



VIEWPOINTS

Spring 2023

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Quarterly Newsletter
by Parkinson Society
British Columbia

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Your support is essential.

Parkinson Society BC would not exist without the support of our members, donors, and volunteers.

OUR MISSION

Parkinson Society British Columbia exists to empower people with Parkinson's in British Columbia through providing resources and services to enable self-management, self-reliance, and self-advocacy.

Here are a few of the ways you can support the Society:

MEMBERSHIP

For an annual fee of \$25, your household benefits from unlimited access to our education and support services, events, and resources.

DONATIONS

Contact us to set up monthly, quarterly or annual donations, or think of us when giving through United Way.

PLANNED GIVING & BEQUESTS

Consider Parkinson Society British Columbia as a beneficiary in your will.

FUNDRAISING

Become a Champion for Parkinson's by organizing your own event benefiting the Society. For more information on how you can support us, visit www.parkinson.bc.ca/donate.

SUPPORT GROUPS

100 Mile House, Abbotsford, Advanced Carepartner Online, Burnaby, Campbell River, Carepartner Bereavement Online, Chilliwack, Chinese Speaking (Burnaby), Courtenay/Comox Valley, Cranbrook, Deep Brain Stimulation, Duncan/Cowichan Valley, Early-Mid Stage Carepartner Online, Gabriola Island, Kamloops, Kelowna, Kelowna Carepartners, Langley, Langley YOPD, Maple Ridge/Pitt Meadows, Maple Ridge Caregivers, Nanaimo, Nanaimo Carepartners, New Diagnosis, New Westminster, North Shore, Parkinson's Online, Parksville/Qualicum, Parksville/Qualicum Caregivers, Powell River, Prince George, Princeton, Quesnel, Richmond, Richmond Carepartners, South Okanagan, South Delta/Tsawwassen, Surrey, Sechelt/Sunshine Coast, Trail/Castlegar, Tri Cities Caregivers, Vancouver Arbutus, Vancouver Carepartners, Vancouver Downtown, Vancouver West Side, Vernon, Vernon Caregivers, Weekly Parkinson's Online, White Rock Carepartners, Williams Lake, Young Onset Parkinson's Online

EDITORIAL STATEMENT

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Phone: 604-662-3240

Toll Free: 1-800-668-3330

Fax: 604-687-1327

www.parkinson.bc.ca
info@parkinson.bc.ca

Address:

Suite 600-890 West Pender Street,
Vancouver, BC V6C 1J9

Charitable Registration Number:
11880 1240 RR0001



Ask an Expert

Drs. Lorraine and Suneil Kalia discuss the current developments and future applications of focused ultrasound technology for people with Parkinson's



Dr. Lorraine Kalia, MD, PhD, FRCP is a senior scientist at the Krembil Research Institute, University Health Network. She is also an

associate professor in the Division of Neurology and Tanz Centre for Research in Neurodegenerative Diseases at the University of Toronto. As a neurologist, she specializes in Parkinson's disease and related movement disorders at the Toronto Western Hospital Movement Disorders Clinic. She is also co-editor-in-chief of the *Journal of Parkinson's Disease*.



Dr. Suneil Kalia, MD, PhD, FRCS is a senior scientist at the Krembil Research Institute and KITE Research Institute, University Health

Network. He is also an associate professor in the Division of Neurosurgery at the University of Toronto. As a stereotactic and functional neurosurgeon at the Toronto Western Hospital, he focuses on the surgical management of Parkinson's disease, other movement disorders, epilepsy, and pain. He holds the R. R. Tasker Chair in Stereotactic and Functional Neurosurgery.

What is focused ultrasound technology and how does it change the brain?

Focused ultrasound (FUS) is a technology that uses a computer system and real-time imaging in a magnetic resonance imaging (MRI) machine to precisely focus and deliver ultrasound waves to any area of the brain. FUS can be either high- or low-intensity.

High-intensity FUS uses ultrasound energy to burn millimeter-sized hotspots in the brain (for example, in brain cells generating tremor). By creating small lesions in the brain, we can disrupt abnormal circuitry that is present in people with Parkinson's, thereby reducing their tremor or other motor symptoms.

Low-intensity FUS, on the other hand, is currently investigational, and uses lower ultrasound energy to vibrate small bubbles within blood vessels to temporarily disrupt the blood-brain barrier (BBB). The BBB acts as a protective mechanism, regulating what chemicals can and cannot penetrate the brain. This is especially important, because the body can be host to many neurotoxic substances. In particular, the BBB blocks the passage of large molecules, which include many dangerous pathogens, but also unfortunately include many helpful drug therapies. By opening the BBB, low-intensity FUS can help to more effectively deliver medications and other therapeutic agents directly into brain tissue.

Presently, only high-intensity FUS is Health Canada-approved, and it is only approved for the treatment of tremor. All other applications of FUS are currently experimental.

How is FUS being used or explored as a treatment for Parkinson's disease? What are its effects and benefits?

