parkinson SuperWalk

To make our largest fundraising event possible, we are seeking walk coordinators across five communities (Abbotsford, Comox Valley, Kamloops, Langley, and Prince George). Learn more and apply at www.parkinson.bc.ca/sworgrecruit.

Above and Beyond Awards

Please nominate a person with Parkinson's and/or their carepartner who embraces the "Above and Beyond" philosophy in their life at www.parkinson.bc.ca/aboveandbeyond. We will recognize these dedicated individuals at our upcoming Annual General Meeting on April 23. Nominations will be accepted through Friday, March 25.

Step by Step walk leaders needed

Step by Step is a 12-week walking program aimed at improving physical fitness to combat the symptoms of PD. To learn more or start a group in your community, please visit

www.parkinson.bc.ca/stepbystepleaders.

Class action lawsuit: Gramoxone® (paraquat)

Gramoxone® is an herbicide used to control weeds and grasses with an active ingredient called paraquat. It is alleged that paraquat exposure is linked to Parkinson's disease (PD). Law firm Siskinds Desmeules has filed proposed class action lawsuits on behalf of all Canadians who have been diagnosed with PD after using and/or being exposed to Gramoxone®, since July 1, 1963. To learn more, visit www.parkinson.bc.ca/gramoxoneclassaction.

COVID-19 vaccination

Throughout 2022, COVID-19 vaccines will be made available to all Canadians. Read Parkinson Society BC's COVID-19 Vaccination Statement for more information about the vaccine – including how it works, how it will be distributed, and considerations for people with Parkinson's – at

www.parkinson.bc.ca/covid-vaccine.

DISCUSSION TOPIC: The importance of awareness***Discussion Questions***

1. How do you think greater public awareness of Parkinson's disease (PD) would impact your life, and the lives of other people with PD?
2. How have others responded to you disclosing you have PD? In what ways have their responses surprised you (positive or negative)?
3. How do you help raise awareness of PD? What obstacles do you encounter in raising awareness?

Please see the last page of GroupLink for a suggested group activity to support Parkinson's Awareness Month.

Parkinson's Awareness Month is just around the corner! Every year, we dedicate the month of April to raising public awareness of the challenges and triumphs experienced by people with Parkinson's disease, of which there are nearly 15,000 in British Columbia alone. Approximately 12% of Canada's population over the age of 80 are living with PD – and that number is expected to double by 2040. Parkinson's Awareness Month is an opportunity to recognize the unique experiences of people with Parkinson's, while drawing attention to the needs of our growing community.

Myths and misconceptions

While most people have heard of Parkinson's, less understand the complexities and uniqueness of the disease. Despite its prevalence, there remain many misconceptions and myths about PD, which can sometimes lead to confusion and misunderstanding, for both the person with PD and the general public. Some common myths include:

- **"It is only an 'older' person's disease."** While the majority of people diagnosed are over the age of 60, up to 20% of people with Parkinson's develop symptoms before then. Those diagnosed with Young Onset Parkinson's Disease (YOPD) may be in very different stages of their lives than what most people picture when they think of a 'typical' person with PD – individuals with YOPD may have children or be planning a family, may be caring for elderly parents, and may be at the peak of their career. Seeing Parkinson's through a narrow lens does not capture the richness and diversity of the lived experience of so many of our community members.
- **"Parkinson's is only a tremor."** It is true that many individuals with Parkinson's experience a tremor, but did you know that 20% of people with PD will never develop a tremor throughout the course of their illness (Newman, 2021)? In fact, there are over 40 different symptoms of Parkinson's (Parkinson's UK, n.d.). What is certain is that no two people will experience this disease in the same way.
- **"That person is intoxicated or aggressive."** Some Parkinson's symptoms, like slurred speech, slowness of movement, and reduced facial expressions can sometimes be

misinterpreted as anger or fear. Also, when individuals experience 'Off' periods between medication doses, they may be mistakenly seen as intoxicated or aggressive. Because of this, people with PD may be subject to situations that result in bias and discrimination, sometimes escalating to the involvement of law enforcement. Greater widespread awareness of the presentations of PD could help mitigate such encounters, and provide members of the Parkinson's community the safety that everyone deserves while enjoying a public space.

- **"Drugs are the only thing that help Parkinson's."** There is growing scientific evidence that exercise can have neuroprotective benefits for people with PD. Research has also found that exercise helps both the motor and non-motor symptoms of the illness (Newman, 2021). Awareness of exercise as a treatment option could help people with PD feel more empowered in knowing that they can be active agents in their own care.

How to help increase awareness

Fortunately, there are many ways to increase awareness of Parkinson's within your community and the general public, such as:

- **Participating in the Faces of PD campaign:** In honour of Parkinson's Awareness Month, we will be collecting photos from people with PD across the province to help draw attention to the diversity of the community. If you wish to participate in this awareness campaign, please submit your photo at www.parkinson.bc.ca/facesofpd.
- **Participating in the Deep Brain Stimulation (DBS) campaign:** People with PD in BC continue to face undue hardship and suffering due to long waits for DBS. We need the BC Ministry of Health to follow through on their promise to hire a second neurosurgeon. Drawing attention to the importance of DBS and the challenges faced by people with PD will help inform those in your network about Parkinson's, while also raising awareness of this life-changing procedure. Learn more about getting involved at www.parkinson.bc.ca/dbs.
- **Talking to your family about PD, including children:** A diagnosis of Parkinson's will impact everyone in the family – it is truly a family affair. Having a parent with PD can teach children to become more self-sufficient and independent, but also more compassionate,

understanding, and patient. By opening the lines of communication, you can ensure that your family is better able to support and understand your unique Parkinson's journey.

