

SPECIAL NOTICE

In response to the global outbreak of COVID-19, Parkinson Society BC 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, please visit this PSBC web page: www.parkinson.bc.ca/coronavirus. If you have any questions, please contact us at info@parkinson.bc.ca.

UPCOMING EVENTS

- **April Challenger** | Thursdays, April 1 – 22
Learn more & register: www.parkinson.bc.ca/april-challenger
 - **Mindful Moments** | Tuesdays, April 13 – June 1
Learn more & register: www.parkinson.bc.ca/mindful-moments
 - **Recreational Singing** | Wednesdays, April 14 – May 26
Learn more & register: www.parkinson.bc.ca/rec-singing
 - **Our Journey: Living with Parkinson's** | Wednesday, April 14
Learn more & register: www.parkinson.bc.ca/pd-panel
 - **Improv for Parkinson's** | Wednesdays, April 14 – May 19
Learn more & register: www.parkinson.bc.ca/improv-laughter
 - **Songshine with Sharon** | Thursdays, April 15 – May 20
Learn more & register: www.parkinson.bc.ca/april-songshine
 - **Beginner Bollywood Dance Series** | Tuesdays, May 4 – 25
Learn more & register: www.parkinson.bc.ca/bollywood-dance
 - **Chair Yoga** | Thursdays, May 6 – 27
Learn more & register: www.parkinson.bc.ca/chair-yoga
 - **SongShine with Joani** | Wednesdays, June 2 – July 14 | Wednesdays, July 21 – August 25
Learn more & register: www.parkinson.bc.ca/songshine-with-joani
 - **Dancing with Latin Rhythms** | Thursdays, June 3 – 24
Learn more & register: www.parkinson.bc.ca/latin-dance
 - **Parkinson's Medication Q&A** | Friday, June 11
Learn more & register: www.parkinson.bc.ca/medication-webinar
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UPCOMING FUNDRAISING EVENTS

Champions for Parkinson's

- The Mighty Moose Beard Oil Co. is a small business based in the heart of the Fraser Valley. All of their beard oils and balms are handmade with 100% natural ingredients. They pride themselves in creating exceptional products at reasonable prices. For the month of April, they will be donating \$1.00 to Parkinson Society BC from every bottle of beard oil sold. Shop their selection at www.mightymoosbeard.com.
- 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? 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.

TIP JAR

The Tip Jar is where we share advice from Parkinson's community members. This month, we share advice on maintaining your vocal abilities!

- Some individuals with Parkinson's have found that avoiding foods with ascorbic and citric acids helped ease vocal symptoms of Parkinson's, as well as putting coconut oil in coffee.
- Songshine is a singing program designed for those with communication and vocal issues due to Parkinson's or other neurological challenges. Visit our website at www.parkinson.bc.ca/events to view PSBC's own SongShine classes, or learn more about the program at www.songshineforparkinsons.com.

Do you have any tips or tricks that you would like to share with the PD 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**Choose your own April Adventure!**

While we've all been staying closer to home, with warmer and more predictable weather ahead, you may be looking for opportunities to get active. Exercise is a great way to manage Parkinson's symptoms, as well as reduce anxiety and stress – which we can all use a little extra help with lately.

Now is the perfect time to pick a virtual hike/walk in this distance-based challenge! Over the course of the month, the goal is to try to walk enough to accumulate the same distance of one of the suggested trails. Visit www.parkinson.bc.ca/april-adventure to learn more and get hiking!

A warm welcome to our new staff!

Parkinson Society British Columbia is pleased to welcome two new staff members!

Liz Janze has joined us as a full-time Education and Support Services Coordinator. Liz has a Bachelor's degree in Community Rehabilitation and Disability Studies, and experience working with a variety of disabilities and health conditions. She is compassionate, resourceful and enthusiastic! We are very glad to add her to our team, where she will be our main support for volunteer support groups and facilitators. Liz can be reached by email at ljanze@parkinson.bc.ca or by phone at 1-800-668-3330 ext. 228 or 604-662-3240 ext. 228.