For Parkinson's, high-intensity FUS may be helpful for a small sub-group of patients with tremor-dominant disease. In collaboration with the teams of Drs. Nir Lipsman and Kullervo Hynynen, we have set out to investigate low-intensity FUS to open the BBB in individuals with Parkinson's, with the hope of delivering

new drugs to slow disease progression. In our study, we aimed to deliver an active enzyme called glucocerebrosidase, which may be inactive in some people with Parkinson's. In fact, mutations in a gene called GBA1, which encodes glucocerebrosidase, is one of the strongest genetic risk factors for developing Parkinson's. This enzyme is already safely and routinely infused for patients with a rare neurological condition called Gaucher disease, however, it does not cross the BBB. We started by delivering this enzyme to a brain area within the basal ganglia called the putamen, which is thought to be the site where degeneration of dopamine-producing brain cells begins in those with Parkinson's. Although our first trial focused on safety, we selected glucocerebrosidase, since there are laboratory data that suggest it may be helpful in maintaining the survival of remaining dopamine-producing brain cells.

Our study described above included four people with Parkinson's whom we treated with glucocerebrosidase using low-intensity FUS, three times each. We established that the treatments were safe and well tolerated. Our team is embarking on a new study to determine if there will be any clinical benefits or side effects in the short and long term.

What criteria would make someone with Parkinson's an ideal candidate for FUS?

The low-intensity procedure is still under investigational study, so we cannot make any recommendations. For patients with tremor-dominant Parkinson's, high-intensity FUS may be a treatment option but, in its current form, will not treat the other symptoms of Parkinson's. Therefore, deep brain stimulation will be the recommended option for most people with Parkinson's who are surgical candidates. All surgical treatments are specialized therapies requiring a multidisciplinary team. Treatment options should be reviewed with the person's neurologist, as not everyone is a surgical candidate.

What have been some challenges you have come across in your clinical trials and how have you handled them?

Funding remains a major barrier to these trials. Our team persevered and is grateful for the support we have received from the FUS Foundation and Weston Foundation to do this work. The only option for us is to continue to advocate for people with Parkinson's. We understand that without this type of work, the urgent need for disease-modifying therapy will not be met.

What are some potential drawbacks of this type of therapy?

In our low-intensity FUS studies, we are actively looking for possible side effects, which may include scalp numbness and headaches. We are vigilant in monitoring for any new or worsening symptoms of Parkinson's. This work is early on the research pathway to develop new therapies for Parkinson's, so we must first establish safety.

If trials are successful, how do you envision FUS changing the landscape of Parkinson's disease treatments/therapies?

By providing safe and highly accurate targeting of drugs to specific areas in the brain, low-intensity FUS may allow for the advancement of disease-modifying treatments.

How accessible do you anticipate focused ultrasound technology may become for the average Parkinson's patient?

Currently, FUS therapies for brain diseases are only available at specialized centres and must be administered by multidisciplinary teams. With telemedicine, geographical barriers could potentially be reduced, as the technology could be installed in existing MRI scanners with relative ease. However, much work still needs to be done to learn how best to use this novel technology for Parkinson's and other diseases of the brain.

Research

The Canadian-Open Parkinson Network

The Canadian-Open Parkinson Network (C-OPN) brings together researchers, data, and scientific resources from all across Canada to support and accelerate Parkinson's disease (PD) research. The C-OPN has been made possible by the Canada Brain Research Fund (CBRF), an innovative arrangement between the Government of Canada (through Health Canada) and Brain Canada Foundation, as well as Parkinson Canada. Its objective is to reduce barriers and expedite meaningful discoveries, which are not possible in any single laboratory or clinic anywhere in the world. Through the C-OPN, expert clinicians and researchers across the country coordinate their efforts and dramatically enhance the capacity to deliver personalized treatments and services that improve lives.

The C-OPN does this by bringing participants living with Parkinson's disease and similar disorders together with scientists across Canada for studies and trials. As a result, individuals are better able to access and participate in clinical trials for new treatments. To help achieve their objectives, the C-OPN has developed a National Patient Registry, which collects anonymous clinical data with comprehensive information about each participant's family history, lifestyle, and environment, along with details of their Parkinson's symptoms, medications, test results (including cognitive and motor information), and biomaterials extracted from blood samples (including DNA). Most of the data collection can be done online from the comfort of participants' homes; however, the biomaterials collection must be completed in one of nine Canadian-Open Parkinson Network sites. Participants are able to choose to what extent they would like to be involved and how much data they would like to provide.

Parkinson Society BC (PSBC) is proud to support the operations of the University of British Columbia C-OPN site, which is involved in the collection of biobank data, in the amount totaling \$50,000 from October 2022 - 2023. Angela and Mark Hutchinson participate in the C-OPN and can attest to its powerful potential. Mark serves on the Board of Directors for PSBC and is a carepartner to his wife, Angela, who was diagnosed with PD in 2008.

“I initially became involved when I learned of how the C-OPN was an organized group across Canada, who were striving to collaborate instead of just relying on local pools of people,” says Mark. “Angela and I fully endorse this great research initiative and encourage as many people as possible to participate. The more people step up and get involved, the more we are all helping to find a cure for Parkinson's.”