- **Talking to your employer:** It may be daunting to discuss Parkinson's in the workplace. However, some of the symptoms that you experience may result in a need for accommodation, which your employer is legally required to provide. If you decide to disclose your diagnosis to an employer, it is important to have a plan. Generally, it is best to stay positive and focus on your skills and qualifications, as well as how any present or future accommodations may help you to maximize your potential as an employee. Openness in the workplace can also help to normalize Parkinson's disease, and show others that people with PD can be productive, successful individuals.
- **Utilizing the "I have PD" reminder slips:** People with Parkinson's face greater risks in the hospital due to more frequent visits and a high sensitivity to the timing and dosing of their medications. The "I have PD" reminder slips are a convenient way to provide essential reminders of Parkinson's-specific treatment requirements to your healthcare team. These slips bring awareness to the importance of getting one's medications on time, as well as what medications might be contraindicated for people with PD. Please see <https://bit.ly/ihavepdcard> for a digital copy, or phone 1-800-668-3330 for a printed version.

It takes courage to speak openly about Parkinson's, but by doing so, you can help raise awareness and reshape understanding of this disease.

Additional Resources

A Family Affair: Talking to Children about PD | Helpsheet | <http://bit.ly/pdguidekids>
Duty to Accommodate & Disability Insurance | Helpsheet | <http://bit.ly/pddutytoaccommodate>
Discrimination & Healthcare Issues Affecting People with Advanced PD | Viewpoints Article | <https://bit.ly/advancedpddiscrimination>

Sources

Newman, T. (2021, April 5). *Medical myths: All about Parkinson's disease*. Medical News Today. <https://www.medicalnewstoday.com/articles/medical-myths-all-about-parkinsons-disease>

Parkinson's UK. (n.d.). *Parkinson's symptoms*. <https://www.parkinsons.org.uk/information-and-support/parkinsons-symptoms>

Support Group Awareness Activity

We are asking for people to fill out our Parkinson's Awareness Month postcards, reflecting on their personal journey with Parkinson's in an effort to educate the public. These postcards may also be used in future communications to raise awareness of the diversity of the PD community in British Columbia.

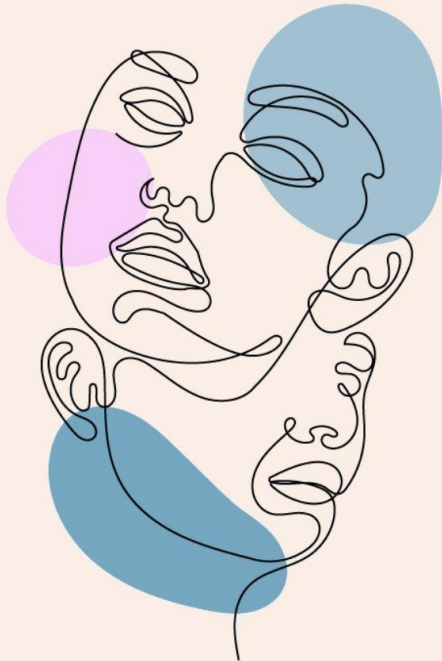
Examples of what you may want to include on the card:

- Symptoms you experience and how they affect your day to day life. Consider mentioning lesser known symptoms, so that members of the general public may better understand the diverse nature of the disease.
- Your change in life perspective. Some people with Parkinson's report that the disease helped them prioritize their goals and desires in life, which may include travel, spending more time with family, exercising more frequently, etc.

Cards can be completed in the following ways:

1. **Fillable PDF.** Download a copy of our fillable PDF and email it to kperez@parkinson.bc.ca. A copy can be downloaded at: www.parkinson.bc.ca/awarenesspostcard.
2. **Scan/photograph/print.** You can print out the last page of this issue of GroupLink and either print, scan, or photograph and return to Parkinson Society BC by mail or e-mail (kperez@parkinson.bc.ca).
3. **Form submission (text only).** If you have access to a computer and would like a simple way of contributing to this campaign activity, you can fill out the following form, which will also allow you to provide more detail about your Parkinson's experience: <https://bit.ly/pdpostcardsubmission>.
4. **Physical copies.** Printed copies of these postcards, for completing and returning to Parkinson Society BC, are available upon request. To request cards, please fill out this form: <https://bit.ly/pdpostcardrequest>.

Please note that you will find a space to include your contact information. This is not required and submissions will remain anonymous. However, if you are willing to share your experience with Parkinson's more in-depth, we are looking to speak with people for future publications and campaigns.



*The Faces of
Parkinson's*



PARKINSON'S HAS AFFECTED ME BY...

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Share your story on social media using
hashtag **#morethanatremor**
www.parkinson.bc.ca/awareness