Madelaine Ross, RPN, BFA, M.Sc., is our newest part-time counsellor. She was the Parkinson's Client and Family Service Manager for HeadWay in Victoria for several years, where she also provided counselling to people with Parkinson's and carepartners. Her support was greatly appreciated by the Victoria and area Parkinson's community, and we are very pleased to have her join our team! Madelaine can be reached by email at mross@parkinson.bc.ca or by phone at 1-800-668-3330 ext. 266 or 604-662-3240 ext. 266.

COVID-19 Vaccination

Throughout 2021, COVID-19 vaccines will be made available to all Canadians. The Government of Canada has announced a phased approach to immunization, and high-risk communities have begun receiving vaccinations to protect those who are most likely to develop complications from the virus. 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.

April is Parkinson's Awareness Month!

Every year, Parkinson Society BC dedicates the month of April to raising awareness of the unique experiences of people with Parkinson's, and the needs of our community. Awareness Month is an opportunity to engage the public in expanding their understanding of Parkinson's, and its profound effects on the lives of over 13,000 British Columbians living with the disease.

This April, we want to spread the message that Parkinson's is *more than a tremor*. The disease can affect all aspects of one's life, and there is no cure.

Our 2021 campaign highlights:

- **Personal journeys** shared by people with Parkinson's, their families, and carepartners.
- The importance of **living well with Parkinson's**, through self-management, self-reliance, and self-advocacy.
- **Community ties and peer support** bringing together the Parkinson's community across British Columbia.

In recognition of Parkinson's Awareness Month, and World Parkinson's Day on April 11, we are encouraging individuals affected by the disease to share their experiences through our **#MoreThanATremor** campaign. In light of the COVID-19 pandemic, our campaign will be focused online, so be sure to follow us on social media for stories from the community, PD tips, and inspiring interviews! Find us on social media at www.instagram.com/ParkinsonsBC, www.twitter.com/ParkinsonsBC, and www.facebook.com/ParkinsonSocietyBritishColumbia.

Learn more about our April Awareness campaign plans at www.parkinson.bc.ca/awareness.

DISCUSSION TOPIC: Parkinson's Awareness & Advocacy**Discussion Questions**

1. How long did it take you to feel comfortable talking about your diagnosis? What helped you overcome any initial fears or anxieties about sharing?
2. What helps you feel most supported in your journey with Parkinson's?
3. What practical steps do you take to raise awareness for Parkinson's, and advocate for yourself and the PD community?

April is Parkinson's Awareness Month! This year, our campaign is centred on sharing the journeys of people with Parkinson's disease (PD), their families, and carepartners. We hope these stories will help bring awareness to the resilience and strength of those living with PD. Every journey with Parkinson's is unique – by sharing your own personal experience with PD, you can help advocate for yourself and increase visibility for the entire community.

What is advocacy and why is it important?

Advocacy seeks to ensure your voice is heard on issues important to you. For the PD community, raising public awareness is an important way to shed light on common struggles faced by people with Parkinson's, and advocate for change, such as increased access to life-changing treatments like Deep Brain Stimulation and Duodopa® therapy. Enhancing understanding and visibility of the diverse experiences of people with Parkinson's is the first step in advocating for better healthcare, resources, and support services for the community as a whole. The goal of Parkinson's Awareness Month is to engage the public in championing a cause they may otherwise not have known about.

Many individuals may not know very much about PD before a loved one is diagnosed, and they may not recognize what kind of impact this diagnosis can have on someone's life. Awareness efforts can help guide people's understanding of the disease, correct misinformation, and foster a sense of connection and openness, which is crucial for successful advocacy.