Presently, nine sites are actively recruiting in British Columbia, Alberta, Ontario, and Quebec for the Network.

To learn how you can become involved as a participant, please visit www.copn-rpco.ca/participants

IF YOU HAVE ANY QUESTIONS ABOUT THE C-OPN, PLEASE CONTACT:

Catherine Normandeau

National Manager, Canadian-Open Parkinson Network

national.manager@copn-rpco.ca

www.copn-rpco.ca

Living Well

Apathy and Parkinson's Disease



Apathy is an often-distressing non-motor symptom that affects many people with Parkinson's disease (PD). The definition of what apathy means in the context of Parkinson's has changed substantially over the years, but is now defined as a profound reduction of feeling, interest, and motivation that is not a result of cognitive impairment, reduced consciousness, or emotional upset. Due to the limited number of studies on this topic, estimates of the prevalence of apathy range from 12% to 70% of people with Parkinson's. To this day, there also exist few standardized assessment tools to measure apathy. What is known, however, is that it poses a significant challenge to people with Parkinson's and their loved ones. Experiencing apathy can result in a significant decrease in quality of life and increase in caregiver burden (Foley & Cipolotti, 2021).

There is growing evidence that like anxiety, apathy in Parkinson's is not just a response to living

with a chronic health condition, but may instead originate from disruption in brain pathways, as well as decreased levels of dopamine. It is also not the same thing as depression, even though there is some overlap between their respective symptoms, with studies showing that apathy can be a separate condition from depression in people with Parkinson's. However, apathy is strongly correlated with several factors, such as also experiencing depression, anxiety, and fatigue (Ineichen & Baumann-Vogel, 2021).

One small study followed two groups (one group experiencing apathy, another not) of people with Parkinson's disease for 18 months. At the time of the first assessment, both groups were receiving PD medications that were optimally dosed for each individual, yet there were clear differences in the levels of apathy between the two groups. As a result, the study authors suggested it is not

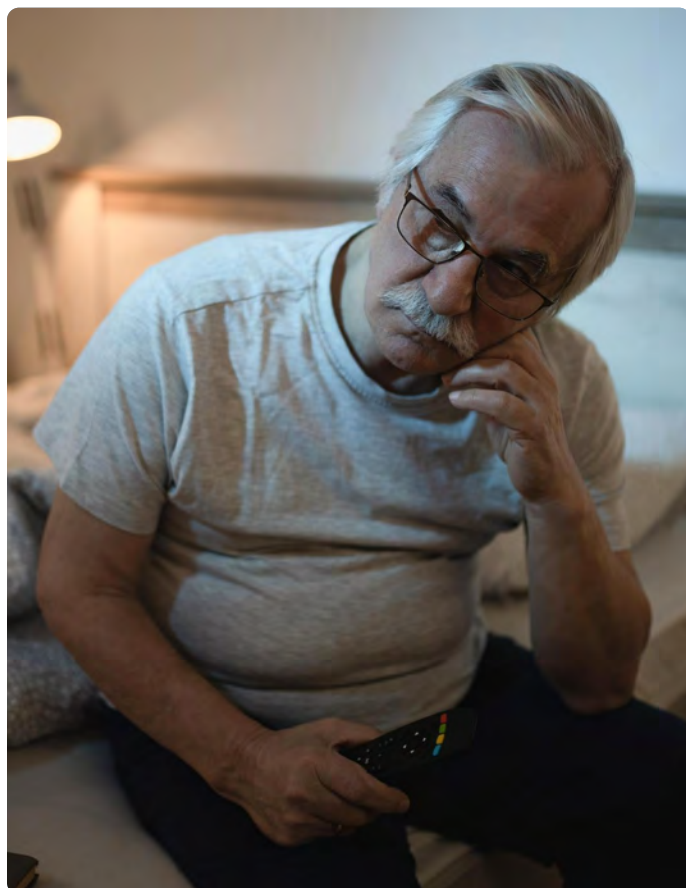
possible for dopamine levels to completely explain rates of apathy amongst people with Parkinson's. However, they acknowledged feedback from a fellow researcher that argued the 'optimal' dose of anti-parkinsonian medication is usually based only on control of motor symptoms, not non-motor ones like apathy. Because dopaminergic medications affect both motor and non-motor parts of the brain, it is possible the dose that is best for motor symptoms may not be ideal for controlling non-motor ones (*Dujardin et al., 2009*).

Additionally, apathy is linked to a higher risk of developing dementia as the disease progresses. The study mentioned above proposed the idea that the loss of basal forebrain cholinergic neurons (BFCNs) as a result of Parkinson's disease is a major cause of cognitive decline and dementia, as well as neuropsychiatric symptoms like apathy. BFCNs are a special type of nerve cell in the brain that play an important role in cognition, as well as attention and memory (*Martinez et al., 2021*). In the study, the group of people with apathy showed lower cognitive function scores after 18 months than the non-apatetic group, suggesting that apathy may be predictive of dementia over time (*Dujardin et al., 2009*).

In addition to the associations with dementia, apathy also can have a negative impact on carepartners, sometimes even impacting them more than the person with Parkinson's. In fact, some studies have shown that carepartners report apathy to be the single most troublesome symptom in people with PD (*Foley & Cipolotti, 2021*). If a carepartner does not understand the origins of apathy, they may see their loved one as lazy, difficult, and hard to motivate. As a result, the carepartner may experience burnout, and the relationship may suffer. This is why it is imperative that family and friends see apathy as a symptom of the illness itself, not as a personal failing. Adjusting expectations can go a long way. No one would ever tell a person with Parkinson's to "just stop their tremor or freezing." Similarly, this compassion must be extended to non-motor symptoms like apathy (*Kluger, 2017*).

If you or your loved one are struggling with apathy, make sure to discuss your concerns with your healthcare team. There may be possible medication changes or additions that can help. Don't be discouraged if it takes several trials to find the right dose or type of medication for you. It is also important to make sure any healthcare practitioner prescribing medication specifically to treat apathy is familiar with Parkinson's disease. Sometimes people with PD are given antidepressant medications for apathy by their psychiatrist, but these may not always be effective at treating the condition and, in some cases, can actually make it worse (*Kluger, 2017*).

It also may not come as a surprise that, like many Parkinson's symptoms, apathy seems to be reduced by regular physical activity. In 2021, a study found that people with early-stage Parkinson's disease that were more active were less apathetic. The researchers of that study also suggested that exercise can act as a motivating force by encouraging self-help behaviours, resulting



in an overall improvement in other Parkinson's symptoms (Ng *et al.*, 2021). Another academic review of non-pharmacological interventions for treating apathy in PD found that a Nordic walking program, which uses walking poles to engage the upper body, was especially effective. It seems the full-body involvement increased participants' sense of safety while exercising, which gave them a boost in feelings of autonomy (Mele *et al.*, 2021). Regardless of what exercise program you choose, the most important part is that it is something you find empowering and enjoyable.

ADDITIONAL RESOURCES

- **Apathy**

Helpsheet: <http://bit.ly/pdapathy>

SOURCES

- Dujardin, K., Sockeel, P., Delliaux, M., Destée, A., & Defebvre, L. (2009). Apathy may herald cognitive decline and dementia in Parkinson's disease. *Movement Disorders*, 24(16), 2391-2397. <https://doi.org/10.1002/mds.22843>
- Foley, J. A. & Cipolotti, L. (2021). Apathy in Parkinson's disease: A retrospective study of its prevalence and relationship with mood, anxiety, and cognitive function. *Frontiers in Psychology*, 22. <https://doi.org/10.3389/fpsyg.2021.749624>
- Ineichen, C. & Baumann-Vogel, H. (2021). Deconstructing apathy in Parkinson's disease: challenges in isolating core components of apathy from depression, anxiety, and fatigue. *Frontiers in Neurology*, 12. <https://doi.org/10.3389/fneur.2021.720921>
- Kluger, B. (2017). Provincial Conference 2017: Apathy & Non-Motor Symptoms with Dr. Benzi Kluger. [Video file]. YouTube. <https://bit.ly/apathydrkluger>
- Martinez, J. L., Zammit, M. D., West, N. R., Christian, B. T., & Bhattacharyya, A. (2021). Basal forebrain cholinergic neurons: Linking down syndrome and Alzheimer's disease. *Frontiers in Aging Neuroscience*. <https://doi.org/10.3389/fnagi.2021.703876>
- Mele, B., Ismail, Z., Goodarzi, Z., Pringsheim, T., Lew, G., & Holroyd-Leduc, J. (2021). Non-pharmacologic interventions to treat apathy in Parkinson's disease: A realist review. *Clinical Parkinsonism & Related Disorders*, 4. <https://doi.org/10.1016/j.prdoa.2021.100096>
- Ng, S. Y., Chia, N. S., Abbas, M. M., Saffari, E. S., Choi, X., Heng, D. L., Xu, Z., Tay, K., Au, W., Tan, E., & Tan L. C. (2021). Physical activity improves anxiety and apathy in early Parkinson's disease: A longitudinal follow-up study. *Frontiers in Neurology*, 11. <https://doi.org/10.3389/fneur.2020.625897>



Carepartner's Corner

Understanding and coping with impulse control disorders

Impulse control disorders (ICDs) can occur in people with Parkinson's disease (PD) due to a variety of factors, and may present complex challenges for carepartners. Examples of behaviours seen in people with ICDs include hypersexuality, compulsive gambling or shopping, binge eating, and aggressive outbursts. There are estimates that between 10% and 20% of people with PD will develop some form of impulse control disorder throughout the course of their illness (*International Parkinson and Movement Disorder Society, 2018*). ICDs can develop in gradual and subtle ways, with neither the person with Parkinson's nor their loved ones immediately recognizing what is happening. Because of their close relationship to the person with PD, carepartners are uniquely positioned to help spot the earliest signs of impulse control problems, but may also be on the receiving end of the negative effects of such disorders.