Self-advocacy also starts with awareness, so it is important for people with PD to be educated about their condition. Advocating for yourself and talking about the challenges faced by the Parkinson's community may help you and others access better care, and can enable you to maintain open and honest relationships with those you care about. Fostering a dialogue around Parkinson's can open the door to invaluable support and help you feel less alone.

What can I do in my daily life to raise awareness and advocate for my community?

You are your own best advocate – you know your experience best, and when you share your perspective with others it can help the public understand the impacts of Parkinson's. While no two journeys with the disease are the same, talking about your experience can shed light on the commonalities of managing a chronic illness like PD.

Before sharing your experience with the public, it is important to take some time to process your diagnosis and understand Parkinson's. Educate yourself using reliable resources, determine the types of support you may need, and identify your limits so you can clearly communicate these aspects when the time comes.

If you are newly diagnosed, it can also be useful to find someone you trust to help you work through the beginning stages of your diagnosis. After you have had time to process and understand the implications of a Parkinson's diagnosis, you may then wish to begin sharing your story with more people. The following strategies may help you become more comfortable talking about Parkinson's with others:

- Start by sharing your diagnosis with your close family members and friends, and slowly ease into talking about your story with the rest of your social circle.
- When people inquire about your symptoms or well-being, take the opportunity to share more information about PD with them – this can feel daunting, but a small conversation can go a long way in increasing visibility of the diverse experiences of PD.
- Proactively consider what you wish to share and what you wish to keep private – remember, it is always your decision if, when, and what you would like to disclose.
- To help you feel more in control of the situation, anticipate people's potential reactions and questions ahead of time. Individuals may ask questions like "*what caused it?*" or "*isn't that a condition that only affects older people?*". You may answer these questions personally or refer them to a trusted resource so they can do research on their own. PSBC's helpsheets and educational resources are a great place to start: www.parkinson.bc.ca/resources.
- Be ready to give clear examples of practical support that people can offer. People may want to help, but don't know how – you can put them at ease by helping them understand their role and how they can support you.

- Become part of the community by joining a support group (www.parkinson.bc.ca/groups) or engaging with events like Parkinson Superwalk (www.parkinson.bc.ca/superwalk)! These events can be easy conversation starters, and the sense of community can help equip you with confidence to share your journey.
- If you are nervous or apprehensive about sharing, remember that talking about your experience can help you feel less alone, lighten your load, and provide meaningful support.

How can I get involved in Parkinson's Awareness Month, and other awareness efforts?

Parkinson's Awareness Month is a great time to share your story and get engaged with advocacy for the PD community. Throughout April, follow along with Parkinson Society BC's campaign on Facebook, Twitter, and Instagram, to see inspirational stories, read about our advocacy efforts, and learn more about Parkinson's disease. You can share our posts, or make posts of your own, to share more information with those in your social circle who may not know much about Parkinson's and the PD community in BC.

As a person with Parkinson's, carepartner, family member, or friend, you are a PD expert in your own right. You can raise awareness every single day simply by keeping an open mind, and engaging in conversation with those who are less informed about Parkinson's.

People may be curious about PD symptoms, which can lead them to stare, or ask questions. Although this can sometimes come off as impolite, it can also be a chance to share information about PD with those who seem interested to learn. For example, you may say to someone, *"You may have noticed I have a tremor in my hand. I have Parkinson's, and this is one of my symptoms. Have you heard of Parkinson's before?"* Situations like this come up often in everyday life, so if you feel comfortable doing so, try using them as opportunities to raise awareness.

Additional Resources

Parkinson's Awareness Month | www.parkinson.bc.ca/awareness

Our Experience with Parkinson's | Video | <http://bit.ly/ourexperiencePD>

Frequently Asked Questions about PD | Video | <http://bit.ly/questionspd>

Understanding and Moving Forward | Booklet | <http://bit.ly/pdmovingforward>

Living with Purpose & Resilience | Presentation | <https://bit.ly/purposeresilience>

A Family Affair: Talking to Children about PD | Helpsheet | <http://bit.ly/pdguidekids>