Parkinson's medications, especially dopamine agonists, have long been known to contribute to the development of impulse control disorders. For some people with Parkinson's, dopaminergic drugs may boost levels of dopamine in motor pathways, but can also cause an unwanted overabundance of dopamine in other parts of the brain that are less affected by PD, such as the mesocorticolimbic system, which plays an important role in learning, memory, and motivation. As a result, the individual may become especially sensitive to rewards and develop an impulse control disorder (*Eisinger et al., 2019*).

However, medications are not the only cause of ICDs – there are many additional risk factors that may make someone more susceptible to their development. In general, men are more likely than woman to develop an ICD, especially those of a hypersexual nature. Younger people with Parkinson's are also more susceptible, as well

as those with a longer disease duration. Some researchers have suggested that the reason for this is because younger individuals will be exposed to more dopaminergic medication throughout their lives simply by getting the disease at an earlier age, but studies are still divided on the topic. Finally, people who have a family history of impulsivity are more likely to develop impulse control disorders, as well as those who have experienced anxiety and depression in the past (*Eisinger et al., 2019*).

Understandably, impulse control disorders can be especially distressing for carepartners. What is more frustrating is that the person with Parkinson's may not be able to identify that they have a problem. In fact, the impulse control behaviours that cause carepartners the most difficulty are those the person with PD does not see as troublesome; they may deny that there is a problem at all, or disagree with the carepartner's assessment of its severity (*Erga et al., 2020*). One study interviewed over a dozen carepartners about their experiences with impulse control disorders and found similar patterns in their stories. The impulsive behaviour tended to come on gradually, which often resulted in a delay in identifying that the medication may have been causing the changes. Some carepartners thought they could stop the impulsive behaviours by persuading or bribing their partner. Others tried to accept the problematic changes due to shame in discussing these topics with a neurologist, or fear of damaging their partner's reputation with loved ones. However, as time went on, all the carepartners in the study described the behaviours as having a significant impact on their quality of life. This included feeling distressed when being on the receiving end of explosive aggressive outbursts, anxiety watching their spouse overspend, and relationship strain caused by attempts to stop the behaviours (*McKeown et al., 2020*).

Fortunately for both people with PD and their loved ones, there are ways to manage impulse control disorders and their effects, such as:

Talking to a neurologist or doctor:

As soon as an impulse control disorder is suspected, it is essential to speak with one's healthcare provider. As ICDs may make people with PD unable to see the problematic nature of their behaviour, carepartners may need to seek advice on their loved one's behalf. Medication changes can be made, but people with PD should never attempt to reduce or stop dopaminergic medication without the guidance a medical professional (*International Parkinson and Movement Disorder Society, 2018*). It is important to note that while medication changes or reductions are likely to help the problem, this is not a guarantee. In some people with Parkinson's, ICDs may persist – one large study found that more than 50% of ICDs did not go away after stopping dopamine agonists (*Eisinger et al., 2019*).

Implementing behavioural measures:

Carepartners can help manage ICDs by helping prevent the negative consequences by limiting access to things such as credit cards, the Internet, and unhealthy food. Gambling intervention programs can also be helpful in some instances (*Pontone, 2018*).

Seeking mental health support:

The help of a trained professional, such as a psychologist or counsellor, is critical when dealing with an impulse control disorder. Professionals can help the person with PD better cope with their impulses and break the habit of reward-seeking. One

study found that cognitive behavioural therapy (CBT) greatly improved impulse control disorder severity in people with Parkinson's (*Kelly et al., 2020*). Parkinson Society British Columbia offers free, short-term, and non-crisis counselling services for people touched by Parkinson's disease. To learn more, please visit www.parkinson.bc.ca/counselling.

Finding a supportive community:

Support groups are a safe space to share with others who are experiencing similar difficulties. Carepartners can greatly benefit from knowing they are not alone. Parkinson Society BC offers numerous carepartner support groups; to learn more and join a group, please visit www.parkinson.bc.ca/supportgroups.

Impulse control disorders are a challenge for people with Parkinson's and their loved ones:

While much is understood about how and why they develop, there still remains a lot we do not fully understand. Carepartners, despite weathering many of the hardships that come about as a result of ICDs, can be powerful catalysts for change.

ADDITIONAL RESOURCES

- **Impulse Control Disorders and Parkinson's with Dr. Catharine Winstanley**

YouTube video:

<https://bit.ly/impulsecontrolpd>





SOURCES

- Eisinger, R. S., Ramirez-Zamora, A., Carbutaru, S., Ptak, B., Peng-Chen, Z., Okun, M.S., & Gunduz A. (2019). Medications, Deep Brain Stimulation, and Other Factors Influencing Impulse Control Disorders in Parkinson's Disease. *Frontiers in Neurology*, 10. <https://doi.org/10.3389/fneur.2019.00086>
- Erga, A. H., Alves, G., Tysnes, O. B., & Pedersen, K. F. (2020). Impulsive and compulsive behaviors in Parkinson's disease: Impact on quality of and satisfaction with life, and caregiver burden. *Parkinsonism & Related Disorders*, 78, 27-30. <https://doi.org/10.1016/j.parkreldis.2020.07.007>
- International Parkinson and Movement Disorder Society. (2018). Impulse Control Disorders in Parkinson's Disease: Essential Facts for Patients. <https://www.movementdisorders.org/MDS/Resources/Patient-Education/Impulse-Control-Disorders-in-Parkinsons-Disease.htm>
- Kelly, M. J., Baig, F., Hu, M. T., & Okai, D. (2020). Spectrum of impulse control behaviours in Parkinson's disease: pathophysiology and management. *Journal of Neurology, Neurosurgery & Psychiatry* (91), 7. <http://dx.doi.org/10.1136/jnnp-2019-322453>
- McKeown, E., Saleem, T., Magee, C., & Haddad, M. (2020). The experiences of carers looking after people with Parkinson's disease who exhibit impulsive and compulsive behaviours: An exploratory qualitative study. *Journal of Clinical Nursing*, 29(23-24), 4623-4632. <https://doi.org/10.1111/jocn.15499>
- Pontone, G. (2018). What are Impulse Control Disorders? <https://www.apdaparkinson.org/what-is-parkinsons/symptoms/impulse-control-disorders>

April is Parkinson's Awareness Month

Every year, April is recognized by the Province of British Columbia and Parkinson Society British Columbia as Parkinson's Awareness Month. This provides us with the opportunity to engage the public in expanding their understanding of Parkinson's disease (PD) and the profound effects it has on the lives of over 15,000 British Columbians living with the disease.

The vast majority of the general public have a limited understanding of PD, particularly as it relates to the variances in symptom manifestation and progression.

Additionally, historically, the disease has been recognized as one that affects a more senior population, and while most people diagnosed are over the age of 60, we know that there is a significant subset of those living with the disease that get diagnosed at younger ages, classified as Young Onset Parkinson's Disease.

For our Parkinson's Awareness Month efforts, it is critical that we have representation from a variety of sources in order to more accurately reflect the community as a whole. This year, we hope to continue with spreading the message that Parkinson's is more than a tremor, but we need your help!

We are calling upon you to help make this year's campaign a success.

This April, we are encouraging British Columbians affected by Parkinson's to submit content that tells their story, their way.

What we're looking for:



Writing Pieces

Original poems, short stories, or essays are invited to submit.



Artwork

Unique pieces such as paintings, illustrations or photography.



Written Interviews

We want to hear your uniquely diverse voices and perspectives.

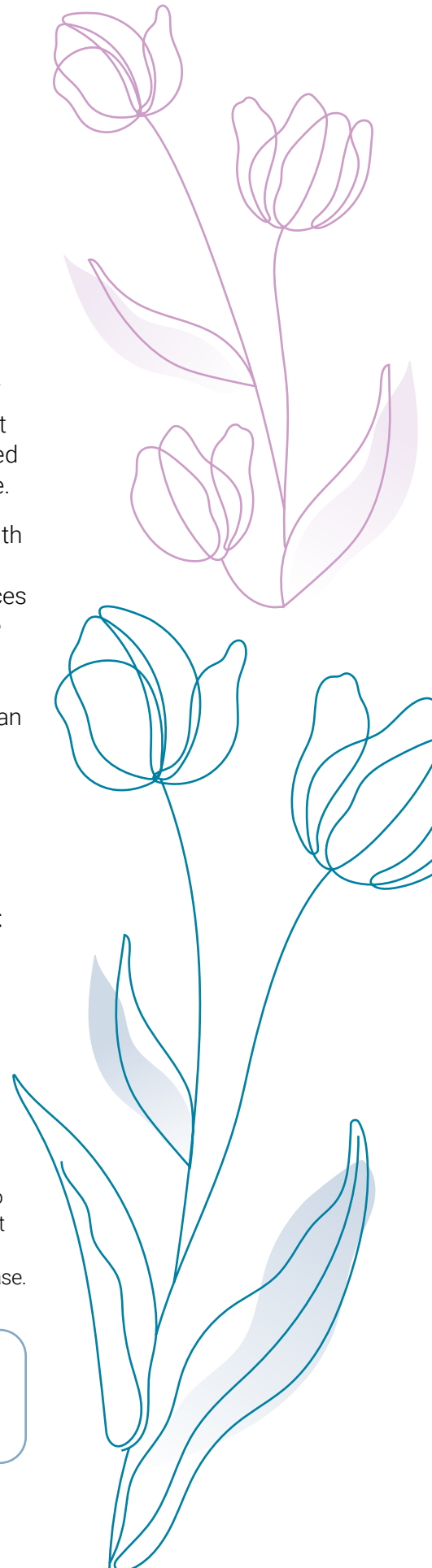


Videos

All types of video submissions that tell your story of Parkinson's Disease.

For submission information, please visit us online at:

<https://bit.ly/PDStory23>



Watch out for us!

Radio partnerships have been established with these stations:

- **Virgin 94.5** (Vancouver), from April 3 – 11
- **Virgin 107.3** (Victoria), from April 3 – 11
- **Virgin 99.9** (Kelowna), from April 3 – 11
- **980 CKNW** (Vancouver), from April 3 – 9
- **Radio NL, K97.5, New Country 103.1** (Kamloops), from April 1 – 30

Public library displays will be available in the following areas to expand awareness and provide educational materials to the public:

- **100 Mile House**, Cariboo Regional District Library, 100 Mile House Branch
- **Abbotsford**, Fraser Valley Regional Library, Abbotsford Branch
- **Cranbrook**, Cranbrook Public Library
- **Fort St. John**, Fort St. John Public Library
- **New Westminster**, New Westminster Public Library, Central Branch
- **Okanagan**, Okanagan Regional Library, Various branches and online
- **Port Moody**, Port Moody Public Library
- **Prince Rupert**, Prince Rupert Library
- **Vancouver**, Vancouver Public Library, Central Branch
- **Victoria**, Greater Victoria Public Library
- **West Vancouver**, West Vancouver Memorial Library
- **Williams Lake**, Cariboo Regional District Library, Williams Lake Branch

Landmark lighting will take place at various monuments and structures across the province. Look out for Parkinson Society BC's magenta and/or teal colours!

The above activities are only a sampling of our initiatives, for a complete listing of our **Parkinson's Awareness plans**, and the most up-to-date information, please visit:

www.parkinson.bc.ca/awareness

Other Ways to Get Involved

Let others know that April is Parkinson's Awareness Month, and use the hashtag **#MoreThanATremor** on social media to tell your story. Be sure to follow the Society online, and tag us in your April Awareness Month posts:



Facebook:

@ParkinsonSocietyBritishColumbia



Instagram:

@ParkinsonsBC



Twitter:

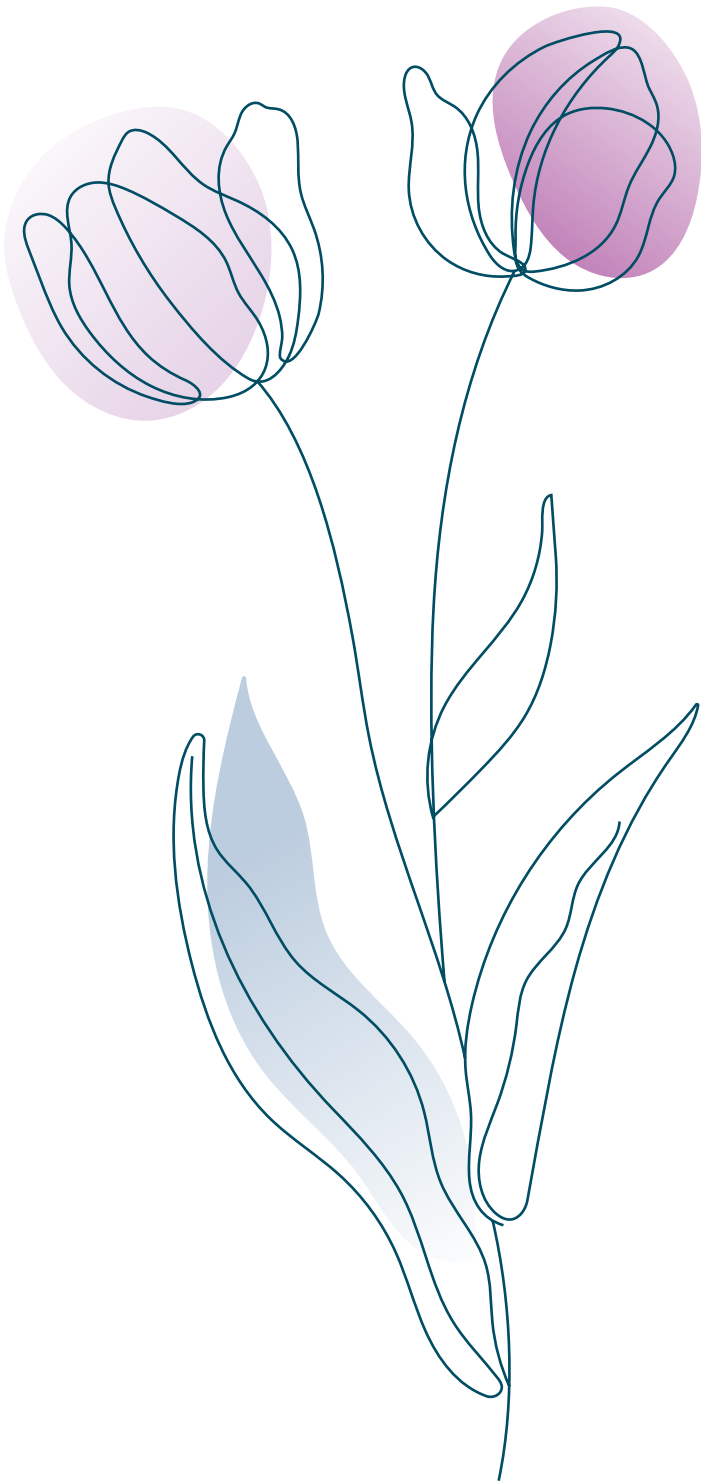
@ParkinsonsBC

Parkinson Society BC wishes to extend thanks to the individuals who graciously contributed their time in January 2023 for an Awareness Focus Group. Your feedback has provided us with valuable insight and direction for our continued efforts in expanding awareness of Parkinson's disease.

Community Submission

Ode to the Mothership by Debbie Hartley

Kelowna Parkinson's Support Group



Went to the doctor the other day
He made some notes and said, "prepare to sway"
My 10-year honeymoon is over now,
The slope is slippery; holy cow!

Freezing, swaying, blurry eyes
Each day offers another surprise.
This bossy, independent self
Refuses to be put on the shelf.

Calls for help were heard aloud
And the Mothership appeared as from a cloud.
We've got what you need, the speaker blared,
We can help so don't be scared!

Information and support is what I need,
"No problem" they said, just take our lead.
Webinars, help sheets, resources galore,
I stepped right through their magic door.

The journey is a challenge, that's for sure,
And so far there is no cure,
But with the Mothership in our zone,
I clearly know we're not alone.

During Covid, when Zoom was born
It saved the members from being forlorn,
"What the heck is Zoom?" some ask,
Not to worry ~ there's an App for that.

Some may wonder what I'm talking about,
Parkinson Society BC ~ without a doubt.
Their support, compassion and dedication
Light the path with care and education.

We deeply appreciate the work they do,
With sincere gratitude, we say *THANK YOU!*

Newsworthy

Upcoming Education & Exercise Events

📍 · Events Hosted in Person

🌐 · Online Events

Thursdays
April 13 – May 18

SongShine

🌐 Online

Instructor Joani Bye will help participants harnesses the power of the brain, breath, and emotion to reclaim and strengthen voices affected by Parkinson's or other neurological challenges.

Saturday
April 29

Victoria Regional Conference

📍 Hotel Grand Pacific

This conference will feature talks from: Dr. Keiran Tuck on Motor Symptoms, Naomi Casiro on Functional Movement Patterns, and Dr. Sanjeet Pakrasi on Psychiatric Issues in Parkinson's. Member pricing available.

Monday, May 1
& Thursday, May 4

May Symposium Series

🌐 Online

Join us to learn from leading Parkinson's experts, featuring the following talks: Dr. Jenn Locke on Bladder and Constipation Issues, Dr. Jan Dutz on Skin Changes, and another talk (speaker to be determined) on Foot Problems.

Other May Events
(TBD)

Communication and Swallow, Victoria

📍 In Person

Sherri Zelazny & Jasmine Cload, registered speech-language pathologists, will help participants learn how to manage common communication and swallowing difficulties using the Lee Silverman Voice Treatment®. Member pricing available.

Carepartner Series

🌐 Online

Three informative talks in this series will feature topics such as: Female and Male Carepartner Needs, Navigating Guilt in Providing Care, and Reconciling Care with Dignity of Risk.

Parkinson's Movement Class

🌐 Online

Get moving this spring with this fun and interactive class, led by personal trainer, Janey Enmil!

Voice Aerobics®

🌐 Online

Mary Spremulli, registered speech-language pathologist, will lead this 50-minute class that combines voice practice with movement.

Other June Events
(TBD)

Seated Exercise Circuit

🌐 Online

Join Parkinson Society BC's very own neuro physiotherapist, Shelly Yu, in a three-week exercise series, which will be fully seated and moderately-paced.

Move with Shelly

🌐 Online

This fun and energetic Parkinson's exercise class, also led by Shelly Yu, is designed to challenge your strength, balance, and mobility.

Kelowna Regional Conference

📍 Ramada Kelowna Hotel

This conference will feature talks on the following topics: "On" & "Off" Periods: Understanding & Managing "Off" Periods, How to Prepare for a Neurology Appointment, and Strategies for Freezing and Fall Prevention. Member pricing available.

Thank you to Our Fundraisers & Donors



Thank you to Mr. Farooque Syed, who donated a percentage of the sales from his book, "Stolen Dreams: How to Help Children Avoid Gangs, Drugs & Violence" to the Society.

Save the Date

2022 Annual General Meeting

We welcome all members of Parkinson Society British Columbia (PSBC) to join us for our 2022 Annual General Meeting (AGM) this spring.

Following the meeting, Dr. Silke Appel-Cresswell will be joining us for a special presentation about cognitive decline in Parkinson's disease. Symptoms of mild, moderate, and advanced cognitive impairment will be discussed, as well as research on the impact of lifestyle interventions that may prevent or offset cognitive impairment.

Date:

Saturday, April 22, 2023

Time:

9:30am to 11:30 am PT

Location:

Online via Zoom

Cost:

Free for Members

Non-members interested in attending must sign up to be a member of PSBC, and pay the \$25 annual membership fee. *Should you wish to obtain more information on becoming a member, please contact:*

Susan Atkinson

Donor & Member Services Coordinator

satkinson@parkinson.bc.ca

1-800-668-3330 ext. 263

Register today at www.parkinson.bc.ca/agm



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